



Canadian Journal of
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The front cover depicts the main stairwell, leading to the atrium of the law school. The back cover depicts the distinct exterior of the law school. The rippled design of the roof is inspired by the natural beauty of the Kamloops mountains visible from the building.

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Preface by the Editors-in-Chief

We are delighted to launch the *Canadian Journal of Comparative and Contemporary Law* with this inaugural issue focused on the theme of health law and human rights.

When the three of us came together last year to discuss the possibility of founding a new law journal, we looked for a way to strike common ground as emerging scholars with seemingly different preoccupations, from public to private law. We wondered how we might make a meaningful contribution to a larger scholarly conversation in law, given the wide range of existing law journals in Canada and abroad.

Part of the answer was found in the common value we place on taking a comparative approach to legal scholarship and a shared desire to gain a global perspective on the legal issues that we study. Although Canadian law schools already host a number of high quality journals, none are focused primarily on fostering comparative legal scholarship, and journals abroad that do so are few in number. Yet, across the many fields and subfields of our discipline, comparative scholarship is undergoing a kind of renaissance. Scholars are increasingly framing their inquiries by crossing jurisdictions, theoretical boundaries, and disciplinary borders. While comparative legal scholarship can trace its roots to figures such as Aristotle, Montesquieu, and Maine, it has become critically relevant to the global age in which we live, an age in which laws and ideas about law are constantly crossing borders and forging broader, more intricate links. Within this global horizon, the idea of a law journal with a domestic focus is beginning to seem anachronistic. We therefore encourage contributors to take a comparative approach, understanding this in a broad sense of drawing upon different jurisdictions, methods, theories, or disciplines.

Another part of the answer was found in the experience of conducting our own past research initiatives, in which we valued high quality publications that offered an in-depth examination of a particular legal issue or area of law. Although there are already a number of established specialist journals in Canada and abroad, our idea to select a new theme for each issue uniquely enables us to respond to contemporary legal problems and debates as they arise.

In this inaugural issue, we have selected the theme of health law and human rights given a host of recent developments in the field that stand to benefit from a comparative approach, and for reasons that Dean Lorne Sossin has aptly identified in his foreword to this issue. Our second issue, to be published in the fall of 2015, explores equity in the 21st century, which will be a valuable addition to the literature by taking a comparative perspective on new challenges and persistent problems in the field. Contributors to the second issue include nationally and internationally renowned scholars, with further details to be posted shortly on our website.

The final part of the answer was grounded in our shared approach to embracing new technological possibilities as part of a newly established and innovative law school at Thompson Rivers University in Kamloops, British Columbia, Canada. We have been inspired by the growing number of scholars seeking to make their research more accessible through open access and online journals. We have therefore adopted an open access model to provide the widest possible dissemination of scholarship that we publish. In addition to its availability through the usual legal databases, all of our published content will be available for free online.

We hope that you find this issue on health law and human rights to be both engaging and informative. We invite you to explore the themes of future issues of the *Canadian Journal of Comparative and Contemporary Law* as we aspire to provide a dynamic forum for quality scholarship, making an important contribution to debates on contemporary legal issues.

ROBERT DIAB
CHRIS DL HUNT
LORNE NEUDORF
Editors-in-Chief

January 2015
Thompson Rivers University
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Kamloops, British Columbia, Canada

Foreword

Lorne Sossin*

It is my privilege to offer this brief foreword for the inaugural issue of the *Canadian Journal of Comparative and Contemporary Law* (CJCCL), launched in 2013 by Thompson Rivers University Faculty of Law. I will offer a word or two about the Journal and then a word or two about its first issue, which grapples with the complex interrelationship between health law and human rights.

Some might see this as a perilous moment at which to launch a new law journal. We are by any measure at the crossroads of significant change in the dissemination of ideas about law and justice. Those ideas may now be found in the blogosphere, in real time listserv debates or from your favourite scholar on iTunes as readily as within the pages of a venerable law review. Law journals wrestle with whether to move purely online, and if so whether to be open access or throw up subscription pay-walls. Authoritative voices have heralded the demise of the law review. Chief Justice Roberts of the US Supreme Court questioned their relevance with this widely circulated comment:

Pick up a copy of any law review that you see, and the first article is likely to be, you know, the influence of Immanuel Kant on evidentiary approaches in 18th Century Bulgaria, or something, which I'm sure was of great interest to the academic that wrote it, but isn't of much help to the bar.¹

* Professor and Dean, Osgoode Hall Law School, York University.
1. "Law Prof. Ifill Challenges Chief Justice Roberts' Take on Academic Scholarship" *American Constitution Society: ACS blog* (5 July 2011), online: American Constitution Society for Law and Policy <<http://www.acslaw.org/acsblog/law-prof-ifill-challenges-chief-justice-roberts%E2%80%99-take-on-academic-scholarship>>.

Follow up studies highlighted that by 2011, no major law review had more than 2,000 paying subscribers and arguably the top law review, the *Harvard Law Review*, shrank from 10,895 subscribers in 1963-64 to 1,896 by 2011.² Such statistics drove Walter Olson to pen a screed in *The Atlantic* entitled, simply, “Abolish the Law Reviews.”³ He referred to Judge Richard Posner’s oft-invoked anecdote that 90 percent of what is written in law reviews is useless but it is impossible to know which 90 percent. To this, Olson added:

What we do know is that the page volume of law reviews has proliferated beyond reason with no corresponding rise in compelling content. Even low-ranked law schools often publish six or eight of them. There’s no secret as to why: students crave the credential of having worked on law review, while faculty crave a high likelihood of being published. Legal educator Harold Havighurst nailed it half a century ago: “Whereas most periodicals are published primarily in order that they may be read, the law reviews are published primarily in order that they may be written.”⁴

While criticism of many law reviews may be merited (though this seems to blur with a general critique of “ivory tower” research which glosses over how so many of the legal doctrines lawyers and courts rely on had their origins in university-based research and writing), the metrics referred to above certainly miss the point. The measure of a law review’s relevance should be downloads and citations, not paid subscriptions – or, more elusively, the kind of influence that is more difficult to quantify. I would call this metric, “shaping the debate.”

Peter Hogg and Allison Bushell’s article on “The Charter Dialogue Between the Courts and the Legislatures (Or Perhaps The *Charter of Rights* Isn’t Such a Bad Thing After All)”⁵ was published by the *Osgoode Hall Law Journal* in 1997, and cited for the first time by the Supreme Court of Canada the following year in *Vriend v Alberta*,⁶ and frequently

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2. Ross E Davies, “Law Review Circulation 2011: More Change, More Same” (2012) 1:1 J Legal Metrics 179 at 179, 185.
 3. Walter Olson, “Abolish the Law Reviews!”, *The Atlantic* (5 July 2012) online: theatlantic.com <<http://www.theatlantic.com/national/archive/2012/07/abolish-the-law-reviews/259389/>>.
 4. *Ibid.*
 5. Peter W Hogg & Allison A Bushell, “The Charter Dialogue Between Courts and Legislatures” (1997) 35:1 Osgoode Hall LJ 75.
 6. [1998] 1 SCR 493 at 565, 578.

thereafter. Few public law scholars (or lawyers) are indifferent to the “dialogue” debates as to whether judicial review under the *Charter* leads to unelected activist judges which undermines democracy, or vigorous and healthy exchanges between judges and legislators which strengthens democracy (or some variation of one of these themes or another). What is not in doubt is that this single law review article has shaped the public law debate in Canada. As the authors noted in a follow up piece on the tenth anniversary of the article’s publication, “[i]n short, a law journal article on ‘*Charter* dialogue’ has precipitated its own vigorous, multi-faceted dialogue.”⁷

In my view, this catalytic role for legal scholarship – to spark a dialogue (or debate) remains the goal of the best law reviews. We need more rather than fewer such publications. The achievement of this goal for a law review is not a matter of subscriptions, or even downloads or citations, but of influence. To invoke a twist on the Havighurst critique quoted by Olsen above, the point of law review articles should not be simply to be written, or simply to be read, but rather to be discussed and debated. Influence, in turn, is also a matter of quality and readability. Badly written and badly reasoned articles tend to slip into obscurity; great articles, by contrast, are woven into subsequent scholarly exchanges, academic conferences, judicial deliberation, classroom discussions and then become a necessary reference point. For example, few speak about the right to privacy without allusion to the simple but powerful reference to, “the general right of the individual to be let alone” in Samuel Warren and Louis Brandeis’ landmark article, “The Right to Privacy.”⁸

All this is to say not only is the idea of the law review alive and well, but its ideal has never been more important. Shaping the debate today consists not necessarily of bringing new information or ideas to light, but in filtering and sifting through the dizzying onslaught of information

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7. Peter W Hogg, Allison A Bushell Thornton & Wade K Wright, “Charter Dialogue Revisited – Or, ‘Much Ado about Metaphors’” (2007) 45:1 Osgoode Hall LJ 1 at 6.
 8. Samuel Warren & Louis Brandeis, “The Right to Privacy” (1893) 4:5 Harv L Rev 193 (cited most recently by the Ontario Court of Appeal as they crafted the first recognition of the tort of “intrusion upon seclusion” in Canada). See *Jones v Tsige*, 2012 ONCA 32 at para 16.

and ideas in a digital and interactive world. The best law review articles provide the analytic perspective necessary to enable readers to reach their own conclusions and to enhance our understanding of the world around us in the process.

For this reason, the establishment of the CJCLL as a new open access law journal is particularly welcome. Law is best understood through its interconnectedness – whether to society, to history, to other disciplinary perspectives or to similar and contrasting developments in other jurisdictions. Making sense of law, in other words, requires both an insider and an outsider perspective. The CJCLL's mission is ideally suited to this venture. It is also significant that its home is Thompson Rivers University, one of Canada's newest law schools, and one dedicated to the pursuit of new perspectives on legal education.

The inaugural issue of the CJCLL does justice to these ambitions, both to shape the debate and to do so through melding insider and outsider perspectives on law. The setting for this examination is the intersection of health and law. Contributors tackle the legal dynamics of health from a number of perspectives, from access to health care services to the status of health benefits within the constitutional order. Issues ranging from the nature of consent to the privatization of health care dominate headlines and water cooler discussions alike. Law's relation to health, however, always has been complex and contentious.

Health debates have a way of polarizing both the public and the judiciary like no other issue. In *Chaoulli v Quebec*,⁹ Deschamps J observed:

In order to receive federal funds, a provincial plan must conform to the principles set out in the *Canada Health Act*, R.S.C. 1985, c. C6: it must be administered publicly, it must be comprehensive and universal, it must provide for portability from one province to another and it must be accessible to everyone. These broad principles have become the hallmarks of Canadian identity. Any measure that might be perceived as compromising them has a polarizing effect on public opinion. The debate about the effectiveness of public health care has become an emotional one. The Romanow Report stated that the *Canada Health Act* has achieved an iconic status that makes it untouchable by politicians (*Building on Values: The Future of Health Care in Canada: Final Report* (2002) (Romanow Report), at p. 60). The tone adopted by my colleagues Binnie and LeBel JJ. is indicative of this type of emotional

9. 2005 SCC 35.

reaction. It leads them to characterize the debate as pitting rich against poor when the case is really about determining whether a specific measure is justified under either the *Quebec Charter* or the *Canadian Charter*.¹⁰

As this passage reflects, health debates in the context of legal disputes often have a text and a subtext. The text might be whether, as in *Chaoulli*, a particular person has a right to a particular health service by virtue of a particular statutory or constitutional provision, but the subtext has more to do with broad social commitments and shared values. The universal nature of the health care system in Canada makes each individual decision in relation to health care (whether funding a service, limiting a doctor's discretion, holding a hospital liable, etc.) a matter, at some level, of public interest. Health, distinct among fields of legal interest, affects and matters to everyone. Policy, legal doctrine, principle and lived experience all inform debates over health and justice. For these reasons, in this field in particular, we need more interdisciplinary, comparative and conceptual scholarship.

I hope the articles within these pages are not only read but debated, and I look forward to this first issue of the CJCCL representing the arrival of a fresh and timely voice within the Canadian legal academy. I am confident the CJCCL will help shape the debate in the thematic areas of focus it selects for each year's special issue. I wish the CJCCL much success into the future!

10. *Ibid* at para 16.

“Love Is Just A Four-Letter Word”: Sexuality, International Human Rights, and Therapeutic Jurisprudence

Michael L Perlin* & Alison J Lynch**

One of the most controversial social policy issues that remains underdiscussed in scholarly literature is the sexual autonomy of persons with disabilities. This population has faced a double set of conflicting prejudices: on one hand, people with disabilities are infantilized (as not being capable of having the same range of sexual desires, needs and expectations as persons without disabilities), and on the other hand, this population is demonized (as being hypersexual, unable to control primitive urges). Although attitudes about the capabilities of persons with disabilities are changing for the better, attitudes toward persons with disabilities engaging in sexual behavior have remained firmly in place for centuries. However, the ratification of the United Nations' Convention on the Rights of Persons with Disabilities (CRPD) demands we reconsider these attitudes.

This paper will (1) review the history of how legal and social issues regarding sexuality have been ignored and trivialized by policy makers and the general public; (2) highlight sections of the CRPD that force us to reconsider the scope of this issue; (3) offer suggestions as to how states must change domestic policy to comport with CRPD mandates; and (4) consider the implications of therapeutic jurisprudence insights for the resolution of these issues.

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I. Introduction

One of the most controversial social policy issues that remains dramatically under-discussed in scholarly literature is the sexual autonomy of persons with psychosocial and intellectual disabilities, especially those who are institutionalized. This population – always marginalized and stigmatized – has traditionally faced a double set of conflicting prejudices: on one hand, people with disabilities are infantilized (as not being capable of having the same range of sexual

A portion of this paper was presented (by MLP) at the Biennial Congress of the International Academy of Law and Mental Health, July 2013, Amsterdam, The Netherlands. The authors wish to thank Dr. Maya Sabatello for her sharing of Israeli source materials.

desires, needs and expectations as persons without disabilities), and on the other hand, this population is demonized (as being hypersexual, unable to control base or primitive urges).¹ Although attitudes about the abilities and capabilities of persons with disabilities are changing for the better, it remains true that, “many people still struggle to accept that mentally disabled individuals engage in sexual activity.”² Even as the “sexual revolution” in the United States recognized sex and sexuality were needs rather than simply desires, persons with disabilities were left out of this shift in perception.³ Attitudes toward persons with disabilities engaging in

1. See e.g. Maya Sabatello, “Disability, Human Rights and Global Health: Past, Present, Future” in Michael Freeman, Sarah Hawkes & Belinda Bennett, eds, *Law and Global Health: Current Legal Issues*, vol 16 (Oxford: Oxford University Press, 2014) (“women with disabilities are ... assumed to be a-sexual, sexually inactive or else, that their sexuality and fertility should be controlled” (emphasis added) at manuscript 8) [Sabatello, “Disability, Human Rights and Global Health”]. Compare Doug Jones, “Domestic Violence Against Women With Disabilities: A Feminist Legal Theory Analysis” (2007) 2:1 Florida A&M University Law Review 207 (“[p]erhaps the most significant myth is that women with disabilities are asexual” at 223); Andreas Dimopoulos, “Let’s Misbehave: Intellectual Disability and Capacity to Consent to Sex” (paper delivered at the Society of Legal Scholars, Faculty of Law, Brunel University, 1 September 2012), online: SSRN <<http://ssrn.com/abstract=2332259>> (discussing the “social stereotype for persons with intellectual disability that they should not be having sex, that they should be asexual” at 9); Rangita de Silva de Alwis, “Mining the Intersections: Advancing the Rights of Women and Children with Disabilities Within an Interrelated Web of Human Rights” (2009) 18 Pac Rim L & Pol’y J 293 (women with disabilities are especially vulnerable to “the imposition of social stereotypes of asexuality and passivity” at 296), to Amy Spady, “The Sexual Freedom of Eve: A Recommendation for Contraceptive Sterilization Legislation in the Canadian Post Re Eve Context” (2008) 25 Windsor Rev Legal Soc Issues 33 (“[i]t is accepted that many persons with mental disabilities experience the same, if not greater, sexual urges as other individuals” at 56).
2. Maura McIntyre, “Buck v. Bell and Beyond: A Revised Standard to Evaluate the Best Interests of the Mentally Disabled in the Sterilization Context” (2007) 1:4 U Ill L Rev 1303 at 1309.
3. Oana Georgiana Girlescu, *Sexuality and Disability: An Assessment of Practices Under the Convention for the Rights of Persons with Disabilities* (Master of Laws in Human Rights Thesis, Central European University, 2012) [unpublished]. See Balázs Tarnai, “Review of Effective Interventions for Socially Inappropriate Masturbation in Persons with Cognitive Disabilities” (2006) 24:3 Sexuality and Disability 151 (quoting

sexual behaviour have remained firmly in place for centuries; perhaps the most famous characterization remains US Supreme Court Justice Oliver Wendell Holmes's line in *Buck v Bell*,⁴ a case involving sterilization of a woman allegedly intellectually disabled: “[t]hree generations of imbeciles are enough.”⁵ People with disabilities, simply put, are frequently stripped of their sexuality.⁶

The ratification of the United Nations' *Convention on the Rights of Persons with Disabilities* (CRPD)⁷ demands that we reconsider this issue. In light of Convention Articles mandating, *inter alia*, “respect for inherent dignity,”⁸ the elimination of discrimination in all matters

the director of a large German institution: “[s]exual expression is not a problem for people with cognitive disabilities – but for those who work with them” at 151).

4. 274 US 200 (1927).
5. *Ibid* at 207. The underpinnings of Holmes' arguments are eviscerated and shredded in Paul A Lombardo, *Three Generations, No Imbeciles: Eugenics, the Supreme Court, and Buck v. Bell* (Baltimore: John Hopkins University Press, 2008). Beyond the scope of this paper are the issues that are raised in what is known as “growth attenuation surgery” – when parents of young children with severe disabilities choose to have them undergo hysterectomies to avoid the onset of menstruation, mastectomies to prevent breast development, and the administration of high doses of estrogen to ensure that the children remain at a size that would facilitate care. See *e.g.* Alicia R Ouellette, “Growth Attenuation, Parental Choice, and the Rights of Disabled Children: Lessons from the Ashley X Case” (2008) 8:2 *Houston Journal of Health Law and Policy* 207 at 210-17 (discussing the “Ashley X” case); Ravi Malhotra & Katharine Neufeld, “The Legal Politics of Growth Attenuation” (2013) 34 *Windsor Rev Legal Soc Issues* 105.
6. Michael Oliver, *Understanding Disability: From Theory to Practice* (New York: Palgrave Macmillan, 1996).
7. 30 March 2007, 2515 UNTS 3 [CRPD]; see generally Michael L Perlin, *International Human Rights and Mental Disability Law: When the Silenced are Heard* (USA: Oxford University Press, 2011) at 143-49 [Perlin, *International Human Rights*].
8. CRPD, *supra* note 7, Article 3. On how dignity is the first “fundamental axiom” upon which the Convention is premised, see Raymond Lang, “The United Nations Convention on the Right and Dignities for Persons with Disability: A Panacea for Ending Disability Discrimination?” (2009) 3 *ALTER: European Journal of Disability Research* 266 at 273. On the relationship between human dignity and “inner worth,” see Amanda Ploch, “Why Dignity Matters: Dignity and the Right (or Not) to

related to interpersonal relationships,⁹ and services in the area of sexual and reproductive health,¹⁰ it is time for a radical change of perspective and attitude in how society views the sexuality, and right to express that sexuality, of persons with disabilities. Following the approach already adopted in international law, society as a whole must recognize that “[b]eing deemed a ‘person’ or sexual is not contingent upon ability.”¹¹ Yet, the literature surrounding the sexual autonomy and issues of sexuality that people with disabilities continue to confront remains remarkably silent on this issue in general,¹² and totally silent about the issue we discuss in this paper: the CRPD’s impact on the rights to sexual autonomy for persons institutionalized because of psychosocial or intellectual disability.¹³

This subject is particularly nettlesome in light of another reality.

Rehabilitation from International and National Perspectives” (2012) 44:3 NYU Int’l L & Pol 887 at 895-96.

9. CRPD, *supra* note 7, Article 23.
10. *Ibid*, Article 26.
11. Bethany Stevens, “Structural Barriers to Sexual Autonomy for Disabled People” (2011) 38:2 Human Rights 14 at 16; Girlescu, *supra* note 3 at 16.
12. On how the entire question is often seen as “taboo,” see *e.g.* Michael L Perlin, “‘Make Promises by the Hour’: Sex, Drugs, the ADA, and Psychiatric Hospitalization” (1997) 46:4 DePaul L Rev 947 [Perlin, “Promises by the Hour”] (“[t]he taboo and stigma attached to sexual behaviour is inevitably heightened when it is coupled with and conflated with stereotypes of the meaning of mental disability” at 965); from a clinical perspective, see *e.g.* Eddie McCann, “The Expression of Sexuality in Persons with Psychosis: Breaking the Taboo” (2000) 32:1 Journal of Advanced Nursing 132 [McCann, “Breaking the Taboo”].
13. Special issues may be raised in cases of individuals with autism or those with autism spectrum disorders (ASD). Compare Laura Gilmour, Melike Schalomon & Veronica Smith, “Sexuality and ASD: Current State of Research” in Vanood E Patel et al, eds, *Comprehensive Guide to Autism* (New York: Springer New York, 2014) 569 at 569 (people with ASD have sexual interests and engage in sexual behaviours with others), to Laura Gilmour, Melike Schalomon & Veronica Smith, “Sexuality in a Community Based Sample of Adults with Autism Spectrum Disorder” (2012) 6:1 Research in Autism Spectrum Disorders 313 (although individuals with ASD display an interest in sex and engage in sexual behaviours and showed no significant differences in breadth and strength of sexual behaviours and comprehension of sexual language when contrasted with non-ASD participants, nonetheless, a higher rate of asexuality was found among individuals with ASD).

One of the authors (MLP) has spent over 40 years involved with mental disability law as a legal practitioner, advocate, academic and scholar. The other author (AJL) has just embarked on her career as a lawyer on behalf of these populations. Through our careers, one thing has been clear. *Nothing* has ever touched as raw of a nerve as our discussion concerning whether persons with mental disabilities have a right to voluntary sexual interaction, especially when such individuals are institutionalized.¹⁴ Why is this? And how does this relate to “sanism” – an irrational prejudice of the same quality and character as other irrational prejudices that cause and are reflected in prevailing social attitudes of racism, sexism, homophobia, and ethnic bigotry¹⁵ – that permeates all aspects of mental disability law and affects all participants in the mental disability law system: litigants, fact finders, counsel, and expert and lay witnesses.¹⁶ Consider this conclusion:

Society tends to infantilize the sexual urges, desires, and needs of the mentally disabled. Alternatively, they are regarded as possessing an animalistic hypersexuality, which warrants the imposition of special protections and

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14. For a discussion of hostile audience reaction to presentations about this topic, see Michael L Perlin, “‘Limited in Sex, They Dare’: Attitudes Toward Issues of Patient Sexuality” (2005) 26:3 *American Journal of Forensic Psychiatry* 25. Eddie McCann has speculated that this may be because of a fear that simply *addressing* this issue “will be seen as actively encouraging widespread institutional promiscuity”; see McCann, “Breaking the Taboo”, *supra* note 12 at 133. On how institutionalization may be a “compounding” problem in this context, see McCann “Breaking the Taboo”, *supra* note 12 at 133.
 15. The word “sanism” was, to the best of our knowledge, coined by Dr. Morton Birnbaum. See Morton Birnbaum, “The Right to Treatment: Some Comments on Its Development” in Frank Ayd, ed, *Medical, Moral and Legal Issues in Mental Health Care* (Baltimore: Williams & Wilkins, 1974) 97 at 105; see also *Koe v Califano*, 573 F (2d) 761 at 764, n 12 (2d Cir 1978). We believe it best explains the roots of our attitudes towards persons with mental disabilities. See *e.g.* Michael L Perlin, “‘Half-Wracked Prejudice Leaped Forth’: Sanism, Pretextuality, and Why and How Mental Disability Law Developed as it Did” (1999) 10 *J Contemp Legal Issues* 3; see generally, *e.g.* Michael L Perlin, *The Hidden Prejudice: Mental Disability on Trial* (Washington, DC: American Psychological Association, 2000).
 16. On the way that sanism affects lawyers’ representation of clients, see Michael L Perlin, “‘You Have Discussed Lepers and Crooks’: Sanism in Clinical Teaching” (2003) 9:2 *Clinical L Rev* 683 at 689-90.

limitations on their sexual behavior to stop them from acting on these “primitive” urges. By focusing on alleged “differentness,” we deny their basic humanity and their shared physical, emotional, and spiritual needs. By asserting that theirs is a primitive morality, we allow ourselves to censor their feelings and their actions. By denying their ability to show love and affection, we justify this disparate treatment.¹⁷

The foregoing observation may best explain the difficulty so many of us have in dealing with the question of the sexual autonomy of persons with disabilities, and explains why policymakers are often unable to approach such issues thoughtfully, even-handedly, and with clear heads. There is no question that Dr. Julie Tennille’s observation – “individuals with mental health conditions face additional obstacles to exploring their sexuality and forging satisfying intimate relationships”¹⁸ – must be “center stage” for this entire investigation. We must accept the reality that virtually all people are “sexual beings.”¹⁹

This paper will (1) briefly review the history of how significant legal and social issues regarding sexuality have been ignored and trivialized by legislators, policy makers, and the general public; (2) highlight those sections of the CRPD that force us to reconsider the scope of this issue; (3) offer some suggestions as to how ratifying and signatory states must change domestic policy so as to comport with CRPD mandates; and (4) consider the implications of therapeutic jurisprudence insights for the resolution of these issues.

The article title draws, in part, on Bob Dylan’s song *Love Is Just a Four-Letter Word*,²⁰ a song that Dylan has never sung (although it remains

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17. Michael L Perlin, “Hospitalized Patients and the Right to Sexual Interaction: Beyond the Last Frontier?” (1994) 20:3 NYU Rev L & Soc Change 517 at 537 [Perlin, “Beyond the Last Frontier?”]. For a subsequent consideration of the impact of this infantilization, see Janine Benedet & Isabel Grant, “Hearing the Sexual Assault Complaints of Women with Mental Disabilities: Evidentiary and Procedural Issues” (2007) 52:3 McGill LJ 515.
 18. Julie Tennille & Eric Wright, *Addressing the Intimacy Interests of People with Mental Health Conditions: Acknowledging Consumer Desires, Provider Discomforts, and System Denial* (2013) at 2 [unpublished monograph, archived at <http://tucollaborative.org/pdfs/Toolkits_Monographs_Guidebooks/relationships_family_friends_intimacy/intimacy.pdf>].
 19. McCann, “Breaking the Taboo”, *supra* note 12 at 134.
 20. Bob Dylan, “Love is Just a Four-Letter Word”, online: The Official Bob

a frequent staple in Joan Baez's repertoire).²¹ The standard "take" on the song is that it is "the bridge between his [Dylan's] end-of-relationships blues and his giddy poetic streaks."²² Yet, consider these lines in the context of the arguments we make in this paper:

She sat with a baby heavy on her knee
Yet spoke of life most free from slavery

and

To you I had no words to say
My experience was limited and underfed
You were talking while I hid

and

Drifting in and out of lifetimes
Unmentionable by name.²³

We believe that there is a deep "fit" between these lyrics, the song's title, and the points we seek to make in this paper. Persons with disabilities seeking sexual autonomy are in a kind of emotional and physiological "slavery"; their experiences are certainly "limited and underfed," and what they wish for is seen, by so many, as "unmentionable by name." The idea that persons with disabilities can love and be loved *is* a "four letter word" to many. We use this lyric here to stress the sadness of that reality.

Dylan Site <<http://www.bobdylan.com/us/home>>.

21. See *e.g.* Scott Johnson, "Love is Just a Four-Letter Word", (blog), online: Power Line <<http://www.powerlineblog.com/archives/2012/01/love-is-just-a-four-letter-word.php>>. One of the authors (MLP) last saw her sing it on 11 November 2011. See online: Joan Baez <<http://www.joanbaez.com/tourschedule11.html>>.
22. Tim Riley, *Hard Rain: A Dylan Commentary* (New York: Random House, 1992) at 109.
23. Dylan, *supra* note 20.

II. How Sexuality Issues Have Been Treated by Law and Society

A. In Psychiatric Institutions²⁴

1. An Overview

Before we can analytically approach the question of whether institutionalized persons with mental disabilities have the right to engage in consensual sexual activity, we must attempt some modest deconstruction. No doctrinal or theoretical formulation can be seriously undertaken until we articulate our perspective. Are we looking for a legal answer, a clinical answer, a social answer, an administrative answer, or a behavioural answer (or, as we should, a combination of all of these)? Surely we must consider each area of analysis separately, and in concert with each other, if we wish to construct a meaningful, multi-textured, and comprehensive response.

2. What is Meant by “Sex”?

Twenty years ago, one of the authors (MLP) noted:

We must consider whether any of these answers depends upon our definition of sex. Do we need to consider every possible permutation of sexual behavior? Does it make a difference if we are discussing monogamous heterosexual sex, polygamous heterosexual sex, monogamous homosexual sex, polygamous homosexual sex, or bisexual sex? Does sex mean intercourse? What about oral sex? Anal sex? Masturbation? Voyeurism? Exhibitionism?²⁵

It probably makes sense, at the outset, to keep in mind that any consideration of the issues under discussion here must, at the least,

24. This section is largely adapted from Perlin, “Beyond the Last Frontier?”, *supra* note 17 at 522-28.

25. Perlin, “Beyond the Last Frontier?”, *supra* note 17 at 527, citing in part to Michael L Commons et al, “Professionals’ Attitudes Towards Sex Between Institutionalized Patient” (1992) 46:4 American Journal of Psychotherapy 571 (discussing ways that mental health professionals’ attitudes towards sex are influenced by the nature of the sexual activity and the patients’ sexual orientation). See *e.g.* Stevens, *supra* note 11 (“[i]n the limited amount of cases where sexual activity is permitted, it is generally only heterosexual marital sex that is allowed” at 16).

take into account the realities that “sex” means much more than simply heterosexual intercourse. Although an exhaustive discussion of all permutations is not possible here, we will discuss briefly the question of sexual-contact-other-than-“standard”-intercourse, the surprisingly nettlesome issue of masturbation, and the most controversial question of compensated sexual assistance.

i. Other kinds of Sex

A recent article – about a civil law suit that followed litigation over a long-term relationship between a man with a psychosocial disability (schizophrenia) and a priest with AIDS – questions whether sex can be ordered like a “Guttman scale,”²⁶ involving a “unidimensional behavioral hierarchy from French kissing to penetrative intercourse,”²⁷ and wonders if “someone has consented to touching genitals over clothing ... implies consent to French kissing,”²⁸ asking whether “consent to one step automatically insure[s] consent to others below it?”²⁹ This article does not begin to answer the preceding question, but the perspective of ordering is raised here to clarify that sex and sexual activities are not “unidimensional” questions, and that policymakers should be aware of the complexity of these issues.

With non-normative sexual behaviour (including sexual activities engaged in with and without a partner) come other discriminatory beliefs by the majority of society that sub-cultures practicing such behaviours are “different” and “abnormal.” While there are many variations of sexual behaviour, we will briefly examine the issues surrounding masturbation

26. In which items are arranged in an order so that an individual who agrees with a particular item also agrees with items of lower rank-order. See e.g. Judy A Andrews et al, “The Construction, Validation and Use of a Guttman Scale of Adolescent Substance Use: An Investigation of Family Relationships” (1991) 21:3 *Journal of Drug Issues* 557; Andreas Mokros et al, “Psychopathy and Sexual Sadism” (2011) 35:3 *Law & Human Behavior* 188 at 192.

27. Paul R Abramson, Terry Gross & Annaka Abramson, “Consenting to Sex and Severe Mental Illness: *Terra Incognita* and a Priest with AIDS” (2012) 30:3 *Sexuality and Disability* 357 at 362.

28. *Ibid.*

29. *Ibid.*

and sexual surrogates, since some amount of research has been done in evaluating their impact on the community of persons with disabilities.

ii. Masturbation³⁰

Although at least one study has found that staff workers at a medium-security facility for persons with intellectual disabilities generally held “liberal attitudes” toward masturbation,³¹ and another article has called for “masturbation training,”³² much controversy swirls around the question of *facilitated* masturbation and the role of the caregiver in the facilitation process.³³ It goes without saying that this is an issue that must

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30. On the roots of the 19th century view that masturbation was a cause of mental disorder, see EH Hare, “Masturbatory Insanity: The History of an Idea” (1962) 108 *Journal of Mental Science* 1.
31. Linda Yool et al, “The Attitudes of Medium-Secure Unit Staff Toward the Sexuality of Adults with Learning Disabilities” (2003) 21:2 *Sexuality and Disability* 137. On the needs of staff in dealing with sexuality issues, see generally Sharon Foley & Grace Kelly, *Friendship and Taboos: Research on Sexual Health Promotion for People with Mild to Moderate Intellectual Disabilities in the 18-25 Age Range: Results of a Consultation Process and Literature Review* (Cork: Health Service Executive South, 2009); see also Mental Welfare Commission for Scotland, *Consenting Adults? Guidance for Professionals when Considering Rights and Risks in Sexual Relationships Involving People with a Mental Disorder* (Edinburgh: Mental Welfare Commission for Scotland, 2011).
32. Michael Gill, “Sex Can Wait, Masturbate: The Politics of Masturbation Training” (2012) 15:314 *Sexualities* 472; see generally Frederick Kaeser, “Developing a Philosophy of Masturbation Training for Persons with Severe or Profound Mental Retardation” (1996) 14:4 *Sexuality and Disability* 295. Virtually all of the literature focuses solely on issues of *males* masturbating as “the sexuality and sexual experiences of women with ... disabilities have remained relatively hidden,” see Paul Cambridge, Steven Carnaby & Michelle McCarthy, “Responding to Masturbation in Supporting Sexuality and Challenging Behaviour in Services for People with Learning Disabilities” (2003) 7:3 *Journal of Learning Disabilities* 251 at 253. See also, *e.g.* Dorothy M Bell & Lois Cameron, “The Assessment of the Sexual Knowledge of a Person with Severe Learning Disability and a Severe Communication Disorder” (2003) 31:3 *British Journal of Learning Disabilities* 123 at 128 (discussing a woman with limited verbal communication who “appeared to have no recognition of female masturbation”).
33. See *e.g.* Sara Earle, “Disability, Facilitated Sex, and the Role of the Nurse” (2001) 36:3 *Journal of Advanced Nursing* 433.

be subject to discussion in an “open and value-free environment.”³⁴

iii. Care Workers

Perhaps the most controversial question – in a *sea* of controversial questions – is the appropriateness of using care workers as sexual surrogates in cases involving persons with disabilities. Such surrogacy can involve masturbation or intercourse.³⁵ Several European nations – including The Netherlands, Germany, Denmark, and Switzerland – allow “limited ‘touching’ services for [persons with severe disabilities] through non-profit organizations.”³⁶ Elsewhere, there are organizations in Canada,³⁷ Australia,³⁸ Japan,³⁹ and New Zealand,⁴⁰ that, in the words of the Australian-based Touching Base website, “developed out of the need to assist people with disability and sex workers to connect with each other, focusing on access, discrimination, human rights and legal issues and the attitudinal barriers that these two marginalised communities can face.”⁴¹ An administrative decision in Denmark has approved the payment of social welfare funding for an “escort girl” as a “handicap benefit.”⁴²

It has been suggested by one medical ethicist that “jurisdictions that

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34. Clive Glass & Bakulesh Soni, “Sexual Problems of Disabled Patients” (1999) 318:7182 *British Medical Journal* 518. At least one academic consideration of the issue has noted that, concern within services often returns to the question of “whether such interventions, if successful, will then lead to the person spending too much time masturbating, as they may have learnt how to do it well and effectively,” see Cambridge, Carnaby & McCarthy, *supra* note 32 at 260.
 35. See online: Touching Base Inc <<http://www.touchingbase.org/>>.
 36. Jacob Appel, “Sex Rights for the Disabled?” (2010) 36:3 *Journal of Medical Ethics* 152 at 153.
 37. See online: EASE Canada <<http://easecanada.org/>>.
 38. See Touching Base, *supra* note 35; online: Scarlet Road <<http://www.scarletroad.com.au>>.
 39. See online: White Hands <<http://www.whitehands.jp/e.html>>.
 40. See online: Paths Together <<https://www.facebook.com/pages/PathsTogether/552620361438711>>.
 41. See Touching Base, *supra* note 35.
 42. See email from Professor Kirsten Ketscher, WELMA – Centre for Legal Studies in Welfare and Market, Faculty of Law, University of Copenhagen (30 December 2013) (discussing the decision in Escort Girl C-106 Danish Social Appeals Board).

prohibit prostitution should carve out narrow exceptions for individuals whose physical or mental disabilities make sexual relationships with non-compensated adults either impossible or highly unlikely.⁴³ Although there is at least one report of this having been done using Social Security funds in the USA,⁴⁴ it is clearly an idea that has not gained significant traction in that jurisdiction. In fact, any such use of sexual surrogacy has been sharply criticized as “distort[ing] sympathies for the situations of people with disabilities to promote prostitution.”⁴⁵

This question, out of all those that arise when looking at sexual autonomy for persons with disabilities, is compounded by societal views about prostitution, exacerbated by the often-sanist thinking about the sexual needs of persons with disabilities.⁴⁶ It is not surprising to see that nations that have legalized the profession of sex worker are more likely to have opportunities for sexual surrogacy.⁴⁷ These nations are allowing some of the stigma surrounding sex (and in particular, sex for people with disabilities) to be lifted, leading to a more honest discussion about meeting the basic needs of people, including the need for sex.

Sexual surrogacy also challenges society to imagine that a non-disabled person would be willing to engage in sexual activity with a disabled person. Entrenched sanism and long-standing fear of “contamination” or

43. Appel, *supra* note 36 at 153. But see Ezio Di Nucci, “Sexual Rights and Disability” (2011) 37:3 *Journal of Medical Ethics* 158 (criticizing Appel’s position).

44. See David J Lillesand & Gina M Nguyen, SSI Trust and Transfer Rules, 17 *NAELA Q* 3 (Spring 2004) (recounting case where a “sympathetic sister/trustee purchased ‘entertainment services,’ consisting of nursing home visits by ‘escort services’ personnel to the nursing home where her severely disabled and dying brother resided”).

45. Dianne Post, “Legalization of Prostitution Is a Violation of Human Rights” (2011) 68:2 *National Lawyers Guild Review* 65 at 92.

46. See generally Perlin, “Beyond the Last Frontier?” *supra* note 17; Michael L Perlin, “‘Everybody Is Making Love/Or Else Expecting Rain’: Considering the Sexual Autonomy Rights of Persons Institutionalized Because of Mental Disability in Forensic Hospitals and in Asia” (2008) 83:4 *Wash L Rev* 481 [Perlin, “Everybody is Making Love”].

47. See *e.g.* The Legal Status of Prostitution by Country, online: Charts Bin <<http://chartsbin.com/view/snb>> (listing nations in which sex work is legal, overlapping in a large part with nations in which surrogates may be used, as discussed in *supra* notes 35-42 and accompanying text).

disability as a “contagion” also make this concept a difficult one to grasp for many who may be confronted with this form of sexuality.⁴⁸

Although surrogacy is not identical to engaging in an emotional relationship in which sex is a component, it is yet another option for people with disabilities to gain some autonomy in their decision making about their own needs. Under the CRPD, they have the same right to engage in sex that non-disabled people do,⁴⁹ and surrogacy may afford an opportunity to those people who are, for many reasons, unable to or uninterested in engaging in a non-surrogate sexual relationship.

The differences between nations’ views on the “acceptability” of masturbation and sexual surrogacy are also indicative of those nations’ dominant norms and values. Professor Elaine Craig has discussed the danger of regulating activity based on the dominant norms of a society, stating that if legal standards are applied based only on dominant belief systems, they “[privilege] dominant social, cultural and religious practices.”⁵⁰ Further, in the context of consent laws, she notes that “[s]ocial approval is not an equitable basis upon which to criminalize particular sexual activities.”⁵¹ Although the disability rights movement has made great strides, persons with disabilities continue to remain a minority group, rather than a part of the dominant culture in most nations.⁵² Their

48. See *e.g.* Judith S Neaman, *Suggestion of the Devil: The Origins of Madness* (Garden City, NY: Anchor Press, 1975) at 31, 144 (addressing the stereotype of persons with mental illness as evil), cited in Michael L Perlin, “‘She Breaks Just Like a Little Girl’: Neonaticide, The Insanity Defense, and the Irrelevance of Ordinary Common Sense” (2003) 10:1 *Wm & Mary J Women & L* 1 at 9, n 54 [Perlin, “Neonaticide”].

49. See CRPD, *supra* note 7, Article 23 (discussed in this context, see text accompanying note 103).

50. Elaine Craig, “Capacity to Consent to Sexual Risk” (2014) 17:1 *New Criminal Law Review* 103 at 117.

51. *Ibid.*

52. Interestingly, much of the literature about the CRPD has focused upon persons with disabilities as the “world’s largest minority,” see *e.g.* Rosemary Kayess & Phillip French, “Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities” (2008) 8:1 *Human Rights Law Review* 1 at 4, n 16, discussed in this context in, *inter alia*, Michael L Perlin, “‘Striking for the Guardians and Protectors of the Mind’: The Convention on the Rights of Persons with Mental Disabilities and the Future of Guardianship Law” (2013) 117:4 *Penn St L Rev* 1159

rights and needs may not be legislated away by that dominant culture because majority populations believe sexual activities of persons with disabilities do not produce “socially desirable cultural products.”⁵³

B. Current Laws Relating to Sexual Autonomy of Persons with Disabilities

As noted previously, discussion of sexual autonomy relating to persons with disabilities are few and far between in scholarly journals. In the United States, the law has followed this trend, with very little attention paid to the legal rights of persons with disabilities to exercise their autonomy, especially in an institutional setting. Many critical questions remain unanswered in the law, leaving hospitals and community treatment facilities to decide for themselves how to best deal with these issues. Often, these decisions are made with no clear guidelines and carried out on a case-by-case basis. Remarkably, none of the respondents questioned in a British study were even *aware* that they had *any* “sexual rights.”⁵⁴ And we virtually never consider the argument posited by the medical ethicist Jacob Appel in this context that sexual *pleasure* is a *fundamental* human right.⁵⁵

The United States Supreme Court, federal district courts, and state courts have all addressed the range of constitutional rights held by involuntarily committed individuals, such as the right to counsel,⁵⁶

at 1173, n 62 [Perlin, “Striking for the Guardians”].

53. Craig, *supra* note 50 at 117.

54. McCann, “Breaking the Taboo”, *supra* note 12 at 136.

55. Appel, *supra* note 36 at 154. See also Stevens, *supra* note 11 (“[p]oliticizing sexual pleasure and oppression of disabled people through enacting cripsex is a powerful way to affirm our humanity,” where author defines “cripsex” to “express the political nature of the sexuality of disabled people” at 16). Compare Di Nucci, *supra* note 43 at 160 (responding to Appel, and disagreeing with this thesis, in large part, because, if Appel’s theory was to be adopted, “we would end up with a situation in which severely disabled people have their sexual satisfaction paid for them by the state, while everybody else will have to pay for it, or go through the trouble of finding willing non-compensated sexual partners”).

56. *In the matter of the Mental Health of KGF*, 29 P (3d) 485 at 491 (Mont Sup Ct 2001).

the right to refuse medication,⁵⁷ and the right to be treated in the least restrictive environment,⁵⁸ to name but a few.⁵⁹ The number of cases litigated by persons with disabilities has grown exponentially since the 1970s.⁶⁰ However, the right to sexual autonomy has remained an elusive topic, with very few references to it in any major state or federal court decision involving persons with disabilities.⁶¹

Legislation has also failed to adequately address issues of sexual autonomy both in and out of mental health facilities. A case may be made for regulations or laws allowing sexual activity in certain settings based on domestic disability anti-discrimination laws. If sexual activity is banned for no other reason than the “disabled” status of the consenting adults wishing to engage in such activity, it may be argued that this sort of *per se* discrimination violates the *Americans with Disabilities Act* or other similar pieces of legislation.⁶²

C. The Effects of Institutionalization on Persons with Disabilities and Sexual Autonomy

Next, we must consider the practical implications of sexual relationships in a closed institution like a psychiatric hospital.⁶³ Under the best of

57. *Riggins v Nevada*, 504 US 127 (1992).

58. *Olmstead v LC*, 527 US 581 (1999).

59. The broad range of topics also includes competency evaluations for mentally ill criminal defendants (*Dusky v United States*, 362 US 402 (1960); *Drope v Missouri*, 420 US 162 (1975); *Pate v Robinson*, 383 US 375 (1966)); illegality of indefinite confinement of persons found incompetent to stand trial (*Jackson v Indiana*, 406 US 715 (1972)); prisoners’ rights (*Estelle v Gamble*, 429 US 97 (1976); *Washington v Harper*, 494 US 210 (1990)); the civil commitment process (*Addington v Texas*, 441 US 418 (1979)); and rights of civilly committed patients (*Youngberg v Romeo*, 457 US 307 (1982); *O’Connor v Donaldson*, 422 US 563 (1975)).

60. See Michael L Perlin, *Mental Disability Law: Civil and Criminal*, 2d ed, vol 1 (Charlottesville, VA: Lexis Law Publishing, 1998) at § 1-1, 1 [Perlin, *Mental Disability Law*] (discussing the “astonishing development of mental disability litigation” over past decades).

61. But see *Foy v Greenblott*, 190 Cal Rptr 84 (Ct App 1983) discussed below and notes 91-95 and accompanying text.

62. See generally Perlin, “Promises by the Hour”, *supra* note 12.

63. On the issues of sexual autonomy in *forensic* facilities in general, see

circumstances, entering into a new sexual relationship can be stressful and confusing. Are these stresses “inappropriately” exacerbated when the universe in question is that of institutionalized mental patients? To what extent should the differing stress management abilities of institutionalized individuals be factored into any policy ultimately adopted? Conversely, can preoccupation with sex systemically distort all matters involving ward behaviour? How does this focus affect questions of individual versus group needs? Might an excessive concern with sex blunt the consideration of other related issues, such as self-esteem, the importance of developing a full range of interpersonal relationships, and the ability to deal with intimacy? We impose significant barriers that prevent institutionalized persons with mental disabilities from establishing intimacy.⁶⁴ Yet, one study showed that most patients in *high-security* hospitals “valu[ed] being in a caring relationship [while] in the hospital,”⁶⁵ and that there was likely “an ongoing desire for intimacy regardless of gender, diagnosis or offense group.”⁶⁶

A closed institution, by its nature, places substantial limits on individuals’ mobility and freedom of action. In considering how best to allow individuals to express their autonomy, it is important to consider all aspects of a relationship, including issues indirectly raised by sexual intimacy. For example, when people in the “free world” terminate a

Perlin, “Everybody is Making Love”, *supra* note 46. On the relationship between the CRPD and forensic facilities in general, see Michael L Perlin & Meredith R Schriver, “‘You That Hide Behind Walls’: The Relationship between the Convention on the Rights of Persons with Disabilities and the Convention Against Torture and the Treatment of Institutionalized Forensic Patients” in *Torture in Healthcare Settings: Reflections on the Special Rapporteur on Torture’s 2013 Thematic Report* (American University: Center for Human Rights & Humanitarian Law, 2013) at 195; Michael L Perlin & Alison J Lynch, “‘Toiling in the Danger and in the Morals of Despair’: Risk, Security, Danger, the Constitution, and the Clinician’s Dilemma” (2015) 26 *Stan L & Pol’y Rev* – [in press].

64. On the “false assumptions” made by many care providers about the “fundamental importance of intimacy to consumer well-being,” see Tennille & Wright, *supra* note 18 at 9.

65. See Heidi Hales et al, “Sexual Attitudes, Experience and Relationships Amongst Patients in a High Security Hospital” (2006) 16:4 *Criminal Behaviour and Mental Health* 254 at 260.

66. *Ibid.*

stormy love affair, frequently they can adjust their lives so as not to have much contact with their former lovers. What happens if that ex-lover lives on the same floor of an inpatient hospital (especially if it is a locked ward hospital), and neither patient can leave without a court order? Conversely, what happens when a couple is split up by a court order transferring one patient to another ward or facility for clinical or legal reasons?⁶⁷ These are decisions that must be considered in order to allow individuals confined in an institution the ability to engage in a relationship just as they would in the “free world.” Although an institution may need to restrict some privileges based on safety or treatment concerns, it will be critical for institutions to consider a “least restrictive environment” approach when dealing with patients’ sexual autonomy, as it is undoubtedly part of their rights under the CRPD.

Another series of issues to consider comes from differences in the status of institutionalized persons.⁶⁸ Those institutionalized after being civilly committed, ordered confined for a competency evaluation, or held in a locked facility after a plea of not guilty by reason of insanity each have rights and aspects of law that are unique to each particular status. Assuming the individuals wishing to engage in sexual activity are competent to consent,⁶⁹ are all patients to be treated in the same way, or are there differences between voluntarily and involuntarily committed

67. This is made more complicated by decisions such as *Kulak v City of New York*, 88 F (3d) 63 at 73 (2d Cir 1996) (no liberty interest created by court recommendation that mental hospital transfer involuntarily-committed patient to less restrictive environment because transfer was not mandatory).

68. See e.g. Michael L Perlin, “‘Too Stubborn To Ever Be Governed By Enforced Insanity’: Some Therapeutic Jurisprudence Dilemmas in the Representation of Criminal Defendants in Incompetency and Insanity Cases” (2010) 33:5-6 *Int’l J L & Psychiatry* 475 at 480 (discussing significance of patients’ “litigational status” on questions involving right to refuse treatment).

69. The topic of competency to consent to sexual activities in a psychiatric institution is an extremely complex topic that should be addressed separately, in great depth. See generally Michael L Perlin & Alison J Lynch, “All His Sexless Patients’: Persons with Mental Disabilities and the Competence to Have Sex” (2014) 89:2 *Wash L Rev* 257 [Perlin, “All His Sexless Patients”]. For the purposes of this paper, the authors choose to assume the individuals discussed are legally competent to consent.

patients that are relevant to this inquiry? Further, should involuntary commitment implicitly restrict one's freedom to engage in sexual activity? Is it justifiable, or even legally required, to place different restrictions on patients who have been committed following their involvement in the criminal justice system, in comparison to those imposed on civilly committed patients? If competency to consent is not at issue, disallowing sexual activity solely based on legal status appears punitive, rather than therapeutic.

Ultimately, the lingering question when considering sexual autonomy of institutionalized persons is, in any event, can patients be stopped from having sex?

D. Clinical Questions Regarding Sexual Autonomy of Persons with Disabilities

Next, we must consider clinical questions. A patient's treatment team is charged with finding the most therapeutic treatment in the least restrictive environment. For many patients, this involves therapy intended to help them transition back to living in the "real world." That can include behavioural therapy and group programs that encourage social interaction. Questions of sexual autonomy should also be considered within that context in developing and assessing a treatment plan and long-term goals for a patient both in and out of a treatment facility. For example, clinicians should note whether the patient in question ever expressed any wish to engage in sexual activity, and then discuss whether it is clinically beneficial or anti-therapeutic to allow institutionalized patients autonomy in sexual decision-making.⁷⁰ In answering this question, to what extent should clinicians consider research on the therapeutic value of touching and physical intimacy?⁷¹ Should the projected length of a patient's

70. On how interpersonal relationships among patients can help further treatment goals, see Edmund G Doherty, "Social Attraction and Choice Among Psychiatric Patients and Staff: A Review" (1971) 12:4 *Journal of Health & Social Behavior* 279 at 287. See also Stevens, *supra* note 11 ("[r]ecognition and expression of sexual autonomy has many health benefits, including analgesic effects, hypertension reduction, and increased relaxation" at 23).

71. See McCann, "Breaking the Taboo", *supra* note 12 (quoting patient,

hospitalization affect the restrictions placed on their sexual autonomy? If so, how?⁷² What is the impact of sexual activity on different methods of treatment? On the overall ward milieu? What correlative responsibilities come with the assertion of rights?⁷³

These questions also lead to a consideration of patient sexual autonomy from the perspective of hospital officials, and the reasons for their discomfort with the subject. Why are hospital administrators resistant to expanded sexual activity on the part of patients? Is it more than simple inconvenience, or even the fear of unwanted pregnancies? How much does a fear of a potential hospital-wide AIDS epidemic contribute to this resistance?⁷⁴ How realistic and genuine is this fear? The expansion of provider liability is the source of realistic concerns on the part of therapists that an ever-expanding range of clinical decisions may lead to ever-expanding personal liability.⁷⁵ One commentator has suggested that the threat of litigation has led hospital administrators to

responding to survey question on the meaning of intimacy: “[s]ex, love, caring, *and sharing* ... things like that” [emphasis added] at 136). There has been academic literature available about this for over 40 years, though it is rarely cited in the *legal* literature. See *e.g.* Ashley Montagu, *Touching: The Human Significance of Skin*, 2d ed (USA: Harper & Row, Publishers, 1971); Harry F Harlow, Margaret K Harlow & Stephen J Suomi, “From Thought to Therapy” (1971) 59:5 *American Scientist* 538. Professor Heather Ellis Cucolo has focused on this in her recent work on sex offenders. She asks why we fail to acknowledge that the concept of intimacy is “the key to preventing and minimizing re-offense.” See Heather Ellis Cucolo, “Right to Sex in the Treatment and Civil Commitment of Sexual Violent Predators” (2007) [unpublished, on file with authors]. This is a reality that must be considered as we further explore this issue.

72. See generally Douglas J Mossman, Michael L Perlin & Deborah A Dorfman, “Sex on the Wards: Conundra for Clinicians” (1997) 25:4 *Journal of the American Academy of Psychiatry and the Law* 441.
73. Mossman, Perlin & Dorfman, *supra* note 72.
74. On the fear of an AIDS epidemic in the context of disability rights issues, see Samuel R Bagenstos, “The Americans with Disabilities Act as Risk Regulation” (2001) 101:6 *Colum L Rev* 1479 at 1492.
75. See *e.g.* Allison Faber Walsh, “The Legal Attack on Cost Containment Mechanisms: The Expansion of Liability for Physicians and Managed Care Organizations” (1997) 31:1 *J Marshall L Rev* 207; Robert John Kane, “Illinois Legal Developments Affecting Physicians and Hospitals” (2010) 31:1 *J Legal Med* 73.

“attempt to minimize the complexity of patient sexuality by focusing on the symbolic, simplistic reassurance of written procedures.”⁷⁶ Was this response idiosyncratic to the circumstances at a particular hospital, or is this practice more common? Professor Bernadette McSherry and Professor Margaret Somerville note on this point:

[E]ven if a written policy on sexual activity is put in place, the fear of litigation by institution administrators may still lead to the “policing” of such activity in case some form of harm may be taking place. The threat of litigation may therefore lead to staff members erring on the side of caution in relation to sexual activity among those in institutions.⁷⁷

E. Cultural Issues Surrounding Sexual Autonomy of Institutionalized Patients

The nature of this topic makes it, inevitably, a contentious point among the various groups that will debate it, legislate it, and implement it. Beliefs and values beyond law and legislation are intertwined with attitudes toward sexual activity. Culture, politics, religion, and senses of “morality” are all elements that must be addressed in order to realistically work through these difficult issues and come to a consensus on the proper way to address them. Even if policies are promulgated to protect and respect the sexual autonomy of institutionalized individuals, what happens when individual line staff at a hospital, the people to whom the implementation of the policy inevitably falls, simply refuse to cooperate with the policy because their own sense of religious “morality” forbids it?⁷⁸ For example, their religion may teach that unmarried persons – of

76. Terry Holbrook, “Policing Sexuality in a Modern State Hospital” (1989) 40:1 *Hospital & Community Psychiatry* 75 at 79 (discussing the results of a psychiatric hospital’s failure to notify the police of the sexual assault of one patient by another).

77. Bernadette McSherry & Margaret A Somerville, “Sexual Activity Among Institutionalized Persons in Need of Special Care” (1998) 16 *Windsor YB Access Just* 90 at 124. On how the avoidance of anticipated prospective harm has become central to much of disability law policy in this area, see generally Dimopoulos, *supra* note 1 (Dimopoulos argues that, “[b]y seeking to avoid harm to self we are perpetuating oppressive social and legal responses which presented persons with disabilities as asexual, or worse still, as individuals who should be asexual” at 8).

78. In general, on the significance of care provider *discomfort* around sexual

any mental capacity – should not have sex, or that married persons – of any mental capacity – should not have extramarital sex. Is it justifiable for private facilities that are church-affiliated, or private nonsectarian facilities that retain units specially designated for practitioners of specific religions, to apply different restrictions in these areas?⁷⁹

F. Conclusion

The issues discussed above should underscore the point that this topic is complex and under-considered in the literature and laws regarding persons with disabilities.⁸⁰ These complexities are compounded by society's generally irrational attitudes towards persons with mental disabilities.⁸¹ The lack of attention, litigation, and commentary on this subject appears anomalous. Institutionalized persons self-evidently do not lose their sexuality or sexual desires when they lose their liberty. There is some added irony to be found in the fact that litigation over antipsychotic medication refusal – the most contentious aspect of institutionalized patients' rights law – centers on drug side effects, and the loss of sexual desire is one of the most highly-noted amongst them.⁸² Thus, the law

expression by persons with mental disabilities, see Tennille & Wright, *supra* note 18 at 8-9.

79. *Ibid* (“[f]aith-based provider services ... often care for consumers who do not share the same religious traditions or spiritual beliefs about expressions of sexuality” at 11).
80. Suzanne Doyle, “The Notion of Consent to Sexual Activity for Persons with Mental Disabilities” (2010) 31:2 *Liverpool Law Review* 111.
81. See Tom Koch, “The Ideology of Normalcy: The Ethics of Difference” (2005) 16:2 *Journal of Disability Policy Studies* 123 at 125 (individuals with disabilities are thought to be “different” by society. The ideology of normalcy, which applies to issues facing individual with disabilities, is based on the idea that “persons of difference necessarily possess a diminished level of personhood” which extends to every aspect of their daily lives).
82. The loss of sexual desire as a side effect to be considered in determining the scope of patients' right to refuse treatment is weighed in, *inter alia*, *In re Orr*, 531 N E (2d) 64 at 74 (Ill App Ct 1988); *In re Roe*, 421 N E (2d) 40 at 54 (Mass Sup Ct 1981); *Jarvis v Levine*, 418 N W (2d) 139 at 145-46 (Minn Sup Ct 1988). See also Tennille & Wright, *supra* note 18 (“[b]eyond having difficulty merely meeting someone interesting with whom to become sexually intimate, an important part of the story for many consumers is the frustrating sexual dysfunction

acknowledges that sexual desire of a person in need of medication is a sufficiently important personal trait so that its diminution must be weighed into the formulation of a medication refusal policy. Yet the law simultaneously denies patients the power and importance of sexual desire with respect to hospital ward life.⁸³

Most states do not recognize a patient's right to personal or interpersonal sexual relationships. In practice, a patient's right to sexual interaction often depends on the whim of line-level staff or on whether such interaction is seen as a feature of the patient's treatment plan. It has even been suggested that "sexual activity between psychiatric inpatients should be strictly prohibited and when it occurs patients should be isolated ... and tranquilized if necessary."⁸⁴ One hospital's guidelines counsel patients as follows: "[i]f you develop a relationship with another patient, staff will get together with you to help decide whether this relationship is beneficial or detrimental to you."⁸⁵ Hospital staff are often hostile to the idea that patients may be sexually active in any way.⁸⁶

However, many institutional mental health professionals and

that occurs from adhering to prescribed psychotropic medication regimes" at 6-7); Peter Bartlett, "'The Necessity Must Be Convincingly Shown to Exist': Standards for Compulsory Treatment for Mental Disorder under the Mental Health Act 1983" (2011) 19:4 *Med L Rev* 514 (antipsychotic medications "cause impotence or other sexual dysfunction in approximately 45% of individuals" at 518); McCann, "Breaking the Taboo", *supra* note 12 at 133 (discussing how full range of antipsychotic medication side-effects "may greatly affect the potential to form relationships").

83. On the ways that the stigma of mental illness increases isolation, and its impact on sexual behaviour and autonomy, see Eric Wright et al, "Stigma and the Sexual Isolation of People with Serious Mental Illness" (2007) 54:1 *Social Problems* 78. On how neglecting consumer sexuality issues reinforces stigma, see Tennille & Wright, *supra* note 18 at 13.
84. Renee Binder, "Sex Between Psychiatric Inpatients" (1985) 57:2 *Psychiatric Quarterly* 121 at 125.
85. Gabor Keitner & Paul Grof, "Sexual and Emotional Intimacy Between Psychiatric Inpatients: Formulating a Policy" (1981) 32:3 *Hospital & Community Psychiatry* 188 at 193. See also Tennille and Wright, *supra* note 18 at 9 (discussing false belief of care providers that "[i]t is the providers' role to protect consumers from romantic rejection").
86. See *e.g.* *Rogers v Okin*, 478 F Supp 1342 at 1373-74 (Mass D 1979) (noting that patients are secluded for engaging in sexual behaviour).

behaviourists now recognize that patients “are and wish to be sexually active,”⁸⁷ and that sexual freedom often has therapeutic value.⁸⁸ Writing about this recently, Andreas Dimopoulos has argued forcefully that, “[b]y seeking to avoid harm to self we are perpetuating oppressive social and legal responses which presented persons with disabilities as asexual, or worse still, as individuals who should be asexual.”⁸⁹

Others call attention to our societal obligation to provide family planning assistance to women institutionalized in psychiatric hospitals.⁹⁰ Nonetheless, many hospitals remain reluctant to promulgate such policies. This is not surprising, given the aforementioned paucity of legal authority requiring them to do so. Moreover, there is a near complete lack of literature generally available to guide hospitals and their staff, should they even desire to formulate such procedures.

There is little case law on the questions addressed in this paper. Of the few litigated cases, the most important is *Foy v Greenblott*.⁹¹ There, an institutionalized patient and her infant child (conceived and born while

87. Steven Welch et al, “Sexual Behavior of Hospitalized Chronic Psychiatric Patients” (1991) 42:8 *Hospital & Community Psychiatry* 855 at 855.

88. Binder, *supra* note 84 at 122.

89. Dimopoulos, *supra* note 1 at 8.

90. See e.g. Virginia Abernethy et al, “Family Planning During Psychiatric Hospitalization” (1976) 46:1 *American Journal of Orthopsychiatry* 154. On the ways that coercive family planning is sometimes imposed in facilities in China, see Sean D Murphy, “Criticism of PRC’s Human Rights Practices” (2000) 94:3 *Am J Int’l L* 526 at 527. On the question of forced contraception, see Carolyn Frohmader & Stephanie Ortoleva, “The Sexual and Reproductive Rights of Women and Girls with Disabilities” (Paper prepared for the ICPD Human Rights Conference on Sexual and Reproductive Health, sponsored by OHCHR, UNFPA, and the Government of the Netherlands, 1 July 2013), online: Women Enabled <<http://womenenabled.org/publications.html>> (“[f]orced contraception, recognised as a form of torture, is commonly used on women and girls with disabilities to suppress menstruation or sexual expression for various purposes, including eugenics-based practices of population control, menstrual management and personal care, and pregnancy prevention (including pregnancy that results from sexual abuse)” at 5). On the relationship of feminist legal theory to disability theory, see Doyle, *supra* note 80.

91. 190 Cal Rptr 84 (Ct App 1983) [*Foy*]. See generally Perlin, “Make Promises by the Hour”, *supra* note 12 at 966-67.

the mother was a patient in a locked psychiatric ward) sued the mother's treating doctor for his failure to either maintain proper supervision over her so as to prevent her from having sex or to provide her with contraceptive devices and/or sexual counseling.⁹²

The Court rejected the plaintiff's claims of improper supervision, finding that institutionalized patients had a right to engage in voluntary sexual relations as an aspect of either the "least restrictive environment" or "reasonably non-restrictive confinement conditions" and that that right (to less or reasonably non-restrictive confinement) included suitable opportunities for the patient's interactions with members of the opposite sex.⁹³ On the other hand, the Court did characterize the defendant's failure to provide the plaintiff with contraceptive devices and counseling as a deprivation of her right to reproductive choice.⁹⁴ It also rejected a claim for "wrongful birth" by the infant child, concluding that "[o]ur society has repudiated the proposition that mental patients will necessarily beget unhealthy, inferior or otherwise undesirable children if permitted to reproduce."⁹⁵

While *Foy* has been applauded as "a model exposition of the reproductive rights of institutionalized women,"⁹⁶ it is an isolated case. A reading of the case law reveals that this area simply does not exist as an active area of patients' rights litigation.⁹⁷

92. *Foy, ibid* at 87.

93. *Ibid* at 90, n 2.

94. *Ibid* at 91-92.

95. *Ibid* at 93.

96. Susan Stefan, "Whose Egg is it Anyway?: Reproductive Rights of Incarcerated, Institutionalized and Incompetent Women" (1989) 13:2 *Nova L Rev* 405 at 433.

97. See Perlin, *Mental Disability Law, supra* note 60 at § 3C-5.1, 416-21 (reviewing developments). See also Dimopoulos, *supra* note 1, discussing – and sharply criticizing – recent British cases of *A Local Authority v H* [2012] EWHC 49 (COP), and *D Borough Council v AB* [2011] EWHC 101 (COP), both of which concluded that individuals with intellectual disabilities did not have the capacity to consent to sexual interaction. A recent case in Israel has found that a person with schizophrenia has a right to family, and that sperm retrieval for this purpose is allowed. See *Ploni v Israel Legal Attorney*, Case # 6036-10-08 (Haifa Family Ct, 29 Dec 2013) (decision, in Hebrew, and explanatory email from Dr. Maya Sabatello, on file with authors).

At the same time, there is little in the way of legislation. By way of example, although many American jurisdictions have enacted “patients’ bills of rights” providing a broad array of civil rights and liberties for persons institutionalized in psychiatric hospitals, only a few jurisdictions mandate a limited right to sexual interaction.⁹⁸

In general, the lack of statutory authority and case law logically leads to the next question: since we are, by all accounts, a fairly litigious group of people, why not? Why hasn’t this area – one that deals with the most personal of rights⁹⁹ – been the subject of greater scrutiny or of court decrees (or even of substantial scholarly writings)?¹⁰⁰ Although there *has*

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98. See *e.g.* Ohio Rev Code, § 5122.29(I) (“[t]he right to social interaction with members of either sex, subject to adequate supervision, unless such social interaction is specifically withheld under a patient’s written treatment plan for clear treatment reasons.”); Mont Code Ann, § 53-21-142(10) (“[p]atients have the right to be provided, with adequate supervision, suitable opportunities for interaction with members of the opposite sex except to the extent that a professional person in charge of the patient’s treatment plan writes an order stating that the interaction is inappropriate to the treatment regimen.”); NJ Stat Ann, § 30:4-24.2(10) (“[[p]atients have the right to] suitable opportunities for interaction with members of the opposite sex, with adequate supervision”).
99. This is especially ironic in that we acknowledge the significance of sexual autonomy in other related areas of law, but ignore it here, see Perlin, “Beyond the Last Frontier?”, *supra* note 17 (“the law acknowledges that sexual desire is a sufficiently important personal trait so that its diminution must be weighed into the formulation of a medication refusal policy. Yet the law simultaneously denies the power and importance of sexual desire with respect to hospital ward life” at 531).
100. There are remarkably few modern law review articles on the global issue of mental patient sexuality published in the US. See *e.g.* Winiviere Sy, “The Right of Institutionalized Disabled Patients to Engage in Consensual Sexual Activity” (2001) 23:2 Whittier Law Review 545; and Evelyn M Tenenbaum, “To Be or to Exist: Standards for Deciding Whether Dementia Patients in Nursing Homes Should Engage in Intimacy, Sex, and Adultery” (2009) 42:3 Ind L Rev 675. See also, discussing Professor Tenenbaum’s work, J Richard Lindsay, “The Need for More Specific Legislation in Sexual Consent Capacity Assessments for Nursing Home Residents” (2010) 31:3 J Legal Med 303 at 306. For a transnational perspective, see Hella von Unger, “The Meaning and Management of Women’s Sexuality in Psychiatric vs. Community Psychiatric Settings in Berlin, Germany” (Paper delivered at the Thirtieth International Congress on Law and Mental Health, in Padua, Italy, 26 June 2007), [unpublished,

been attention paid to this issue in nursing and psychiatric literature,¹⁰¹ there has been virtually no “carryover” to the question of the legal implications of the policies for clinicians (or lack of policies).¹⁰² And, of course, our attitudes exhibit willful blindness to the reality that patients *are* – and likely always have been – sexually active.¹⁰³

We also need to consider how we set priorities in defining the underlying question of how we, as a society, can restructure our laws regarding the autonomy of individuals with disabilities to engage in sexual activities of their choice. What do we look at first: autonomy rights, civil libertarian concerns, due process requirements, privacy interests, competency criteria, clinical needs, therapeutic jurisprudential concerns, tort liability worries, voluntariness constructs, or the immutable fact that sexual interaction, by its very description, entails the participation of more than one individual? No resolution of the underlying issues can be contemplated unless we distinguish these approaches and carefully

powerpoint on file with author], cited in Perlin, “Everybody is Making Love”, *supra* note 46 at 489, n 33.

101. See *e.g.* Diane J Torkelson & May T Dobal, “Sexual Rights of Persons with Serious and Persistent Mental Illness: Gathering Evidence for Decision Making” (1999) 5:5 *Journal of the American Psychiatric Nurses Association* 150; May T Dobal & Diane J Torkelson, “Making Decisions about Sexual Rights in Psychiatric Facilities” (2004) 18:2 *Archives of Psychiatric Nursing* 68; Eddie McCann, “Exploring Sexual and Relationship Possibilities for People with Psychosis – A Review of the Literature” (2003) 10:6 *Journal of Psychiatric and Mental Health Nursing* 640; Ronald WD Stevenson, “Sexual Medicine: Why Psychiatrists Must Talk to Their Patients about Sex” (2004) 49:10 *Canadian Journal of Psychiatry* 673.
102. See Perlin, “Beyond the Last Frontier?”, *supra* note 17 (“many hospitals remain reluctant to promulgate such policies” at 532); but compare Dobal & Torkelson, *supra* note 101 at 68 (60% of psychiatric facilities polled reported having such policies).
103. Perlin, “Beyond the Last Frontier?”, *supra* note 17 at 532; Welch et al, *supra* note 87 at 855. See Susan Stefan, “Joshua’s Children: Constitutional Responsibility for Institutionalized Persons after *Deshaney v. Winnebago County*” (2013) 70:1 *Wash & Lee L Rev* 793 (“[s]exual activity in institutional settings is more common than outsiders might imagine, and runs that gamut from mutual and supportive relationships between patients through exploitation, coercion, and rape by other patients and staff” at 800).

articulate their interrelationships, their potential conflicts, and their relative values as competing social choices. In short, this is a very difficult project.

III. Other Approaches

A. International Human Rights

Scholars have begun in recent years to focus more carefully and thoughtfully on the relationship between mental disability law and international human rights law.¹⁰⁴ In our own writing, we have explored this connection in the context of forensic facility conditions, correctional law, appointment of counsel, psychological evaluations in criminal cases, and how the law shames and humiliates persons with mental disabilities.¹⁰⁵

104. See *e.g.* Aaron Dhir, “Human Rights Treaty Drafting Through the Lens of Mental Disability: the Proposed International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities” (2005) 41:2 *Stan J Int’l L* 181; Paul Harpur, “Time to Be Heard: How Advocates Can Use the Convention on the Rights of Persons with Disabilities to Drive Change” (2011) 45:3 *Val U L Rev* 1271; Bryan Y Lee, “The U.N. Convention on the Rights of Persons with Disabilities and Its Impact upon Involuntary Civil Commitment of Individuals with Developmental Disabilities” (2011) 44:3 *Colum JL & Soc Probs* 393; István Hoffman & György Könczei, “Legal Regulations Relating to the Passive and Active Legal Capacity of Persons with Intellectual and Psychosocial Disabilities in Light of the Convention on the Rights of Persons with Disabilities and the Impending Reform of the Hungarian Civil Code” (2010) 33:1 *Loy LA Int’l & Comp L Rev* 143.

105. See *e.g.* Perlin, *International Human Rights*, *supra* note 7; Perlin & Schriver, *supra* note 63; Michael L Perlin, “‘A Change Is Gonna Come’: The Implications of the United Nations Convention on the Rights of Persons with Disabilities for the Domestic Practice of Constitutional Mental Disability Law” (2009) 29:3 *N Ill UL Rev* 483; Michael L Perlin & Valerie R McClain, “‘Where Souls Are Forgotten’: Cultural Competencies, Forensic Evaluations and International Human Rights” (2009) 15:4 *Psychol Pub Pol’y & L* 257; Astrid Birgden & Michael L Perlin, “‘Tolling for the Luckless, the Abandoned and Forsaked’: Therapeutic Jurisprudence and International Human Rights Law As Applied to Prisoners and Detainees by Forensic Psychologists” (2008) 13:2 *Legal & Criminological Psychology* 231; Michael L Perlin, “‘I Might Need a Good Lawyer, Could Be Your Funeral, My Trial’: Global Clinical Legal Education and the Right to Counsel in Civil Commitment Cases” (2008) 28 *Wash UJL & Pol’y* 241; Perlin & Lynch, *supra* note

We believe that the ratification of the *Convention on the Rights of Persons with Disabilities* demands that society and legislators alike reconsider this entire issue. First, the CRPD mandates nations to “[p]rovide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes.”¹⁰⁶ Beyond that, the other Convention Articles referred to above speak to dignity, the absence of discrimination, and the provision of sexual/reproductive health services.¹⁰⁷ The Convention goes further than most legislation and court decisions, directly addressing not only the freedom to engage in sex, but *outcomes* of sexual activity, by codifying the disabled person’s right to form a family, right to information and services for sexual health, and notably, the right to “retain their fertility on an equal basis with others.”¹⁰⁸ Yet, even given the specific and detailed language of the CRPD, the literature has been remarkably silent on these issues in general, especially as they relate to the CRPD’s impact on the rights of persons institutionalized due to psychosocial or intellectual disability, to sexual autonomy.¹⁰⁹ This

63; Michael L Perlin & Naomi Weinstein, “‘Friend to the Martyr, a Friend to the Woman of Shame’: Thinking About The Law, Shame and Humiliation” (2014) *Southern California Review of Law and Social Justice* [in press].

106. CRPD, *supra* note 7, Article 25.

107. See *supra* notes 8-10 and accompanying text.

108. CRPD, *supra* note 7, Article 23.

109. There has been only sporadic attention paid to sexuality issues in the country reports issued by the UN Committee on the Rights of Persons with Disabilities; see Committee on the Rights of Persons with Disabilities, *Implementation of the Convention on the Rights of Persons with Disabilities*, online: United Nations High Commissioner for Human Rights <<http://www.ohchr.org/en/hrbodies/crpd/pages/crpdindex.aspx>>; Committee on the Rights of persons with Disabilities, *Implementation of the Convention on the Rights of Persons with Disabilities*, OHCHR, 10th Sess, CRPD/C/AUS/1, (2012) (Australia, the sole mention of sexuality issues: “[t]he WA Department of Health funds the Sexuality Education Counselling and Consulting Service, which develops and implements health promotion programs to enhance the health and wellbeing of persons with disabilities and educate the wider community in areas of sexuality and disability” at 33, para 152); Committee on the Rights of Persons with Disabilities, *Implementation of the Convention on the Rights*

takes on even more significance when we consider how, in at least one CRPD signatory nation (China), the prevailing governmental policy is to prevent “pre-birth disabilities” via compelled abortion.¹¹⁰

Three scholarly articles in the literature stand out as lone examples of what scholars should focus their attentions on: (1) Maya Sabatello’s paper on the intersection between infertility, reproductive technologies and disability rights law;¹¹¹ (2) Sabatello’s paper on how sexuality was considered in the debate on the CRPD;¹¹² and (3) most directly, Marta Schaaf’s article on sexuality in the context of the CRPD.¹¹³ Drawing on

of Persons with Disabilities, OHCHR, 10th Sess, CRPD/C/AUT/1, (2011) (Austria: “[several disability organizations] stress that people with disabilities also have a right to sexuality, partnership and family. Education and information on the issues of sterilisation and abortion is often insufficient” at 35, para 235); Committee on the Rights of Persons with Disabilities, *Implementation of the Convention on the Rights of Persons with Disabilities*, OHCHR, 10th Sess CRPD/C/SLV/1, (2011) (El Salvador: “[i]n order to enhance the effectiveness of the Government’s sexual and reproductive health programmes, it is nonetheless important to provide for the various means of personal expression used by persons with disabilities, such as Braille or Salvadoran sign language, thereby ensuring that everyone has the information they need to make informed decisions” at 29, para 153); Committee on the Rights of Persons with Disabilities, *Implementation of the Convention on the Rights of Persons with Disabilities*, OHCHR, 9th Sess, CRPD/C/PRY/1, (2011) (Paraguay: no mention of sexuality issues).

110. See Yee-Fui Ng, “Disability Rights v. Quality Birth Rhetoric: The Construction of Disability in China” (2012) *LAWASIA Journal* 1 at 1-2. On forced or coerced abortion in this context in general, see Frohmader & Ortoleva, *supra* note 90.
111. Maya Sabatello, “Who’s Got Parental Rights? The Intersection Between Infertility, Reproductive Technologies, and Disability Rights Law” (2010) 6:2 *Journal of Health & Biomedical Law* 227 [Sabatello, “Who’s Got Parental Rights?”]. See generally Stevens, *supra* note 11 (“[a]nother crucial issue in the lives of disabled people is the experience of legal intervention to deny parental rights. Denial of parental rights occurs across types of disabilities but occurs perhaps most fervently with intellectually and developmentally disabled people – as in many cases they lack the autonomy to consent to sexual activity, the choice to reproduce, and the ability to retain children after birth” at 16).
112. Sabatello, “Disability, Human Rights and Global Health”, *supra* note 1.
113. Marta Schaaf, “Negotiating Sexuality in the Convention on the Rights of Persons with Disabilities” (2011) 8:14 *Sur International Journal on Human Rights* 113.

Articles 2 (one of the “reasonable accommodation” articles), 23, and 26, Sabatello concludes that the CRPD provides a “possible venue to further advance a right to found a family through “assisted reproductive technologies.”¹¹⁴ In assessing the drafting process, Sabatello notes how all conversations about sexuality “raised acute debates,”¹¹⁵ and that, as a result, sexuality *per se* “was not elevated to a right.”¹¹⁶ Schaaf – who frontally notes that disabled sexuality is often perceived as a “threat to others”¹¹⁷ – discussed the “tension” that underlay the negotiations leading to the adoption of the CRPD “between efforts to promote sexual rights and efforts to protect PWDs [persons with disabilities] from unwanted sterilization.”¹¹⁸ Further, Schaaf notes that disability-focused NGOs “continue to be reluctant to engage sexuality,”¹¹⁹ but concludes that “[s]exual rights as a rubric of rights’ claiming will likely continue to grow, providing greater and better opportunities to move beyond current understandings of sexual citizenship to include disabled and all other bodies.”¹²⁰

Professor Michael Stein and Professor Janet Lord have written eloquently about how *another* Article in the convention – Article 30, setting out social rights of participation in cultural life – “serves as a vital channel of engagement with society when such participation is embraced by the community,” and increases “self-reliance and empowerment.”¹²¹

114. Sabatello, “Who’s Got Parental Rights?”, *supra* note 111 at 259.

115. Sabatello, “Disability, Human Rights and Global Health”, *supra* note 1 at manuscript 23.

116. *Ibid* at manuscript 25. On the opposition of the Arab Group of nations, the Holy See and Yemen to expanded mention of sexuality – unmoored from traditional marriage – see *ibid* at manuscript 23-24.

117. Schaaf, *supra* note 113 at 114.

118. *Ibid* at 124.

119. *Ibid*.

120. *Ibid* at 125.

121. Michael Ashley Stein & Janet E Lord, “Jacobus tenBroek, Participatory Justice, and the UN Convention on the Rights of Persons with Disabilities” (2008) 13:2 Texas Journal of Civil Liberties & Civil Rights 167 at 182, discussed extensively in Michael L Perlin, “‘Through the Wild Cathedral Evening’: Barriers, Attitudes, Participatory Democracy, Professor tenBroek, and the Rights of Persons with Mental Disabilities” (2008) 13:2 Texas Journal of Civil Liberties & Civil Rights 413 at 413-16.

Other commentators have concluded that the Convention “is regarded as having finally empowered the ‘world’s largest minority’ to claim their rights, and to participate in international and national affairs on an equal basis with other minority groups who have achieved specific treaty recognition and protection.”¹²²

The CRPD Committee has already begun to outline legislation and policies required to ensure implementation, a process that may prove useful in addressing the many unanswered questions posed in this paper. The Committee has worked on issuing recommendations for services and programs aimed at people with disabilities to assist them in informed decision-making, regardless of whether they are institutionalized or not.¹²³ These programs would work on mainstreaming disability issues into legislation, and disseminating information about sexual and reproductive health in an accessible format for individuals who want to become informed about their right to engage in sexual activity.¹²⁴ Further, the Committee supports teaching sexual health to children with intellectual disabilities.¹²⁵

If the Convention is taken seriously – if it is, in fact, more than

122. See *e.g.* Kayess & French, *supra* note 52 (“[s]ee, for example, statements made by the High Commissioner for Human Rights, Louise Arbour, and the Permanent Representative of New Zealand and Chair of the Ad-Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, Ambassador Don Mackay, at a Special Event on the Convention on Rights of Persons with Disabilities ... convened by the UN Human Rights Council, 26 March 2007, available at [http://www.unog.ch/80256EDD006B9C2E/\(httpNewsByYear\)/7444B2E219117CE8C12572AA004C5701?OpenDocument](http://www.unog.ch/80256EDD006B9C2E/(httpNewsByYear)/7444B2E219117CE8C12572AA004C5701?OpenDocument)” at 4, n 17).

123. UN Committee on the Rights of Persons with Disabilities, Guidelines on Treaty-Specific Document to Be Submitted by State Parties Under Article 35, Paragraph 1, of the Convention on the Rights of Persons with Disabilities (UN Document CRPD/C/2/3, October 2009) [Guidelines on Treaty-Specific Document], online: United Nations High Commissioner for Human Rights <<http://www.ohchr.org/Documents/HRBodies/CRPD/CRPD-C-2-3.pdf>>.

124. Girlescu, *supra* note 3 at 21; Guidelines on Treaty-Specific Document, *ibid* at 123.

125. Guidelines on Treaty-Specific Document, *ibid*.

a “paper victory”¹²⁶ – then, perhaps, it can be a vehicle to uproot that aspect of sanism that continues to deny the institutionalized persons the rights to their own sexuality.¹²⁷ Throughout the CRPD, it is apparent that the preferences and decisions of persons with disabilities must be respected and promoted. Expanding on this idea of self-determination, it follows that decisions about sex, sexuality, and reproduction are to be made by the person with a disability, rather than a “caretaker” or a facility superintendent. This kind of decision-making is a core element of self-determination and empowerment that is promoted by the CRPD.¹²⁸ However, in order to bring about such a dramatic shift in thinking (and translating that to concrete action which will allow for such decisions to be made by persons with disabilities) on this issue, it is necessary that other scholars follow the lead of Professors Sabatello and Schaaf to

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126. Michael L Perlin, “‘What’s Good is Bad, What’s Bad is Good, You’ll Find out When You Reach the Top, You’re on the Bottom’: Are the Americans with Disabilities Act (and *Olmstead v. L.C.*) Anything More Than ‘Idiot Wind?’” (2002) 35:1-2 U Mich JL Ref 235 (“[m]ental disability law is strewn with examples of ‘paper victories’” at 246), quoting Michael Lottman, “Paper Victories and Hard Realities” in Valerie J Bradley & Gar J Clarke, eds, *Paper Victories and Hard Realities: The Implementation of the Legal and Constitutional Rights of the Mentally Disabled* (Washington, DC: Georgetown University, 1976) at 93. In the specific context of other United Nations Conventions, see Sara Dillon, “What Human Rights Law Obscures: Global Sex Trafficking and the Demand for Children” (2008) 17:1 UCLA Women’s LJ 121 (“[a] specialized human rights convention does not in itself guarantee substantial change” at 154).
127. There is some evidence that in other jurisdictions, parallel rights are being taken seriously. See e.g. *Convention for the Protection of Human Rights and Fundamental Freedoms, as amended by Protocols No. 11 and No. 14, Nov. 1*, Art 8(1), online: Council of Europe <<http://conventions.coe.int/>>; as construed in *X v Iceland*, (1976) 5 DR 86 at 87 (Article 8 prohibiting public authorities from interfering with a person’s right “to respect for his private and family life, his home and his correspondence” is broad enough to encompass an entitlement “to establish and to develop relationships with other human beings, especially in the emotional field for the development and fulfillment of one’s own personality”). This issue is discussed in Lawrence O Gostin & Lance Gable, “The Human Rights of Persons with Mental Disabilities: A Global Perspective on the Application of Human Rights Principles to Mental Health” (2004) 63:1 Md L Rev 20 at 94.
128. Girdlescu, *supra* note 3 at 19.

seriously engage this topic.¹²⁹

B. Therapeutic Jurisprudence

Another important lens through which to view this issue is that of therapeutic jurisprudence (TJ). Therapeutic jurisprudence “asks us to look at law as it actually impacts people’s lives”¹³⁰ and focuses on the law’s influence on emotional life and psychological well-being.¹³¹ It suggests that “law should value psychological health, should strive to avoid imposing anti-therapeutic consequences whenever possible, and when consistent with other values served by law, should attempt to bring about healing and wellness.”¹³² The ultimate aim of therapeutic jurisprudence is to determine whether legal rules, procedures, and lawyers’ roles can or should be reshaped to enhance their therapeutic potential, while refraining from subordination of due process principles.¹³³ There is an

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129. See *e.g.* Willene Holness, “Informed Consent for Sterilisation of Women and Girls with Disabilities in the Light of the Convention on the Rights of Persons with Disabilities” (2013) 27:4 *Agenda: Empowering Women for Gender Equity* 35 (questioning whether South Africa’s sterilization law meets the requirements of the CRPD, and concluding that the enhancement of the decision-making capacities of the population in question will require “demystifying the sexuality of women with disabilities”). On how sexual health for persons with intellectual disabilities is a rights issue under the CRPD, see Foley & Kelly, *supra* note 31 at 20.
130. Bruce J Winick, “Foreword: Therapeutic Jurisprudence Perspectives on Dealing With Victims of Crime” (2009) 33:2 *Nova L Rev* 535 at 535.
131. See David B Wexler, “Practicing Therapeutic Jurisprudence: Psycholegal Soft Spots and Strategies” in Daniel P Stolle, David B Wexler & Bruce J Winick, eds, *Practicing Therapeutic Jurisprudence: Law as a Helping Profession* (Durham, NC: Carolina Academic Press, 2000) at 45.
132. Bruce J Winick, “A Therapeutic Jurisprudence Model for Civil Commitment” in Kate Diesfeld & Ian Freckelton, eds, *Involuntary Detention and Therapeutic Jurisprudence: International Perspective on Civil Commitment* (Great Britain: Ashgate Publishing, 2003) 23 at 26.
133. See Michael L Perlin, “‘And My Best Friend, My Doctor, Won’t Even Say What it is I’ve Got’: The Role and Significance of Counsel in Right to Refuse Treatment Cases” (2005) 42:2 *San Diego L Rev* 735 at 751 [Perlin, “Role of Counsel”]; Perlin & Lynch, “All his Sexless Patients”, *supra* note 69 at 277-78; Perlin, “Everybody is Making Love”, *supra* note 46 at 510, n 139; Perlin, “Striking for the Guardians”, *supra* note 52 at 1184. See also Michael L Perlin, “Baby, Look Inside Your Mirror”:

inherent tension in this inquiry, but David Wexler clearly identifies how it must be resolved: the law's use of "mental health information to improve therapeutic functioning [cannot] impinge upon justice concerns."¹³⁴ As one of the authors (MLP) has written elsewhere, "an inquiry into therapeutic outcomes does not mean that therapeutic concerns 'trump' civil rights and civil liberties."¹³⁵ In its aim to use the law to empower individuals, enhance rights, and promote well-being, TJ has been described as "a sea-change in ethical thinking about the role of law ... a movement towards a more distinctly relational approach to the practice of law ... which emphasises psychological wellness over adversarial triumphalism."¹³⁶ That is, TJ supports an ethic of care.¹³⁷

The Legal Profession's Willful and Sanist Blindness to Lawyers with Mental Disabilities" (2008) 69:3 U Pitt L Rev 589 at 591 [Perlin, "Sanist Blindness"] (discussing how TJ "might be a redemptive tool in efforts to combat sanism, as a means of 'strip[ping] bare the law's sanist façade"); Bernard P Perlmutter, "George's Story: Voice and Transformation through the Teaching and Practice of Therapeutic Jurisprudence in a Law School Child Advocacy Clinic" (2005) 17:2 St Thomas L Rev 561 at 599, n 111; Ian Freckelton, "Therapeutic Jurisprudence Misunderstood and Misrepresented: The Price and Risks of Influence" (2008) 30:2 Thomas Jefferson L Rev 575 at 585-86.

134. See David B Wexler, "Therapeutic Jurisprudence and Changing Concepts of Legal Scholarship" (1993) 11:1 Behav Sci & L 17 at 21; see also David Wexler, "Applying the Law Therapeutically" (1996) 5:3 Applied & Preventive Psychology 179.
135. Michael L Perlin, "A Law of Healing" (2000) 68:2 U Cin L Rev 407 at 412; Michael L Perlin, "'Where the Winds Hit Heavy on the Borderline': Mental Disability Law, Theory and Practice, Us and Them" (1998) 31:3 Loy LA L Rev 775 at 782.
136. Warren Brookbanks, "Therapeutic Jurisprudence: Conceiving an Ethical Framework" (2001) 8 Journal of Law & Medicine 328 at 329-30; see also Bruce J Winick, "Overcoming Psychological Barriers to Settlement: Challenges for the TJ Lawyer" in Marjorie A Silver, ed, *The Affective Assistance of Counsel: Practicing Law as a Healing Profession* (Durham, NC: Carolina Academic Press, 2007) 341; Bruce J Winick & David B Wexler, "The Use of Therapeutic Jurisprudence in Law School Clinical Education: Transforming the Criminal Law Clinic" (2006) 13:1 Clinical L Rev 605 at 605-06. The use of the phrase dates to Carol Gilligan, *In a Different Voice* (Cambridge, Mass: Harvard University Press, 1982).
137. See e.g. Winick & Wexler, *supra* note 136 at 605-07; David B Wexler, "Not Such a Party Pooper: An Attempt to Accommodate (Many of) Professor Quinn's Concerns about Therapeutic Jurisprudence Criminal

One of the central principles of TJ is a commitment to dignity.¹³⁸ Professor Amy Ronner describes the “three Vs” as voice, validation, and voluntariness,¹³⁹ arguing:

What “the three Vs” commend is pretty basic: litigants must have a sense of voice or a chance to tell their story to a decision maker. If that litigant feels that the tribunal has genuinely listened to, heard, and taken seriously the litigant’s story, the litigant feels a sense of validation. When litigants emerge from a legal proceeding with a sense of voice and validation, they are more at peace with the outcome. Voice and validation create a sense of voluntary participation, one in which the litigant experiences the proceeding as less coercive. Specifically, the feeling on the part of litigants that they voluntarily partook in the very process that engendered the end result or the very judicial pronouncement that affects their own lives can initiate healing and bring about improved behavior in the future. In general, human beings prosper when they feel that they are making, or at least participating in, their own decisions.¹⁴⁰

The question to be addressed here is this: given the way we deny the sexuality rights of persons with disabilities, is it remotely possible that Professor Ronner’s vision – of voice, voluntariness and validation – will be fulfilled? In a thoughtful analysis of the underlying issues, Professor Julie Tennille has listed multiple benefits of a “communicative climate” for consumers with regard to sexuality issues.¹⁴¹ Janine Benedet

Defense Lawyering” (2007) 48:3 BCL Rev 597 at 599; Brookbanks, *supra* note 136; Gregory Baker, “Do You Hear the Knocking at the Door? A “Therapeutic” Approach to Enriching Clinical Legal Education Comes Calling” (2006) 28:1 Whittier Law Review 379 at 385.

138. See Bruce J Winick, *Civil Commitment: A Therapeutic Jurisprudence Model* (Durham, NC: Carolina Academic Press, 2005) at 161.

139. Amy D Ronner, “The Learned-Helpless Lawyer: Clinical Legal Education and Therapeutic Jurisprudence as Antidotes to Bartleby Syndrome” (2008) 24:4 Touro L Rev 601 at 627. On the importance of “voice,” see Freckelton, *supra* note 133 at 588.

140. Amy D Ronner, “Songs of Validation, Voice, and Voluntary Participation: Therapeutic Jurisprudence, Miranda and Juveniles” (2002) 71:1 U Cin L Rev 89 at 94-95.

141. See Tennille & Wright, *supra* note 18 (“[h]ealthy sexual relationships can foster development and maintenance of new relationships, a key element in social integration; positive sexual partnerships can increase quality of life, and those with mental health conditions who maintain relationships often have better treatment outcomes; some research indicates that hospital readmission rates dropped if consumers were able to develop romantic relationships; and stigma of mental illness may be reduced” at 13-14).

and Isabel Grant have also used a therapeutic jurisprudential filter in weighing these issues.¹⁴² Both commentators have considered how to define “capacity to consent”¹⁴³ and “engage in sexual activities,”¹⁴⁴ and how to ensure that such definitions remain person-centered and allow for a “situational approach”¹⁴⁵ to each case. They write: “incapacity can and should be defined situationally – in a functional manner that maximizes [a person’s] sexual self-determination.”¹⁴⁶ However, Benedet and Grant’s thoughtful analysis and emphasis on the individual and his or her self-determination – two concepts linked with dignity – have not been greatly expanded upon in case law or legislation so as to give life to the therapeutic jurisprudential lens that they employ to view these issues of sexuality.

Twenty years ago, one of us (MLP) wrote the following about sexuality issues in the domestic context, and we believe that little has changed in the intervening two decades:

We must also question the therapeutic or antitherapeutic implications of official hospital policies that control the place, manner, and frequency with which such individuals can have sexual interactions. We must consider the implications of these policies on ward life and their implications for patients’ post-hospital lives. These questions are difficult ones, but we must ask them nonetheless if we wish to formulate a thoughtful, comprehensive response to the wide range of questions this subject raises.¹⁴⁷

How does this all “fit” with the CRPD? We believe that the Convention “is a document that resonates with TJ values,”¹⁴⁸ and that it reflects the three principles articulated by Professor Ronner – voice, validation and voluntariness,¹⁴⁹ by looking at law “as it actually impacts people’s lives.”¹⁵⁰ Each section of the CRPD empowers persons with mental disabilities, and one of the major aims of TJ is explicitly the empowerment of those

142. Janine Benedet & Isabel Grant, “A Situational Approach to Incapacity and Mental Disability in Sexual Assault Law” (2013) 43:1 Ottawa L Rev 447.

143. *Ibid* at 456.

144. *Ibid* at 453.

145. *Ibid* at 466.

146. *Ibid* at 450.

147. Perlin, “Beyond the Last Frontier?”, *supra* note 17 at 547.

148. Perlin, “Striking for the Guardians”, *supra* note 52 at 1188.

149. Ronner, *supra* note 140 at 94-95.

150. Perlin, *International Human Rights*, *supra* note 7 at 21.

whose lives are regulated by the legal system.¹⁵¹ The CRPD is, in many ways, a TJ blueprint. It privileges autonomy, promotes dignity, and values psychological health. If TJ encourages the law to “enhance [its] therapeutic potential,”¹⁵² enforcement of the CRPD serves that enforcement role in the way that persons with mental disabilities are treated with regard to their sexual being. If a TJ perspective is adopted, that will also be the best way to ensure that the sanism that pervades the law’s treatment of persons with mental disabilities on questions of sexuality and sexual expression is rooted out of the system.¹⁵³

If institutionalized persons with mental disabilities are granted the same sexual autonomy that the rest of us have, the former population will be given a voice. If persons with mental disabilities are allowed voluntary sexual interaction, that, by definition, provides the sort of participatory experience that leads to a sense of voluntariness within a therapeutic jurisprudence framework. And together, the grant of sexual autonomy and the concomitant right to voluntary sexual interaction help increase the self-validation of those in question.

We hope that scholars and advocates take seriously the intersection between sexuality issues, TJ issues and human rights issues, and turn their attention more fully to this question in future years.

IV. Conclusion

As society in general becomes increasingly open and direct about sex and sexuality, “[a]ided by the values of a consumer culture and encouraged by the growing visibility of sex in the public realm, many now regard sexual pleasure as a legitimate component of their lives.”¹⁵⁴ This openness and

151. *Ibid.* See also, e.g. Astrid Birgden & Michael L Perlin, “‘Where the Home in the Valley Meets the Damp Dirty Prison’: A Human Rights Perspective on Therapeutic Jurisprudence and the Role of Forensic Psychologists in Correctional Settings” (2009) 14:4 *Aggression & Violent Behavior* 256.

152. See e.g. Perlin, “Role of Counsel”, *supra* note 133 at 751.

153. Perlin, “Neonaticide”, *supra* note 48 at 25. On “[t]he peculiar interplay between sanism and sexuality” see Perlin, “Everybody is Making Love”, *supra* note 46 at 506; see generally Perlin, “Sanist Blindness”, *supra* note 133 at 591 (discussing how TJ “might be a redemptive tool in efforts to combat sanism, as a means of ‘strip[ping] bare the law’s sanist façade”).

154. Raie Goodwach, “Sex Therapy: Historical Evolution, Current Practice.

directness must be allowed to extend to persons with disabilities if full equality for this population is to be achieved.

Given the lack of statutory authority, case law, and scholarly articles within this topic, we can only offer conclusions based on our beliefs on the rights of persons with disabilities to their sexual autonomy. There is minimal research to analyze, few statutes to interpret, and few articles to debate; rather, we must rely on the school of thought that upholds equality in every aspect of life for persons with disabilities. The CRPD and the guidelines of therapeutic jurisprudence offer us a starting point from which to offer recommendations for scholars, lawmakers, clinicians, and those with mental disabilities.

First, sexual issues must be seen as multi-textured, and the meaning of “sex” must be carefully defined.

Second, we ignore cultural attitudes at our own risk.

Third, many of the critical issues – behavioural, legal, social, and political – remained unanswered, in large part because of the taboos that surround this entire area of law, policy, and social inquiry. This all remains very under-discussed because we are still so astonishingly uncomfortable thinking about the questions at hand. We desire to close our eyes to the reality that persons with mental disabilities are sexual beings, and close our minds to the fact that their sexuality may be much more like “ours” than it is different.

Fourth, the UN Convention – finally – forces us to reconsider how myopic we continue to be about these issues, and realize that sexuality rights are rights that must be enforced.

Fifth, application of a therapeutic jurisprudence lens to this question forces us to confront how the core principles of TJ are regularly disregarded in our social responses to these issues, and that the three V’s articulated by Professor Ronner are rarely, if ever, honoured.

Sixth, the use of the TJ filter – in the context of the articulated principles of international human rights law – offers us a means of approaching these questions in a new and, potentially, socially redemptive

Part I” (2005) 26:3 Australian & New Zealand Journal of Family Therapy 155 at 157; see also Appel, *supra* note 36 at 154 (on the fundamentality of sexual pleasure as a right).

way, and in a way that, optimally, erases sanist attitudes.

In *Love Is Just a Four-Letter Word*, Bob Dylan characterizes love, in the context of the relationship about which he is singing as “unmentionable by name.”¹⁵⁵ Love and sex have forever been “unmentionable by name” when we discuss persons with mental disabilities, especially those who are institutionalized, notwithstanding the revolutions that we have seen in the past four decades: sexual revolutions, civil rights revolutions, and disability rights revolutions.¹⁵⁶ And these issues – in the context of this paper – have become even more pointed in the years since the international human rights movement and the mental disability law movement have been joined, and the CRPD ratified.¹⁵⁷ Perhaps, now, we can finally devote to this area of law and policy the attention it deserves.

155. Dylan, *supra* note 20.

156. Perlin, *International Human Rights*, *supra* note 7 at 547.

157. See *e.g.* Michael L Perlin & Eva Szeli, “Mental Health Law and Human Rights: Evolution and Contemporary Challenges” in Michael Dudley, Derrick Silove & Fran Gale, eds, *Mental Health and Human Rights: Vision, Praxis, and Courage* (Oxford: Oxford University Press, 2012) 80 at 98.

Putting Health To Rights: A Canadian View on Global Trends in Litigating Health Care Rights

Bryan Thomas* & Colleen M Flood**

The majority of the world's constitutions now include mention of a right to health or health care. Will the courts be effective at championing the health rights of vulnerable populations? Courts recognize that health systems embody complex tradeoffs, and have struggled to draw a principled line of deference to government decision-making. Worldwide, one finds courts drawing this line in various ways, depending, among other things, on their country's constitutional aspirations, the maturity and internal accountability of its health system, and broader currents of social mobilization. For their part, Canadian courts have been very restrained, conceptualizing health rights largely in negative terms – overturning restrictions on access to abortion, medical marijuana, and so on – while refusing to recognize any positive duty on the part of government to provide particular health services. Could Canadian courts do more, without tumbling into overreach? The paper ends by sketching options for a more robust and progressive approach to adjudicating health rights claims.

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- I. INTRODUCTION
 - II. THE CENTRAL DILEMMA IN ADJUDICATING HEALTH RIGHTS
 - III. HEALTH CARE RIGHTS IN CONTEXT
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I. Introduction

The majority of the world's constitutions now include mention of a right to health or health care.¹ Though in some countries health rights are purely symbolic or aspirational, it is often assumed that courts will play a role in holding governments accountable under these rights.² Proponents of a rights-based approach believe (or hope) that "[r]ights remove discretion from development and provide a framework of accountability. Rights ensure services for the most marginalised and vulnerable populations, making it hard to claim progress by reference to

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1. Office of the UN High Commission for Human Rights, *The Right to Health: Fact Sheet No. 31* (Geneva: UN High Commission for Human Rights, 2008).
 2. A recent study finds that approximately 70% of constitutions worldwide contain health-related guarantees, while the right is justiciable in approximately 40%. See Courtney Jung, Ran Hirschl & Evan Rosevear, "Economic and Social Rights in National Constitutions," *Am J Comp L* [forthcoming] at 6-9, online: Social Science Research Network <http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2349680>.

numerical aggregates.”³ Will health rights live up to this promise?⁴

Answering this question is difficult as a thorough comparative analysis is complicated, perhaps insurmountably, by various confounding factors. Still, we can marshal what empirical evidence there is and rely on insights from experts in health law and policy across different countries witnessing the litigation of health care rights. In what follows, we explore the contextual factors that shape the impact of health care rights, moving from global trends to the specifics of the Canadian context. As a starting point, in Part I (below) we provide an overview of the basic dilemma facing courts as they venture into the adjudication of health care rights, namely, the challenge of staking out a legitimate institutional role and avoiding overreach into areas that are the purview of elected or executive bodies. This dilemma does not arise in a vacuum, however, and Part II explores some of the contextual factors that shape courts’ approaches to the adjudication of health rights, including national aspirations and constitutional traditions, the maturity of existing health systems, their mix of public/private financing and administration and broader currents of social mobilization. As explained, these contextual factors may partly explain Canadian courts’ general conservatism vis-à-vis health rights, as compared to the bolder approach taken by courts in other countries.

Of course, context does not wholly determine the path of health rights. Canadian courts have made pivotal interpretive choices, which have seriously limited the effectiveness of rights as an accountability mechanism in health care for marginalized groups. Part III explores Canadian jurisprudence in this arena, focusing on the Supreme Court’s largely ‘negative’ conception of the rights to life and security of the person, and its very restrained reading of the section 15 equality guarantee as it applies to health. To date, these rights have done little

3. Michel Sidibe & Kent Buse, “Global Health Governance After 2015 – Authors’ Reply” *The Lancet* (21 September 2013) 382:9897, online: [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(13\)61967-4/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(13)61967-4/fulltext).
4. Our discussion focuses largely on rights to *health care*, as this has been the primary focus of litigation in Canada and abroad. For ease of expression we will occasionally use the terms ‘health rights’ or ‘right to health,’ though strictly speaking this encompasses a broader range of interests (*e.g.* rights to public health prevention and equitable health outcomes).

to ensure accountability to vulnerable populations, and indeed the negative interpretation favoured by the Court is being used to challenge the legal foundations of universal health care.⁵ Even taking into account the contextual factors that recommend judicial restraint in the Canadian context, the results have been disappointing. As will be explained, courts in similarly-situated countries, such as the UK, have had success in pressing for greater accountability in health care decision-making, while heeding the concern about overreach.

II. The Central Dilemma in Adjudicating Health Rights

Though jurisdictions vary considerably in their approach to conceptualizing and enforcing health care rights, a basic concern arises irrespective of context – over the legitimacy of having courts oversee the allocation of health care resources. Decisions about the allocation of health care resources are ‘polycentric’ by nature, requiring robust evidence of complex tradeoffs at a systems level,⁶ while the courts’ institutional competence lies, it is claimed, in adjudicating discrete conflicts between two parties. As Christopher P. Manfredi and Antonia Maioni argue,

The strength of the adversarial system is its capacity to sort through the historical facts about past events that transpired between disputing parties in order to implement retrospective remedies that will restore each party to the status it enjoyed prior to the dispute. By contrast, general policy formation requires the analysis of complex social facts about the relationship between ongoing phenomena in order to regulate those relationships prospectively.⁷

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5. *Chaoulli v Quebec (Attorney General)*, 2005 SCC 35 [*Chaoulli*]; *Canadian Independent Medical Clinics Association v Medical Services Commission of British Columbia* (28 January 2009), Vancouver S-090663 (BCSC) (Writ of Summons of Plaintiffs) online: Medicare.ca <<http://medicare.ca/wp-content/uploads/2009/05/cimcawrit.pdf>>.
 6. Lon Fuller & Kenneth Winston, “The Forms and Limits of Adjudication” (1978) 92:2 Harv L Rev 353.
 7. Christopher P Manfredi & Antonia Maioni, “Judicializing Health Policy: Unexpected Lessons and an Inconvenient Truth” in James B Kelly & Christopher P Manfredi, eds, *Contested Constitutionalism* (Vancouver: UBC Press, 2009) 129 at 137. See also Kent Roach, “The Courts and Medicare: Too Much or Too Little Judicial Activism” in Colleen M Flood, Kent Roach & Lorne Sossin, eds, *Access to Care, Access to Justice: The Legal Debate Over Private Health Insurance in Canada* (Toronto: University

The dilemma is especially vivid in lower income countries, where scarce resources often mean that one life can be saved at the expense of another. South Africa's Constitutional Court acknowledged this reality in its often-cited *Soobramoney* ruling, as it declined to intervene on behalf of an elderly patient seeking access to dialysis, underscoring "the danger of making any order that the resources be used for a particular patient, which might have the effect of denying those resources to other patients to whom they might be more advantageously be devoted."⁸ Institutional competence aside, there are also separation of powers arguments against having courts second-guess decision-making by the legislative and executive branches. Elected bodies are democratically entrusted to reconcile the diverse interests at play with these polycentric tradeoffs, it is argued, making judicial forays into this area democratically illegitimate.

There are, of course, replies to these concerns that must be taken seriously. On the issue of resource allocation and polycentrism, courts have long interfered in defense of civil and political rights, though this too has significant resource implications.⁹ Moreover, outside of the rights context, courts adjudicate a host of other polycentric issues in law (*e.g.* competition law, anti-trust law and division of powers questions).¹⁰ Regarding concerns about the courts' ability to regulate relationships prospectively, some have pointed to novel remedies available to courts, including suspended or delayed declarations of invalidity.¹¹ On the issue of democratic legitimacy, some have argued that judicial review can in

of Toronto Press, 2005) 184 at 186-88 (arguing against public interest standing on grounds that it allows abstract claims to proceed, lacking facts 'that add flesh and bone to the case').

8. *Soobramoney v Minister of Health, KwaZulu-Natal* [1998] 1 SA 765 at 776 (S Afr Const Ct) [*Soobramoney*].
9. Kent Roach, "The Challenges of Crafting Remedies for Violations of Socio-economic Rights" in Malcolm Langford, ed, *Social Rights Jurisprudence: Emerging Trends in International and Comparative Law* (Cambridge: Cambridge University Press, 2009) 46 at 49 [Roach, "Crafting Remedies"]; Stephen Homes & Cass Sunstein, *The Cost of Rights: Why Liberty Depends on Taxes* (New York: WW Norton & Co, 1999).
10. Jeff King, *Judging Social Rights* (Cambridge: Cambridge University Press, 2012) at 198-99.
11. Roach, "Crafting Remedies", *supra* note 9.

fact be democracy-enhancing – *e.g.* by targeting judicial scrutiny on government actions undertaken without robust and inclusive democratic deliberation.¹² Together these replies offer a preliminary defense of judicial involvement in the protection of social rights, including rights to health care. The thornier challenge is to strike a proper institutional balance – delivering improved accountability in a manner that plays to the courts’ institutional strengths, while avoiding overreach into areas where the courts have little or no expertise to add, such as the determination of what new drugs and technologies should be funded.

Courts themselves are often keen to avoid overreach, or even the perception of overreach, and this fundamentally shapes jurisprudence in the area of health care rights. An example commonly cited here is *R v Cambridge Health Authority*,¹³ a UK decision concerning a 10-year-old girl, diagnosed with terminal leukemia, whose family launched an administrative law challenge in the hope of securing a further round of chemotherapy and a second bone marrow transplant – therapies the Cambridge Health Authority had refused on grounds of high cost and poor prognosis. In rejecting the family’s claim, the Court of Appeal explained that,

[d]ifficult and agonising judgments have to be made as to how a limited budget is best allocated to the maximum advantage of the maximum number of patients. That is not a judgment which the court can make. In my judgment, it is not something that a health authority ... can be fairly criticised for not advancing before the court.¹⁴

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12. Alana Klein, “Section 7 of the Charter and the Principled Assignment of Legislative Jurisdiction” (2012) 57 Sup Ct L Rev 59; Martha Jackman, “Protecting Rights and Promoting Democracy: Judicial Review under s.1 of the Charter” (1996) 34:4 Osgoode Hall LJ 661. See also *Vriend et al v Alberta*, [1998] 1 SCR 493 (per Iacobucci J: “where the interests of a minority have been denied consideration, especially where that group has historically been the target of prejudice and discrimination, I believe that judicial intervention is warranted to correct a democratic process that has acted improperly” at para 176).
 13. *R v Cambridge Health Authority, ex parte B* (1995), 25 BMLR 5 (QB) [*Cambridge Health Authority QB*], rev’d [1995] 2 All ER 129 (CA) [*Cambridge Health Authority CA*].
 14. *Cambridge Health Authority CA, ibid* at 137. In the Canadian context, see *e.g. Chaoulli, supra* note 5 at para 161 *et seq* (Binnie and Lebel JJ dissenting). In the South African context, see *Soobramoney, supra* note 8 at

This approach of categorical deference to the resource allocation decisions of health authorities lies at one extreme of judicial attitudes towards health care rights. There is justifiable concern that it offers insufficient accountability, allowing health authorities to simply “toll the bell of tight resources,” as the lower court put it in *Cambridge Health Authority*.¹⁵ At the opposite extreme lies the approach taken in Brazil and other Latin American countries, where rights to health care have at times been interpreted as ‘trumps,’ with the judiciary showing little or no deference to overall resource allocations when ruling on individual claims.¹⁶ This approach has its own pitfalls, foremost the risk of scarce health care resources being redistributed under the regressive principle of ‘to each according to their ability to litigate.’ In the end, one hopes that courts will chart a path between deference and activism that advances the goals that inspire the right to health – namely ameliorating the stark inequalities that often exist in health care.

But as discussed in the next section, this path must be charted amidst various context-specific factors, which include the specific wording and method of enactments of health care rights (*e.g.* whether by ordinary statute or as part of a grand vision of transformative constitutionalism), the design and in-built accountability of a country’s health care system and the broader currents of social mobilization that inevitably influence the interpretation and enforcement of health care rights. As we will go on to argue, in Canada we have the luxury of a robust public health care system and thus we are not in the same need as Columbia, South Africa or India of challenging massive historical inequities.¹⁷ Thus in the Canadian context a reasonable solution may lie in the courts offering a measure of accountability, particularly for vulnerable and marginalized

769.

15. *Cambridge Health Authority* QB, *supra* note 13 at 17.
16. Octavio Luiz Motta Ferraz, “The Right to Health in the Courts of Brazil: Worsening Inequities?” (2009) 11:2 Health & Hum Rts 33; Octavio Luiz Motta Ferraz, “Harming the Poor Through Social Rights Litigation: Lessons from Brazil” (2011) 89:7 Tex L Rev 1643 [Ferraz, “Lessons from Brazil”].
17. There are of course serious and systemic health inequities in Canada, including gaping disparities in health outcomes among the country’s Aboriginal population.

populations, while also showing deference both to elected bodies and the expertise of health authorities.

III. Health Care Rights in Context

Much of the research to date on the impact of health rights litigation adopts a comparative lens, contrasting the experiences of diverse countries in search of emerging patterns and workable typologies.¹⁸ Comparative analysis of case law is an important component of this research, but when cases are taken out of context, they offer limited and potentially misleading guidance. For example, Canadian courts have been very conservative – at times arguably regressive – in *Charter* cases concerning access to health care (more on this below). But to what extent is this driven by non-doctrinal factors, such as the design of Canada’s health system, its mix of public and private financing, its administrative processes for rationing and so on? An understanding of these broader factors is essential to sound comparative analyses.¹⁹

Three contextual factors are discussed below: national aspirations underlying rights guarantees, the design and maturity of existing health systems, and levels of social mobilization around vital issues of health equity. These factors are highlighted in part because they are germane to Canada’s experience with health care litigation. A host of other contextual factors – such as extreme resource limitations, bribery and corruption

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18. This paper, particularly in Parts I and IV, draws upon findings of Colleen Flood & Aeyal Gross, eds, *The Right to Health at the Public/Private Divide: A Global Comparative Study* (Cambridge: Cambridge University Press, 2014). Other recent comparative studies on health rights litigation include: Alicia Ely Yamin & Siri Gloppen, eds, *Litigating Health Rights: Can Courts Bring More Justice to Health?* (Cambridge, Mass: Harvard University Press, 2011); Varun Gauri & Daniel M Brinks, eds, *Courting Social Justice: Judicial Enforcement of Social and Economic Rights in the Developed World* (Cambridge: Cambridge University Press, 2008); Jung, Hirschl & Rosevear, *supra* note 2; Katharine G Young & Julieta Lemaitre, “The Comparative Fortunes of the Right to Health: Two Tales of Justiciability in Colombia and South Africa” (2013) 26:1 Harv Hum Rts J 179.
19. Ted Marmor, Richard Freeman & Kieke Okma, “Comparative Perspectives and Policy Learning in the World of Health Care” (2005) 7:4 *Journal of Comparative Policy Analysis* 331.

within health systems and lack of judicial independence – shape the impact of health litigation in other countries, but have less relevance in comparison to Canada.²⁰

A. Health Rights and Broader Constitutional Aspirations

Though fundamental rights are often conceived as ‘universal,’ the purpose and aspirations underlying rights guarantees vary considerably, reflecting a country’s history, its experiences with colonialism, racial or ethnic divisions, its stage of economic development and so on. Courts may be emboldened or inhibited by these factors in their defense of health rights. Thus, for example, South Africa’s post-Apartheid constitution recognizes a right to health care, along with other ‘second generation’ rights, under a general theory of ‘transformative constitutionalism,’ which aims at rectifying deep and longstanding injustices through a process guided by the rule of law.²¹ These transformative aspirations are reflected in the unequivocal language of South Africa’s constitutional guarantees regarding health, which states that “[e]veryone has the right to have access to ... health care services, including reproductive health care,” and mandates that “[t]he state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realization of these rights.”²² Emboldened by this language, the Constitutional Court of South Africa addressed the legitimacy of judicial

20. On judicial independence and health rights, see Oscar Cabrera & Fanny Gomez, “Litigating the Right to Health in Venezuela: A Non-Justiciable Right in the Context of a Deficient Health Care System” in Flood & Gross, *supra* note 18 at 394; on the impact of bribery and corruption, see Eva Foldes, “Addressing Equity in Health Care at The Public-Private Intersection: The Role of Health Rights Enforcement in Hungary” in Flood & Gross, *supra* note 18 at 208; on health rights under extreme resource scarcity, see Remigius N Nwabueze, “The Legal Protection and Enforcement of Health Rights in Nigeria” in Flood & Gross, *supra* note 18 at 371.

21. Karl Klare, “Legal Culture and Transformative Constitutionalism” (1998) 14:1 SAJHR 146; Eric Christiansen, “Transformative Constitutionalism in South Africa: Creative Uses of Constitutional Court Authority to Advance Substantive Justice” (2010) 13:3 J Gender Race & Just 575.

22. *Constitution of the Republic of South Africa, 1996*, No 108 of 1996, s 27.

review unequivocally in its *Treatment Action Campaign* ruling: “[i]n so far as [the adjudication of health care rights] constitutes an intrusion into the domain of the Executive, that is an intrusion mandated by the Constitution itself.”²³

By contrast, inasmuch as Canadian courts have recognized health-related rights, these have been derived from the *Charter’s* open-ended guarantees, notably the section 7 protections against unjust infringements of “life, liberty and security of the person” and the section 15 “right to the equal protection and equal benefit of the law without discrimination ...”²⁴ There is debate, even among progressive legal scholars, as to how far Canadian courts should venture in the direction of recognizing social rights, under this ambiguous constitutional mandate. Some encourage a more rigorous judicial review on questions of access to health care,²⁵ while others caution that “attempts to leverage a *comprehensive* protection of social rights out of an instrument that is chiefly aimed at protecting a class of civil and political rights is not only undesirable, but irresponsible and undemocratic.”²⁶ Perhaps this ambiguous constitutional mandate partly explains the courts’ restrained approach to date: a 2008 comparative study by the International Commission of Jurists, looking at cross-country variations in the adjudication of economic, social, and cultural rights, reveals that Canadian courts have been exceptionally conservative in their approach²⁷ – recognizing positive rights to health care in only one

23. *Minister of Health and Others v Treatment Action Campaign and Others*, [2002] ZACC 15 at para 99 [TAC].

24. Some have long maintained that s 7 is meant only to govern the individual’s “interaction with the justice system and its administration.” See *New Brunswick (Minister of Health and Community Services) v G (J)*, [1999] 3 SCR 46 at para 65.

25. Martha Jackman, “Charter Review as a Health Care Accountability Mechanism in Canada” (2010) 18 Health LJ 1 [Jackman, “Charter Review”]; Bruce Porter, “A Right to Health Care in Canada: Only If You Can Pay For It” (2005) 6:4 ESR Review: Economic and Social Rights in South Africa 8.

26. King, *supra* note 10 at 200 [emphasis in the original].

27. International Commission of Jurists, *Courts and the Legal Enforcement of Economic, Social and Cultural Rights: Comparative experiences of justiciability* (Geneva: ICJ, 2008).

notable ruling.²⁸

This is not to suggest that a broader recognition of health care rights would run contrary to Canada's constitutional values or its aspirations as a nation. Certainly the plain wording of the *Charter* does not bind Canadian courts to a conservative interpretation of health care rights. The wording of article 21 of India's Constitution²⁹ is nearly identical to section 7 of the *Charter*, and yet the Indian Supreme Court has been more active in championing health rights (and economic, cultural and social rights generally).³⁰ Moreover, Canada long ago ratified the *International Covenant on Economic, Social and Cultural Rights*, which includes a "right of everyone to the enjoyment of the highest attainable standard of physical and mental health."³¹ Courts in other countries, such as Israel and the Netherlands, have been swayed in their reading of domestic health rights by their countries' ratification of the right to health under international law.³² In interpreting this right, international law has roundly rejected the negative/positive rights distinction to which, as explained below, Canadian courts continue to cling.³³

On the one hand, lower and middle income countries have led the world in embracing these rights – which is understandable, given there is often an urgent and widespread need for improved access to basic care in these countries and to correct an often appalling imbalance of resources devoted to the private as opposed to public system. Yet the very scale of

28. *Eldridge v British Columbia (Attorney General)*, [1997] 3 SCR 624 [Eldridge].

29. "No person shall be deprived of his life or personal liberty except according to procedure established by law." *The Constitution of India*, 1949, as amended by *The Constitution (One Hundred and Twentieth Amendment) Bill*, 2013, art 21.

30. Jung, Hirschl & Rosevear, *supra* note 2.

31. *International Covenant on Economic, Social and Cultural Rights*, 16 December 1966, 993 UNTS 3. Canada ratified the ECSR in 1976.

32. Aeyal Gross, "The Right to Health in Israel between Solidarity and Neoliberalism" in Flood & Gross, *supra* note 18 at 159; Andre den Exter, "Health Access in the Netherlands" in Flood & Gross, *supra* note 18 at 188.

33. UN Committee on Economic, Social and Cultural Rights (CESCR), *General Comment No. 9: The domestic application of the Covenant*, 3 December 1998, E/C 12/1998/24.

unmet needs in these countries may present a problem that is beyond the power of courts to address. Thus, in making the case that health care litigation in Brazil has led to siphoning of resources by wealthier Brazilians, health law scholar Octavio Ferraz rejects the proposition that *more litigation by the poor* offers a solution:

[E]ven if poor people had effective access to the courts and started to litigate en masse ... and even if courts were as receptive to their claims as they are to those of middle class right-to-health litigants ... their mandatory injunctions would soon face a brick wall due to lack of political will and normative consensus on radical egalitarian measures. No court, however willing, would have the power to overcome that obstacle.³⁴

As we write, however, Columbian courts are charting a very bold course and aim to directly impact health policy through a series of recent rulings that are issuing directions to the government on how to reform health care policy. Arguably these kind of court-induced systemic reforms will benefit all Columbians, including the poor. In the Canadian context, such reforms would challenge entrenched concepts of parliamentary sovereignty and conceptions of judicial deference and, in our view, are unlikely to occur in the foreseeable future.

B. Health Rights, Judicial Deference, and the Public/Private Divide

The trajectory of health care rights litigation is also shaped, in fundamental ways, by the basic design of a country's health system – notably its reliance on private versus public financing and administration. For example, in countries that have adopted a managed competition model whereby universal access is achieved through heavy regulation of private for-profit health insurers, such as Colombia, there is a greater potential for litigation on the part of patients against such insurers. Under a managed competition scheme, laws and regulations stipulate a basic basket of coverage; but where insurers fail to meet these requirements, this results in conflicts with patients that may ultimately be litigated under the right to health. In Colombia, this basic dynamic has in the past contributed to a tsunami of health rights litigation, thanks in part to a low-cost and expeditious

34. Ferraz, "Lessons from Brazil", *supra* note 16 at 1667.

system of adjudication (so-called *tutela* hearings).³⁵

This expanded role for private for-profit insurers changes the basic complexion of health rights litigation, particularly vis-à-vis the worries about polycentrism and democratic legitimacy discussed above. In the Colombian context, courts may reason that the refusal of treatments by private insurers is motivated by profit, and less a reflection of polycentric tradeoff between the interests of all patients. Likewise, there is obviously little concern over the democratic legitimacy of judicial review of rationing decisions by private insurers. In some instances, Colombian courts have scrutinized the government-mandated basket of services, which has predictably been far more controversial, inviting accusations of ‘government by judges.’³⁶

Contrast this with Canada, where the *Canada Health Act*³⁷ stipulates that the financing of medically necessary care must be publicly administered. Given the driving concern about overreach, it is perhaps to be expected that Canadian courts would take a deferential approach under these circumstances, and indeed a degree of reticence is seen across other industrialized countries with (relatively) well-functioning tax-financed health systems.³⁸ In theory at least, when a Canadian patient is denied needed care, a government or a governmental agency has made the decision with a public interest mandate vision. As well, a far more expansive range of tradeoffs are at play as courts second guess resource allocation within a tax-financed system; resources redirected to health care may have to be drawn from a pool that supplies funding for many other vital government services. Finally, whereas Colombia’s *tutela* rulings typically impacted only the parties involved (although the sheer volume of claims ultimately had a systemic effect), judicial precedents related to publicly administered health systems will in theory have a broad and lasting impact – given that “[t]he nature of modern government means that justice for an individual will often require systemic measures that

35. Everaldo Lamprea, “Colombia’s Right-to-health Litigation in a Context of Health Care Reform” in Flood & Gross, *supra* note 18 at 131; Young & Lemaitre, *supra* note 18.

36. Young & Lemaitre, *ibid* at 189.

37. RSC 1985, c C-6 [CHA]

38. See generally Flood & Gross, *supra* note 18.

will deliver justice to much larger groups.”³⁹

Such contextual factors may partly explain Canadian courts’ reluctant and conservative approach to the recognition of health care rights, particularly by comparison to the hyper-individualized approach taken in some Latin American countries. Surface appearances can be somewhat misleading though: under tax-financed universal health systems, judicial approaches which on their face seem cautious and deferential – *e.g.* courts recognizing only negative rights in health care – can potentially have very disruptive effects. The Supreme Court of Canada’s much-criticized *Chaoulli* decision, discussed later, is a case in point.

C. Health Rights and Social Mobilization

It is widely recognized that broader social movements are often instrumental in the success or failure of health rights at every stage, from the launching of claims, through the litigation process, and in pressuring governments to honour their obligations in the wake of a successful court challenge.⁴⁰ Civil society groups can shape the outcome of health rights litigation in various ways, whether by promoting public awareness around an issue, lobbying governments to finance treatments or close access barriers, funding test litigation, participating in litigation as third party interveners and, in the event of a courtroom success, monitoring and reporting on government compliance with court orders.

The importance of social mobilization to success in the litigation of health rights is commonly illustrated with the example of HIV/AIDS activism, and the South African Constitutional Court’s (CCSA) decision in *Treatment Action Campaign*⁴¹ – arguably one of the world’s most discussed and celebrated health rights decisions to date.⁴² In *TAC*,

39. Roach, “Crafting Remedies”, *supra* note 9 at 49. But note discussion below of the less-than-systematic implementation of the Supreme Court of Canada’s *Charter* ruling requiring provision of interpretive services for deaf patients as they seek medically necessary care.

40. Siri Gloppen, “Litigation as a Strategy to Hold Governments Accountable for Implementing the Right to Health” (2008) 10:2 Health & Hum Rts 21.

41. *TAC*, *supra* note 23.

42. Lisa Forman & Jerome Amir Singh, “The Role of Rights and Litigation in Assuring More Equitable Access to Health Care in South Africa” in Flood

the CCSA interpreted the right to health care as requiring the South African government to expand access to a drug (nevirapine) used in preventing mother-to-child transmission of HIV. Prior to the litigation, activists had successfully lobbied the manufacturer to provide the drug free of charge, but the South African government nevertheless restricted its availability to certain test sites, citing *inter alia* safety concerns and the cost of complementary services (*e.g.* counseling services, formula milk). In rejecting these government justifications, the CCSA cited evidence that political pressures had already led to expanded provision of nevirapine in some regions, demonstrating that “provided the requisite political will is present, the supply of nevirapine at public health institutions can be rapidly expanded ...”⁴³ Moreover, the Court explained, the government’s recent infusion of nearly a billion rand in new funding for HIV treatment indicated that, “budgetary constraints ... are no longer an impediment.”⁴⁴

Social mobilization was instrumental to the *TAC*’s success story within the courtroom and beyond. Thus, for example, by building treatment literacy and pressuring drug makers to provide nevirapine at no cost, activists undermined government’s argument from resource constraints; by lobbying successfully for expanded delivery programs in some regions, activists demonstrated that the barriers to national rollout were political, and not resource-related; and social mobilization triggered the government’s decision to pre-emptively expand budgets for HIV treatments while the case was before the courts, further undermining the argument from resource constraints.

A comparison between *TAC* and *Grootboom and Others v Oostenberg and Others*⁴⁵ – another famous South African case related to housing rights – reveals how courtroom victories may ring hollow on the ground,

& Gross, *supra* note 18 at 288; Young & Lemaitre, *supra* note 18 at 215; Mark Heywood, “South Africa’s Treatment Action Campaign: Combining Law and Social Mobilization to Realize the Right to Health” (2000) 1:1 *Journal of Human Rights Practice* 14; Leslie London, “What is a Human-Rights Based Approach to Health and Does it Matter?” (2008) 10:1 *Health & Hum Rts* 65.

43. *TAC*, *supra* note 23 at para 119.

44. *Ibid* at para 120.

45. [2000] ZACC 19 [*Grootboom*].

absent effective and persistent social mobilization.⁴⁶ Eight years after her precedent-setting victory under the South African Constitution's right to housing, Irene Grootboom died in middle age, homeless and destitute.⁴⁷ Summing up the decision's ultimate impact, one commentator explains that, "no major shifts in housing policy have followed this test case, largely because of the lack of civil society pressure or a social movement in the area of housing."⁴⁸

Much the same difficulty has arisen where Canadian courts have recognized positive rights with respect to health care. In *Eldridge*,⁴⁹ the Supreme Court of Canada ruled that government's failure to provide interpretive services for deaf patients was an infringement of equality rights under section 15 of the *Charter*. Though disability activists greeted the decision as a major victory, implementation has been disappointing: to date British Columbia and Ontario have been the only provinces to comply with the ruling. Even in these provinces, medical interpretive services have been plagued by problems of underfunding and interpreter shortages.⁵⁰

Often, when this connection is drawn between social mobilization and the realization of health rights, a tactical lesson is drawn: activists seeking access to a given therapy through court challenges are advised to take a multi-pronged approach, building sustainable political momentum around their cause. Stepping back from that tactical advice, a bigger

46. Forman & Singh, *supra* note 42.

47. *Grootboom*, *supra* note 45; Pearlie Joubert "Grootboom dies homeless and penniless", *Mail & Guardian* (28 August 2008), online: Mail and Guardian <<http://www.mg.co.za/article/2008-08-08-grootboom-dies-homeless-and-penniless>>.

48. London, *supra* note 42 at 67.

49. *Eldridge*, *supra* note 28.

50. Colleen M Flood & YY Brandon Chen, "Charter of Rights & Health Care Funding: A Typology of Canadian Health Rights Litigation" (2010) 19:3 *Annals Health L* 479 at 489-94 and 509-18. The interplay between litigation and social mobilization is a two-way street. In some instances, headline-making cases draw public attention to an issue, potentially shifting public opinion and spurring change through political channels. This dynamic has been observed in Canada as well, as the Supreme Court's rulings on physician assisted suicide, IVF funding, and access to autism therapies have coincided with changing public attitudes on these issues.

picture question is whether – given its dependence on social mobilization – a rights-based approach to health care will tend to advance equity overall.

Effectiveness at social mobilization is, after all, partly a function of a constituency’s resources and political influence, raising the concern that health rights, insofar as their exercise requires societal backing, may tend to benefit comparatively advantaged groups.⁵¹ Some prominent critics of health rights have argued, for example, that groundbreaking progress around HIV/AIDS was due partly to that disease’s impact on middle and upper classes. They point to the fact that global spending on HIV/AIDS has vastly eclipsed spending on other diseases that more narrowly target the poor, killing in comparable numbers, such as malaria and tuberculosis.⁵²

Of course, concerns about health care resources flowing on the basis of ‘ability to mobilize’ can arise even without the courts’ involvement. For example, in New Zealand’s drawn-out debate over public funding for the breast cancer drug Herceptin, the courts sided with the country’s Pharmaceutical Management Agency (PHARMAC), ruling that the latter’s decision to limit funding for the drug to a nine-week regimen was reasonable, and rejecting the claimant’s demand for a twelve-month regimen.⁵³ Following that ruling, however, a new government came to power, and delivered on its election promise to extend funding for Herceptin to twelve months, overriding PHARMAC’s decision that this could not be justified under the country’s guidelines for rationing.⁵⁴

A related concern is that public attention and social mobilization is often stirred by a ‘rescue imperative’ – focusing on discrete health issues for which effective therapies are available. With the development of effective

51. *Ibid* at 71.

52. Roger England, “The Dangers of Disease Specific Programmes for Developing Countries” (2007) 335:7619 *Brit Med J* 565; William Easterly, “Human Rights are the Wrong Basis for Health Care”, *Wall Street Journal* (12 October 2009). See generally Julia H Smith & Alan Whiteside, “The History of AIDS Exceptionalism” (2010) 13:47 *Journal of the International AIDS Society* 1.

53. *Walsh v Pharmaceutical Management Agency*, [2008] NZHC 44.

54. Joanna Manning, “Litigating a Right to Health Care in New Zealand” in Flood & Gross, *supra* note 18 at 19.

anti-retroviral medicines, the HIV/AIDS epidemic came to fit this description and became a candidate for effective social mobilization and judicial intervention in the South African context. It is not clear that the most pressing health inequities in the Canadian context fit this framing. For example, the appalling disparity in health outcomes experienced by Canada's Aboriginal population, or the country's growing epidemic of non-communicable diseases, will not be addressed by expanding access to particular pharmaceuticals. Will the public rally around a rights-based framing of these complex multi-factorial challenges? Are the courts in any position to devise and enforce effective remedies?

IV. Health Care Rights in the Canadian Context

To this point we have seen the central dilemma facing courts in adjudicating health rights (*i.e.* a concern about overreach), and discussed various contextual factors that further shape the prospects for health rights litigation – including factors that partly explain Canadian courts' deferential approach to date. Of course, deference can take many forms, and so a further question is whether Canadian courts, in addressing claims concerning the right to health care, have drawn lines of deference in the right places. To explore that question, we provide an overview of health litigation under the *Charter*, specifically under sections 7 and 15.⁵⁵ It will be argued that in drawing these lines, Canadian courts have favoured formalism over substantive fairness: broadly speaking, a hard line has been drawn, interpreting the section 7 right to life and security of the person as a 'negative' right, while the section 15 equality right has been read as guaranteeing only 'access to the basket' of care committed to statutorily by provincial insurers. One can acknowledge that the Canadian context calls for a degree of judicial deference while questioning the wisdom of this path. Courts in other similarly situated countries, such as the UK, have had success at holding governments

55. Canadians have other options for litigating issues of access to health care (*e.g.* administrative law review). For a brief overview of the options available to patients refused care in Ontario, see Colleen M Flood, Carolyn Tuohy & Mark Stabile, "What Is In and Out of Medicare? Who Decides?" in Colleen M Flood, ed, *Just Medicare: What's In, What's Out, How We Decide* (Toronto: University of Toronto Press, 2006) 15 at 17-30.

accountable for reasonable decision-making in health care.

A. Focus on ‘Negative’ Rights

In the Canadian context, judicial oversight of health care resource allocation has been avoided in part by construing the *Charter’s* section 7 guarantee of ‘life, liberty and security of the person’ as protecting only negative rights. In most cases where Canadian claimants have secured health care related victories through litigation, the prize has been a negative right – for example, overturning restrictions on access to abortion services, safe injection sites and medical marijuana.⁵⁶ This approach can perhaps be defended as a plain reading of the Canadian *Charter*, which as explained, differs from other modern bills of rights in its focus on standard civil and political rights to the exclusion of explicit social and economic rights. At times the Supreme Court of Canada has stated explicitly that the *Charter* grants no positive right to health care, as in this passage from its unanimous 2004 ruling, *Auton v British Columbia*: “[t]his Court has repeatedly held that the legislature is under no obligation to create a particular benefit.”⁵⁷

As many commentators have noted, recognition of a negative right to a particular therapy does little to advance equitable access. Evidence suggests, for example, that access issues worsened in the years following the *Morgentaler* decision, as the number of hospitals offering abortion

56. *R v Morgentaler* [1988] 1 SCR 30 (access to abortion) [*Morgentaler*]; *Canada (Attorney General) v PHS Community Services Society*, 2011 SCC 44 (safe injection sites) [*PHS*]; *R v Parker* (2000), 49 OR (3d) 481 (CA) (medical marijuana). See Flood & Chen, *supra* note 50 at 494.

There have also been a handful of *Charter* challenges to criminal laws impacting health rights, but which do not implicate access to health care *per se*: *Canada (Attorney General) v Bedford*, 2013 SCC 72 (challenging prostitution laws as an infringement of security of the person); *R v Mabior*, 2012 SCC 47 (challenging criminal law provisions requiring disclosure of HIV status).

57. *Auton (Guardian ad litem of) v British Columbia (Attorney General)*, 2004 SCC 78 at para 41 [*Auton*]. See also Chief Justice McLachlin’s comment in *Chaoulli*, *supra* note 5 at para 104 that the *Charter* “does not confer a free standing constitutional right to health care.” In other contexts, the Court has expressed an openness in principle to recognizing positive rights under s 7. See *Gosselin v Quebec (Attorney General)*, 2002 SCC 84.

services declined, forcing many women to incur out-of-pocket expenses traveling to receive the service out of province, or in private clinics.⁵⁸ In countries such as Canada, where citizens rely largely on the state for the financing and governance of health systems, overturning state-imposed obstacles can at best be a first step towards ensuring equitable access.

A deeper concern relates to the insidious effect that negative rights may have when used to challenge laws that promote overall equity. The Supreme Court long ago acknowledged this risk, with Chief Justice Dickson famously writing in an early *Charter* ruling that, “[i]n interpreting and applying the *Charter* ... the courts must be cautious to ensure that it does not simply become an instrument of better situated individuals to roll back legislation which has as its object the improvement of the condition of less advantaged persons.”⁵⁹ Yet this cautionary note was seemingly thrown to the wind with the 2005 decision, *Chaoulli v Quebec*.⁶⁰ There, the co-plaintiffs alleged that, given wait times in the public system, Quebec’s ban on private insurance breached patients’ rights to life and security of the person, under both section 1 of Quebec’s *Charter of Human Rights and Freedoms*⁶¹ and section 7 of the Canadian *Charter*. In a 4-3 decision, the Supreme Court agreed with the petitioners and repudiated the prohibition of private insurance on the basis of the Quebec *Charter*. In their reasoning, the majority relied upon on a crude international comparison of health systems to conclude that the allowance of a parallel private sector would not necessarily undermine the quality of the public health care regime.⁶² Three of the four majority judges in *Chaoulli* also found the legislative prohibition in question to have infringed section 7 of the *Charter*.

Many were surprised at the Court’s willingness to wade into the complex policy issues raised in *Chaoulli*, particularly in light of the

58. See Flood & Chen, *supra* note 50; Sanda Rodgers, “Abortion Denied: Bearing the Limits of Law” in Flood, *supra* note 55 at 107.

59. *R v Edwards Books and Art Ltd*, [1986] 2 SCR 713 at para 136.

60. *Chaoulli*, *supra* note 5.

61. RSQ c C-12, (“[e]very human being has a right to life, and to personal security, inviolability and freedom,” s 1).

62. See Colleen M Flood, “Chaoulli: Political Undertows and Judicial Riptides” (2008) Health LJ at 211 (for a thorough discussion on the flaws of the Supreme Court’s international comparative exercise).

deference shown in earlier rulings in this area.⁶³ Kent Roach has suggested that what distinguished the *Chaoulli* claim, from the Court's perspective, was precisely the negative remedy sought:

The simplicity of the remedy requested by the Charter applicants made their substantive claims attractive to the majority ... The applicants in this case asked for a simple, traditional and easy to enforce remedy. They did not ask the courts to declare that governments had to provide new health care services ... let alone retain jurisdiction to ensure systemic compliance with the Charter ...⁶⁴

This brings us back, in essence, to the basic dilemma concerning the courts' institutional competence, discussed in Part I above. It is easier for courts to strike down law and policy than to oversee its implementation, which does not bode well for the prospects of health rights litigation addressing the needs of disadvantaged groups who depend on government services.

As it happens, *Chaoulli* was the first battle in a larger war to create opportunities for more private financing of medically necessary care and similar litigation is now occurring across Canada. In Alberta, claimant William Murray is currently pursuing a class action against the province for damages he allegedly sustained from the denial of access to a hip replacement procedure under the public health insurance plan. He argues that the denial of public coverage, in conjunction with sections of the *Alberta Health Care Insurance Act*⁶⁵ that prevent treatment access outside of the government-run regime, violates his rights under section 7 of the *Charter*.⁶⁶ An ongoing case initiated by claimants Lindsay McCreith and Ms. Shona Holmes points to wait time problems in Ontario, and calls into question the constitutionality of provincial regulations designed to suppress the expansion of the private health care sector.⁶⁷ A private for-profit clinic, Cambie Surgeries Corporation (Cambie), is contesting the constitutionality of similar provisions under British Columbia's *Medicare*

63. Sujit Choudhry, "Worse than *Lochner*?" in Flood, Roach & Sossin, *supra* note 7 at 76.

64. Roach, *supra* note 7 at 184.

65. RSA 2000, c A-20.

66. *Murray v Alberta (Minister of Health)*, 2007 ABQB 231 at paras 21-22.

67. *McCreith v Ontario (Attorney General)* (5 September 2007), No 07-CU-339454PD3 (Ont Sup Ct) Statement of Claim.

Protection Act.⁶⁸ Cambie is represented by Dr. Brian Day, a past president of the Canadian Medical Association (CMA).⁶⁹

Of late, some more hopeful prospects have emerged in section 7 jurisprudence. In the recent case *Canada v PHS Community Services*,⁷⁰ the issue was whether section 7 was engaged by the federal Minister of Health's withdrawal of an exemption, which had previously allowed the Insite safe injection facility to operate without fear of criminal prosecution under the *Controlled Drugs and Substances Act*.⁷¹ There the majority found that rights to life, liberty and security of the person were engaged by the Minister's decision – forcing as it would the clinic's clientele to dangerous back-alley injection practices.⁷² Continuing with its section 7 analysis, the Court then explored whether the Ministerial decision had been made “in accordance with principles of fundamental justice,” citing evidence of the clinic's success in saving lives to conclude that withdrawal of the exemption was arbitrary and grossly disproportionate.⁷³ Strictly speaking, the claimants in *PHS* secured a negative right, but the decision signals a new willingness on the part of the Court to probe the evidence supporting government decisions to *withdraw* access to health services. Might this precedent carry over to cases where governments attempt to withdraw *funding* for health care programs?

The question may receive an answer in litigation currently underway at the Federal Court, challenging the federal government's recent decision

68. RSBC 1996, c 286.

69. *Cambie Surgeries Corp v British Columbia (Medical Services Commission)*, 2010 BCCA 396. This case is part of an early round of this constitutional battle concerning the ability of the Medical Service Commission to audit Dr. Day's clinic. The audit sampled 468 services provided by two private clinics (Cambie and Specialist Referral Clinic) and found that almost half were illegally billed. See Ministry of Health, Audit & Investigations Branch, *Specialist Referral Clinic (Vancouver) Inc and Cambie Surgeries Corporation Audit Report* (Vancouver: Ministry of Health, Audit and Investigations Branch, 2012), online: BC Ministry of Health <<http://www.health.gov.bc.ca/msp/legislation/pdf/srcsc-audit-report-2012.pdf>>.

70. *PHS*, *supra* note 56.

71. SC 1996, c 19.

72. *PHS*, *supra* note 56 at para 93.

73. *Ibid* at paras 129-33.

to claw back the long-standing *Interim Federal Health Plan*.⁷⁴ Under the new rules, health care coverage for certain categories of refugee claimants is limited to ‘urgent and essential’ care, while others will receive coverage only if their health status poses a threat to public health. The claimants argue, *inter alia*, that the withdrawal of coverage endangers the affected refugees’ section 7 interests – most cannot afford private insurance, and so run the risk of being denied life-saving treatment. The claimants acknowledge that the *Charter* does not confer a positive right to health care, but cite *PHS* to argue that government decisions withdrawing access to care must accord with principles of fundamental justice (*i.e.* avoid arbitrariness and gross disproportionality).⁷⁵

B. Equality of ‘Access to the Basket’

Claimants have used the *Charter*’s section 15 guarantee of “equal benefit of the law without discrimination” to press for access to health goods and services denied under provincial insurance plans. Section 15 does not aim to prevent unequal benefits *per se*, as governments inevitably draw distinctions in the provision of services.⁷⁶ The equality guarantee bars only wrongful forms of discrimination, which deprive individuals of the benefits of the law on the basis of “race, national or ethnic origin, colour, religion, sex, age or mental and physical disability,” along with analogous grounds such as sexual orientation. Canadian courts have disavowed a formalistic approach to the equality guarantee, instead requiring governments to “take into account the underlying differences between individuals in society,”⁷⁷ adjusting laws to achieve substantive equality.

74. *Canadian Doctors for Refugee Care v Attorney General or Canada (Minister of Citizenship and Immigration)* (30 October 2013), T-356-13 (FC) (Memorandum of Fact and Law of the Applicants) online: Justice for Children and Youth <http://www.jfcy.org/PDFs/IFHP_Memo_CDRC_CARL.pdf>.

75. Rather than breaking new ground under s 7, the court may opt to decide this case under s 15, as the new regime discriminates against refugees on the basis of their country of origin.

76. “It must be recognized ... that every difference in treatment between individuals under the law will not necessarily result in inequality ...”: *Andrews v Law Society of British Columbia*, [1989] 1 SCR 143 at 164.

77. *Law v Canada (Minister of Employment and Immigration)*, [1999] 1 SCR

While the equality guarantee does not ground a positive right to health care, it may oblige governments to take positive steps to ensure that citizens enjoy equal benefit of established health systems. The singular instance where Canadian courts have recognized a positive obligation on the part of governments to provide health-related services arose under the rubric of equality rights. In *Eldridge v British Columbia*, the Supreme Court ruled that the government's non-funding of sign language interpretation services at public hospitals violated the equality rights of the province's deaf population.⁷⁸ At the time, many had hoped that the Court's unanimous ruling in *Eldridge* might open the door to increased judicial scrutiny of issues of health care accessibility. In the years that followed, claimants drew on the precedent to argue that non-funding of autism therapies⁷⁹ and *in vitro* fertilization⁸⁰ also infringed the right to equality.

From the outcome of these later decisions, though, it appears that the *Eldridge* precedent applies narrowly, guaranteeing only equal 'access to the basket' of health care services deemed 'medically necessary' by government decision-makers. Nola Ries explains the limiting principle at play here: "the *Eldridge* claim is like a wheelchair user asking a library to build a ramp so she may gain access to the books in the library that are available to patrons who can walk up the stairs. In contrast, *Eldridge* is not like the disabled patron asking the library to purchase new books to put on the shelves."⁸¹

The access to the basket principle was deployed in *Auton*, as the Supreme Court ruled unanimously that non-funding of ABA/IBI autism therapies did not infringe the petitioner's section 15 equality rights.

497 at para 25.

78. *Supra* note 28. See also *Moore v British Columbia (Education)*, 2012 SCC 61 (drawing on the *Eldridge* precedent to find that the closure of a Diagnostic Centre for students with learning disabilities created a discriminatory barrier to public schooling, under the BC *Human Rights Code*).

79. *Auton*, *supra* note 57.

80. *Cameron v Nova Scotia (Attorney General)* (1999), 204 NSR (2d) 1.

81. Nola M Ries, "Charter Challenges" in Jocelyn Downie, Timothy Caulfield & Colleen M Flood, eds, *Canadian Health Law and Policy* (Markham: LexisNexis Canada, 2011) 615 at 628-29.

There, the Court explained that neither the *Canada Health Act*,⁸² nor the relevant British Columbia legislation,⁸³ promised funding for ‘non-core’ services. Legislation instead left it to the discretion of the province’s Medical Services Commission to designate particular practitioners and procedures for non-core funding, and ABA/IBI therapy had not been so designated. Thus Chief Justice McLachlin differentiated *Auton* from *Eldridge* by noting that, “*Eldridge* ... was concerned with unequal access to a benefit that the law conferred and with *applying* a benefit granting law in a non-discriminatory fashion. By contrast, [*Auton*] is concerned with access to a benefit that the law has not conferred.”⁸⁴

In effect, the ‘access to the basket’ principle does for section 15 what the ‘negative rights’ reading does for section 7, carving down the right’s scope to align with the basic premise that “... the legislature is under no obligation to create a particular benefit.”⁸⁵ Ultimately, of course, this traces back to the concern about overreach; as Sujit Choudhry puts it,

[t]his reasoning is so difficult to defend that the only way to read *Auton* [is] as having created a political questions doctrine around the scope of the Medicare envelope. The clear message from the Court was that the Court did not wish judges to be drawn into adjudicating upon the design of Medicare on a case-by-case basis, a task for which they are poorly qualified.⁸⁶

A basic concern here is that the ‘access to the basket’ principle offers questionable guidance for achieving substantive equality. Consider even the conclusion reached in the library analogy, namely, that equality is achieved provided that disabled people have physical access to the collection. Surely, though, a commitment to substantive equality must have some bearing on a library’s basket of offerings – *e.g.* the availability of

82. *Supra* note 36.

83. *Medicare Protection Act*, RSBC 1996, c 286.

84. *Auton*, *supra* note 57 at para 38 [emphasis in the original].

85. *Ibid* at para 41. There are other elements to s 15, including the requirement that claimants articulate an appropriate comparator group, and show harm to dignity. We sidestep these issues for two reasons: (1) The ‘access to the basket’ principle arises at an earlier stage in the court’s analysis, meaning that these other criteria will seldom be determinative in s 15 claims involving Medicare rationing; (2) These later stages of s 15 analysis have been overhauled in recent decisions. See *R v Kapp*, 2008 SCC 41 and *Withler v Canada (Attorney General)*, 2011 SCC 12.

86. Choudhry, *supra* note 63 at 93.

books written in braille. The reality is that many of the gravest threats to equity in Canadian health care stem precisely from decisions about what to include in the basket. Canada currently has roughly a 70:30 mix of public to private funding for health care, behind most comparable OECD countries.⁸⁷ That outsized component of privatized care covers many indispensable elements of modern health care, including prescription drugs, dental care, and long-term care.⁸⁸ Their exclusion from the public basket does not necessarily reflect careful and transparent deliberation over relevant tradeoffs. For example, the omission of prescription drug and long-term care coverage is largely a vestige of Canadian Medicare's 1960s origins – a time when drugs accounted for a much smaller portion of health care spending, and health care was largely provided by physicians and/or in hospitals. Technological advancements and an aging population have meant that those excluded components have grown as a percentage of overall health spending, resulting in passive privatization. Meanwhile, year-to-year decisions over what physician services are included under provincial plans appear to be largely the byproduct of annual fee negotiations between provinces and their respective provincial medical associations – a process biased towards preserving the *status quo*, and liable to be influenced by non-medical considerations.⁸⁹ In short, the 'access to the basket' principle arguably insulates serious and systemic inequalities from rights scrutiny, in formalistic deference to legislative decision-making, which appears variously complacent, opaque and non-evidence-based.

87. William Lahey, "Medicare and the Law: Contours of an Evolving Relationship" in Downie, Caulfield & Flood, *supra* note 81 at 6.

88. Although not required to do so under the *Canada Health Act*, provinces do provide coverage for prescription drugs, home care, etc. however coverage varies significantly from province to province. See Virginie Demers et al, "Comparison of provincial prescription drug plans and the impact on patients' annual drug expenditures" (2008) 178:4 *Can Med Assoc J* 405; Vishnu Kapur & Kosalaya Basu, "Drug coverage in Canada: who is at risk" (2005) 71:2 *Health Policy* 181.

89. Flood, Tuohy & Stabile, *supra* note 55.

V. A Middle Road of Reasonableness Review?

Perhaps it is time that Canadian courts change tack and play a more active role in holding governments accountable for decisions about what to include in the Medicare basket. As Jackman notes, “every major health system review undertaken in Canada over the past decade has concluded with a call for improved health care accountability,”⁹⁰ yet it remains unclear from whence this accountability will originate. At a macro level, the federal government is ostensibly charged with ensuring that provinces comply with principles of comprehensiveness, universality and so on, backed by the threat of financial penalties as authorized by the *Canada Health Act*. Yet the only enforcement action taken by the federal government to date has been with respect to user fees and extra-billing, and even on this score, there has been growing passivity.⁹¹ A key problem here is that the only available enforcement mechanism under the *CHA* – withholding of federal transfers – is likely to exacerbate problems associated with wait times and rationing.

Rather than start from the premise that the Constitution does not confer a free standing constitutional right to health care, courts might begin with a basic recognition that comprehensive and universal public health care are in fact the embodiment of *Charter* values. This might entail opening the door further to positive health rights claims, placing the onus on government to justify denials of care and, where necessary, applying deference at a later stage of analysis. In this way, courts could assist with developing precedents and guidelines that support reasonable, accountable decision-making across the system as a whole, rather than through a blinkered focus on negative rights and ‘access to the basket.’

A potential advantage of such a shift is that it would provide a much-needed counter-balance against regressive *Chaoulli*-style claims. As the issue of access to private insurance for medically necessary care was framed under the existing doctrinal paradigm, the claimant’s section 7 rights were balanced against ‘mere’ policy objectives (*i.e.* maintaining Medicare’s universality) with predictable results: given the complex

90. Jackman, “Charter Review”, *supra* note 25 at 29.

91. Lahey, *supra* note 87 at 48-50.

and uncertain causal dynamics within health systems, governments faced a formidable challenge in *proving* that a ban on private insurance was necessary for the protection of the public tier. Yet surely it is more consonant with *Charter* values, and Canadian public opinion, to frame this as a question of ‘reconciling’ the negative rights of those demanding privately financed care against the positive rights of those dependent on Medicare. In concrete terms, reframing this as an issue of reconciling rights would increase the evidentiary burden on those asserting negative health care rights in a way that threatens principles of universality and solidarity. As Justice Iacobucci has explained,

Under s. 1, the state must justify a violation of an individual’s Charter rights. When reconciling competing Charter rights, on the other hand, a court seeks to reconcile the constitutionally guaranteed rights of one individual with those of another. Consequently, the onus of proof in each of these cases plays out somewhat differently. Under section 1, the party challenging the impugned law must establish a *prima facie* encroachment of a Charter right. The state then bears the serious onus of defending or justifying the violation ... In the reconciling context, there is no rule about onus *per se*.⁹²

The concern of course will be that recognition of positive rights in this context opens a Pandora’s box, leading to the courts micromanaging Medicare. Really though, the question is not *whether* courts should be deferential in adjudicating rights to health care, but *how* that line of deference should be drawn. Experience from similarly situated countries suggests that courts can play an important oversight role without micromanaging health care policy. Short of ordering funding for particular therapies, courts can scrutinize the *process* by which rationing decisions are made, and through evolving jurisprudence, develop guidelines, tests and criteria to ensure ongoing accountability in this regard.⁹³ For example, the ‘Hard Look’ judicial review approach, which has emerged over the past decade in UK administrative law jurisprudence, focuses on ensuring that decision-making processes adhere to principles of procedural fairness, and considers all relevant factors while excluding

92. Justice Frank Iacobucci, “Reconciling Rights’: The Supreme Court of Canada’s Approach to Competing Charter Rights” (2003) 20 Sup Ct L Rev (2d) 137 at 141-42.

93. Lorne Sossin, “Towards a Two-Tier Constitution? The Poverty of Health Rights” in Flood, Roach & Sossin, *supra* note 7 at 172.

irrelevant ones.⁹⁴ Reviewing individual claims, courts look to ensure that the decision-making process has attended to the nature and seriousness of the illness; the cogency of the evidence that the treatment works; the extent and likelihood that it will work in *this* patient; the extent of improvement it might be expected to provide; and the absolute cost of the treatment.⁹⁵ Chris Newdick explains that judicial prodding, focusing on these factors, has incrementally driven improved accountability across the National Health Service (NHS) as a whole – culminating in the codification of guidelines in an NHS Constitution:

The number of cases was limited and, at least at first, their impact on the NHS as a whole was small. However ... as the cases accumulated, they exercised greater influence collectively. As the consistency of the courts' response made the giving of legal advice to health authorities more straightforward (and legal case became increasingly newsworthy), the government responded by publishing the NHS Constitution ... which reduces the cases to a single code of good practice and cements patients' rights.⁹⁶

VI. Conclusion

The aspiration of health care rights is to improve the health of all but particularly to improve upon the health of the most vulnerable. Recognizing health care rights in developing and middle-income countries may be a galvanizing force for progressive changes, supporting and nurturing a radical shift in how resources are allocated to ensure better access for the most vulnerable. But this is not a linear task, and assuming that litigation of health care rights can achieve this goal underestimates the complexity of dealing with issues such as access to justice, the prospect that litigation can distort the socially fair allocation of public resources, the appropriate respective role for courts and governments in health care decision-making and the need for public and policy support for any particular judgment to be implemented on the ground.

In the Canadian context, courts have taken a very conservative approach to the question of health care rights and in only one section 15

94. Chris Newdick, "Promoting Access and Equity in Health: Assessing the National Health Service in England" in Flood & Gross, *supra* note 18 at 118-19 [forthcoming].

95. *Ibid.*

96. *Ibid* at 122.

case has the Supreme Court found that a government should publicly fund a treatment. In all other relevant cases, the Court has only found a “negative” right in the sense of requiring that government laws or policies acting as barriers to the consumption of health care be removed. This conservative approach has now even gone so far as to uphold a challenge to provincial laws banning private health insurance, passed in order to ensure equity and universality in Canadian Medicare. We think the Court has now passed beyond the boundary of showing deference to governmental decision-making in not interpreting section 7 positive rights and crossed the void into attacking values that we see at the core of the *Charter* – equality, access and universality in public Medicare. We recommend that Canadian courts consider, in future *Charter* challenges to public Medicare, that the issue is one of competing rights; any right a petitioner may have to access private care must be weighed against the rights of other Canadians to enjoy a universal, access and equitable public health care system. This would at least attenuate to some degree the extent to which governments are tasked with the near-impossible task of adducing empirical evidence to show that there are no lesser means by which goals of equity, universality and access can be achieved in the Canadian context. Further, we would support that most health care cases be reviewed first through administrative law on grounds that this approach – requiring fair and transparent processes in government decision-making and overall reasonableness of the final decision – is by far the best way for courts to play a role in realizing Canadians’ rights in health care.

Notions of Reproductive Harm in Canadian Law: Addressing Exposures to Household Chemicals as Reproductive Torts

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Mark Pioro*****

Mounting scientific evidence is suggesting that various synthetic chemicals are ubiquitous in the household and natural environment, and are affecting reproductive health in humans. Yet litigation in response to exposure to harmful chemicals has had limited success. This is in large part because causation is often difficult to prove, as exposure often occurs over long periods of time, and the sources of suspected chemical agents are ubiquitous and/or diffuse. In light of these challenges, there is a need to consider new legal strategies to confront these harms.

This article examines the potential for prenatal exposure to harmful chemicals to be approached as reproductive torts as opposed to toxic torts. Focusing on two groups of household chemicals – brominated flame retardants and phthalates – this article identifies the ways in which prenatal injury claims and birth torts (i.e. wrongful pregnancy, wrongful birth, and wrongful life cases) can inform future litigation regarding prenatal exposures to risky household chemicals. In particular, reproductive tort jurisprudence offers a variety of ways of conceptualizing causation, injury and fault in cases where individuals are exposed to synthetic household chemicals before birth.

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I. Introduction¹

The human health effects of exposure to synthetic chemicals, ubiquitous in present-day society, call attention to the vulnerability of reproductive and developmental processes that may be influenced by these substances. Biological systems developing *in utero* and throughout childhood are particularly susceptible to environmental influences,² and exposures may result in negative health effects, including harms to the reproductive system.³ Cases of exposure to diethylstilbestrol (DES) offer a historically significant example in which exposure to synthetic

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1. Supported by grant RHF100625 and grant RHF-100626 from the Institute for Human Development, Child and Youth Health (IHDCYH), Canadian Institutes of Health Research (CIHR).
 2. American College of Obstetricians and Gynecologists Committee on Health Care for Underserved Women & American Society for Reproductive Medicine Practice Committee, “Committee Opinion No 575: Exposure to Toxic Environmental Agents” (2013) 122:4 *Obstetrics & Gynecology* 931 at 931; Philippe Grandjean et al, “The Faroes Statement: Human Health Effects of Developmental Exposure to Chemicals in Our Environment” (2008) 102:2 *Basic & Clinical Pharmacology & Toxicology* 73.
 3. For example, a number of human studies have shown that exposures to common household plasticizers (phthalates) “are associated with a direct adverse effect on androgen function in men,” and linked to shortened anogenital distance. See Richard Grady & Sheela Sathyanarayana, “An Update on Phthalates and Male Reproductive Development and Function” (2012) 13:4 *Current Urology Reports* 307 at 309.

chemicals had substantive effects for those exposed *in utero* and for the children of those exposed *in utero*.⁴ In addition, fetuses and children face higher exposure rates to chemicals due to their smaller size, and, for children, the accumulation of toxic substances in breast milk and their close physical contact with household objects.⁵

Currently, a number of household chemicals are under scrutiny due to their ubiquity and the identification of potential harms to the reproductive health of those exposed *in utero*, particularly harms to male reproductive health. For example, brominated flame retardants (BFRs), found in furniture, carpeting, electronics, children's pyjamas, and a number of other consumer products,⁶ are found in the blood of most of the general population and have been linked to altered testicular cells in male rats exposed *in utero*.⁷ Epidemiological studies have also suggested the existence of correlative relationships between exposures to BFRs and reduced testis size, sperm concentration,⁸ altered hormone

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4. See Richard Goldberg, "Causation and Drugs: The Legacy of Diethylstilbestrol" (1996) 25 *Anglo-Am L Rev* 286; W Lenz, "A Short History of Thalidomide Embryopathy" (1988) 38:3 *Teratology* 203.
 5. See for example Joseph L Jacobson, Sandra W Jacobson & Harold EB Humphrey, "Effects of Exposure to PCBs and Related Compounds on Growth and Activity in Children" (1990) 12:4 *Neurotoxicology and Teratology* 319 at 319 (on the breastmilk point); Theo Colborn, Frederick S vom Saal & Ana M Soto, "Developmental Effects of Endocrine-Disrupting Chemicals in Wildlife and Humans" (1993) 101:5 *Environmental Health Perspectives* 378 (on the vulnerability and permanent nature of exposure during development); Vincent F Garry, "Pesticides and Children" (2004) 198:2 *Toxicology and Applied Pharmacology* 152; Philippe Grandjean et al, "The Faroes Statement: Human Health Effects of Developmental Exposure to Chemicals in Our Environment" (2008) 102:2 *Basic & Clinical Pharmacology & Toxicology* 73 (on sensitivity of fetal and neonatal development).
 6. Sheila R Ernest et al, "Effects of Chronic Exposure to an Environmentally Relevant Mixture of Brominated Flame Retardants on the Reproductive and Thyroid System in Adult Male Rats" (2012) 127:2 *Toxicological Sciences* 496.
 7. Yi-Qian Ma, *Understanding the Effects of Exposure to an Environmentally Relevant Mixture of Brominated Flame Retardant Congeners on the Function and Development of the Male Gonad* (M Sc Thesis, McGill University Faculty of Medicine, 2013) [unpublished] at 61.
 8. K Akutsu et al, "Polybrominated Diphenyl Ethers in Human Serum and Sperm Quality" (2008) 80:4 *Bulletin of Environmental Contamination*

levels,⁹ and birth weight anomalies.¹⁰ Phthalates are another class of household chemicals that are found in cleaning supplies, building materials, cosmetics, toys, food packaging, medical devices, clothing, and other plasticized consumer goods.¹¹ Animal studies have demonstrated negative effects of phthalate exposure *in utero*, including reduced testosterone production¹² as well as cryptorchidism,¹³ hypospadias,¹⁴ and shortened anogenital distance¹⁵ in males.¹⁶ Human studies have also suggested a correlation between *in utero* exposure to phthalates and reduced anogenital distance and cryptorchidism.¹⁷ Though scientific

Toxicology 345 at 349.

9. John D Meeker et al, "Polybrominated Diphenyl Ether (PBDE) Concentrations in House Dust are Related to Hormone Levels in Men" (2009) 407:10 *Science of the Total Environment* 3425 at 3428.
10. Sanna Lignell et al, "Prenatal Exposure to Polychlorinated Biphenyls (PCBs) and Polybrominated Diphenyl Ethers (PBDEs) May Influence Birth Weight Among Infants in a Swedish Cohort With Background Exposure: A Cross-sectional Study" (2013) 12:44 *Environmental Health* 1.
11. American College of Obstetricians and Gynecologists Committee on Health Care for Underserved Women & American Society for Reproductive Medicine Practice Committee, *supra* note 2 at 933.
12. Daniel B Martinez-Arguelles et al, "In Utero Exposure to the Antiandrogen Di-(2-Ethylhexyl) Phthalate Decreases Adrenal Aldosterone Production in the Adult Rat" (2011) 85:1 *Biology of Reproduction* 51 at 60.
13. Jane S Fisher et al, "Human 'Testicular Dysgenesis Syndrome': A Possible Model Using In-utero Exposure of the Rat to Dibutyl Phthalate" (2003) 18:7 *Human Reproduction (Oxford Journals)* 1383.
14. *Ibid.*
15. Bethany R Hannas, "Dose-Response Assessment of Fetal Testosterone Production and Gene Expression Levels in Rat Testes Following *In Utero* Exposure to Diethylhexyl Phthalate, Diisobutyl Phthalate, Diisooheptyl Phthalate, and Diisononyl Phthalate" (2011) 123:1 *Toxicological Sciences* 206; M Ema, E Miyawaki & K Kawashima, "Further Evaluation of Developmental Toxicity of Di-*n*-butyl Phthalate Following Administration During Late Pregnancy in Rats" (1998) 98:1-2 *Toxicology Letters* 87.
16. Cryptorchidism occurs when "one or both testicles do not descend into the scrotum." Hypospadias is a condition in which the "urethral opening is displaced toward the scrotum." See Leonard J Paulozzi, "International Trends in Rates of Hypospadias and Cryptorchidism" (1999) 107:4 *Environmental Health Perspectives* 297 at 297.
17. Shanna H Swan, "Environmental Phthalate Exposure in Relation to

studies have not conclusively demonstrated links between exposures to BFRs and phthalates and intergenerational reproductive harm, there is accumulating evidence about effects of *in utero* exposure to household chemicals and the development of the reproductive system.

Over the past several decades, Canada and other countries have developed legislation and public policy responding to knowledge of these effects.¹⁸ In addition to state-based interventions, consumers

Reproductive Outcomes and Other Health Endpoints in Humans”
(2008) 108:2 Environmental Research 177.

18. For example, the 1999 *Canadian Environmental Protection Act*, SC 1999, c 33 [CEPA] is the primary legislation governing toxic chemicals in Canada, and following an expansion of the Act’s regulatory scheme in 2008, the “use, [sale], offer for sale or import” of some widely used BFRs (namely polybrominated diphenyl ethers or PBDEs) was banned. The 2006 expansion of the federal regulation of toxics was encapsulated under the three-part *Chemicals Management Plan* [CMP], which aimed to get “tough on toxics” through 1) issuing a “challenge” to industry to better self-regulate and provide information to the public about particularly hazardous chemicals; 2) increased regulation of “food, cosmetics, drugs or biological drugs and pesticides”; and 3) an expansion of funding for research “to learn more about the effects of chemical exposure on human health and the environment, as well as to provide the necessary means to measure the success of actions to control or reduce risks.” This included the highly-publicized banning of one phthalate plasticizer, Bisphenol A (BPA), used in hard plastic vessels such as baby bottles and re-usable water bottles. Other phthalates remain on the market and are found in personal care products (*i.e.* cosmetics and shampoo), though as of 1998 there has been a voluntary withdrawal of two phthalates from products intended to be consumed or mouthed by young children. New regulations implemented in 2011 have since restricted the “advertising, sale and importation of toys and child care articles composed of vinyl containing phthalates” containing higher than regulated levels of any of six common phthalates. The regulation of toxic household chemicals in Canada, and particularly the CMP, has not included consistent requirements – leaving some chemicals on the market long after there is consensus about their toxicity while others are quickly banned – and has raised questions about whether government or industry should take on the onus for assessing harm. See *Polybrominated Diphenyl Ethers Regulations*, SOR/2008-218, s 7(1); Dayna Nadine Scott, “Beyond BPA: We Need to Get Tough on Toxics,” *Women & Environments Network Magazine* 88/89 (1 October 2011) 43; Government of Canada, *Overview of the Chemicals Management Plan* (2006), online: Government of Canada <<http://www.chemicalsubstanceschimiques.gc.ca/fact-fait/overview-vue-eng.php>>;

are increasingly expected to manage their exposure, mitigating risk by following the advice of experts and making smart choices about the products they buy and use.¹⁹ Advice about how to reduce exposures to BFRs includes, for example, replacing mattresses and sofas that are coated with BFRs with products that are not, or dusting and vacuuming more frequently to reduce exposures to contaminated house dust.²⁰ Advice about reducing exposure to phthalates includes paying attention to labelling to avoid products containing phthalates, more frequent cleaning of the home, and engaging in food preparation that avoids phthalate-contaminated food-products and food-preparation products. For both groups of chemicals, the dominant means through which exposures can be avoided is household labour that most often falls to women: food preparation, household shopping, and cleaning.²¹

The individualized need to avoid exposures is particularly problematic for pregnant women, who are already expected to make choices that optimize the health of their future child by avoiding certain behaviours (*i.e.* stressful activities, smoking, excessive weight gain)²² and products (*i.e.* raw fish, alcohol, caffeine, unpasteurized dairy)²³ linked to fetal harm. Chemical exposure is particularly suspect given that “chemicals in pregnant women can cross the placenta, and in some cases, such as with methyl mercury, can accumulate in the fetus, resulting in higher fetal exposure than maternal exposure” and is, in many cases, associated

Phthalates Regulations, SOR/2010-298, s 2.

19. Norah MacKendrick, *The Individualization of Risk as Responsibility and Citizenship: A Case Study of Chemical Body Burdens* (PhD Soc Thesis, University of Toronto Graduate Department of Sociology, 2012) [unpublished, archived at <https://tspace.library.utoronto.ca/handle/1807/31850>] at 36.
20. Robyn Lee & Dayna Nadine Scott, “(Not) Shopping Our Way to Safety” (30 April 2014), online: Canadian Women’s Health Network <<http://www.cwhn.ca/en/node/46308>>.
21. *Ibid*; MacKendrick, *supra* note 19 at 42.
22. See for example, Public Health Agency of Canada, *The Sensible Guide to a Healthy Pregnancy* (Ottawa: Public Health Agency of Canada, 2008).
23. *Ibid*. See also “Tips For a Healthy Pregnancy,” online: Eat Right Ontario <<https://www.eatrightontario.ca/en/Articles/Pregnancy/Tips-for-a-healthy-pregnancy.aspx>>.

with adverse “reproductive and developmental health outcomes.”²⁴ The exceptional onus of protecting fetal health falls to pregnant women through their behaviours and consumption practices, even when exposures may be difficult to prevent, either due to the ubiquity of household chemicals or the social, temporal, and economic challenges of avoiding exposures. Responsibility for chemical exposures, and especially fetal exposures, largely falls to women as mothers, pregnant women, or as hypothetical mothers-to-be.²⁵

This “precautionary consumption,” – that is to say, the expectation that consumers should educate themselves about how to selectively choose the products they bring into their home as a means to minimize toxic exposures – works to individualize risk, putting the responsibility of reducing exposures to household chemicals on consumers, largely women, tasked with household management.²⁶ The burdens of precautionary consumption are not only disproportionately placed on women (particularly on pregnant women), but also on women of lower socio-economic status as both exposures and resources (*i.e.* time, financial capacity) differ substantially among those of higher and lower socio-economic status. Precautionary consumption works to shift a collective concern – the toxic chemicals in consumer products and in the environment – and to put the responsibility for reducing exposures on individuals, primarily women, through their engagement with a free market in household chemicals.

Beyond legislative, regulatory, and market-based attempts to mitigate the harms of chemical exposures, there exists limited jurisprudence addressing environmental chemical exposures. This body of law has focused largely on “toxic torts” that, like precautionary consumption, also frame harm as a matter of individual responsibility and injury rather than a matter of collective and public health. In both individual and class-action claims, physiological harms are often too vaguely linked to chemical exposures and, when exposures occur over a long period of time,

24. American College of Obstetricians and Gynecologists Committee on Health Care for Underserved Women & American Society for Reproductive Medicine Practice Committee, *supra* note 2 at 3.

25. Lee & Scott, *supra* note 20.

26. *Ibid.*

the potential impact of other factors is too great to establish causation. In short, these cases have been largely unsuccessful due to the challenging nature of establishing causation in negligence and the complex, diffuse nature of exposure. While toxic household chemicals are ubiquitous and suspected of causing significant physiological harm, there are few avenues for legal remedy. Making claims about harms caused by exposures to household chemicals is particularly challenging when those whose health is harmed are not only existing individuals, but also non-existent, that is to say, future people.

Individual and class-action toxic tort claims in Canada have had little success to date. In contrast, a rich jurisprudence has developed in Canada regarding reproductive harms. These cases cover numerous factual contexts, including (but not limited to): medical malpractice; assisted reproductive technologies; women's conduct during pregnancy; pharmaceutical drug development; motor vehicle accidents; and violence against pregnant women. As noted above, emergent science is linking exposures to household chemicals to specific reproductive harms. The links between BFRs and phthalates and adverse male reproductive health described above²⁷ suggest that exposures to household chemicals are a different sort of toxic tort. That is, they are not merely a matter of environmental or health law, but may also fall under jurisprudence governing reproduction. Harms caused by exposures to household chemicals could be framed at once as matters of toxicity and reproduction and, given the problematic record of case law in Canada regarding toxicity, there might be greater potential for successful litigation if claims were articulated in terms of reproductive or birth torts rather than toxic torts. Characterizing reproductive harms incurred by exposures to household chemicals as a matter of reproductive harm first, and of toxicity second, allows for lines of analysis developed in cases of reproductive injury to be applied to the case of chemical exposures. This line of argumentation at once addresses the need for flexibility in establishing causation of prenatal harms and the need to protect women's reproductive autonomy in the governance of pregnancy (and conception).

This paper identifies the relevance of legal approaches to reproductive

27. Akutsu et al, *supra* note 8 at 349.

harm in Canadian law to the case of harm caused by exposures to household chemicals prior to birth. It examines the broad history of reproductive torts in Canada – namely personal injury claims, “birth torts” (*i.e.* wrongful pregnancy, birth, and life claims), and preconception claims – identifying in turn the jurisprudential principles that may be applied to cases where the tortious act involves exposures to household chemicals prior to birth. To do so, the paper begins with a brief discussion of the harms caused by exposures to toxic chemicals, including household chemicals, identifying the limited potential for arguing causation in Canadian toxic tort cases. It then turns to its main purpose, providing an overview of reproductive torts beginning with the most straightforward type of case, namely, prenatal injury claims. These claims are highly analogous to “ordinary” personal injury cases, the main difference being that the claimant is *in utero* at the time of his or her injury. This section of the paper also examines prenatal injury claims in which the child sues his or her own mother with respect to her prenatal conduct. This type of claim most clearly illustrates the concern over women’s autonomy that permeates reproductive tort. In its third section, the paper examines “birth torts,” in which the alleged harm itself is the birth of an unwanted child. It examines three classes of birth torts, namely “wrongful conception,” “wrongful birth,” and “wrongful life” cases, though these categories are highly contested.²⁸ These cases highlight the struggle to recognize the rights of parents to reproductive autonomy while also recognizing the value of the lives of children. In section four, the paper examines cases of prenatal injury where the negligence is alleged to have occurred not while the child was *in utero*, but prior to conception. This type of claim raises several concerns centering on the feasibility of imposing a duty toward one who does not yet exist. In its fifth section, the paper examines cases that defy the neat characterizations set out above, including cases where both prenatal injury claims or preconception injury claims and “birth torts” are at issue. The paper concludes by identifying that although tort law is limited in its ability to address harms potentially caused by prenatal and preconception exposures to household chemicals, reproductive torts offer important insights useful to developing a more robust approach to

28. See discussion of this categorization below at note 146.

addressing intergenerational reproductive harm.

II. Chemical Exposures and Toxic Torts

Research has long demonstrated that exposure to a wide variety of chemicals in sufficient dosage can have detrimental health effects.²⁹ Canadians are exposed to an array of “known and suspected carcinogens, hormone disruptors, developmental toxins and neurotoxins” due to their presence in consumer products, the food and water supply, soil, and in minute quantities, the environment.³⁰ Indeed, these chemicals are everywhere. Recent attention has been paid to chemicals that alter the development of the reproductive system or that may interfere with the endocrine system when exposures occur *in utero*, resulting in adverse results for sperm and oocyte development, low birth weight, congenital anomalies, premature birth, and other adverse effects.³¹

The known and suspected effects of specific chemical exposures are particularly important to examine in the legal context due to their intergenerational effects and the complex nature of any potential litigation. BFRs and phthalates, for example, are suspected to have adverse effects on both male and female development of the reproductive tract when exposures occur *in utero*, based on findings in rodent studies.³² Although the human health effects of BFRs (as mentioned above) are unknown, epidemiological studies have suggested that there are adverse effects on the male reproductive system including reduced testis size and reduced sperm concentration. The endocrine system may also be affected, as epidemiological studies have shown changes in hormone levels associated

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29. Royal Commission on New Reproductive Technologies, *Proceed with Care: Final Report of the Royal Commission on New Reproductive Technologies* (Ottawa: Minister of Government Services Canada, 1993) at 268.
 30. Lynda Collins & Heather McLeod-Kilmurray, “Toxic Battery: A Tort for our Time?” (2008) 16 Tort Law Rev 131 at 131.
 31. American College of Obstetricians and Gynecologists Committee on Health Care for Underserved Women & American Society for Reproductive Medicine Practice Committee, *supra* note 2 at 933.
 32. Martinez-Arguelles et al, *supra* note 12; Fisher et al, *supra* note 13 at 1383; Hannas, *supra* note 15 at 206.

with exposures to certain BFRs.³³ With respect to phthalates, both human and animal studies have suggested that *in utero* exposures may result in reduced anogenital distance and cryptorchidism.³⁴

Prenatal and preconception exposures are of particular interest in regards to BFRs and phthalates due to the suspected transgenerational effects of these chemicals. Both BFRs and phthalates are known endocrine-disrupting chemicals, that is, chemicals that interfere with normal hormone action in the body and consequently disrupt cell metabolism, “reproduction, development, or behaviour.”³⁵ Perhaps the best-known example is that of diethylstilbestrol (or DES),³⁶ a long-prescribed synthetic estrogen that was used to prevent miscarriages in cases of high-risk pregnancy. Adverse health outcomes of exposure to DES emerged over time, particularly for female offspring exposed *in utero*, including a high occurrence of a rare form of vaginal cancer, reduced fertility, high rates of ectopic pregnancy, increased breast cancer, and early menopause, amongst others.³⁷ Early research on third generation DES offspring suggests adverse health outcomes for the children of those exposed *in utero* including “penile and testicular anomalies” such as high rates of cryptorchidism³⁸ in male offspring; delayed menarche in female offspring;³⁹ and skeletal and heart anomalies in both male and female offspring.⁴⁰ The case of DES illustrates that the implications of exposure

33. Meeker et al, *supra* note 9 at 3428.

34. Swan, *supra* note 17 at 179.

35. *Canadian Environmental Protection Act*, SC 1999, c 33, s 43 [CEPA].

36. See discussion below at note 199.

37. Sheela Sathyanarayana et al, “Environmental Exposures: How to Counsel Preconception and Prenatal Patients in the Clinical Setting” (2012) 207:6 *American Journal of Obstetrics and Gynecology* 463 at 468; D Andrew Crain et al, “Female Reproductive Disorders: The Roles of Endocrine-Disrupting Compounds and Developmental Timing” (2008) 90:4 *Fertility and Sterility* 911 at 912; Nicolas Kalfa et al, “Prevalence of Hypospadias in Grandsons of Women Exposed to Diethylstilbestrol During Pregnancy: A Multigenerational National Cohort Study” (2011) 95:8 *Fertility and Sterility* 2574 at 2574.

38. Kalfa et al, *ibid.*

39. Linda Titus-Ernstoff et al, “Menstrual and Reproductive Characteristics of Women Whose Mothers Were Exposed *In Utero* to Diethylstilbestrol (DES)” (2006) 35:4 *International Journal of Epidemiology* 862.

40. Linda Titus-Ernstoff et al, “Birth Defects in the Sons and Daughters of

may extend far beyond the person immediately exposed, to their child *in utero* as well as to their grandchildren yet-to-be-conceived.

Research on other endocrine disrupters is increasingly demonstrating links between exposures and transgenerational reproductive outcomes recalling the effects of DES. For example, studies demonstrate that rats exposed to certain endocrine disrupters (namely the pesticide vinclozolin) known to cause altered fertility have passed anomalies “down to nearly every male in subsequent generations.”⁴¹ There is also reason to believe that such effects may be occurring in the case of BFRs, as animal studies have shown that exposing American male kestrels to certain BFRs has multigenerational effects on reproductive success.⁴² With respect to phthalates, recent research has demonstrated that following exposure of mice *in utero*, “abnormal testicular function” persisted in subsequent generations, amongst other anomalies.⁴³

While scholars are continuing to study the transgenerational effects

Women Who Were Exposed In Utero to Diethylstilbestrol (DES)” (2010) 33:2 International Journal of Andrology 377.

41. Matthew D Anway et al, “Epigenetic Transgenerational Actions of Endocrine Disruptors and Male Fertility” (2005) 308:5727 Science 1466; Jocelyn Kaiser, “Endocrine Disrupters Trigger Fertility Problems in Multiple Generations” (2005) 308:5727 Science 1391 at 1391.
42. Sarah C Martenson et al, “Multi-generational Effects of Polybrominated Diphenylethers Exposure: Embryonic Exposure of Male American Kestrels (*Falco sparverius*) to DE-71 Alters Reproductive Success and Behaviors” (2010) 29:8 Environmental Toxicology and Chemistry 1740; Kim J Fernie et al, “Changes in Reproductive Courtship Behaviors of Adult American Kestrels (*Falco sparverius*) Exposed to Environmentally Relevant Levels of the Polybrominated Diphenyl Ether Mixture, DE-71” (2008) 102:1 Toxicological Sciences 171; Kim J Fernie et al, “Environmentally Relevant Concentrations of DE-71 and HBCD Alter Eggshell Thickness and Reproductive Success of American Kestrels” (2009) 43:6 Environmental Science & Technology 2124.
43. Timothy J Doyle et al, “Transgenerational Effects of Di-(2-ethylhexyl) Phthalate on Testicular Germ Cell Associations and Spermatogonial Stem Cells in Mice” (2013) 88:5 Biology of Reproduction 1 at 10.

of phthalates and BFRs in both human⁴⁴ and animal⁴⁵ populations, the data is emergent and far from conclusive. Moreover, determining causation of any such effects is particularly difficult given the inconsistent nature of findings in both human and animal studies. Further, exposures to household chemicals typically occur in ways that are diffuse and cumulative, that is to say, emergent from innumerable sources and occurring over a long period of time. Simply put, it is difficult to establish the cause of chemical exposures when the science remains unclear and, furthermore, when we are always already exposed. Exposures may also predate conception and birth, insofar as one's exposure may affect the health of one's child not yet conceived, *in utero*, or the offspring of the child *in utero* (or the child yet-to-be-conceived).

Despite the known and suspected reproductive harms caused by exposure to household chemicals, litigation has been limited. In the Canadian context, there are very few cases that address reproductive harm in relation to exposures to household chemicals, in part because of the challenge of establishing a cause-and-effect relationship between chemical exposures and physiological harm. The criminal justice system offers few opportunities for litigation where harm is incurred due to exposures to household chemicals, and tort law (most often through claims of negligence) has been the site where relevant jurisprudence has been developed. However, toxic tort jurisprudence has not seen much success, either as individual or class action claims. Two successful cases of toxic exposures associated with individual harm are *Leibel v South Qu'Appelle (Rural Municipality)*⁴⁶ and *MacDonald v Sebastian*,⁴⁷ both cases of arsenic-

44. See for example Chanley M Small et al, "Reproductive Outcomes Among Women Exposed to a Brominated Flame Retardant In Utero" (2011) 66:4 Archives of Environmental & Occupational Health 201. See also Donatella Caserta et al, "The Influence of Endocrine Disruptors in a Selected Population of Infertile Women" (2013) 29:5 Gynecological Endocrinology 444.

45. See for example Rylee Phuong Do et al, "Non-monotonic Dose Effects of In Utero Exposure to Di(2-ethylhexyl)phthalate (DEHP) on Testicular and Serum Testosterone and Anogenital Distance in Male Mouse Fetuses" (2012) 34:4 Reproductive Toxicology 614.

46. [1944] 1 DLR 369 (Sask CA) [*Leibel*].

47. (1987), 81 NSR (2d) 189 (SC(TD)) [*MacDonald*].

tainted drinking water. In *Leibel*, the plaintiff was “poisoned with deeply injurious results” by drinking well water that had been contaminated with arsenic due to the negligent mixing of grasshopper poison-bait by the municipality taking place nearby.⁴⁸ The plaintiff suffered “much pain and nausea”; “lost ... use of his hands and feet”; impaired “bodily functions”; and a deterioration of his general “condition of health.”⁴⁹ In *MacDonald*, a landlord did not disclose the toxic levels of arsenic in the water supply of his tenants, despite prior knowledge.⁵⁰ The plaintiffs argued that the landlord had a duty to disclose the levels of arsenic, and Justice Burchell, finding that the actions of the defendant were therefore negligent, awarded damages. The causation in this case was very clear, with the plaintiffs experiencing flu-like symptoms, nausea, cramps, and diarrhoea (which are conclusively linked to arsenic poisoning) following consumption of the toxic water supply.⁵¹

Though reproductive harms were not explicitly at issue, both *Leibel* and *MacDonald* offer examples of the type of negligence claim regarding toxic exposures likely to succeed in Canadian jurisprudence. Negligence claims rely on four requirements for a successful claim, namely the establishment of duty on the part of the defendant, a breach of said duty, a causal connection between the breach of duty and the harm incurred, and real material damage, injury or harm.⁵² Causation is integral here, and the near-immediacy of the harms and the direct relationship between arsenic poisoning and the plaintiffs’ health effects made the tortious actions relatively easy to establish. Unlike *in utero* or preconception exposures to household chemicals, the plaintiffs were either children or adults harmed directly by exposures associated with the negligence of the defendant, causation was clear and direct, and the effects were nearly immediate.⁵³

48. *Supra* note 46 at para 1.

49. *Ibid* at para 9.

50. *Supra* note 47 at paras 1, 3.

51. *Ibid* at para 6.

52. J A Jolowicz & T Ellis Lewis, *Winfield on Tort*, 8th ed (London: Sweet & Maxwell, 1967) at 42 ff.

53. Other cases where injury in negligence is limited to a single or small-group exposed to toxics have generally been dismissed due to a lack of clarity in causation. See for example *Nichols (Guardian of) v Koch Oil*

Where intergenerational harm has been claimed, cases have been dismissed due to an inability to demonstrate clear causation. For example, in the case of *Martin (Litigation guardian of) v Glaze-Bloc Products Inc.*,⁵⁴ an employee of Glaze-Bloc Products Inc. was exposed to trichloroethylene, a synthetic chemical most often used in industrial cleaning and in some household products.⁵⁵ This exposure was alleged to cause the neural tube anomaly experienced by the infant plaintiff, the employee's child.⁵⁶ However, while Glaze-Bloc Products was found to be at fault for the chemical exposures experienced by Tom Martin, Justice Morin found that there was not "valid evidence to support a cause and effect relationship between"⁵⁷ the chemical exposures and the "neural tube defects" of the child.⁵⁸ The significant challenge of establishing causation in cases of environmental exposures is particularly apparent in *Martin* as the possibility that factors and exposures other than that which occurred due to the actions of Glaze-Bloc Products Inc., as well as the limitations of existing research on the chemical in question, undermined the capacity of the plaintiffs to demonstrate concretely a direct relationship between cause and effect.⁵⁹ Given that tort law has conventionally required the plaintiff to demonstrate the likelihood that the defendant's actions or inactions resulted in the injuries in question, in many cases the multifactorial nature of reproductive harm, the diffuse nature of chemical exposures, and the lack of substantive scientific support to make direct evidentiary causal claims, make causation in cases

Col, [1998] BCJ No 1944 (QL) (SC); *Guimond Estate v Fiberglas Canada Inc* (1999), 221 NBR (2d) 118 (CA); *Canada v Grenier*, 2005 FCA 348; *Stucke v Richard McDonald & Associates Ltd*, 2006 ABQB 239; *MacIntyre v Cape Breton District Health Authority*, 2009 NSSC 202.

54. 2007 CarswellOnt 9457 (WL Can) (Sup Ct) [*Martin*].
55. Environment Canada Government of Canada, "Environment Canada - Pollution and Waste – Trichloroethylene" (13 August 2009), online: Environment Canada <<http://www.ec.gc.ca/toxiques-toxics/Default.asp?lang=En&n=98E80CC6-1&xml=8E5CDE87-0226-4C47-BADC-161ED8A72654>>.
56. *Martin*, *supra* note 54 at para 1.
57. *Ibid* at para 73.
58. *Ibid*.
59. *Ibid* at para 131.

like *Martin* nearly impossible to prove.⁶⁰

Class action toxic torts in Canada have been limited by the difficulties of acquiring class certification, though the benefits of pursuing such claims in cases of exposures to environmental toxins are clear. In all claims of toxic torts, the cost, difficulty of identifying the time and place of long-term exposures, and limited scientific evidence substantiating cause and effect too often preclude success in cases where the tort of negligence is argued.⁶¹ Class action suits offer the opportunity for plaintiffs to pool their resources in cases “where complexity and expert scientific evidence make conflicting findings likely and individual litigation virtually impossible to afford.”⁶² Further, for the courts, class actions allow for limited judicial resources to be more economically used in cases where the facts are essentially the same, in order to “improve access to justice by making economical the prosecution of claims that any one class member would find too costly to prosecute on his or her own,” and enable claims substantial enough to require “actual and potential wrongdoers” to change their behaviours to reduce or eliminate the “harm they are causing, or might cause, to the public.”⁶³

However, following Patrick Hayes, there has been a too-narrow understanding of causation in class action claims regarding toxic exposures that has limited success in establishing class-action certification.⁶⁴ Hayes identifies the case of *Hollick v Toronto (City)* as establishing a restrictive framework in recognizing mass toxic torts that set the stage for future refusals to grant certification in environmental torts claims. In *Hollick*, the plaintiff claimed that the “noise and physical pollution”⁶⁵ from a nearby landfill were excessive, making a class action nuisance claim on behalf

60. Jocelyn Kaiser, “Endocrine Disrupters Trigger Fertility Problems in Multiple Generations” (2005) 308:5727 *Science* 1391 at 1391.

61. Patrick Hayes, “Exploring the Viability of Class Actions Arising from Environmental Toxic Torts: Overcoming Barriers to Certification” (2009) 19:3 *J Envtl L & Prac* 189 at 190.

62. Heather McCleod-Kilmurray, “*Hollick* and Environmental Class Actions: Putting the Substance into Class Action Procedure” (2002) 34 *Ottawa L Rev* 263 at 283.

63. *Hollick v Toronto (City)*, 2001 SCC 68 at para 15 [*Hollick*].

64. *Supra* note 61.

65. *Supra* note 63 at para 2.

of 30,000 residents living near the landfill. The motions judge certified a class action, but the class certification was overturned in Divisional Court “on the grounds that the appellant had not stated an identifiable class and had not satisfied the commonality requirement.”⁶⁶ Essentially, each of the individual plaintiffs would have differently experienced the nuisance dependant on various factors, including their proximity to the landfill.⁶⁷ The Supreme Court of Canada dismissed the appeal. The limitations placed on class certification were also made clear in *Ring v Canada*⁶⁸ in which it was alleged that “the spraying of herbicides” near the Gagetown military base from 1956 onward “materially contributed to or materially contributed to the risk of causing, lymphoma”⁶⁹ for the plaintiffs. Though the trial judge found that the certification for a class action had been met, on appeal Justice Cameron found for the court that the class was too broadly conceived, as it included not only those who were exposed to toxic chemicals at Gagetown after 1956, but also those “who claim to”⁷⁰ have been exposed. For Cameron JA, no acceptable limits to the class of those claiming exposure were applied, and therefore class certification could not be accorded.

In contrast, in *Smith v Inco Limited*,⁷¹ certification for a toxic torts case was granted. Initially, certification was denied by Justice Nordheimer at the Ontario Superior Court of Justice as the geographic boundaries of contamination were “arbitrary” (*i.e.* including people without claims and excluding people with relevant claims).⁷² On appeal, class certification was granted, but only once the class was narrowed from the broader class of those who experienced physiological harms alleged to be caused by exposures to certain “toxic and carcinogenic chemicals”⁷³ to extend only

66. *Ibid* at para 8.

67. *Ibid* at para 32.

68. 2010 NLCA 20.

69. *Ibid* at para 1.

70. *Ibid* at para 71.

71. 2011 ONCA 628 [*Smith*].

72. *Pearson v Inco Ltd* (2002), 33 CPC (5th) 264 at para 101 (Ont Sup Ct).

73. There has been greater success in toxic tort class action suits under *Droite Civile* in Quebec. See *St Lawrence Cement v Barrette*, 2008 SCC 64; and *Comité d'environnement de La Baie inc c Société d'électrolyse et de chimie Alcan ltée*, [1990] RJQ 655 (Qc CA).

to those whose property values were adversely affected. The claim on the merits failed at the Court of Appeal.⁷⁴

The poor record of litigation vis-à-vis exposures to synthetic chemicals in Canada has not precluded scholars from theorizing how such tort actions might be undertaken. Though harms caused by exposures to synthetic chemicals have most often been articulated as negligence claims, Lynda Collins and Heather McLeod-Kilmurray imagine how Canadians, exposed to a wide variety of chemicals without their consent, might be able to make a claim of “toxic battery.” “Toxic battery,” they argue, occurs in “any battery in which the alleged intentional contact takes the form of exposure to a toxic substance released by the defendant.”⁷⁵ If battery is “the intentional application of harmful or offensive contact” with the plaintiff’s person,⁷⁶ and intent need not be specific or desired, but merely relies on any consequences that result from the defendant’s conduct (following the doctrine of constructive intent),⁷⁷ it follows that those responsible for exposing plaintiffs to synthetic chemicals might be understood as committing battery.

Collins and McLeod-Kilmurray identify the potential utility of battery in toxic torts in part as a means to circumvent the challenge posed by establishing causation in claims of negligence. As in *Martin*, due to the limitations of existing scientific research on the effects of environmental exposures to synthetic chemicals, and further, because of the often diffuse nature of exposure, causation has been too difficult to establish, rendering negligence claims a losing proposition. As battery relies on the idea that there is “harmful or offensive contact”⁷⁸ experienced by the plaintiff, in which there is some sort of incursion on their person that violates their dignity regardless of the harm, “toxic battery” engenders an understanding that the harm is the exposure in and of itself, rather than any specific physiological effects. However, as these authors identify, given the widespread nature of chemical exposures, the claim that individuals are subject to battery when involuntarily exposed

74. *Smith, supra* note 71.

75. Collins & McLeod-Kilmurray, *supra* note 30 at 132.

76. *Ibid.*

77. *Ibid.*

78. *Ibid* at 143.

to synthetic chemicals could ostensibly be applied to nearly everyone in the industrial world, if not elsewhere. The overly broad scope of toxic battery, then, suggests that it is unlikely to be successful as a strategy to address cases of environmental exposures to synthetic chemicals, though it is particularly useful in its capacity to sidestep the issue of causation that hinders relevant negligence claims.

Rather than theorize toxic torts as battery, Dayna Scott suggests that the preoccupation of tort law with proof of physical damages experienced by individuals impedes justice. Scott interrogates the relationship between tort law and the body, identifying that the association between physical damage experienced by individuals is too limited an understanding of harm to provide a remedy in the case of toxic torts. Scott argues that if tort law is a means to address the harms incurred by one individual (or group) at the hands of another, tort law is insufficient to engage with harms caused by toxic chemicals as it is “blind to the public dimensions of the problem and the way that state law, through the regulatory design, shapes the behaviour of key actors, notably in this case, polluters.”⁷⁹ Addressing the adverse effects of household chemicals as a matter of tort law inherently frames exposure as a private matter when rightly, for Scott, it is a matter of public health, public interest, and state responsibility.

Nevertheless, toxic torts continue to be used to address matters of chemical exposure with limited success. The challenges of proving causation of adverse health effects are often insurmountable for plaintiffs, particularly in cases that are not class-action matters and when the harms are claimed as a matter of negligence. Causation is even more difficult to prove in toxic torts cases when, as in *Martin*, reproductive harms (particularly those that occur prior to conception) are alleged.⁸⁰ However, as research on phthalates and BFRs increasingly demonstrates there are links between *in utero* exposures and reproductive harm, exposures to household chemicals might be thought of both as a toxic tort and as a matter of reproductive harm. As toxic torts claims have largely been unsuccessful in the Canadian context, partly due to the problematic

79. Dayna Nadine Scott, “Gender-benders’: Sex and Law in the Constitution of Polluted Bodies” (2009) 17:3 *Fem Legal Stud* 241 at 260.

80. *Supra* note 54.

nature of establishing causation, cases in which reproductive harms are associated with household chemicals might instead look to reproductive torts as a line of argumentation. Reproductive torts (*i.e.* prenatal injury claims, birth torts, and preconception claims) may offer a point of entry for litigation addressing reproductive harms caused by exposures to household chemicals.

III. Reproductive Torts

A. Prenatal Injury Claims

Prenatal injury claims occur when the tortious act harms or is alleged to have harmed a child *in utero*. These cases can be roughly categorized in two different ways. First, prenatal injury claims may be made when the harm incurred is alleged to be caused by a breach of duty on the part of the defendant. In these cases, the driver of a motor vehicle (as in early cases) or health services workers (*i.e.* physicians, nurses) breach a duty of care resulting in the alleged harms to the fetus. The second type of prenatal injury claim is that in which a pregnant woman is liable for the tortious action. In these particularly controversial cases, a woman in some way harms herself (accidentally or otherwise), and alleged harm to her fetus is the result of her action. Both types of claims are discussed below to demonstrate the theorization of fetal harm, liability, and causation in prenatal injury negligence cases as a means to identify the utility of these approaches for potential litigation regarding reproductive harms caused by *in utero* exposures to household chemicals.

In Canada, the earliest precedents relating to reproductive harm occurred in the case of accidents involving motor vehicles. Though decided under Quebec's civil law, the 1933 Supreme Court of Canada decision in *Montreal Tramways Co v Léveillé*⁸¹ featured a common law analysis, and it has served as a precedent in later common law decisions. In this case, a pregnant woman was “descending from a tram car” when, “by reason of the negligence” of the employee of the appellant (the “motorman”), she fell and was injured; her child was born with “club

81. [1933] SCR 456 [*Montreal Tramways*].

feet.”⁸² At issue was whether the available evidence allowed the jury to reasonably find that the fall caused the child’s club feet, and whether the child, while *in utero*, was covered by Article 1053 of the civil code, which read, “[e]very person capable of discerning right from wrong is responsible for the damage caused by his fault to another, whether by positive act, imprudence, neglect or want of skill.”⁸³

The majority judgment, written by Justice Lamont, surveys UK, Irish, and American precedent on the legal status of the unborn child, finding that the common law recognizes the separate existence of the unborn child for inheritance and criminal law purposes, provided that the child is subsequently born alive. The judgment goes on to state that existing common law authority does not apply this rule in personal injury cases, but that the civil law employs a legal fiction wherein it treats a conceived but unborn child as having been born at a particular time for his or her benefit, if subsequently born alive. With respect to causation, Lamont J held that the medical expert testimony arguing that the cause of club feet was unknown did not negate the testimony of the experts who believed it was very probable that the accident caused the child’s condition, and consequently, the jury could reasonably have found a causal relationship.⁸⁴ Beyond addressing and accepting the vague probability of causation, the result of the majority decision was a precedent-setting judgment that effectively determined the retrospective application of negligence *in utero*, as long as the child was born alive.

The logic of *Montreal Tramways* would be put to use in the Ontario case of *Duval et al v Seguin et al*,⁸⁵ the Canadian common law precedent-setting case on tort recovery for injuries sustained while *in utero*. The facts concerned a motor vehicle accident involving several individuals, one of whom was thirty-one weeks pregnant at the time, and whose child was born prematurely about three weeks later.⁸⁶ The High Court described that the child was “permanently handicapped both physically and

82. *Ibid* at 458.

83. *Ibid* at 459.

84. *Montreal Tramways*, *ibid* at 473.

85. (1973) 1 OR (2d) 482 (CA) [*Duval* 1973], aff’g [1972] 2 OR 686 (H Ct J) [*Duval* 1972].

86. *Duval* 1972, *ibid* at para 32.

mentally”⁸⁷ as a result of “brain injuries suffered in the accident.”⁸⁸ The judgments of the High Court and the Court of Appeal, both of which allowed recovery by the infant plaintiff, referred to American,⁸⁹ Irish,⁹⁰ and Australian⁹¹ authorities promoting recovery for injuries sustained while *en ventre sa mère*. The High Court judgment, echoing *Montreal Tramways*, notes:

In my opinion it is not necessary in the present case to consider whether the unborn child was a person in law or at which stage she became a person. For negligence to be a tort there must be damages. While it was the foetus or child *en ventre sa mère* who was injured, the damages sued for are the damages suffered by the plaintiff Ann since birth and which she will continue to suffer as a result of that injury.⁹²

The High Court dismissed the argument that the difficulty in proving causation in prenatal injury cases justified barring such claims, suggesting that though older cases were invested in the difficulty of establishing causation, “scientific advances”⁹³ suggest that the relationship between certain acts and prenatal injuries are stronger than ever. The High Court also addressed the issue of causation by referring to the then-landmark case of *Donoghue v Stevenson*,⁹⁴ writing that “[u]nder the doctrine of M’Alister (or Donoghue) v. Stevenson ... an unborn child is within the foreseeable risk incurred by a negligent motorist. When the unborn child becomes a living person and suffers damages as a result of prenatal injuries caused by the fault of the negligent motorist the cause of action is

87. *Ibid* at para 37.

88. *Ibid* at paras 35-36.

89. *Ibid* at paras 49-51.

90. *Duval* 1972, *ibid* at paras 56-57.

91. *Duval* 1972, *ibid* at paras 63-64; *Duval* 1973, *supra* note 85 at para 9, citing *Watt v Rama*, [1972] VR 353 [*Watt*]. *Watt* established precedent regarding the capacity to sue for injuries incurred prior to birth, namely *en ventre sa mère*. The case involved a motor vehicle accident in which it was held that a duty of care was owed to a child born alive if injuries were sustained *in utero*. See also Fiona Anne Kumari Campbell, *The Great Divide: Ableism and Technologies of Disability Production* (PhD Thesis, Queensland University of Technology, 2003) [unpublished] at 122-23.

92. *Duval* 1972, *ibid* at para 67.

93. *Ibid* at para 70.

94. [1932] UKHL 100.

completed.”⁹⁵ The court awarded \$31,000 to the infant plaintiff and this award was upheld by the Court of Appeal.⁹⁶

In *Montreal Tramways*, the majority decision did not hinge on causation as conflicting expert witnesses suggested that the child’s club feet may or may not have been the result of the “motorman’s” negligence. Further, in *Duval* the High Court was careful to note that as causation is difficult to establish in cases of prenatal harms, in cases where there is a strong correlation between a negligent act and injuries sustained to a child *en ventre sa mère*, “plaintiffs should not be denied relief in proper cases because of possible difficulties of proof.”⁹⁷ In short, though causation is a critical element of negligence claims, at least in the case of prenatal injuries related to motor vehicles causation is inherently tenuous and a failure to establish clear causation has not always prevented successful claims.⁹⁸

While accidents involving motor vehicles are one of the earliest scenarios in which prenatal injury claims were made in Canada, prenatal personal injury is also often litigated in scenarios involving labour and delivery. Numerous court decisions feature plaintiffs who allege that negligent care they and their mothers received in the hours, minutes or seconds prior to their birth resulted in severe injury.⁹⁹ In light of the

95. *Duval* 1972, *supra* note 85 at para 71.

96. *Ibid* at para 72; *Duval* 1973, *supra* note 85 at para 11.

97. *Duval* 1972, *ibid* at para 70.

98. In addition to *Montreal Tramways* and *Duval*, the case of *LaForge v McGee et al* involves a fact scenario in which a pregnant woman is involved in a motor vehicle accident and her child, subsequently born alive, is born with disabilities. In this case, causation was relatively easily established through medical testimony and a very direct temporal relationship between the motor vehicle accident and pregnant woman’s symptoms (associated with the harm incurred by the infant plaintiff). In this case, causation was seen to be direct and relatively simple for Justice Wood. See *Laforge v McGee*, [1988] BCJ No 1584 (QL) (SC).

99. See e.g. *Preston v Chow*, 2007 MBQB 318 [*Preston*]; *Crawford (Litigation guardian of) v Penney* (2004), 26 CCLT (3d) 246 (CA) [*Crawford*]; *Tsur-Shofer v Grynspan* (2004), 131 ACWS (3d) 545 (Sup Ct); *Fullerton (Guardian ad litem of) v Delair*, 2005 BCSC 204; *Brito (Guardian ad litem of) v Woolley*, 2003 BCCA 397 (claim unsuccessful); *Meyer v Gordon* (1981), 17 CCLT 1 (SC); *Bauer (Litigation guardian of) v Seager*, 2000 MBQB 113 [*Bauer*]; *Anderson v Salvation Army Maternity*

consequences of prenatal injury, which may include the need for constant care and a lifetime's worth of lost earnings, damages in these types of cases often run into the millions of dollars.¹⁰⁰ Care providers that have been found liable for providing negligent prenatal care include obstetricians¹⁰¹ and other attending physicians;¹⁰² medical residents;¹⁰³ nurses;¹⁰⁴ and midwives.¹⁰⁵ Hospitals have also been found liable for negligence.¹⁰⁶

These cases rely on the premise that care providers owe a duty of care to both the pregnant woman and unborn child during pregnancy, as well as during labour and delivery.¹⁰⁷ Further, there must be some causal link between the actions of the care providers and the harm incurred by the plaintiff. For example, the claim might be made that inadequate care in response to a high-risk pregnancy led to oxygen deprivation during labour causing the child to be born with “extensive and permanent brain injuries.”¹⁰⁸ In addition, plaintiffs might claim that the failure to perform a caesarean section or refer to a specialist when raised led to a child being

Hospital (1989), 93 NSR (2d) 141 (SC(TD)) (cerebral palsy and mental retardation allegedly caused by negligently performed vaginal breech delivery – claim failed for failure to establish negligence and causation).

100. *Lusignan (Litigation guardian of) v Concordia Hospital* (1997), 117 Man R (2d) 241 (QB) at para 7 (negligent prenatal/delivery care led infant plaintiff to be “severely mentally handicapped” and have “a mild degree of cerebral palsy” – awarded over \$2.2 million); *Carere v Cressman*, 12 CCLT (3d) 217 (Sup Ct) [*Carere*] (midwife’s negligent prenatal care held to have caused the infant plaintiff’s cerebral palsy – over \$2.3 million in damages awarded); *Ediger (Guardian ad litem of) v Johnston*, 2009 BCSC 386 (negligently performed delivery causes quadriplegia and cerebral palsy – over \$3 million in damages awarded); *Crawford, supra* note 99 (negligent delivery causes permanent brain injuries – infant awarded \$10 million).
101. *Crawford, supra* note 99.
102. *Steinebach (Litigation guardian of) v Fraser Health Authority*, 2011 BCCA 302 [*Steinebach*]; *Crawford, ibid*.
103. See *Milne v St Joseph’s Health Centre* (2009), 69 CCLT (3d) 208 (Sup Ct) [*Milne*]; *Bauer, supra* note 99.
104. *Milne, ibid*; *Steinebach, supra* note 102; *Guerineau (Guardian ad litem of) v Seger*, 2001 BCSC 291 [*Guerineau*].
105. *Carere, supra* note 100.
106. *Guerineau, supra* note 104; *Bauer, supra* note 99.
107. See *Milne, supra* note 103 at paras 63-64; *Crawford, supra* note 99.
108. *Crawford, ibid* at para 1.

affected by the herpes virus.¹⁰⁹

Taken together, the motor vehicle and prenatal care cases discussed to this point illustrate the emergence and entrenchment of the right of the child born alive to sue for damages sustained before birth. Further, as a group these cases, and particularly those cases of fetal harm involving motor vehicle accidents, suggest that causation need not always be direct and clear. Causation, as in *Preston* and *Crawford* cited above, may be inferred from a breach of duty marked by inaction, or as in *Montreal Tramways* and *Duval*, may be based on perceived probability of harm following an injurious event (motor vehicle collision). The challenge of determining causation with certainty in cases of prenatal harm need not stand in the way of a remedy.

In *Duval*, Justice Fraser outlined the challenges of establishing causation in cases of prenatal harm, stating the importance of not dismissing just claims in the absence of the science necessary to prove causation. He wrote for the court that:

Some of the older cases suggest that there should be no recovery by a person who has suffered prenatal injuries because of the difficulties of proof and of the opening it gives for perjury and speculation. Since those cases were decided there have been many scientific advances and it would seem that chances of establishing whether or not there are causal relationships between the act alleged to be negligent and the damage alleged to have been suffered as a consequence are better now than formerly. In any event the Courts now have to consider many similar problems and *plaintiffs should not be denied relief in proper cases because of possible difficulties of proof.*¹¹⁰

Prenatal claims may, then, offer some hope for cases where prenatal exposures to household chemicals are at issue. There is a clear history of negligence claims when fetal harm is linked to a breach of a duty of care including, at times, where a direct line between cause and effect is not apparent. This stands in contrast to claims of negligence related to toxic chemicals which, in the Canadian context, may be dismissed when causation is either unclear or indirect. Whereas in cases like *MacDonald* and *Leibel* exposure to arsenic was clear and specifically related to the symptoms experienced by the plaintiffs, in cases like *Martin* the

109. *Preston*, *supra* note 99 at para 193.

110. *Duval* 1972, *supra* note 85 at para 70 [emphasis added].

relationship between chemical exposures and the adverse health effects were too vague for the claim of negligence to succeed.

In the case of either BFRs or phthalates, there are no clear guidelines regarding acceptable levels of exposure and bioaccumulation, and, as in *Martin*, without such guidelines from scientific or medical communities it might be difficult to establish a relationship between adverse health outcomes and chemical exposures for purposes of litigation. The multifactorial nature of the symptoms that may be associated with exposures to household chemicals, such as cryptorchidism and low birth rate, may also raise doubt about the role of chemical exposures in reproductive health issues that may be experienced by those exposed *in utero*. The issue of establishing causation is further exacerbated by the challenge of finding an identifiable defendant in such cases, as contemporary Western households typically include a wide variety of products that contain either BFRs¹¹¹ or phthalates.¹¹² Furthermore, due to the ongoing nature of these exposures, there is little possibility of identifying the particular product or manufacturer to which specific adverse health effects can be attributed. Establishing direct and clear causation between exposure to household chemicals and adverse health effects is unlikely due to the diffuse and pervasive nature of exposures, compounded by the still-unclear science on the effects of these chemicals, and the challenges of finding an identifiable plaintiff. If tort action requires an identifiable defendant, quantifiable damage, and a causal relationship between the defendant and the harm incurred,¹¹³ in the theoretical cases involving exposures to household chemicals, two out of the three criteria (*i.e.* an identifiable defendant, and a causal connection), are not clearly present.

B. Prenatal Injury Claims Against Pregnant Women

The second category of prenatal injury claims is that which occurs when a mother is the tortfeasor and is believed to have caused harms sustained by

111. See text accompanying note 7.

112. See text accompanying note 2.

113. Albert C Lin, "Beyond Tort: Compensating Victims of Environmental Toxic Injury" (2005) 78:6 S Cal L Rev 1439 at 1445.

a fetus. These cases are limited in the Canadian context as the Canadian judiciary has largely been resistant to interfere with women's reproductive autonomy, particularly following *R v Morgentaler*.¹¹⁴ Women are not typically held liable for risks or harm enacted on a fetus, suggesting that the governance of pregnancy is a matter of reproductive autonomy, and should be addressed by public policy rather than judicial intervention.

The case of *Winnipeg Child & Family Services (Northwest Area) v DFG*¹¹⁵ was critical to establishing the position of non-intervention in pregnancy taken by the courts in Canada,¹¹⁶ though it considers the actions of an organization acting on behalf of the interests of a fetus against a pregnant woman (rather than the *in utero* exposure to harms experienced by a child born alive).¹¹⁷ This case involved the attempt of Winnipeg Child and Family Services to obtain a court order detaining a pregnant Aboriginal woman who was addicted to sniffing glue, in order to protect her unborn child from neurological damage.¹¹⁸ The issues before

114. [1988] 1 SCR 30.

115. [1997] 3 SCR 925 [DFG].

116. Roxanne Mykitiuk & Dayna Nadine Scott, "Risky Pregnancy: Liability, Blame, and Insurance in the Governance of Prenatal Harm" (2010) 43:2 UBC L Rev 311 at 331.

117. See *e.g.* Melanie Randall, "Pregnant Embodiment and Women's Autonomy Rights in Law: An Analysis of the Language and Politics of *Winnipeg Child and Family Services v. D.F.G.*" (1999) 62:2 Sask L Rev 515; Sandra Rodgers, "*Winnipeg Child and Family Services v. D.F.G.*: Juridical Interference with Pregnant Women in the Alleged Interest of the Fetus" (1998) 36:3 Alta L Rev 711; FC DeCoste, "*Winnipeg Child and Family Services (Northwest Area) v. D.F.G.*: The Impossibility of Fetal Rights and the Obligations of Judicial Governance" (1998) 36:3 Alta L Rev 725; Laura Shanner, "Pregnancy Intervention and Models of Maternal-Fetal Relationship: Philosophical Reflections on the *Winnipeg C.F.S. Dissent*" (1998) 36:3 Alta L Rev 751; Bruce P Elman & Jill Mason, "The Failure of Dialogue: *Winnipeg Child and Family Services (Northwest Area) v. G. (D.F.)*" (1998) 36:3 Alta L Rev 768; Timothy Caulfield & Erin Nelson, "*Winnipeg Child and Family Services (Northwest Area) v DFG*: A Commentary on the Law, Reproductive Autonomy and the Allure of Technopolicy" (1998) 36:3 Alta L Rev 799; Emilia Ordolis, "Maternal Substance Abuse and the Limits of Law: A Relational Challenge" (2008) 46:1 Alta L Rev 119; Lorna Weir, *Pregnancy, Risk and Biopolitics: On the Threshold of the Living Subject* (London, UK: Routledge, 2006) at 164; Mykitiuk & Scott, *ibid* at 332.

118. *DFG*, *supra* note 115 at para 1.

the Supreme Court of Canada were whether such an order could be permitted through tort law or through the power of the court to protect children (“*parens patriae* jurisdiction”).¹¹⁹ The majority judgment of Chief Justice McLachlin (as she then was) held that making the major changes to tort law required to support the order was best left to the legislature.¹²⁰ Granting legal rights to a fetus could allow the fetus to bring a variety of causes of action, including seeking an injunction preventing a pregnant woman from having an abortion.¹²¹ The Court would also be required to conceive of the unborn child and its mother “as separate juristic persons in a mutually separable and antagonistic relation,” a position that contrasts both the physical reality and the traditional legal characterization of the relationship.¹²² In addition, pregnant women’s lifestyle choices would be open to outside scrutiny¹²³ and legal action¹²⁴ which could in turn lead to a “conflict between the pregnant woman as an autonomous decision-maker and her fetus.”¹²⁵ The Court was also concerned that restricting women’s behaviours in pregnancy might lead to women engaging in risky activities to avoid medical care.¹²⁶ The judgment went on to hold that an

119. *Ibid* at para 9.

120. *Ibid* at para 20.

121. *Ibid* at para 24. This had been unsuccessfully attempted in an earlier case that went before the Supreme Court of Canada. See *Tremblay v Daigle*, [1989] 2 SCR 530. As the formalistic analysis of whether the fetus is a person at law undertaken in that case is subsumed by the broader analysis in *DFG*, we do not analyze that case in detail.

122. *DFG*, *ibid* at para 29.

123. *Ibid* at para 42.

124. *Ibid* at paras 30-45.

125. *Ibid* at para 37.

126. The dissenting judgment of Justice Major (joined by Justice Sopinka), supported itself with information submitted by various interveners before the Court “on the prevalence of mental and physical disabilities in children as a result of substance abuse by their mothers while pregnant,” including “evidence focused on the ‘crisis situation’ in many aboriginal communities.” In concluding that Canadian law does support a remedy for the claim, Major J’s points include that the born alive rule originated as an evidentiary presumption that responded to limited medical knowledge of whether a child *in utero* was in fact alive at the time it allegedly suffered injury. As such, present medical technologies such as ultrasound and fetal heart monitors render the rule “outdated and indefensible.” With respect to concerns over women’s autonomy,

injunction cannot support an order for detention,¹²⁷ and that the power of *parens patriae* does not apply to the unborn.¹²⁸

Two years later, the Court would apply the broad framework established in *DFG* – that pregnant women cannot be found liable for behaviours that might harm their fetus – to a very different fact scenario, with a slightly different focus. The controversial¹²⁹ case of *Dobson (Litigation Guardian of) v Dobson*¹³⁰ raised the question of whether a child could sue his or her mother for injuries sustained while *in utero* in a motor vehicle accident as a result of her negligent driving. The infant plaintiff Ryan Dobson was delivered prematurely by caesarean section following the accident and was subsequently found to have “permanent mental and physical impairment, including cerebral palsy.”¹³¹ The majority judgment written by Justice Cory noted that the pregnant woman, in addition to fulfilling an important role benefiting society as a whole,¹³² “is also an individual whose bodily integrity, privacy and autonomy rights must be protected.”¹³³ From this perspective, a pregnant woman is fundamentally different than other defendants insofar as imposing a legal duty to protect

the dissent states that the test for justifying confinement is set at a “very high threshold.” That is, “[i]t is only in those extreme cases, where the conduct of the mother has a reasonable probability of causing serious and irreparable harm to the unborn child, and no other reasonable means of treatment exists, that a court should assume jurisdiction to intervene.” *Ibid* at paras 88, 109, 124, 136.

127. *Ibid* at para 46.

128. *Ibid* at paras 49-57.

129. See e.g. Ian R Kerr, “Pregnant Women and the ‘Born Alive’ Rule in Canada” (2000) 8:1 Tort Law Review 713; Diana Ginn, “A Balancing that is Beyond the Scope of the Common Law: A Discussion of the Issues Raised by *Dobson (Litigation guardian of) v. Dobson*” (2001) 27:1 Queen’s LJ 51; Kristin Ali, “Defining the Standard of Prenatal Care: An Analysis of Judicial and Legislative Responses” (2007) 1:1 McGill JL & Health 69; Diana Ginn, “The Supreme Court of Canada and What It Means to Be ‘Of Woman Born’” in Andrea O’Reilly, ed, *From Motherhood to Mothering: The Legacy of Adrienne Rich’s Of Woman Born* (Albany: State University of New York Press, 2004) 27; Weir, *supra* note 117 at 88; Mykitiuk & Scott, *supra* note 116 at 333.

130. [1999] 2 SCR 753 [*Dobson*].

131. *Ibid* at para 2.

132. *Ibid* at paras 24, 45.

133. *Ibid* at para 24.

the life of a fetus could “render the most mundane decision taken in the course of her daily life as a pregnant woman subject to the scrutiny of the courts,”¹³⁴ infringing substantially on women’s autonomy and privacy.¹³⁵ These effects would also result from attempting to articulate the standard of conduct of a “reasonable pregnant woman.”¹³⁶ Cory J concluded that public policy concerns indicated that a duty could not be imposed on pregnant women toward their fetus or subsequently born child, and remarked that provincial legislatures could create legislation to allow for insurance provisions to benefit “both the injured child and his or her family, without unduly restricting the privacy and autonomy rights of women.”¹³⁷

The outcome of *Dobson* was a reiteration and expansion of the principle established in *DFG*, namely that attempts to restrict women’s behaviours in pregnancy through torts (prior to or once the child is born alive) are untenable, given the infringement on women’s reproductive autonomy and the problematic nature of differentiating acceptable and “reasonable” activities from those which might be restricted.¹³⁸ *Dobson* makes clear that women’s bodily integrity and reproductive autonomy covers all actions that they may take throughout their pregnancy. Other cases have applied this principle to tort claims against mothers for harms incurred *in utero*¹³⁹ and similar logic has been used in criminal cases.¹⁴⁰

134. *Ibid* at para 27.

135. *Ibid* at para 44.

136. *Ibid* at paras 52-53.

137. *Ibid* at para 81. Partly as a result of the decision, the province of Alberta enacted legislation to grant the precise cause of action denied in the case. The *Maternal Tort Liability Act*, SA 2005, c M-7.5, reads, in part, “a mother may be liable to her child for injuries suffered by her child on or after birth that were caused by the mother’s use or operation of an automobile during her pregnancy,” and limits liability to “the amount of insurance money payable under contracts of automobile insurance indemnifying the mother that the child can recover as a creditor under s 635 of the Insurance Act.” See ss 1-4. See also Mykitiuk & Scott, *supra* note 116 at 339.

138. *Ibid* at para 52-53.

139. For the application of the principle in *Dobson*, see for example *Hall (Litigaiton guardian of) v Kellar*, 23 CCLT (3d) 40 (Sup Ct).

140. See e.g. *R v Drummond*, [1997] OJ No 6390 (QL) (Ct J (Prov Div)), which involved a charge of attempted murder against a pregnant woman

Furthermore, *Dobson* elucidates that while pregnant women are not liable for injuries sustained by a fetus during pregnancy, this does not preclude the actions of other defendants. Parties other than the pregnant woman are liable for damages incurred by the fetus when the child is born alive, even if the injury is sustained prior to birth.

Overall, the claims of prenatal reproductive injury made in the aforementioned cases demonstrate that there has been hesitation on the part of Canadian courts to intervene in cases where claims of prenatal harm are made by children against their mothers, due to policy considerations related to women's reproductive autonomy.¹⁴¹ Rather than identify fetal harm as separate from the maternal body, this approach supports the understanding that the fetus exists within the woman's body and that, consequently, their relationship cannot be adversarial¹⁴² as the interests of the fetus and the pregnant woman are inherently inseparable. The judgements in *DFG* and *Dobson* recognized that imposing a duty for women to protect a fetus through the regulation of her behaviours would mean imposing a duty on her to treat her body, herself, in ways determined by the Court.

The maternal exception in cases of prenatal harm recognized in Canadian jurisprudence has particular implications for the case of exposures to household chemicals. One of the risks of engaging in litigation addressing toxic exposures is that the responsibility for mitigating those exposures increasingly falls to women managing their households, purchasing household supplies, and engaging in precautionary consumption. The possibility of reproductive torts which can address exposures may implicate manufacturers of these chemicals, or their distributors, but they may also occur on an individualized basis, in

for inserting a pellet gun into her vagina and shooting her fetus. It was apparent that charging women for homicide of the fetus or subsequently born alive child raises the spectre of the slippery slope of prosecuting women for substance abuse or a range of lawful behaviour. This would invite the same type of scrutiny of the conduct of pregnant women and interference with autonomy to which the Supreme Court of Canada in *DFG* and *Dobson* referred in justifying the refusal to recognize the tort duties in question.

141. *BR v LR*, 2004 ABQB 93 at para 35.

142. See *Dobson*, *supra* note 130 at para 72.

which women responsible for exposing their families to toxic household chemicals may be liable for the effects on their future children born alive. If women, and especially pregnant women, are counselled to avoid exposures by making smart decisions about what to eat, what to buy, and what to do, there is a potential duty of care that may be imparted onto women as they are increasingly expected to protect their families from the harms associated with chemical exposures. Women who fail to avoid cosmetics laden with phthalates, or who buy a used sofa leaching flame retardants, may one day be seen as negligent by failing to avoid known toxic substances and thereby exposing their child *en ventre sa mère*.

Dobson and *DFG*, and the maternal exception in prenatal tort liability that they collectively establish, undermine the potential for such claims. These cases offer important examples of the way that Canadian government institutions, namely the judiciary and legislature, have worked to advance women's reproductive autonomy in pregnancy, particularly since the 1990s.¹⁴³ Claims made against pregnant women or mothers for harms that occurred *in utero* are unlikely to garner success following *Dobson*, and offer some protection for women who do not or cannot engage in the laborious and expensive task of avoiding ubiquitous household chemicals.

C. The Birth of a Child as a Legal Harm (“Birth Torts”)

The tortious conduct in all of the above decisions was alleged to have caused physical harm¹⁴⁴ to the fetus. Even though the fetus is not a legal person, once it is born alive tort law imagines how monetary compensation

143. While the Supreme Court of Canada has advanced women's reproductive autonomy in some cases, for some women, in many cases, “[w]hite supremacy, colonialism, oppression on the basis of class, (dis)ability, religion, language, sexual identity, and family status all combine with restrictions tied to both biological and social reproduction to circumscribe the lives of women and preclude their equality,” particularly in the judgments of the Court. Sanda Rogers, “Women's Reproductive Equality and the Supreme Court of Canada” in Jocelyn Downie & Elaine Gibson, eds, *Health Law At the Supreme Court of Canada* (Toronto: Irwin Law, 2007) 189 at 191. See also Elizabeth Comack, ed, *Locating Law: Race/Class/Gender/Sexuality Connections*, 2d ed (Halifax, NS: Irwin Law, 2006).

144. Or a risk of physical injury, in the case of *DFG*.

can put the plaintiff back into his or her “original position” before he or she was injured. The “birth torts,”¹⁴⁵ a major class of reproductive tort, are distinguishable from the preceding prenatal injury cases in that rather than featuring negligence that physically changes the child, it causes the mother of the child to lose the opportunity to avoid or terminate an unwanted pregnancy. In other words, the birth of the child is itself the legal damage. The counterfactual original position is having avoided the unwanted pregnancy or birth. This notion of injury, and courts’ departures from it, poses conceptual and legal difficulties and has problematic social implications. Centrally, the notion of injury in the birth torts involves evaluating the legal significance of the unwanted birth of a “healthy” or “normal” child versus the unwanted birth of a child with a disability.

Birth tort cases can be broken into various broad categories which, though imperfect,¹⁴⁶ permit a view of the different themes that emerge

145. See Melinda Jones, “Valuing All Lives – Even ‘Wrongful’ Ones” in Marcia H Rioux, Lee Ann Basser & Melinda Jones, eds, *Critical Perspectives on Human Rights and Disability Law* (Boston: Martinus Nijhoff, 2011) 87 at 87 [Jones, “Valuing All Lives”].

146. Theorizing cases where the tortious act is the birth of a child has long been the subject of debate, particularly regarding the idea that life itself can be understood as a harm. The rejection of these categories has largely been premised on the assumption that birth or life can be conceptualized as a legal harm, and challenge the morality and capacity of the judiciary to assess whether a life is worth living. The categories of “wrongful pregnancy” (sometimes called “wrongful conception”) “wrongful birth” and “wrongful life” are used here for purposes of clarity, without intent to normalize or judge this categorization. See, for example, David Archard, “Wrongful Life” (2004) 79:309 *Philosophy* 403; Kelly E Rhinehart, “Debate over Wrongful Birth and Wrongful Life” (2002) 26 *Law & Psychol Rev* 141; Jillian T Stein, “Backdoor Eugenics: The Troubling Implications of Certain Damages Awards in Wrongful Birth and Wrongful Life Claims” (2010) 40:3 *Seton Hall L Rev* 1117; Harvey Teff, “The Action for ‘Wrongful Life’ in England and the United States” (1985) 34:03 *ICLQ* 423; Stephen Todd, “Wrongful Conception, Wrongful Birth and Wrongful Life” (2005) 27:3 *Sydney L Rev* 525. It is also worth noting that “wrongful pregnancy” and “wrongful birth” as well as “wrongful birth” and “wrongful life” claims are not always distinguished from one another. See discussion in *Bevilacqua v Altenkirk*, 2004 BCSC 945, at n 1 [*Bevilacqua*].

within each. For heuristic purposes we divide birth torts into three categories, namely “wrongful pregnancy,” “wrongful birth,” and “wrongful life” claims. Wrongful pregnancy is claimed where a woman becomes pregnant despite not wanting a pregnancy, often resulting from a failed vasectomy;¹⁴⁷ tubal ligation;¹⁴⁸ incorrect advice stating that an individual is infertile;¹⁴⁹ a failed abortion attempt;¹⁵⁰ or incorrect diagnosis that a woman is not pregnant.¹⁵¹ In these cases, the tort is the negligent failure of a health-care provider to prevent the conception or birth of a child when no child at all is wanted.¹⁵²

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147. See *e.g.* *McFarlane v Tayside Health Board*, 1999 UKHL 50; *Bevilacqua, ibid*; *Thake v Maurice* [1986] All ER 513 (QBD) [*Thake*].
148. See *e.g.* *Kealey v Berezowski* (1996), 30 OR (3d) 37 (SC) [*Kealey*]; *Parkinson v St James and Seacroft University Hospital NHS Trust*, [2001] EWCA Civ 530; *Rees v Darlington Memorial NHS Trust*, [2003] UKHL 52; *S(M) v Baker*, 2001 ABQB 1032; *Suite c Cooke*, [1995] RJQ 2765 (CA) [*Suite*].
149. See *e.g.* *Cattanach v Melchior*, [2003] HCA 38 [*Cattanach*].
150. See *e.g.* *Fredette v Wiebe* (1986), 29 DLR (4th) 534 (BCSC); *Roe v Dabbs*, 2004 BCSC 957.
151. See *e.g.* *RKP v Borkent*, 2005 ABQB 42 (claim failed for lack of breach of the standard of care).
152. There have been a number of different approaches in the common law as to how to award damages where a healthy child is born. One such approach is awarding no damages in holding that the birth of a healthy child is not an injury recognized by the law, though this approach is rare and currently only taken in Nevada. See *e.g.* *Christensen v Thornby*, 255 NW 620 (Minn Sup Ct 1934); *Szekeres v Robinson*, 715 P (2d) 1076 (Nev Sup Ct 1986) [*Szekeres*]; *Dotson v Bernstein*, 207 P (3d) 911 at 915 (Colo Ct App 2009), citing *Szekeres*. A second, more common approach is the “limited damages” approach, wherein courts award compensation only for the costs of the pregnancy, but not for child-rearing. See *e.g.* *Cattanach, supra* note 149 at 174. A third approach – the offset-benefit approach – recognizes the costs of raising a healthy child as a “compensable loss” but reduces the award on the basis that having the child also brings benefits to the plaintiffs. *Kealey, supra* note 148 at para 41; *Cataford v Moreau*, [1978] CS 933 (Qc Sup Ct); *Thake, supra* note 147 (interestingly, in this case child-rearing costs were awarded in a modest amount agreed by the parties, but damages relating to labour and delivery was found to have been completely offset by the benefits of having the child); *Suite, supra* note 148; *Troppi v Scarf*, 187 NW (2d) 511 (Mich Ct App 1971). Courts have, in some cases, found that the benefits may or may not completely cancel out the burdens. Under a fourth approach, the “total recovery” approach, courts award compensation for all the reasonably foreseeable

Wrongful birth claims involve claims brought by the parent(s) of a child with a disability against a health-care provider for negligent failure to provide the parent(s) the opportunity to avoid or terminate¹⁵³ the pregnancy. Unlike wrongful pregnancy claims, in the case of wrongful birth a child is wanted, though not a child with a disability. The fact scenarios which precipitate these claims vary, and include: negligent failure to offer an amniocentesis to a woman at risk of having a child with Down syndrome;¹⁵⁴ failure to properly diagnose or warn the mother about the risk to the fetus of contracting rubella during early pregnancy;¹⁵⁵ and negligent performance of or failure to warn about the results of an ultrasound.¹⁵⁶ The negligence may also occur prior to conception, where it generally consists of inadequate genetic diagnosis or counselling regarding the likelihood of the parents conceiving and having a child with a genetic anomaly.¹⁵⁷ The use of assisted reproductive

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- damages resulting from the negligence, including the costs of raising the child. Decisions in which this approach has been adopted include *Custodio v Bauer*, 251 Cal App (2d) 303 (Cal Ct App 1967); *Emeh v Kensington and Chelsea and Westminster Area Health Authority*, [1984] 3 All ER 1044 (CA) (though this case dealt with the birth of a child with a disability, the Court rejected the legal distinction in reaching its decision); *Joshi (Guardian ad litem of) v Woolley* (1995), 4 BCLR (3d) 208 (SC).
153. See *Kealey*, *supra* note 148 at para 38; Nadia N Sawicki, “Wrongful Pregnancy, Wrongful Life and Wrongful Birth” (2005) 51:3 Medical Trial Technique Quarterly 283 at 284.
154. See *e.g.* *Jones (Guardian ad litem of) v Rostvig*, 2003 BCSC 1222 [*Jones*]; *Krangle (Guardian ad litem of) v Brisco* (1997), 154 DLR (4th) 707 (SC); *Zhang v Kan*, 2003 BCSC 5; *Raina v Shaw*, 2006 BCSC 832 (claim failed for failure to establish negligence).
155. See *e.g.* the American case of *Gleitman v Cosgrove*, 227 A (2d) 689 (NJ Sup Ct 1967). An English example is that of *McKay v Essex Area Health Authority*, [1982] QB 1166 (CA) [*McKay*]. The Canadian case of *Arndt v Smith*, [1994] 8 WWR 568 (SC) [*Arndt*], *aff’d* [1997] 2 SCR 539, dealt with the analogous fact situation pertaining to maternal chickenpox.
156. *McColl v Hudson*, [1998] BCJ No 801 (QL) (SC); *McDonald-Wright (Litigation Guardian of) v O’Herlihy*, 2007 ONCA 89, *aff’g*, 75 OR (3d) 261 (SC); *Mickle v Salvation Army Grace Hospital, Windsor Ontario* (1998), 166 DLR (4th) 743 (Ont Ct J (Gen Div)) [*Mickle*]; *Petkovic (Litigation Guardian of) v Olupona*, [2002] OTC 221 (Ont Sup Ct J (Div Ct)) [*Petkovic*], leave to appeal to ONCA refused, 30 CCLT (3d) 266 (Sup Ct J (Div Ct)).
157. *Bartok v Shokeir*, [1999] 2 WWR 386 (QB) [*Bartok*], *aff’d* (1998),

technologies can also lead to wrongful birth and wrongful life claims, for example through failure to screen for or avoid implantation of an embryo that will produce a child with a disability.¹⁵⁸

Wrongful life claims are similar to those of wrongful birth, except that rather than parent(s) making the claim that they have been injured by negligence leading to pregnancy or a “wrongful birth,” an individual (usually a child) is arguing that his or her own birth is a harm.¹⁵⁹ In such cases the plaintiff argues that, but for the negligence of the defendant, his or her mother would have avoided or terminated her pregnancy and thus would have prevented his or her birth. These claims are often brought based on practical considerations, namely that the time limitation period for children to bring an action in tort is usually significantly longer than that for adults, and the parents may have missed the window in which they could bring their claim. Also, the anticipated award of damages to the child may be greater than that to the parents, since the child-rearing obligations of the parents generally cease when the child attains majority, yet the child when grown may still incur expenses relating to his or her condition.¹⁶⁰ These cases have been met with almost universal refusal among common law jurisdictions.¹⁶¹

168 Sask R 280 (CA); *Holowaychuk v Hodges*, 2003 ABQB 201 [*Holowaychuk*]; *H(R) v Hunter* (1996), 32 CCLT (2d) 44 (Ct J (Gen Div)).

158. See e.g. *Waller v James*, [2006] HCA 16; *Johnson et al v Superior Court of Los Angeles County*, 124 Cal (2d) 650 (Ct App 2002); *Paretta v Medical Offices for Human Reproduction*, 760 NYS (2d) 639 (Sup Ct 2003).

159. See *Kealey*, *supra* note 148 at para 39.

160. *Paxton v Ramji*, 2008 ONCA 697 at para 80 [*Paxton*], aff'g *Paxton v Ramji* (2006), 146 ACWS (3d) 913 (SC) [*Paxton* 2006].

161. Only one Canadian appellate court has addressed the validity of the claim, and refused to recognize it. See *Lacroix (Litigation guardian of) v Dominique*, 2001 MBCA 122 [*Lacroix*], leave to appeal to SCC refused, 2000 SCC A No 477. The superior courts in several provinces have refused to recognize the action either at trial or on motion to dismiss. See *Arndt*, *supra* note 155 at paras 16-28; *Mickle*, *supra* note 156 at para 11; *Jones*, *supra* note 154. In other instances, courts have refused motions to dismiss wrongful life claims, noting the unsettled nature of the area of law, and also that dismissal would not save time at trial as the remaining wrongful birth claim would cover many of the same issues. See *Bartok*, *supra* note 157; *Holowaychuk*, *supra* note 157; *Sharma (Litigation guardian*

Though wrongful pregnancy, wrongful birth, and wrongful life respond primarily to instances of medical malpractice, they may also address reproductive harms associated with exposures to household chemicals. If prenatal testing and screening develops to the point where the effects of household chemical exposures can be detected, it is not farfetched to anticipate that some women may base a decision about whether to maintain or terminate a pregnancy on this basis. In turn, medicine and law could normalize this practice through birth tort claims involving failure to detect and terminate a pregnancy where the child was born with a condition resulting from prenatal chemical exposure. Whether or not this contingency comes to pass, existing birth tort jurisprudence offers important insights into some of the complexities of understanding disability as a legal harm. Both in birth torts and cases of exposure to, for example, BFRs and phthalates, a nuanced view of disability is necessary to limit the stigmatization of people with disabilities while simultaneously addressing the harms incurred through tortious action(s).

Commentators have taken different positions with respect to whether wrongful birth and wrongful life claims should be permitted, primarily in relation to the way that such claims theorize disability. Some affirm the *status quo* of permitting wrongful birth but reject wrongful life claims,¹⁶² while others argue that wrongful life actions too, should be allowed.¹⁶³

of v Mergelas, [1997] OJ No 5304 (QL) (Ct J (Gen Div)) (unreported); *Petkovic*, *supra* note 156. Also, the common law of England, Australia, and most US states do not recognize the action. See *McKay*, *supra* note 155.

162. See *e.g.* Penny Dimopoulos & Mirko Bagaric, "The Moral Status of Wrongful Life Claims" (2003) 32:1 C L World Rev 35; Penny Dimopoulos & Mirko Bagaric, "Why Wrongful Birth Actions are Right" (2003) 11:2 Journal of Law and Medicine 230.
163. See *e.g.* John Anthony Eaton, "Wrongful Life Claims: A Comparative Analysis" (2005) 35 Hong Kong LJ 671; Deana A Pollard, "Wrongful Analysis in Wrongful Life Jurisprudence" (2003) 55:2 Ala L Rev 327; Amos Shapira, "'Wrongful Life' Lawsuits for Faulty Genetic Counseling: The Impaired Newborn as a Plaintiff" (1997) 13 Tel Aviv University Studies in Law 97; Dean Stretton, "The Birth Torts: Damages for Wrongful Birth and Wrongful Life" (2005) 10:1 Deakin Law Review 319; Mark Strasser, "Wrongful Life, Wrongful Birth, Wrongful Death, and the Right to Refuse Treatment: Can Reasonable Jurisdictions Recognize All But One" (1999) 64:1 Mo L Rev 29; Wendy F Hensel, "The Disabling

Though these commentators differ in their particular rationales for recognizing the tort and in their visions of how courts ought to approach it, some ideas appear repeatedly. In reference to the concern that the law would devalue life by considering an impaired existence an injury vis-à-vis death or non-existence, they assert that the law regularly makes this comparison in the area of refusal of medical treatment.¹⁶⁴ They also cite the right of abortion as reinforcing this conception of injury.¹⁶⁵ As for the difficulty of conceptualizing and calculating damages in such cases, these commentators view the expenses associated with raising a child who has a disability and damages for pain and suffering as straightforward heads of damage that further the interests of deterring medical malpractice and promoting distributive justice.¹⁶⁶ In this way, commentators explicitly or implicitly treat the birth of the child with a disability as equivalent to the injury of a “healthy” child,¹⁶⁷ or to the same effect, consider non-existence to possess the same quality of symmetry, equilibrium, or neutrality of being healthy and uninjured.¹⁶⁸ Finally, they frame the award of damages as promoting respect for individuals with disabilities by enabling the acquisition of necessary care.¹⁶⁹

Other commentators oppose the wrongful birth cause of action (and explicitly or implicitly the wrongful life cause of action as well).¹⁷⁰ Among those opposed, some have focused on the impact of the tort on the rights of people living with disabilities.¹⁷¹ Wendy Hensel argues that wrongful

Impact of Wrongful Birth and Wrongful Life Actions” (2005) 40:1 Harv CR-CLL Rev 141. See also Ronen Perry, “It’s a Wonderful Life” (2007) 93:2 Cornell L Rev 329 at 329, regarding alternative mechanisms for recognizing the action of wrongful life as a breach of contract theory (rather than as a tort).

164. Eaton, *ibid* at 679; Pollard, *ibid* at 359-61; Stretton, *ibid* at 357; Strasser, *ibid* at 64, 75.

165. Eaton, *ibid* at 692; Pollard, *ibid* at 330.

166. Pollard, *ibid* at 338-42, 354; Shapira, *supra* note 163 at 100-01.

167. Shapira, *ibid* at 105-07.

168. Stretton, *supra* note 163 at 356, 358-59; Strasser, *supra* note 163 at 63.

169. Shapira, *supra* note 163 at 103-04; Stretton, *ibid* at 362.

170. See e.g. R Lee Akazaki, “‘Wrongful Birth’: An Ironic Name for a Cause of Action in the Law of Medical Malpractice” (1999) 22:1 Advocates’ Q 102.

171. See e.g. Hensel, *supra* note 163; Darpana M Sheth, “Better Off Unborn? An Analysis of Wrongful Birth and Wrongful Life Claims under the

birth and wrongful life claims send a “demeaning and demoralizing” message to people with disabilities and society in general.¹⁷² Obtaining compensation requires plaintiffs to “openly disavow their self-worth and dignity,” as children or their mothers must testify that the pregnant woman would have had an abortion.¹⁷³ Legal inquiry in turn focuses on the functional impairment of the child rather than the shared experience of the stigmatization of disability, or on the socially constructed nature of disability.¹⁷⁴ As a result, “[a]ny benefits secured by individual litigants in court are thus taxed to the community of people with disabilities as a whole, placing at risk, in the drive for individual compensation, the gains secured by collective action and identity.”¹⁷⁵ Therefore, neither action should be recognized.¹⁷⁶

Sensitive to the messages these claims send, yet maintaining that courts are unlikely to abandon them, Kerry Cooperman argues that the recommended approach to upholding parental autonomy while respecting individuals living with disabilities is to fashion remedies and write judgments in a manner sensitive to the nature of disability.¹⁷⁷

Americans with Disabilities Act” (2006) 73:4 Tenn L Rev 641.

172. Hensel, *ibid* at 164.

173. *Ibid* at 171-72.

174. *Ibid* at 144, 174-75.

175. *Ibid* at 144.

176. *Ibid* at 145. But see Jones, “Valuing All Lives”, *supra* note 145, arguing that human rights principles *support* recovery in wrongful life claims. Sheth builds on the arguments made by Hensel in describing how wrongful birth and wrongful life claims violate the *Americans with Disabilities Act*, 42 USC 12101 (1990). See Sheth, *supra* note 171. Interestingly, at least one scholar has put forth a detailed argument focusing on human rights principles, in particular that of human dignity, in an attempt to *support* recovery in wrongful life claims. Jones considers that an award of damages recognizing a wrong promotes dignity. She conceives of the harm in wrongful life through comparing the position of the disabled child with that of a healthy child, as the latter is the child the mother believed she was carrying. She states that the main problem with the tort is its name, which denotes a focus on the “victim” rather than on the wrongful conduct of the defendant. Ideally a universal welfare scheme would provide for the needs of all disabled individuals, rather than a tort system offering compensation only to those who can make out a cause of action.

177. Kerry T Cooperman, “The Handicapping Effect of Judicial Opinions in

Cooperman supports the approach taken in *Procanik v Cillo*,¹⁷⁸ the New Jersey wrongful life decision accepting the claim for damages associated with the costs of living with a disability but not for general damages covering pain and suffering. Such an approach, he writes, avoids viewing being born disabled as a harm, instead favouring a “contextual jurisprudence that accounts for the social, financial, and moral concerns of families, people with disabilities, and communities.”¹⁷⁹ In particular, it focuses on the “needs of the living” rather than on the preference of non-life over life.¹⁸⁰

These analyses of the birth torts offer a ready critique of notions of reproductive harm where they involve negligence that leads to the birth of a child living with a disability. The birth tort cases stand in contrast to conventional prenatal injury claims where the negligence caused the injury of a child who otherwise would have been born “healthy.” Such situations raise difficult questions about the nature of harm or injury. For example, an emphasis on the prevention of disability, which tort law promotes through its deterrence function, risks portraying individuals with disabilities in a stigmatizing manner.¹⁸¹ In contrast, tort law may have difficulty recognizing that an injury has taken place in situations where some of the parties concerned do not feel aggrieved or “wounded.”¹⁸² Decisions in the birth torts ought to avoid the dichotomy of viewing a healthy child as a blessing versus a child with a disability as a harm, and evaluate damages in terms of a nuanced view of disability taking into account “biological, familial, financial, attitudinal, and social factors.”¹⁸³ Reducing stigma against individuals living with disabilities depends on

Reproductive Tort Cases: Correcting the Legal Perception of Persons with Disabilities” (2008) 68 Md L Rev Endnotes 1 at 14-15.

178. 478 A (2d) 755 (NJ Sup Ct 1984) [*Procanik*].

179. Cooperman, *supra* note 177 at 19.

180. *Ibid* at 18, citing *Procanik*, *supra* note 178. See also Stein, *supra* note 146.

181. See Caroline Wang, “Culture, Meaning and Disability: Injury Prevention Campaigns and the Production of Stigma” (1992) 35:9 Social Science & Medicine 1093.

182. See Sarah S Lochlann Jain, *Injury: The Politics of Product Design and Safety Law in the United States* (Princeton, NJ: Princeton University Press, 2006) at 6.

183. Cooperman, *supra* note 177 at 18.

Careful characterization of injury, particularly in wrongful birth and wrongful life claims.

Though not a matter of medical malpractice, and therefore currently outside of the framework of “birth torts,” cases in which household chemicals are linked to adverse health outcomes will similarly need to strike a balance between openness to change in the human form and acknowledging the blameworthiness of wrongdoers. However, the consideration of being born with a disability as a harm or injury is important to claims linked to exposure to toxic household chemicals. To this end, successful birth torts affirm that causing fetal harm through negligence in pregnancy is a legitimate site for legal action when the negligence results in the birth of a child with a disability. If exposures to household chemicals can be understood as a matter of negligence (*i.e.* a failure to warn consumers of the potential effects of exposure during pregnancy), it stands to reason that the principles of wrongful birth claims may be extracted for application in factual scenarios addressing prenatal exposures to household chemicals.

D. Pre-Conception Torts

The third unique set of circumstances in reproductive tort involves claims of negligence that occurred not simply prior to the birth of the child, but prior to his or her conception. Pre-conception torts generally involve negligence that occurs prior to conception and *injury* that occurs *in utero*. The injury may also be alleged to have occurred prior to conception. This situation can arise if gametes sustain damage prior to *in vitro* fertilization,¹⁸⁴ or if radiation or toxic substances influence the germ-line cells of an individual who later has a child.¹⁸⁵

184. See for example, Evi ML Petro et al, “Endocrine-disrupting Chemicals in Human Follicular Fluid Impair *In Vitro* Oocyte Developmental Competence” (2012) 27:4 Human Reproduction 1025; Victor Y Fujimoto et al, “Serum Unconjugated Bisphenol A Concentrations in Women May Adversely Influence Oocyte Quality During *In Vitro* Fertilization” (2011) 95:5 Fertility and Sterility 1816.

185. See for example, Susan M Duty et al, “The Relationship Between Environmental Exposures to Phthalates and DNA Damage in Human Sperm Using the Neutral Comet Assay” (2003) 111:9 Environmental Health Perspectives 1164; Russ Hauser, “Urinary Phthalate Metabolites

Canadian courts have not explicitly addressed the viability of pre-conception tort claims. An overview of the American case law that has dealt with the issue is helpful. On surveying the jurisprudence, one finds that the prospect of recovery varies by fact scenario and by state. The most successful cause of action has been that of a child injured as a result of failure of the mother's physician to treat her against Rh sensitization following the birth of a prior child with incompatible Rh factor blood.¹⁸⁶ A standard and straightforward treatment, its omission can lead to serious illness or stillbirth of a subsequently conceived child with incompatible Rh factor blood.¹⁸⁷ Courts in various states have allowed this type of claim, even where the injured child was not conceived until several years after the negligence occurred.¹⁸⁸ The state of New York, however, which has consistently denied pre-conception tort claims, refused to recognize this cause of action in a relatively recent decision.¹⁸⁹

In contrast to the overall success of the above cause of action, no court has allowed a claim involving injury resulting from an automobile accident to a child that was not yet conceived at the time of the accident.¹⁹⁰ This example provides an illustration of how conception can serve as a dividing line with respect to duty. Recognizing the claim of a child *in utero* has been unproblematic in the automobile collision context. However, courts dealing with pre-conception claims have held that it is not foreseeable that a child would be injured as a result of a collision

and Semen Quality: A Review of a Potential Biomarker of Susceptibility" (2008) 31:2 International Journal of Andrology 112.

186. Julie A Greenberg, "Reconceptualizing Preconception Torts" (1997) 64:2 Tenn L Rev 315 at 336-37.
187. Karen Fung Kee Fung et al, "Prevention of Rh Alloimmunization" (2003) 25:9 Journal of Obstetrics and Gynaecology Canada 765; *Lough v Rolla Women's Clinic, Inc*, 866 SW (2d) 851 at 852 (Mo Sup Ct 1993).
188. Greenberg, *supra* note 186 at 323-26; Matthew Browne, "Preconception Tort Law in an Era of Assisted Reproduction: Applying a Nexus Test for Duty" (2001) 69:6 Fordham L Rev 2555 at 2567-72. As a variation on the facts of the majority of cases cited involving Rh sensitization, the successful 1967 preconception tort case of *Renslow v Menmonite Hospital*, 367 NE (2d) 1250 (Ill Sup Ct 1977) [*Renslow*], involved the negligent transfusion of Rh positive blood to an Rh negative woman who became sensitized and later conceived and gave birth to a child harmed as a result.
189. *Barakov v Beth Israel Med Ctr*, 44 AD (3d) 981 (NY App Div 2007).
190. Browne, *supra* note 188 at 2578.

involving a woman who was not yet pregnant at the time.¹⁹¹

Less consistent in terms of outcome are cases centring on surgery and other medical treatment, products including pharmaceuticals, and exposure to toxic substances (usually in an employment context).¹⁹² Successful surgery actions have taken place in Michigan¹⁹³ and Missouri.¹⁹⁴ Both actions involved a subsequently conceived child injured by negligent performance of a caesarean section during the birth of a prior child. The case of *Albala v City of New York*¹⁹⁵ similarly involved the negligent performance of an abortion that led to the injury of a child subsequently conceived. In that case, the New York Court of Appeals held that to allow the proposed cause of action would “require the extension of traditional tort concepts beyond manageable bounds.”¹⁹⁶ The Court also noted that the proposed duty would encourage doctors to practice defensive medicine, and that “society as a whole would bear the cost of our placing physicians in a direct conflict between their moral duty to patients and the proposed legal duty to those hypothetical future generations outside the immediate zone of danger.”¹⁹⁷

With respect to products liability, recovery has been sparse. Though one court refused to dismiss a claim alleging injury to children conceived and born subsequent to their mother’s taking birth control pills,¹⁹⁸ most pre-conception actions involving pharmaceuticals have been unsuccessful claims by grandchildren of women who took DES during pregnancy.¹⁹⁹ As noted above, women exposed to DES *in utero* had an array of

191. *McAuley v Wills*, 303 SE (2d) 258 (Ga Sup Ct 1983).

192. Browne, *supra* note 188 at 2555 ff.

193. *Martin v St John Hospital and Medical Center*, 517 NW (2d) 787 (Mich Ct App 1994).

194. *Bergstreser v Mitchell*, 577 F (2d) 22 (8th Cir 1978).

195. 54 NY (2d) 269 (Ct App 1981).

196. *Ibid* at 271-72.

197. *Ibid* at 274.

198. *Jorgensen v Meade*, 483 F (2d) 237 (10th Cir 1973).

199. The lack of success in DES claims has been attributed in part to the long latency period between exposure and the discovery of reproductive harm in DES granddaughters. See Glen O Robinson, “Multiple Causation in Tort Law: Reflections on the *DES* Cases” (1982) 68:4 Va L Rev 713. See also discussion of difficulty identifying a plaintiff in multigenerational DES cases below at note 272 and accompanying text.

adverse health outcomes including uterine anomalies that impeded their capacity to carry a pregnancy to term. As a result, some of their children suffered injury due to premature birth. In one such claim – *Enright v Eli Lilly* (which involved claims made by a “DES granddaughter” born with cerebral palsy) – the New York Court of Appeals held that the principles expressed in *Albala* applied, as recognizing liability could lead to over-deterrence and a disincentive for drug manufacturers to produce generally useful products.²⁰⁰ The Court also worried that recognizing a duty here would lead to claims for damages by subsequent generations of plaintiffs.²⁰¹

Several decisions suggest that some jurisdictions may recognize a duty to plaintiffs not yet conceived in workplace and other exposure scenarios, though having to satisfy every element of the relevant cause of action, including causation, has limited recovery.²⁰² The United States Supreme Court in *International Union, UAW v Johnson Controls*²⁰³ referred in passing to the possibility of pre-conception tort liability. In the decision, the Court held that an employer measure prohibiting women of childbearing capacity from participating in work activities where they would be exposed to lead, a teratogen, impermissibly discriminated against women and was not accepted as a bona fide occupational qualification (BFOQ). The majority found the prospect of tort liability to injured infants to be remote.²⁰⁴ They based this conclusion on the facts that the employer was informing women of the risks associated with lead exposure and complying with Occupational Safety and Health Administration standards concerning such exposure, and that federal anti-discrimination law would pre-empt state tort law if it were impossible to comply with both.²⁰⁵ The concurring judgment of

200. 77 NY (2d) 377 at 386-87 (Ct App 1991).

201. *Ibid* at 387.

202. See e.g. *Coley v Commonwealth Edison Co*, 768 F Supp 625 (Ill Dist Ct 1991); *Second Nat'l Bank v Sears, Roebuck & Co*, 390 NE (2d) 229 (Ind Ct App 1979). See also Daniel S Goldberg, “Against Genetic Exceptionalism: An Argument in Favor of the Viability of Preconception Genetic Torts” (2007) 10:2 J Health Care L & Pol’y 259.

203. 499 US 187 (US 1991) [*Johnson Controls*].

204. *Ibid* at 208.

205. *Ibid* at 208-09.

Justice Scalia similarly states that, as the employer has not demonstrated “a substantial risk of tort liability,” the argument that its fetal protection policy is a BFOQ is necessarily defeated.²⁰⁶ In contrast, Justice White, though concurring in the result, emphasized that given the increasing recognition of pre-conception tort,²⁰⁷ a fetal protection policy could be justified if an employer could establish that it was “reasonably necessary to avoid substantial tort liability.”²⁰⁸

Perhaps most relevant to the case of exposure to household chemicals is a more recent American pre-conception tort case in which the District Court for the Northern District of California decided a case involving alleged genetic damage and injury due to toxic environmental emissions. The Court held with respect to the pre-conception claims that the defendant emitter did not owe a duty to the plaintiffs as it did not provide “goods or services related to the reproductive process.”²⁰⁹ Following the precedent set in a California pre-conception automobile injury case,²¹⁰ the Court held that the alleged injuries were not reasonably foreseeable. The Court suggested that the law may change when “science and medicine progress to the point that scientists can interpret individual DNA histories or can confidently attribute injuries to chemical exposure.”²¹¹

Despite the suggestion of the District Court for the Northern District of California regarding the potential for future claims in which injuries can be clearly attributed to chemical exposures, and the increased recognition of pre-conception torts outlined in *Johnson Controls*, the challenge posed by the lack of concrete evidence of intergenerational reproductive harm in the case of household chemicals is, as yet, a particularly difficult legal obstacle to overcome. Yet, it is pre-conception injury scenarios that may be most useful to theorizing intergenerational reproductive harm that may be caused by exposure to household chemicals. Pre-conception injury scenarios by their nature raise concern over liability for harm

206. *Ibid* at 223-24.

207. *Ibid* at 213.

208. *Ibid* at 212-13.

209. *Avila v Remco Hydraulics*, 633 F (3d) 828 at 848 (9th Circ 2011).

210. *Hegyesh v Unjian*, 234 Cal App (3d) 1103 at 1138 (Ct App 1991)[*Hegyesh*].

211. *Whitlock v Pepsi Americas*, 681 F Supp (2d) 1123 at 1127 (Cal Dist Ct 2010).

to future generations. As such, they clearly implicate indeterminacy of liability in time and class, and by a function of these, together with the fact that damages for injuries to infants often amount to millions of dollars, indeterminacy in amount as well. American pre-conception tort judgments have noted the “staggering” implications of recognizing a duty: courts have referred to the prospect of liability to younger siblings of the plaintiff child conceived and born to a woman previously injured in an automobile collision,²¹² or, in the case of a young woman who becomes sensitized to the Rh factor through blood transfused at a young age and whose child brings a claim upon reaching majority, liability to children in a proceeding taking place “half a century after the negligent act was performed.”²¹³ Given the ubiquity of household chemicals, lack of knowledge about their health effects (particularly in terms of multigenerational effects and exposures *in utero*), and the diffuse, often-gradual nature of exposure, factual scenarios that will pertain to harm caused by BFRs and phthalates may often involve indeterminate liability.

Courts and scholars attempting to allay concerns regarding the potential burden of indeterminate liability make several points. First, they assert that the actual number of pre-conception tort claims is and will be very small.²¹⁴ This may not be persuasive in Canadian courts as indeterminate liability has been noted to be a concern over just that: indeterminacy, and not simply the volume of claims.²¹⁵ Next, concern over indeterminate liability has been addressed by distinguishing certain injuries from “self-perpetuating” conditions such as exposure to chemicals or radiation resulting in germ-line genetic changes.²¹⁶ Any indeterminacy would be far less pronounced if liability only extends to individuals in a single generation. This approach, however, distinguishes rather than

212. *Hegyves*, *supra* note 210 at 1119.

213. *Renslow*, *supra* note 188 at 376 (quoted from the dissenting judgment).

214. *Hegyves*, *supra* note 210 at 1151-52 (dissenting judgment); *Goldberg* *supra* note 202 (referring to “the problem of multi-generational liability” as “the proverbial storm in a teacup” at 282), and citing *Greenberg*, *supra* note 186.

215. See *e.g.* *Canadian National Railway Co v Norsk Pacific Steamship Co*, [1992] 1 SCR 1021 at 1126-27 [*Norsk*].

216. See *e.g.* *Hegyves*, *supra* note 210 at 1146 (dissenting judgment); *Renslow*, *supra* note 188 at 358.

resolves the issue of transgenerational harm. To this latter end, some advocate employing a case-by-case analysis of what essentially amounts to foreseeability and proximity, rather than categorically denying any pre-conception duty.²¹⁷ Others propose drawing the line at allowing recovery only for first generation pre-conception claimants.²¹⁸ In Canadian law, sufficient proximity may address concerns over indeterminate liability.²¹⁹

As precedent in pre-conception tort is limited, it is not possible to confidently predict how Canadian courts will resolve the issues of foreseeability, proximity, and the residual policy consideration of indeterminate liability, and further, how they might do so in a factual scenario involving exposures to household chemicals. Given the holdings in *Bovingdon v Hergott*²²⁰ and *Paxton*,²²¹ it is probable that courts in Ontario, if not Canada as a whole, will take a conservative approach, not recognizing all of the pre-conception causes of action that have been successful in the US. This will make recovery difficult where household chemicals result in injuries, reproductive or otherwise, for a child yet-to-be-conceived.

IV. Rethinking the Categorization of “Reproductive Torts”

There are a number of Canadian cases which do not fit neatly into the aforementioned scheme, and which have ultimately motivated courts to rethink their approach to reproductive tort. These cases simultaneously consider some combination of prenatal injury, birth torts, and

217. See Tracey I Batt, “DES Third-Generation Liability: A Proximate Cause” (1996) 18:3 *Cardozo L Rev* 1217 at 1232. Granted, this is a somewhat circular argument in that it does not explain what factors would lead to a finding of foreseeability and proximity or address concerns over indeterminate liability; however, it does argue against a blanket no-duty rule for preconception claims.

218. See the dissenting judgment in *Grover v Eli Lilly & Co*, 63 Ohio St (3d) 756 at para 766 (Ohio Sup Ct 1992).

219. See *Norsk*, *supra* note 215 at para 258, but see *contra* the minority concurring judgment at para 321.

220. (2006), 83 OR (3d) 465 (Sup Ct), *aff’d* 2008 ONCA 2 [*Bovingdon* 2008].

221. *Paxton*, *supra* note 160. See also *Liebig v Guelph General Hospital*, 2009 CanLII 56297 (Ont Sup Ct).

preconception injury with varying outcomes. Taken together, these cases suggest a shift away from categorical classification of reproductive tort, and towards determining the legitimacy of prenatal and preconception claims drawing on the two-stage *Anns* test.²²² As discussed below, this approach at once promotes the recognition of women's autonomy by providing a means to balance the duty of care against relevant policy considerations, while establishing a need for a clear and direct relationship between the tortfeasor and plaintiff through foreseeability and proximity in duty of care.

The 1992 decision of the British Columbia Court of Appeal in *Cherry (Guardian ad litem of) v Borsman*²²³ concerned facts that resembled both prenatal injury and wrongful life situations. The adult plaintiff, while pregnant, was the patient of the defendant who performed an abortion procedure on her, which failed. The infant plaintiff alleged that negligent performance of the procedure itself caused her to be born with a severe disability. At trial the defendant was found liable to both plaintiffs. One of the key issues on appeal was whether the trial judge erred in holding that the defendant owed a duty to the fetus not to harm it while performing an abortion procedure at the request of the adult plaintiff. The Court held that this was not a wrongful life case, as the defendant argued. Agreeing with the trial judge and with the infant plaintiff, the court noted that wrongful life cases are characterized by an assertion of "a legal obligation to the foetus to terminate its life,"²²⁴ while the case in question involved an infant plaintiff physically injured by the defendant's negligence. This supported a cause of action as the defendant owed a duty to the mother to properly perform the procedure, as well as to the subsequently born child not to harm it if he failed in carrying out his duty to the mother. Thus, though in actual fact the child would not have been born but for the negligence, the court afforded the child a remedy by defining the claim through the duty not to injure.

In another case, *Lacroix v Dominique*,²²⁵ the Manitoba Court of

222. *Anns v Merton London Borough Council*, [1977] All ER 118 [*Anns*].

223. 94 DLR (4th) 487 (BCCA) [*Cherry*], aff'g (1990), 75 DLR (4th) 668 (BCSC).

224. *Ibid* at para 71.

225. *Supra* note 161.

Appeal was also faced with a factual scenario in which it was unclear whether the injury was harm to the child *en ventre sa mère*, or a wrongful life claim. The plaintiff parents consulted the defendant neurologist about whether the medication the mother was taking to control her epilepsy would pose risks to any children they would have while she was taking the medication. The parents alleged, and the trial judge found, that the defendant had not properly advised the plaintiff parents of the risks. Their second child, the infant plaintiff Donna, “was born with physical anomalies and was diagnosed as being developmentally delayed and retarded.”²²⁶ The trial judge had found that the cause of her disabilities was the medication, and that had the parents been properly advised the mother would not have become pregnant.²²⁷

In setting out its analysis concerning the child’s claim, the Court of Appeal stated, “[c]ases involving a claim by a child born with abnormalities generally fall within one of two categories: (1) cases in which the abnormalities have been caused by the wrongful act or omission of another; and (2) cases in which, but for the wrongful act or omission, the child would not have been born at all.”²²⁸ The Court cited *Cherry* as an example of a case falling under the first category, noting the ultimate award of damages to the child.²²⁹ As for the second category, the court in *Lacroix* concluded that, based on the fact that the mother would not have become pregnant had she been properly advised, the case fell into the second category, and that the trial judge was therefore correct in rejecting the child’s claim.²³⁰

The 2008 decision of the Ontario Court of Appeal in *Bovingdon* responded to both *Cherry* and *Lacroix*. The case featured a woman who was prescribed Clomid to aid with ovulation, and who later gave birth to twins with disabilities. The plaintiffs alleged that the defendant obstetrician negligently failed to inform the mother of the risks associated with taking the drug, specifically the possibility of prematurely giving birth to twins, and of the risks associated with premature birth, including

226. *Ibid* at para 5.

227. *Ibid* at para 8.

228. *Ibid* at para 24.

229. *Ibid* at para 25.

230. *Ibid* at para 42.

cerebral palsy.²³¹ At trial, the defendant was found to have owed a duty of care to the infant twin plaintiffs. Pardu J held, relying on *Lacroix*, that this was not a wrongful life case because the defendant, in prescribing Clomid, caused not only the birth of the children, but also their injury.²³² The defendant appealed.

Justice Feldman, in her judgment on behalf of the Court of Appeal, reviewed the two-category analysis set out in *Lacroix*, and rejected it as failing to provide “a coherent theory that can assist courts in making the difficult decision of when a child should be able to recover damages from a doctor for being born with disabilities.”²³³ The trouble with the approach was that cases such as *Cherry* and *Lacroix* could be viewed as falling into either category, with the negligence capable of being viewed as causing both the injury as well as the birth of the child. She preferred to approach the claim “through the normal analysis of tort liability: duty of care, standard of care, breach, and damage.”²³⁴ With respect to the first issue, the infant plaintiffs argued that the defendant owed them a duty co-extensive to that owed to their mother, namely, to properly inform her of the risks associated with taking the fertility drug Clomid.²³⁵ The plaintiffs further asserted, likely in order to avoid the characterization of their claim as one for wrongful life, that they had the right “to have a drug-free conception, with a reduced risk of disability, rather than a right not to be born.”²³⁶

Feldman JA held that because the defendant’s duty was to provide information to help the mother make the decision of whether or not to take the drug, it could not be said that the children had a right to a drug-free birth. Neither could they be owed a duty co-extensive with that owed to the mother, since it is the mother’s choice whether to take the drug or not. She could, after all, have chosen to take the drug notwithstanding any risks to the children.²³⁷ The defendant therefore did not owe a duty

231. *Bovingdon* 2008, *supra* note 220 at para 13.

232. *Ibid* at para 4.

233. *Ibid* at para 55.

234. *Ibid* at para 61.

235. *Ibid* at para 62.

236. *Ibid*.

237. *Ibid* at para 68.

to the children not to cause them harm in prescribing Clomid to their mother.²³⁸ Policy considerations also supported this conclusion, in that recognizing the duty would create a potential conflict: physicians might refuse to offer to prescribe Clomid to women for fear that doing so could breach a duty owed to their future children.²³⁹ Feldman JA indicated that in deciding the case at bar on the basis of duty, she was not commenting on the viability of the wrongful life cause of action.²⁴⁰ She also distinguished the case at bar from the case where a child alleges that a physician negligently prescribed his or her mother a drug that is contraindicated for pregnant women.²⁴¹

Later the same year, the Court took on this very issue in the case of *Paxton v Ramji*. In this case, Dawn Paxton had requested her physician, the defendant Dr. Ramji, to prescribe Accutane to treat her acne condition.²⁴² As Accutane is a teratogen, as per the standard of care, specific precautions are supposed to be taken to ensure that the patient does not become pregnant while taking Accutane, namely the use of two forms of birth control (when the patient is not abstinent).²⁴³ In prescribing the drug,²⁴⁴ Dr. Ramji relied on the fact that Ms. Paxton's husband had undergone a vasectomy about 4 1/2 years prior to her commencing the treatment.²⁴⁵ Shortly after commencing treatment, however, Ms. Paxton became pregnant due to failure of the vasectomy.²⁴⁶ As a result, Jaime Paxton was born "with a number of severe disabilities

238. *Ibid* at para 70.

239. *Ibid* at para 71.

240. *Ibid* at para 72.

241. *Ibid* at para 69.

242. *Paxton*, *supra* note 160 at para 5.

243. *Ibid* at paras 6-7.

244. As Accutane is a teratogen, it was only supposed to be prescribed following the Pregnancy Protection Mainpro-C Program (PPP) developed by the drug's manufacturer, which stipulates that the patient use effective contraception from one month prior to commencing treatment, until one month after ceasing treatment. Specifically, two reliable birth control methods were to be used simultaneously, unless abstinence was the chosen method (not merely a vasectomy as in *Paxton*). See *ibid* at paras 6-7; *Paxton* 2006, *supra* note 160 at para 136.

245. *Paxton*, *ibid* at para 2.

246. *Ibid* at para 9.

as a result of her exposure to Accutane while *in utero*, including a right facial palsy; seizures; generalized hypotonia; megalencephaly of the left occipital lobe of the brain; prominent dysmorphic features; hearing loss; anotia (absent right ear); and microtia (malformed left ear).²⁴⁷

The infant plaintiff brought a claim in negligence against Dr. Ramji.²⁴⁸ At trial, Justice Eberhard held that a physician owes a duty to the “unconceived child of a woman of childbearing potential”²⁴⁹ not to prescribe Accutane if it was contraindicated, specifically if the patient is of childbearing potential and the physician is not satisfied that she will avoid pregnancy while taking the drug.²⁵⁰ In arriving at this conclusion, Eberhard J first turned to the classification of causes of action in reproductive tort, considering the analysis in *Lacroix* as particularly persuasive.²⁵¹ Viewing the duty as one not to prescribe the drug to a woman if she were unable or unwilling to follow the required birth control methods, she concluded that the duty was owed to the potential child of the patient (not to injure her/him).²⁵² She acknowledged that “in the abstract” this duty gave rise to a concern about conflict with the physician’s duty to his or her patient.²⁵³ However, “in the real world,” physicians already deal with this conflict, as the standard of care imposed by the medical community “demands that protections must be put in place to avoid pregnancy before Accutane can be given.”²⁵⁴

Eberhard J distinguished the facts of the case at bar from those in *Lacroix*. As the medication in *Lacroix* was required for the mother’s health as well as for that of her future child, it was impossible to hold that the physician owed a duty to the future child in prescribing the drug.²⁵⁵ She also justified holding that a duty of care could be owed in this case to a child before he or she was conceived. She noted that whether a woman is already pregnant or later becomes pregnant when prescribed Accutane,

247. *Ibid* at para 11.

248. *Ibid* at paras 2, 17.

249. *Ibid* at para 22.

250. *Paxton* 2006, *supra* note 160.

251. *Ibid* at para 157.

252. *Ibid* at para 194.

253. *Ibid* at para 196.

254. *Ibid*.

255. *Ibid* at para 199.

the risk and injury to the child may be the same and the pregnancy is equally “foreseeable and proximate.”²⁵⁶ Notwithstanding, having held that the defendant owed a duty to the infant plaintiff not to prescribe Accutane to her mother if it was contraindicated, the trial judge found that Dr. Ramji had met the standard of care in relying on the vasectomy as an effective means of addressing Ms. Paxton’s child bearing potential. Thus, the prescription of Accutane was not contraindicated and the claim was dismissed.²⁵⁷

The plaintiffs appealed the trial judge’s findings with respect to standard of care,²⁵⁸ while the defendants used the appeal to argue against the recognition of a duty of care to Jaime. The Court of Appeal disposed of the appeal by overturning the trial judge’s holding with respect to duty. Feldman JA, who wrote the decision, echoed her judgment in *Bovingdon* in criticizing the *Lacroix* approach of evaluating claims by determining whether or not they could be characterized as wrongful life.²⁵⁹ Instead, she referred to a line of tort cases decided by the Supreme Court of Canada, relating to various factual subject matters, which set out and apply the basic test for determining whether a duty of care should be recognized.²⁶⁰ To this end, the Court held that there was “no settled jurisprudence in Canada on the question whether a doctor can be in a proximate relationship with a future child who was not yet conceived or born at the time of the doctor’s impugned conduct,”²⁶¹ nor was there an analogous duty of care.²⁶² Feldman JA thus turned to the *Anns* test²⁶³ to first establish whether the foreseeability and proximity of duty of care necessary to establish a *prima facie* duty of care exists, and then, if such a duty existed, to examine whether residual policy considerations should

256. *Ibid* at para 206.

257. *Ibid* at paras 211-16.

258. They also appealed a finding that Jaime would not be entitled to punitive damages.

259. *Paxton*, *supra* note 160 at paras 28-29.

260. *Ibid* at para 29.

261. *Ibid* at para 53.

262. *Ibid* at para 54.

263. See *ibid* at paras 60-80, citing *Anns*, *supra* note 222 and subsequent Canadian jurisprudence.

limit recognition of the duty.²⁶⁴

Feldman JA found that, though the injury was foreseeable, the physician's relationship with the child-yet-to-be-conceived was not proximate enough to recognize a duty. Imposing a duty of care for children not yet conceived could result in physicians offering "treatment to some female patients in a way that might deprive them of their autonomy and freedom of informed choice in their medical care."²⁶⁵ Citing the Supreme Court of Canada decisions in *Dobson* and *DFG*, Feldman JA stated that "[b]ecause women are autonomous decision makers with respect to their own bodies, they neither make the decision on behalf of the future child, nor do they owe a duty to act in the best interests of a future child."²⁶⁶ In the case of prescribing a teratogenic drug, the physician can only enlist the agreement of the woman not to become pregnant, but he or she cannot ensure that she will abide by that agreement.²⁶⁷ Feldman JA went on to state that residual policy considerations would likewise make imposition of a duty seem unwise.²⁶⁸ It could, for example, destabilize women's right to abortion,²⁶⁹ presumably by promoting the view that the future child has its own legal interests apart from those of the mother. As a result of the holding with respect to duty, the appeal was dismissed.²⁷⁰

The Canadian case law covering reproductive tort cases involving multiple claims (*i.e.* a combination of prenatal injury, wrongful birth, wrongful life, and preconception claims), culminating in the decision in *Paxton*, signifies a shift away from resolving disputes by determining whether they give rise to wrongful life claims, to approaching them using the ordinary principles of tort law. As noted above, this approach to reproductive tort law is particularly useful to address conflicting duties of care. In such cases, determining a duty of care relies on first proximity and foreseeability (following the *Anns* test), balanced against specific

264. *Ibid* at para 35, quoting *Syl Apps Secure Treatment Centre v BD*, 2007 SCC 38 at para 3.

265. *Ibid* at para 68.

266. *Ibid* at para 73.

267. *Ibid* at paras 74-75.

268. *Ibid* at para 77.

269. *Ibid* at para 79.

270. *Ibid* at para 88.

policy considerations.

The idea that a duty of care to a woman may preclude a duty of care to a fetus or preconceived embryo, following the policy considerations of the *Anns* test recognized in *Paxton*, is integral to upholding the principles of judicial non-intervention in the governance of pregnancy established in *DFG* and *Dobson*. The inseparability of a woman, a fetus, and her preconceived embryos is important here, and *Paxton* asserted that the unique nature of this relationship cannot require a duty of care.²⁷¹ Applied to the case of exposures to toxic household chemicals, this may mean that through the application of the *Anns* test, and the policy considerations emergent in *DFG* and *Dobson*, women, and in certain cases the physicians treating them, may not be liable for the exposure of either fetuses or preconceived embryos to exposures to household chemicals that may result in injury.

Apart from the issues of proximity and foreseeability raised in the application of the *Anns* test to prenatal and preconception claims, recovery will be unlikely in cases where the harms incurred cannot be clearly and directly linked to a particular origin, or where cause-and-effect in injury are unclear. For example, determining a duty of care for particular pharmaceutical companies has been difficult as plaintiffs whose mothers took DES are often unable to determine the manufacturer of the drugs taken by their mothers decades ago.²⁷² Factual scenarios where individuals may be exposed to a wide array of household chemicals prior to conception, *in utero*, and/or in breastfeeding make it difficult to discern when and how exposures took place, which chemicals are responsible for what physiological harms, and which manufacturers should be held liable.

V. Conclusion

Reproductive tort jurisprudence has a number of significant implications for the litigation of injuries caused by prenatal and preconception exposure to household chemicals. The decisions in prenatal injury cases

271. *Ibid* at para 68.

272. "Jury Awards \$42.3 Million to Women in Drug Lawsuit", *The New York Times* (9 January 1994) 28.

(including *Montreal Tramways* and *Duval*) that do not include claims against a pregnant woman suggest that the cause of action for personal injury sustained while *in utero* is well-established. Though reproductive harms caused by household chemicals are, as noted above, most often the result of diffuse, cumulative exposures, these cases identify the potential for such claims to succeed. Further, they remind us that causation need not be definitively proven, as long as the relationship between the harm done and the purported causation can be reasonably established on a balance of probabilities.

Canadian courts have, following *DFG* and *Dobson*, established a legal framework that demonstrates flexibility in conceptualizing prenatal claims made against pregnant women.²⁷³ Recognizing the pre-eminence of the right to reproductive autonomy, the Supreme Court of Canada has refused to permit claims of prenatal harm brought by a child, once born, against his or her mother. In *Paxton* and *Lacroix*, the courts also refused to permit claims in cases of preconception injury insofar as claims against individuals who owe the pregnant woman a duty would conflict with any duty owed to her future child. Given the undue burdens on women to avoid exposing themselves and their families to toxic household chemicals, these principles are particularly relevant.

While the recognition of women's reproductive autonomy attributable to the application of the *Anns* test in *Paxton* is important, the dominance of proximity and foreseeability in the *Anns* test renders this model problematic in cases where the factual scenario involves intergenerational harms caused by ongoing, diffuse exposures to household chemicals. Foreseeability might be addressed simply by the knowledge that household chemicals may adversely affect the reproductive system. However, if there is widespread public knowledge that exposures are harmful, the onus might equally fall to consumers to avoid products containing these chemicals. The costs of educating oneself about household chemicals, of finding the right stores and the right products with phthalate-free shampoo and flame-retardant free pajamas will, following *Lee and Scott*,²⁷⁴ fall to women, plagued by

273. Mykitiuk & Scott, *supra* note 116 at 341.

274. See generally *Lee & Scott*, *supra* note 20.

the challenges of engaging in precautionary consumption. For those financially or otherwise unable to avoid exposures, seeking damages in tort might not be an option due to difficulty in pointing to a duty of care or in establishing causation, depending on the nature of the particular situation. Further, proximity in such cases could be easily undermined by an understanding that only those exposed are eligible to seek damages, mitigating problems of indeterminate liability.

In addition, the recognition of birth or life with a disability as a legal harm has important implications for the disability community, insofar as “disability comes to be seen as an injury, something located in the individual, and something for which someone ought to be held at fault.”²⁷⁵ Alternative approaches such as judgements that do not identify being born with a disability as a harm, but rather provide for the financial costs of living with a disability in contemporary society (following Cooperman),²⁷⁶ may work to identify the problematic nature of theorizing birth and life as harms, while providing for peoples’ needs. Reproductive torts jurisprudence needs to consider the diversity of human experience while recognizing the needs plaintiffs may experience in living with or raising a child with a disability.

Overall, reproductive tort law offers insightful principles for approaching cases involving the adverse health outcomes linked to exposures to brominated flame retardants and/or phthalates. However, the potential for obtaining a remedy is limited. Given the state of the science, demonstrating a clear relationship between exposures and physiological harms incurred is unlikely, and defendants are not easily identified. Moreover, success for claims of intergenerational reproductive harm caused by exposures to household chemicals is unlikely under Canadian tort law.

What remains is that Canadians and others continue to be exposed to household chemicals suspected of causing harms to the reproductive systems of those exposed, and to future generations. Existing animal and

275. Jennifer Ann Rinaldi, “Wrongful Life and Wrongful Birth: The Devaluation of Life with Disability” (2009) 1:1 *Journal of Public Policy, Administration and Law* 1 at 6.

276. Cooperman, *supra* note 177 at 14-15.

human studies, as noted above, demonstrate important implications of these exposures, to the extent that particular phthalates have already been banned from the Canadian marketplace. If tort law is insufficient to address these intergenerational reproductive harms, then further study is required to establish how chemical and product manufacturers can be deterred from causing the injuries associated with production of these chemicals, how states can better regulate their use, and what legal recourse can be sought if and when all else fails.

“Science Powers Commerce”: Mapping the Language, Justifications, and Perceptions of the Drive to Commercialize in the Context of Canadian Research

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The push to commercialize publicly funded, academy-driven scientific research has emerged as a significant science policy challenge. In this article, we investigate whether evidence of this push exists in Canadian scientific research policies through a comprehensive review of legislation, government policy instruments, funding agencies' program and awards guides and policy statements, political commentary, and university policies. The study maps and discusses the language and justifications used to promote this commercialization push, and examines possible impacts on the Canadian research environment. The article also presents the views of some members of Canadian scientific research community regarding the push or pressure to commercialize their work.

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I. Introduction

The push to commercialize publicly funded, academy-driven scientific research has emerged as a significant science policy challenge.¹ Advocates of this push include Prime Minister Stephen Harper of Canada, who recently declared that “science powers commerce,”² and President Barack Obama, who has urged Americans to “win the future” and claim “our generation’s Sputnik moment” by supporting government investment in scientific research that will create new industries and “countless new jobs” and make the US economy more competitive.³ Likewise, Prime Minister David Cameron, announcing a £180m “catalyst” grant for “new British ideas,” referred to the life sciences as “a jewel in the crown of [the

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1. Timothy Caulfield, “Talking Science – Commercialization Creep” (2012) 34:1 *Policy Options* 20 [Caulfield, “Commercialization Creep”]; Timothy Caulfield, “Patents or Commercialization Pressure?: A (Speculative) Search for the Right Target” (2012) 22:1 *Journal of Law, Information and Science* 122; Timothy Caulfield & Ubaka Ogbogu, “Biomedical Research and the Commercialization Agenda: A Review of Main Considerations for Neuroscience” (2008) 15:4 *Accountability in Research* 303; Timothy Caulfield, “Stem Cell Research and Economic Promises” (2010) 38:2 *JL Med & Ethics* 303 [Caulfield, “Economic Promises”]; Jocelyn Downie & Matthew Herder, “Reflections on the Commercialization of Research Conducted in Public Institutions in Canada” (2007) 1:1 *McGill JL & Health* 23.
 2. Stephen Harper, “PM Announces Banting Postdoctoral Fellowships, Support for Next Einstein Initiative” (6 July 2010), online: Office of the Prime Minister <<http://pm.gc.ca/eng/news/2010/07/06/pm-announces-banting-postdoctoral-fellowships-support-next-einstein-initiative-0>>.
 3. Barack Obama, “Remarks by the President in State of Union Address” (25 January 2011), online: The White House <<http://www.whitehouse.gov/the-press-office/2011/01/25/remarks-president-state-union-address>>.

UK] economy” and called for a new model of research and development focused on “getting the best ideas through the proof of concept stage so we can get them into clinical development and get our entrepreneurs selling them around the world.”⁴ In the European Union, member states have announced reforms aimed at linking research innovation with “entrepreneurship, the business environment and the labour market, with a strong focus on better commercialization of research results.”⁵ These claims and statements have generated some concern, especially regarding whether this “ever-intensifying pressure to commercialize research” overstates what scientific research can actually or realistically deliver.⁶ As one critic has observed, key features of the commercialization trend, such as biotech start-ups and activities of university technology transfer offices, resemble Ponzi schemes because they purport by “all appearances to be a success when careful measurement reveals ... failure[s].”⁷

There are, of course, arguments that can be put forward in support of both perspectives. Contemporary commercialization initiatives are chiefly characterized by academy-industry partnerships, and public funding support for research projects that are able to obtain matching private sector funds, or that can show evidence of near-term commercializable outcomes (or at a minimum, a clear route to commercial exploitation).⁸ These initiatives can and have produced beneficial outcomes, including useful products, jobs, increased research funding and public-private sector linkages.⁹ However, these initiatives have also been linked with

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4. David Cameron, “PM Speech on Life Sciences and Opening Up the NHS” (6 December 2011), online: GOV.UK <<https://www.gov.uk/government/speeches/pm-speech-on-life-sciences-and-opening-up-the-nhs>>.
 5. European Commission, “State of the Innovation Union 2012: Accelerating change” (21 March 2013), online: Innovation Union <http://ec.europa.eu/research/innovation-union/pdf/state-of-the-union/2012/state_of_the_innovation_union_report_2012.pdf> at 10.
 6. Caulfield, “Commercialization Creep”, *supra* note 1 at 20.
 7. Philip Mirowski, “The Modern Commercialization of Science is a Passel of Ponzi Schemes” (2012) 26:3-4 *Social Epistemology* 285 at 296.
 8. Ubaka Ogbogu, “A Review of Pressing Ethical Issues Relevant to Stem Cell Translational Research” (2006) 14:3 *Health Law Review* 39.
 9. Caulfield, “Commercialization Creep”, *supra* note 1; Ogbogu, *ibid*; Commission on the Future of Health Care in Canada, *Building on Values*:

adverse impacts on the integrity of scientific processes,¹⁰ scientific collaborations, exchanges and “open science” initiatives,¹¹ loss of public trust,¹² hyped representations of research realities and outcomes

The Future of Health Care in Canada (Saskatoon: Commission on the Future of Health Care in Canada, 2002).

10. Vincent Mangematin, Paul O'Reilly & James Cunningham, “PIs as Boundary Spanners, Science and Market Shapers” (2014) 39:1 *The Journal of Technology Transfer* 1; Riccardo Fini & Nicola Lacetera, “Different Yokes for Different Folks: Individual Preferences, Institutional Logics, and the Commercialization of Academic Research” in Gary D Libecap, Marie Thursby & Sherry Hoskinson, eds, *Spanning Boundaries and Disciplines: University Technology Commercialization in the Idea Age* (Bingley, UK: Emerald Group, 2010) 1; Bertrand R Jordan & Daniel Fu Chang Tsai, “Whole-Genome Association Studies for Multigenic Diseases: Ethical Dilemmas Arising from Commercialization – The Case of Genetic Testing for Autism” (2010) 36:7 *Journal of Medical Ethics* 440; Philip Morowski, *Science-Mart: Privatizing American Science* (Cambridge, MA: Harvard University Press, 2011); Francesco Rentocchini et al, “Working Paper No. 2011/03: The Effect of Academic Consulting on Research Performance: Evidence from Five Spanish Universities” (2011), online: Ingenio Working Paper Series <http://www.ingenio.upv.es/sites/default/files/working-paper/2011-03_-_the_effect_of_academic_consulting_on_research_performance_evidence_from_five_spanish_universities.pdf>.
11. Timothy Caulfield, Shawn HE Harmon & Yann Joly, “Open Science Versus Commercialization: A Modern Research Conflict?” (2012) 4:2 *Genome Medicine* 17; Tania Bubela et al, “Commercialization and Collaboration: Competing Policies in Publicly Funded Stem Cell Research?” (2010) 7:1 *Cell Stem Cell* 25 [Bubela et al, “Commercialization and Collaboration”]; Sotaro Shibayama, John P Walsh & Yasunori Baba, “Academic Entrepreneurship and Exchange of Scientific Resources: Material Transfer in Life and Materials Sciences in Japanese Universities” (2012) 77:5 *American Sociological Review* 804; Shawn HE Harmon, Timothy Caulfield & Yann Joly, “Commercialization Versus Open Science: Making Sense of the Message(s) in the Bottle” (2012) 12:1 *Medical Law International* 3.
12. Christine R Critchley, Gordana Burce & Matthew Farrugia, “The Impact of Commercialization on Public Perceptions of Stem Cell Research: Exploring Differences Across the Use of Induced Pluripotent Cells, Human and Animal Embryos” (2013) 9:5 *Stem Cell Reviews & Reports* 541; Christine R Critchley & Dianne Nicol, “Understanding the Impact of Commercialization on Public Support for Scientific Research: Is it about the Funding Source or the Organization Conducting the Research?” (2011) 20:3 *Public Understanding of Science* 347; M Norton Wise, “Thoughts on the Politicization of Science through Commercialization” (2006) 73:4 *Social Research* 1253; Ubaka Ogbogu &

(especially in innovative fields that have captured public attention and purse strings, such as genetics and stem cell research),¹³ and neglect of basic research programs.¹⁴ The latter concern has generated some push

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- Amy Zarzeczny, “Ethical, Legal and Social Implications of Translational Stem Cell Research: Effects of Commercialization on Public Opinion and Trust of Stem Cell Research” in Kristina Hug & Göran Hermerén, eds, *Translational Stem Cell Research: Issues Beyond the Debate on the Moral Status of the Human Embryo* (New York: Humana Press, 2011) 341; Deborah Zucker, “Ethics and Technology Transfer: Patients, Patents, and Public Trust” (2011) 59:5 *Journal of Investigative Medicine* 762; Christine R Critchley, “Public Opinion and Trust in Scientists: The Role of the Research Context, and the Perceived Motivation of Stem Cell Researchers” (2008) 17:3 *Public Understanding of Science* 309.
13. Caulfield, “Economic Promises”, *supra* note 1; Tania Bubela et al, “Is Belief Larger than Fact: Expectations, Optimism and Reality for Translational Stem Cell Research” (2012) 10:1 *BMC Medicine* 133; Zubin Master & David B Resnik, “Hype and Public Trust in Science” (2013) 19:2 *Science and Engineering Ethics* 321; Zubin Master & David B Resnik, “Promoting Public Trust: ESCROs Won’t Fix the Problem of Stem Cell Tourism” (2013) 13:1 *American Journal of Bioethics* 53; James Porter et al, “On Being a (Modern) Scientist: Risks of Public Engagement in the UK Interspecies Embryo Debate” (2013) 31:4 *New Genetics and Society* 408; T Caulfield & C Condit, “Science and the Sources of Hype” (2009) 15:3-4 *Public Health Genomics* 209; Cong Cao, Richard P Appelbaum & Rachel Parker, “Research is High and the Market is Far Away’: Commercialization of Nanotechnology in China” (2013) 35:1 *Technology in Society* 55; Michael P Messenger & Paul E Tomlins, “Regenerative Medicine: A Snapshot of the Current Regulatory Environment and Standards” (2011) 23:12 *Advanced Materials* H10.
14. Laura Eggertson, “Scientists, Supporters Rally in Canadian Cities to Support Basic Research” (2013) 185:15 *Canadian Medical Association Journal* E707; Shirley Leitch et al, “The Fall of Research and Rise of Innovation: Changes in New Zealand Science Policy Discourse” (2014) 41:1 *Science and Public Policy* 119; Gürol Irzik, “Why Should Philosophers of Science Pay Attention to the Commercialization of Academic Science?” in Mauricio Suárez, Mauro Dorato & Miklós Rédei, eds, *EPSA Epistemology and Methodology of Science* (Dordrecht: Springer Netherlands, 2010) 129; Leland L Glenna et al, “Commercial Science, Scientists’ Values, and University Biotechnology Research Agendas” (2011) 40:7 *Research Policy* 957; Lee Davis, Maria Theresa Larsen & Peter Lotz, “Scientists’ Perspectives Concerning the Effects of University Patenting on the Conduct of Academic Research in the Life Sciences” (2011) 36:1 *Journal of Technology Transfer* 14; Hanna Hottenrott & Susanne Thorwarth, “Industry Funding of University Research and Scientific Productivity” (2011) 64:4 *Kyklos* 534; Dominique Foray &

back from the scientific community. For example, this past September, over 200 Canadian university researchers rallied at the nation's capital in Ottawa to express dismay over government neglect of basic research in favour of applied research programs and grants “that specify industrial partnerships or are directed at solving applied research problems or at increasing innovation and commercialization.”¹⁵

As the debate rages on, there remains a considerable lack of clarity regarding the true nature and scope of this “commercialization creep,”¹⁶ where the *pressure* comes from and the nature of the pressure it supposedly exerts on scientists and the scientific research environment. No studies have explored, for instance, the actual sources of the commercialization ethos or the language employed to express or justify the push or pressure to commercialize science. Similarly, with the exception of studies that have investigated the impact of commercialization trends on the scientific research environment, much remains unknown about how the scientific research community views this trend or pressure or about the impact of existing commercialization programs on the conduct or culture of scientific research.¹⁷

Francesco Lissoni, “University Research and Public-Private Interaction” in Bronwyn H Hall & Nathan Rosenberg, eds, *Handbook of The Economics of Innovation*, vol 1 (Amsterdam: Elsevier, 2010) 275; James A Evans, “Industry Induces Academic Science to Know Less about More” (2010) 116:2 *American Journal of Sociology* 389; Ferric C Fang & Arturo Casadevall, “Lost in Translation – Basic Science in the Era of Translational Research” (2010) 78:2 *Infection and Immunity* 563; Martin Carrier, “Knowledge, Politics, and Commerce: Science Under the Pressure of Practice” in Martin Carrier & Alfred Nordmann, eds, *Science in the Context of Application* (Amsterdam: Springer Netherlands, 2011) 11; Daniel H Nickolai, Steve G Hoffman & Mary Nell Trautner, “Can a Knowledge Sanctuary also be an Economic Engine? The Marketization of Higher Education as Institutional Boundary Work” (2012) 6:3 *Sociology Compass* 205.

15. Eggertson, *ibid* at E708.

16. Caulfield, “Commercialization Creep”, *supra* note 1.

17. Bubela et al, “Commercialization and Collaboration”, *supra* note 11; Glenna et al, *supra* note 14; Timothy Caulfield et al, “Patents, Commercialization and the Canadian Stem Cell Research Community” (2008) 3:4 *Regenerative Medicine* 483 [Caulfield et al, “Patents”]; CJ Murdoch & Timothy Caulfield, “Commercialization, patenting and genomics: researcher perspectives” (2009) 1:2 *Genome Medicine* 22;

In Canada, there are several well-known examples of the degree to which the political rhetoric has translated into tangible changes in the way research is funded, such as the Alberta Government's decision to create the commercialization-focused Alberta Innovates (which replaced the more research oriented Alberta Heritage Foundation for Medical Research), and the federal government's recent push to more closely align the work of National Research Council with the needs of industry.¹⁸ However, despite the high profile nature of these examples, much remains unclear, such as the degree to which political commentary about the commercialization imperative has penetrated formal research funding requirements and expectations and, if it has, how that change is explicitly justified.¹⁹

In this article, we seek to address some of these gaps through a comprehensive review of over one hundred relevant Canadian documents identified through database searches, including legislation; government policy instruments; funding agencies' program and awards guides and policy statements; political commentary; and university policies. We seek

Yann Joly et al, "The Commercialization of Genomic Research in Canada" (2010) 6:2 Health Policy 24; Valentina Tartari & Stefano Breschi, "Set Them Free: Scientists' Evaluations of the Benefits and Costs of University-Industry Research Collaboration" (2012) 21:5 Industrial and Corporate Change 1117.

18. Eggertson, *supra* note 14; Carol Goar, "How to Modernize Canada's Science Policy; Report sees National Research Council as a Bridge between Science and Industry", *Toronto Star* (17 June 2013) A15; Peter Howitt, "Let Curiosity Drive Commerce", *The Globe and Mail* (6 June 2013) A17; Ivan Semeniuk, "Budget Ignites Science Debate; Questions Arise over Merits of Basic and Applied Research as Government Tables Funding Allocations", *The Globe and Mail* (25 March 2013) A4; National Research Council Canada, News Release, "Open for Business: Refocused NRC will Benefit Canadian Industries; The Government of Canada Launches Refocused National Research Council" (7 May 2013) online: National Research Council Canada <http://www.nrc-cnrc.gc.ca/eng/news/releases/2013/nrc_business.html>.
19. Eggertson, *supra* note 14; Goar, *ibid*; Howitt, *ibid*; Semeniuk, *ibid*; C Scott Findlay, "Big Boasts, Little Proof; Ottawa Claims it has Provided Unprecedented Support for Science. The Evidence says Otherwise", *National Post* (8 April 2013) A14; Mia Rabson, "Federal Cuts Dubbed 'Attack on Science' – Researchers to Protest with 'Funeral Procession'", *Winnipeg Free Press* (10 July 2012) B3.

to identify and thematically assess concrete sources of and justifications for the commercialization push in the context of the Canadian research environment. However, we also briefly highlight emerging empirical evidence on the impact of existing commercialization programs on the conduct or culture of scientific research and on the views of the Canadian scientific research community regarding the push or pressure to commercialize their work.

II. Sources of and Justifications for the Commercialization Imperative

We explored documents from Canada's federal and provincial research funding agencies, from relevant publicly funded research non-profit organizations (*e.g.* Genome Canada), and from relevant research institutions (*e.g.* universities). In short, we sought to identify and analyze any language that could be interpreted as creating commercialization pressure within the Canadian research environment. We found that this ethos was ubiquitous. References to the imperative need to commercialize scientific research and justifications for doing so exist in most of the documents we reviewed, and permeate virtually all sources of governmental and institutional science and funding policy.

Specifically, the pursuit of commercialization is mandated by federal and provincial legislation governing Canada's research funding agencies. For example, the Canadian Institutes for Health Research (CIHR), the primary health research funding agency, is directed by legislation to "facilitat[e] the commercialization of health research ... and promot[e] economic development through health research."²⁰ Similarly, legislation governing National Research Council Canada (Canada's premier organization for research and development) and key provincial research policy and funding institutions such as Alberta Innovates; British Columbia's Innovation Council; Nova Scotia's Innovation Corporation; and New Brunswick's Research and Innovation Council variously mandate a focus on the following objectives: translating research knowledge into clinical applications; promoting research that

20. *Canadian Institutes of Health Research Act*, SC 2000, c 6, s 4(i).

will result in the formation of new industries or expansion of existing ones; establishment of funding programs specifically aimed at applied research; job creation; “promot[ing] industrial, economic and social development”; and translating research knowledge into lofty goals such as improving Canadians’ quality of life and creating value for Canadians (see Table A for more examples).²¹

Beyond the realm of law and high-level policy, similar references and justification abound in the other sources reviewed, notably in research funding documents, granting peer review policies, and university policies (see Table B for specific examples of funding and institutional statements). CIHR’s Grant and Awards Guide, for instance, includes a provision that requires applicants for research funding to “endeavour to obtain the greatest possible economic benefit to Canada from any commercial activity resulting from research findings.”²² Genome Canada’s Guidelines for Funding Research Projects states that grant applicants “must describe, with supporting evidence, the deliverable(s) that will be realized by the end of the project that will lead to social and/or economic benefits for Canada.”²³ Similar language is present in the advertised funding opportunities included in our review, with some opportunities requiring applicants to demonstrate that their research will “accelerate commercialization”; “foster an entrepreneurial culture within and around the health research community”;²⁴ and facilitate “commercial

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21. *British Columbia Innovation Council Act*, RSBC 1997, c 415, s 3; *National Research Council Act*, RSC 1985, c N-15; *Alberta Research and Innovation Act*, SA 2009, c A-31.7; *Innovation Corporation Act*, SNS 1994-95, c 5; *New Brunswick Research and Innovation Council Act*, SNB 2013, c 5.
 22. Canadian Institutes of Health Research, “CIHR Grants and Awards Guide” (1 April 2013), online: Canadian Institutes of Health Research <<http://www.cihr-irsc.gc.ca/e/805.html>>.
 23. Genome Canada, “Guidelines for Funding Research Projects” (June 2012), online: Genome Canada <<http://www.genomecanada.ca/medias/PDF/en/2012-bcb-competition-guidelines.pdf>> at 6.
 24. Canadian Institutes of Health Research, “Proof of Principle: Phase I (Fall 2013 Competition)” (19 June 2013), online: ResearchNet <<https://www.researchnet-recherchenet.ca/rnr16/vwOpprtntyDtls.do?prog=1858&view=currentOpps&type=EXACT&resultCount=25&sort=program&all=1&masterList=true>>.

development of products”²⁵ (see List A for more examples).

On the institutional side, universities in the Province of Alberta are required to allocate institutional resources in a manner that ensures “excellence in research, innovation, and commercialization” and that the province’s economy “is competitive and sustainable,”²⁶ while the University of Toronto views research commercialization, specifically, translating research results “into products and processes with economic and social benefit” as “an important measure of impact beyond the University”²⁷ (see List B for more examples). These statements and policies express and govern the granting and institutional requirements and expectations facing researchers, and operate informally as indicators of successful research careers.

Viewed as a whole, our review confirms the presence of systemic and systematic pressure on Canadian researchers to commercialize research outcomes. The overall message appears to be that commercialization is now a central element and goal of the scientific research enterprise. Indeed, in the past decade, the federal and provincial governments have allocated significant public resources to shifting the focus of Canadian science towards this commercialization ethos.²⁸ At the federal level, several initiatives and programs specifically devoted entirely to research commercialization have emerged in recent years, including the Centres of Excellence for Commercialization and Research program (annual budget: \$30m) and the Business-Led Networks of Centres of Excellence

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25. Alberta Innovates – Health Solutions, “AIHS Knowledge-to-Action Grant” (2013), online: Alberta Innovates – Health Solutions <<http://www.aihealthsolutions.ca/rtna/grant.php>>.
 26. Government of Alberta, “Draft Letter of Expectation between the Minister of Alberta Enterprise and Advanced Education and the Board of Governors of the University of Alberta”, online: Change@UAlberta <<http://change.ualberta.ca/-/media/change/letter-of-expectation---u-of-a/letter-of-expectation---u-of-a.pdf>>.
 27. University of Toronto, “University of Toronto Performance Indicators 2012: Our Research Excellence – Innovation and Commercialization”, online: University of Toronto <http://www.utoronto.ca/__shared/assets/A_05_a-c_Innovation_Commercialization4920.pdf>.
 28. Einar Rasmussen, “Government Instruments to Support the Commercialization of University Research: Lessons from Canada” (2008) 28:8 *Technovation* 506.

program (annual budget: \$12m), both of which channel publicly funded university research towards the commercialization pipeline and to responding to challenges identified by industry. The provinces have established similar programs, including Alberta Innovates – Health Solutions, which supports research activities that “create ... health related social and economic benefits for Albertans,”²⁹ and Fonds de recherche Santé Québec, a Québec government-backed funding initiative designed to support scientific and technological research that will “contribute to Québec’s economic growth,”³⁰ among other things.

Our review also revealed a number of justifications for the push to commercialize, including enabling improved health care and quality of life; making the innovation system more sustainable (economically); faster product development; creation of new industries and expansion of existing ones; realizing returns on research investments; accountability to taxpayers; promoting economic growth and social development; job creation; and creating value for Canadians. These justifications were typically expressed in broad, aspirational language, with little or no explanation regarding meaning, scope or how they can be achieved in practical terms. Put differently, the justifications are presented in a manner that suggests they are obvious endpoints. The presentation also does not provide any evidence to support the suggested link between research commercialization and the stated justifications (this is a topic for further research), nor are there, in most cases, identified metrics for measuring successful outcomes for each of the stated justifications.³¹ Also worrisome, from a policymaking perspective, there is no mention of the potential downsides or risks of commercialization. This side of the policy debate is completely absent from national, provincial and institutional science funding policy. Given the evidence of possible risks, this is a troubling absence as one would hope that emerging policy would

29. Alberta Innovates – Health Solutions, “Mandate and Roles Document” (April 2010), online: Alberta Innovates – Health Solutions <<http://www.aihealthsolutions.ca/docs/mandate%20and%20roles.pdf>> at 1.

30. Fonds de recherche du Québec – Santé, “FRQS Mission” (25 November 2004), online: FRQS <http://www.frsq.gouv.qc.ca/en/a_propos/popup/mission_integrale.html>.

31. Rasmussen, *supra* note 28.

explicitly recognize and balance both potential benefits and risks.

III. Brief Highlights of Emerging Evidence on Community Reaction and Impacts on Research Environment

Existing studies from Canada and elsewhere have observed a disconnect between policy and practice with respect to commercialization of publicly funded research. For example, a recent study found that professionals working in Canadian Technology Transfer Offices (TTOs) view their practical role as supporting the social and academic missions of their universities rather than their primary mandate, which is to promote and achieve research commercialization targets.³² Another study found that commercialization activities (chiefly patenting) by members of the Stem Cell Network impact negatively on their collaborative behaviour (specifically, co-authorship), which is, arguably, an incidental outcome of the Network's commercialization-driven research approach and mandate.³³ Similarly, a study of technology commercialization via licensing contracts between US universities and the life sciences industry found evidence of the so-called "anticommons" effect;³⁴ specifically, that exclusive licensing of patented technologies to single firms had a "dampening effect" on "innovation diffusion" by reducing researchers' propensity to publish or collaborate with others.³⁵ The pressure to commercialize has also been linked to secretive behaviour among academic scientists and with creating disincentives to information sharing,³⁶ and with having undesirable

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32. Tania M Bubela & Timothy Caulfield, "Role and Reality: Technology Transfer at Canadian Universities" (2010) 28:9 *Trends in Biotechnology* 447.
 33. Bubela et al, "Commercialization and Collaboration", *supra* note 11.
 34. Michael A Heller & Rebecca S Eisenberg, "Can Patents Deter Innovation? The Anticommons in Biomedical Research" (1998) 280:5364 *Science* 698.
 35. Joshua B Powers & Eric G Campbell, "Technology Commercialization Effects on the Conduct of Research in Higher Education" (2011) 52:3 *Research in Higher Education* 245.
 36. Wei Hong & John P Walsh, "For Money or Glory? Commercialization, Competition, and Secrecy in the Entrepreneurial University" (2009) 50:1 *The Sociological Quarterly* 145.

effects on the quantity and quality of research outputs.³⁷

Regarding community reaction, a number of published studies have shed some light on the views and perspectives of the scientific research community on the push to commercialize research.³⁸ A recent nationwide study of US biotechnology scientists found a “strong positive association” between market-driven views and values and the tendency to pursue applied research programs, and that this association directly affects industry funding, the proprietary nature of research outputs, and the degree of focus on basic research programs.³⁹ Similarly, surveys of Canadian genomics and stem cell researchers reveal that while views regarding commercialization and patenting pressure are sharply divided between supportive and critical, such pressures are correlated with an increased tendency to engage in data withholding practices and publication delays.⁴⁰

A recent informal sampling of the views of members of the Canadian Stem Cell Network regarding commercialization pressure – conducted by our research team for the primary purpose of informing proposed semi-structured interviews – adds some colour to the existing evidence.⁴¹ The Network is one of Canada’s Networks of Centres of Excellence (NCEs), a funding initiative established in 1989 by Canada’s three major research funding agencies (CIHR; the National Sciences and Engineering Research Council, which funds research in the natural sciences and engineering; and the Social Sciences and Humanities Research Council, which funds research in the social sciences and humanities) in collaboration with Health Canada and Industry Canada.⁴² NCEs unite

37. Hottenrott & Thorwarth, *supra* note 14.

38. Glenna et al, *supra* note 14; Caulfield et al, “Patents”, *supra* note 17; Murdoch & Caulfield, *supra* note 17; Joly et al, *supra* note 17; Tartari & Breschi, *supra* note 17.

39. Glenna et al, *supra* note 14.

40. Caulfield et al, “Patents”, *supra* note 17; Murdoch & Caulfield, *supra* note 17.

41. Ubaka Ogbogu, Amir Reshef & Timothy Caulfield, “Under Pressure? Stem Cell Research and the Commercialization Imperative” (Poster presentation delivered at the Canadian Stem Cell Network Till and McCulloch Meetings, Banff Springs Hotel, Banff, 23-25 October 2013) [unpublished].

42. Ogbogu, *supra* note 8; Donald Fisher, Janet Atkinson-Grosjean & Dawn

Canada's leading researchers in a field of common interest, with the aim and mandate to "commercialize and apply ... homegrown research breakthroughs, increase private-sector R&D, and train highly qualified people."⁴³ SCN is one of the program's success stories, and has received over \$82m since it was created in 2001. The Network's primary mandate is to "be a catalyst for enabling translation of stem cell research into clinical applications, commercial products or public policy."⁴⁴

We learned that many in the community are wary of current commercialization trends and are concerned about its effects on the scientific research environment. Specifically, most members reported that they face considerable pressure to commercialize and/or translate their research in the near term and that it would be more difficult to secure research funding without proposing a commercialization and/or translation plan. They identified main sources of pressure to commercialize as including granting agencies, patient/disease advocacy groups, their universities, and the government. Members expressed concern that commercialization trends will adversely affect research funding and opportunities for pursuing basic research, and that public trust in research will be compromised if the promised benefits of commercialization do not materialize in the near term or at all. They felt that commercialization and/or research translation targets were more likely to materialize in the longer rather than short term, and that the most important outcome they expect from their research are scholarly publications. These observations, which we caution are neither representative of the views of this community nor intended to serve as robust evidence of such views, do suggest the possibility that research communities primed for commercialization may hold an unfavourable or unenthusiastic view of their commercialization mandate, and may perceive this mandate to be associated with undesirable

House, "Changes in Academy/Industry/State Relations in Canada: The Creation and Development of the Networks of Centres of Excellence" (2001) 39:3 *Minerva* 299.

43. Networks of Centres of Excellence, "About the Networks of Centres of Excellence" (17 October 2013), online: Networks of Centres of Excellence <http://www.nce-rce.gc.ca/About-APropos/Index_eng.asp>.
44. Networks of Centres of Excellence, "Stem Cell Network – SCN" (4 April 2013), online: Networks of Centres of Excellence <http://www.nce-rce.gc.ca/NetworksCentres-CentresReseaux/NCE-RCE/SCN-RCS_eng.asp>.

social and research-related costs, such as loss of public trust in research and loss of opportunities for research funding and basic research. They also prompt questions about whether scientists' expectations are aligned with policies urging aggressive commercialization of the research.

IV. Conclusion

Our analysis illustrates the degree to which the commercialization imperative has become near universal. There is almost no place within the Canadian research-funding environment that is not touched by the commercialization ethos. And there is, at least within the policy documents themselves, very little substantive justification for this shift. Indeed, its value is presented as axiomatic and universally accepted – which, given the recent protests in Canada by researchers, is clearly not the case. More worrisome, at least from the perspective of transparent policymaking, there is virtually no explicit mention of the potential costs and harms associated with the push to commercialize. Few would argue that there are not benefits to the commercialization of research or with links to industry. But research tells us there are trade-offs, including a loss of public trust, decreased collaborative behaviour and, possibly, the premature implementation of technologies.

Given these downsides, one would hope that there would be explicit reference to evidence regarding the purported social benefits of this trend, but this too, as noted, is missing. Regardless of how one views such ambitious and unsubstantiated promotion of research commercialization, it should prompt serious questions about whether scientists and the scientific research infrastructure can presently deliver the promised benefits, and whether achieving such benefits is justified in light of the possible social costs of the trend. That said, interesting questions remain, including whether this pressure *actually* changes researcher behaviour and the direction of research. Perceptions and fears aside, scientists may simply adapt to the new environment in nimble fashion, and realign their research agendas accordingly.

Table A: Examples of Commercialization Language in Legislation
(continued on next page)

Source	Reference
Canadian Institutes of Health Research Act	“The objective of the CIHR is to excel ... in the creation of new knowledge and its translation into improved health for Canadians, more effective health services and products ... by ... facilitating the commercialization of health research in Canada and promoting economic development through health research in Canada” ⁴⁵
National Research Council Act	“Council may ... undertake, assist or promote scientific and industrial research, including ... researches with the object of improving the technical processes and methods used in the industries of Canada, and of discovering processes and methods that may promote the expansion of existing or the development of new industries” ⁴⁶
Alberta Research and Innovation Act	“The purpose of this Act is to promote and provide for the strategic and effective use of funding and other resources to meet the research and innovation priorities of the Government, including fostering the development and growth of new and existing industries” ⁴⁷
New Brunswick Research and Innovation Council Act	“Council shall advise and make recommendations to the Executive Council on all aspects of research and innovation and on the development and commercialization of technology in order to advance these activities in New Brunswick and to foster ... increased collaboration between government and the business, industry, post secondary education and research communities” ⁴⁸
Innovation Corporation Act (Nova Scotia)	“The objects of the Corporation are to ... mobilize the necessary resources, nationally and internationally, to allow for technological development and commercialization in priority technology areas defined by the Corporation” ⁴⁹

45. *Supra* note 20, s 4.

46. *Supra* note 21, s 5(c).

47. *Supra* note 21, s 2.

48. *Supra* note 21, s 7.

49. *Supra* note 21, s 5(a).

**Economic Innovation
and Technology
Council Act
(Manitoba)**

“The objects of the council are to foster economic development and to support economic restructuring through innovation and the development and commercialization of technology so as to enable Manitoba to compete effectively in a global market economy”⁵⁰

List A: Examples of Commercialization Requirements in Funding Opportunities *(continued on next page)*

- CIHR Open Operating Grant, 2013-2014: Grants are expected to “[c]ontribute to commercialization/ knowledge translation”⁵¹
- Alberta Innovates – Alberta/Pfizer Translational Research Fund Opportunity (June 2013): “The funding opportunity will focus on the development and commercialization of innovations in health that support the interests and priorities of Alberta and Pfizer and serve as a catalyst for innovative research in Alberta”⁵²
- Alberta Innovates – Knowledge-to-Action Grant (2013): “Grant opportunity is intended to support the uptake of research evidence into health policy, practice and commercial development of products”⁵³
- Ontario Research Fund – Early Researcher Awards Program Guidelines (March 2013): Applications must demonstrate “potential for strategic value for Ontario based on ... economic benefits [and] entrepreneurial focus”⁵⁴
- Innovation PEI – Pilot and Discovery Fund Program Guidelines (2013): Proposed project must “[d]evelop a product or service that demonstrates a high level of innovation, commercial viability, and market potential ... [and] [c]reate a positive economic impact for the Province (jobs, economic spin-offs, etc.)”⁵⁵

50. *The Economic Innovation and Technology Council Act*, CCSM c E7, s 3.

51. Canadian Institutes of Health Research, “CIHR Open Operating Grant” (19 June 2013), online: ResearchNet <<https://www.researchnet-recherchenet.ca/rnr16/vwOpprntnyDtls.do?prog=1873&view=search&terms=commercialization&org=CIHR&type=EXACT&resultCount=25>>.

52. Alberta Innovates – Health Solutions, “Alberta/Pfizer Translational Research Fund Opportunity” (June 2013), online: Alberta Innovates – Health Solutions <<http://www.aihealthsolutions.ca/grants/industry-partnered-translational-fund/pfizer/docs/AB-Pfizer-Program-Guide%202013-07.pdf>>.

53. Alberta Innovates – Health Solutions, “AIHS Knowledge-to-Action Grant” (2013), online: Alberta Innovates – Health Solutions <<http://www.aihealthsolutions.ca/rtna/grant.php>>.

54. Ontario Research Fund, “Early Researcher Awards Program Guidelines” (March 2013), online: <<http://docs.files.ontario.ca/documents/275/mediera-round-9-program-guidelines.pdf>>.

55. Innovation PEI, “Pilot and Discovery Fund: Program Guidelines” (2013),

- Ontario Genomics Institute – Pre-Commercialization Business Development Fund (2013): “[U]nique and useful investment fund that is helping to enable the economic impact of outcomes of genomics and proteomics research projects and technology development. Specifically, it aims to provide early-stage funding as researchers move towards commercial applications and to speed up transfer of products from lab to marketplace”⁵⁶
- CIHR Operating Grant – Industry-Partnered Collaborative Research (Fall 2013): Objective of funding opportunity includes to “promote economic development through health research in Canada” and “encourage and facilitate mutually beneficial university-industry collaborations in health research”⁵⁷
- Canadian Foundation for Innovation – 2012 Leading Edge and New Initiatives Funds Competition: “The research or technology development enabled by CFI funding creates the necessary conditions for sustainable, long-term economic growth, including the creation of spin-off ventures and the commercialization of discoveries. It supports improvements to society, quality of life, health, the environment, and public policy”⁵⁸

List B: Examples of Commercialization Language in University Documents *(continued on next page)*

- University of Toronto (2013): “U of T is a leading university in Canada for commercialization and entrepreneurship and is a global leader in turning ideas and innovations into products, services, companies and jobs.”⁵⁹
- University of Alberta (2013): “UAlberta benefits society by transferring research, knowledge and discoveries out of the institution and into the community. One way to ensure UAlberta research solutions have the greatest

online: Innovation PEI <<http://www.gov.pe.ca/photos/original/IPEI-Pilot-Guid.pdf>>.

56. Ontario Genomics Institute, “Pre-commercialization Business Development Fund” (2013), online: Ontario Genomics Institute <<http://www.ontariogenomics.ca/business-development/pre-commercialization-business-development-fund>>.
57. Canadian Institutes of Health Research, “Operating Grant: Industry-Partnered Collaborative Research” (Fall 2013), online: ResearchNet <<https://www.research-net-recherchenet.ca/rnr16/vwOpprtntyDtIsdo?prog=1871&view=search&terms=commercialization&org=CIHR&type=EXACT&resultCount=25>>.
58. Canada Foundation for Innovation, “2012 Leading Edge and New Initiatives Funds Competition” (September 2011), online: Canada Foundation for Innovation <http://www.innovation.ca/sites/default/files/Funds/Call-LEFNIF2012_EN.pdf>.
59. University of Toronto Research and Innovation, “Commercialization at U of T” (2013), online: University of Toronto <<http://www.research.utoronto.ca/industry-and-partners/commercialization-at-u-of-t/#top>>.

reach and impact on both society and the economy is commercialization.”⁶⁰

- University of Alberta (2013): “The University actively transfers new knowledge and creative works to Alberta, Canada and the world for community benefit, including commercial development of intellectual property when appropriate and feasible”⁶¹
- University of British Columbia: “For transformational research discoveries with the potential to generate significant impacts, whether financial, economic, or societal, the traditional technology transfer approach of IP-protection, development and commercialization will frequently remain essential.”⁶²
- McGill University (2013): “The commercialization of research outcomes is an important objective not just of researchers, but of most public and private funding programs as well. It can also be very rewarding, with potential impact on society, the economy and the environment at large”⁶³
- University of Saskatchewan (2011): “We want to ensure that the relationships created through the commercialization of a technology continue to add value for all partners; leading to ongoing research projects for the inventor and the industry partner and to the commercialization of complementary technologies”⁶⁴
- Queen’s University (2013): “The role of Innovation Park is to foster interaction among the participants in the research and innovation system and thus stimulate commercialization and economic development in the South Eastern Ontario region.”⁶⁵
- University of Calgary (1994): “The nature and scope of University scholarly activity is such that industrially useful and/or commercially valuable

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60. University of Alberta Research, “Commercialization” (2013), online: University of Alberta <<http://www.research.ualberta.ca/MobilizingKnowledge/Commercialization.aspx>>.
61. University of Alberta Board of Governors, “Mandate and Roles Document” (2013), online: University of Alberta <http://www.governance.ualberta.ca/-/media/Governance/Documents/GO09/MAN/Mandates_and_Roles-_Approved_October_2011.pdf>.
62. University of British Columbia University-Industry Liaison Office, “Technology Transfer/Commercialization”, online: University of British Columbia <<http://www.uilo.ubc.ca/uilo/knowledge-mobilization/channels/commercialization>>.
63. McGill Research and International Relations, “Managing Your Intellectual Property” (2013), online: McGill <<http://www.mcgill.ca/research/researchers/ip>>.
64. University of Saskatchewan, “Industry Liaison – Who Are We?” (2013), online: University of Saskatchewan <<http://www.usask.ca/research/ilo/whoware.php>>.
65. Queen’s University, “Innovation Park – Who We Are”, online: Queen’s University <<http://www.innovationpark.com/content/who-we-are>>.

Intellectual Property is sometimes the result. Indeed, there is a societal expectation that University scholarly activities will include activities which, applied, lead to useful outcomes.”⁶⁶

Table B: Examples of Commercialization Language in Political/Institutional Commentary (*continued on next two pages*)

Source	Reference
National Research Council (2013)	“We are committed to being a strong partner for innovation, and focused on achieving the concrete outcomes that will contribute to a stronger and more prosperous Canada. We will measure our success by the success of our clients.” ⁶⁷
Minister of State Gary Goodyear (Industry Canada 2013)	“Capitalizing on the momentum generated by ... investments [in research], we will continue to improve commercialization performance by transforming research outcomes into economic benefits for Canadians” ⁶⁸
Canadian Institutes of Health Research (2009)	“Through its commercialization and innovation strategy, CIHR will continue to catalyze collaborations between industry and the research community to translate health research into improved health products, technologies, tools and services” ⁶⁹
Networks of Centres of Excellence (2011)	“The goal of the NCE Program is to mobilize Canada’s research talent in the academic, private, public, and not-for-profit sectors and apply it to the task of developing the economy and improving the quality of life of Canadians.” ⁷⁰

66. University of Calgary, “Intellectual Property Policy” (2014), online: University of Calgary <<http://www.ucalgary.ca/policies/files/policies/Intellectual%20Property%20Policy.pdf>>.

67. National Research Council Canada, *supra* note 18.

68. Industry Canada, News Release, “Minister of State Goodyear Promotes Commercialization of Canadian Research at International Forum” (19 March 2013) online: Government of Canada <<http://news.gc.ca/web/article-en.do?nid=727519>>.

69. Canadian Institutes of Health Research, “Health Research Roadmap: Creating Innovative Research for Better Health and Health Care”, online: Canadian Institutes of Health Research <<http://www.cihr-irsc.gc.ca/e/40490.html>>.

70. Networks of Centres of Excellence of Canada, “Program Guide” (2011),

Centres of Excellence for Commercialization and Research Program (2013)	“The innovative ... program bridges the challenging gap between innovation and commercialization. The program matches clusters of research expertise with the business community to share the knowledge and resources that bring innovations to market faster.” ⁷¹
Centre for Commercialization of Regenerative Medicine (2011)	“CCRM represents a tremendous opportunity for Canadians to lead RM commercialization ... CCRM engages industry partners, making CCRM a global hub of RM commercialization and attracting investment to Ontario, leading to new jobs and economic growth.” ⁷²
Government of Canada (2007); 2009	“Canada must translate knowledge into commercial applications that generate wealth for Canadians and support the quality of life we all want in order to create an Entrepreneurial Advantage.” ⁷³ <i>“Canada’s ability to gain a competitive advantage in the modern economy increasingly depends on our ability to translate knowledge and ideas into commercial products.”</i> ⁷⁴
Innovate Nova Scotia (2009)	“The Innovate Nova Scotia policy framework has been developed to stimulate awareness of and discussion on the importance of maximizing the impact of innovation to enhance economic growth and employment in this province.” ⁷⁵

online: Networks of Centres of Excellence <http://www.nce-rce.gc.ca/ReportsPublications-RapportsPublications/NCE-RCE/ProgramGuide-GuideProgramme_eng.asp>.

71. Networks of Centres of Excellence of Canada, “Centres of Excellence for Commercialization and Research Program” (2013), online: Networks of Centres of Excellence <http://www.nce-rce.gc.ca/Programs-Programmes/CECR-CECR/Index_eng.asp>.
72. Centre for Commercialization of Regenerative Medicine, “Mission” (2011), online: CCRM <<http://ccrm.ca/mission>>.
73. Industry Canada, “Mobilizing Science and Technology to Canada’s Advantage” (2007), online: Industry Canada <<http://www.ic.gc.ca/eic/site/icgc.nsf/eng/00871.html>>.
74. Industry Canada, “Mobilizing Science and Technology to Canada’s Advantage: Progress Report” (2009) online: Industry Canada <[http://www.ic.gc.ca/eic/site/icgc.nsf/vwapj/STProgressReport2009.pdf/\\$file/STProgressReport2009.pdf](http://www.ic.gc.ca/eic/site/icgc.nsf/vwapj/STProgressReport2009.pdf/$file/STProgressReport2009.pdf)> at 13 [emphasis added].
75. Nova Scotia Economic Development, “Innovate Nova Scotia: An Innovation Policy for the Nova Scotia Economy”, online: Nova Scotia <<http://www.novascotia.ca/econ/innovativenovascotia/docs/>>

Genome Canada (2013)	“Genome Canada is a catalyst for developing and applying genomic sciences that create economic wealth and social benefit for Canadians. We work in partnership to invest in and manage large-scale research and translate discoveries into commercial opportunities.” ⁷⁶
British Columbia Research and Innovation Strategy	“Research and innovation creates and activates the knowledge that British Columbia needs to compete in the global economy. It leads to new, exciting products and processes that help British Columbia prosper and raise our standard of living. It fosters social and economic development, creates jobs and supports our efforts to address climate change and clean energy.” ⁷⁷
MaRS Innovation “How We Work” <i>Vision and Mission</i>	“MaRS Innovation collaborates with its 16 Toronto-based member institutions ... to commercialize market-disruptive intellectual property ... Our mandate includes seeking opportunities to increase the social, health and economic benefits of our activities to Canadians and others around the world.” ⁷⁸ <i>“To monetize the research assets found within its member institutions, thereby converting great science into commercially viable products and services”⁷⁹</i>

InnovativeNovaScotia.pdf>.

76. Genome Canada, “About Genome Canada”, online: Genome Canada <<http://www.genomecanada.ca/en/about/>>.
77. British Columbia Ministry of Advanced Education and Ministry Responsible for Research and Technology, “Local Excellence – Global Impact: BC Research and Innovation Strategy”, online: Ministry of Advanced Education <<http://www.aved.gov.bc.ca/researchandinnovation/Documents/strategy.pdf>>.
78. MaRS Innovation, “How We Work”, online: MaRS <<http://marsinnovation.com/how-we-work/>>.
79. MaRS Innovation, “Vision and Mission”, online: MaRS <<http://marsinnovation.com/about/vision/>> [emphasis added].

Medical Tourism, Access to Health Care, and Global Justice

I Glenn Cohen*

Medical tourism – the travel of patients from one (the “home”) country to another (the “destination”) country for medical treatment – represents a growing business. A number of authors have raised the concern that medical tourism reduces access to health care for the destination country’s poor and suggested that home country governments or international bodies have obligations to curb medical tourism or mitigate its negative effects when they occur.

This article is the first to comprehensively examine both the question of whether this negative effect on access to health care occurs for the destination country’s poor, and the normative question of the home country and international bodies’ obligations if it does occur. I draw on the work of leading theorists from the Statist, Cosmopolitan, and Intermediate camps on Global Justice and apply it to medical tourism. I also show how the application of these theories to medical tourism highlights areas in which these theories are underspecified and suggests diverging paths for filling in lacunae. Finally, I discuss the kinds of home country, destination country, and multilateral forms of regulation this analysis would support and reject.

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I. Preface

When the editors of the *Canadian Journal of Comparative and Contemporary Law* approached me about republishing my article *Medical Tourism, Access to Health Care, and Global Justice* to share with a Canadian audience, I welcomed the opportunity to add this short preface that would allow me to focus on developments since I published the original text.

Turner, and Mark Wu for comments on earlier drafts. For their comments, I also thank participants at the Harvard Law School/Program on Ethics and Health Population-Level Bioethics Reading Group on January 6, 2011, the International Conference on Ethical Issues in Medical Tourism at Simon Fraser University on June 25, 2010, and at the Health Law Scholars Workshop of the American Society for Law, Medicine & Ethics and the St. Louis University School of Law Center for Health Law Studies on September 12, 2009. Excellent research assistance was provided by Russell Kornblith, Katherine Kraschel, and Teel Lidow. Originally published in the *Virginia Journal of International Law*: Glenn Cohen, "Medical Tourism, Access to Health Care, and Global Justice" (2011) 52:1 *Va J Int'l L* 1. Reproduced with permission. Copyright © 2011 Virginia Journal of International Law Association; I Glenn Cohen.

The first development is conceptual, and relates to dialogue about my work led by excellent colleagues in Canada. I will focus on three.

First, in their thoughtful paper in the *Journal of Law, Medicine, and Ethics*, commenting on my own prior work on this subject, YY Brandon Chen and Colleen Flood (of the University of Toronto) suggest that in this paper, I have been wrong in the questions that I focus on:

[W]e argue that there is an *a priori* bias embedded in how Cohen (and other commentators) has framed the problématique of medical tourism ... [In Cohen and other commentators' writing,] the burden appears to rest on opponents of medical tourism to prove its negative consequences on LMICs' [low- and middle-income countries'] health care access before regulatory actions may be considered. In contrast, we argue in this paper that the evidentiary burden should be reversed. We contend that even when access to health care in LMICs is not adversely affected by medical tourism, there are still equity-related concerns that in and of themselves render medical tourism normatively problematic. As we discuss further below, this inequity can (and often does) arise, for example, when access to primary and preventive health services for the general LMIC populations maintains the inadequate *status quo* while medical tourists from well-resourced developed countries are afforded cutting-edge secondary and tertiary care. If equity is considered a relevant goal for health care systems and one accepts our conclusion that medical tourism in LMICs will likely have deleterious equity impacts, then the burden should be borne by medical tourism's proponents to demonstrate its benefits on health care access and to justify why some degree of government regulation is inappropriate.¹

Though I am not sure I completely agree with their read of my work, Flood and Chen usefully press me to be clearer that there are three distinct versions of the empirical question that will tie into various potential approaches to global justice: (1) Are there disparities in access to health care for the general population between destination countries in the developing world and home countries in the developed world (call this the *equity* question)?; (2) Do we have evidence that medical tourism causes deficits or worsens inequities, or, at the very least, is it associated with deficits or worsening inequities in access by home country citizens to health care (call this the *causation* question)?; (3) Irrespective of what

1. YY Brandon Chen & Colleen M Flood, "Medical Tourism's Impact on Health Care Equity and Access in Low-and Middle-Income Countries: Making the Case for Regulation" (2013) 41:1 *JL Med & Ethics* 286 at 287-88.

caused the deficits, would regulation of medical tourism reduce these deficits or inequities (call this the *redressability* question)?

Chen and Flood assert that “even when access to health care in LMICs is not adversely affected by medical tourism, there are still equity-related concerns that in and of themselves render medical tourism normatively problematic,”² suggesting a focus on only the equity question. But later, they say: “[i]f equity is considered a relevant goal for health care systems and one accepts our conclusion that medical tourism in LMICs *will likely have deleterious equity impacts*.”³ Those last words suggest that the causation question, or at least the redressability question, is what matters to them after all.

In any event, Chen and Flood helpfully press me to say what I think the empirical evidence, they and others have produced, can and cannot do. The *equity* question, as such, is *not* my concern in this article or my larger project. The empirical answer to that question is easy: it is beyond cavil that there are deep disparities in health care access between developed and developing countries, as there are to accessing many good things that make a life go well. For those whom the existence of such disparity, whatever its cause and whether or not regulating medical tourism will ameliorate matters, is enough to motivate an obligation to render aid, empirical evidence is largely beside the point.

By contrast, I am interested in the *causation* question. To the extent medical tourism causes (or at least is associated with) these diminutions in health care access and thus worsens inequities, then it is easier to build a moral case for intervention.⁴ And, even if medical tourism does not

2. Chen & Flood, *ibid* at 287.

3. *Ibid* at 288 [emphasis added].

4. What if medical tourism did not worsen the health care for the destination country poor, or in fact improved it, but also increased disparities since the wealthy benefitted even more? That is, both the worse and best off are made better off, but not equivalently. For true pure egalitarians, who believe inequality is bad, that would be a problem, but of course that view has some well-accepted problems relating to leveling down. For prioritarians, the pertinent question is whether the worse-off are made better off, and whether they are made as better-off as they might be compared to other feasible regulatory re-arrangements. I am more drawn to the latter view, and so I focus on whether medical tourism “causes deficits” or “fails to improve” the health care of the destination

cause the negative effects, for some theories of global justice, it may still be important that regulations of the industry can *redress* health inequities. Thus, in this article, I review empirical data suggesting that medical tourism causes (or is at least associated with) diminutions in health care access, as well as data suggesting regulation of the sector might ameliorate health inequities. I do not focus on the existence of general health inequities that are unconnected to medical tourism.

The second development is just to note that there has been additional empirical evidence offered about some of the negative effects of medical tourism.⁵ I discuss some of this new evidence in greater depth in my new book *Patients With Passports: Medical Tourism, Law, and Ethics*.⁶ That said, as I suggest in my article, the evidence is still patchy and any assessment can only be made country-by-country and indeed practice-by-practice.

The third thing I want to add is to emphasize some aspects of the Canadian context in the analysis. In Canada we have two separate potential pools of medical tourists – those who are traveling out of country with the support of the Canadian health care system, and those paying out-of-pocket to go. The latter group is well covered in the original article. The former group is worth further attention. In accord with the *Canada Health Act*,⁷ each of the Canadian provincial and territorial health care

country poor, not on whether it worsens inequality per se. For those who are more attracted to purer egalitarian views, much of what I say in this chapter can be re-analyzed under that standard.

5. See Chen & Flood, *supra* note 1; Matthias Helble, “The Movements of Patients Across Borders: Challenges and Opportunities for Public Health” (2011) 89:1 *Bulletin of the World Health Organization* 68, online: World Health Organization <<http://www.who.int/bulletin/volumes/89/1/10-076612/en/>>; Jeremy Snyder et al, “Caring for Non-Residents in Barbados: Examining the Implications of Inbound Transnational Medical Care for Public and Private Health Care” in David Boterrill, Guido Pennings & Tomas Mainil, eds, *Medical Tourism and Transnational Health Care* (Hampshire: Palgrave Macmillan, 2013) 48 at 51; Jeremy Snyder et al, “Beyond Sun, Sand, and Stitches: Assigning Responsibility for the Harms of Medical Tourism” (2013) 27:5 *Bioethics* 233 at 234; Zahra Meghani, “A Robust, Particularist Ethical Assessment of Medical Tourism” (2011) 11:1 *Developing World Bioethics* 16 at 28.
6. I Glenn Cohen, *Patients With Passports: Medical Tourism, Law, and Ethics* (New York: Oxford University Press, 2014).
7. RSC 1985, c C-6.

plans must reimburse for out-of-country care in emergency situations.⁸ Strictly speaking, this is not medical tourism as I defined it, but medical care coincident with tourism or other travel. However, the Canadian provinces *also* all fund patients who travel abroad for health care and are *sent* there by the provincial health plans.

As Runnels and Packer note:

Depending on the patient's specific situation and the province/territory, some or all of the costs of OOCC will be covered under provincial/territorial health insurance plans, determined by a process designed to ascertain that the patient meets the conditions for OOCC. These criteria for eligibility are generally similar in all provinces and territories, and are as follows:

- the treatment or care must be medically required;
- the medical or hospital service must be demonstrated to be unavailable in the province/territory and/or elsewhere in Canada; that is, "if all Canadian medical resources have been exhausted";
- the delay in the provision of medical care available in the province/territory or elsewhere in Canada must be considered to be immediately life threatening or may result in medically significant irreversible tissue damage;
- the treatment must fall under insured medical, oral surgeries and/or hospital services; and,
- the applicant must be a resident of the province/territory.⁹

There are also some variations between the provinces, for example, Manitoba will cover some transportation costs while most of the other

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8. See Vivien Runnels & Corinne Packer, "Travelling for Healthcare from Canada: An Overview of Out-of-Country Care Funded by Provincial/Territorial Health Insurance Plans" in Ronald Labonté et al, eds, *Travelling Well: Essays in Medical Tourism* (2013) 4:1 Transdisciplinary Studies in Population Health Series 133 at 135-37, online: University of Ottawa <<https://www.ruor.uottawa.ca/bitstream/10393/23788/1/Travelling%20Well-%20Essays%20in%20MedicalTourism.pdf>>; Canadian Institute for Health Information, *Have Health Card, Will Travel: Out-of-Province/-Territory Patients* (Canada: CIHI, 2010) online: Analysis in Brief <https://secure.cihi.ca/free_products/out_of_province_aib_201003_e.pdf>.
 9. Runnels & Packer, *ibid* at 136-37, citing Manitoba Health, *Out-of-Province Medical Referrals*, online: Province of Manitoba <<http://www.gov.mb.ca/health/mhsip/oop.html>>; British Columbia Medical Services Commission, *Out of Province and Out of Country Medical Care Guidelines* (Canada: Medical Services Commission, 2011) online: Government of British Columbia <http://www.health.gov.bc.ca/msp/infoben/ooc_funding_guidelines.pdf>.

provinces do not.¹⁰ Each of the provinces has a process for review of requests, approval or disapproval, and ultimately appeal. To take the example of Ontario:

[A] family physician (general practitioner) must take the first steps towards determining need with the patient. The family physician initiates the request for approval, and is required to refer a patient to a specialist physician or an assessment centre within Ontario for assessment. Only after the specialist physician has seen the patient and judged that the care needed cannot be obtained within the province does the specialist write an application for funding for out-of-country health services to the provincial health authority. The referring physician and a specialist must both complete and sign the application form, along with the patient or his/her representative who has power of attorney. The form must be accompanied by relevant documentation, such as clinical reports and lab test results ...

Information must be provided on the case and explanations given as to why OOCC is needed. The Ministry of Health reviews the application, and must approve it before treatment is obtained abroad, otherwise costs will not be reimbursed. In other words, not only must eligibility be established, but a patient must be pre-approved for OOCC by the provincial ministry of health if the costs of the healthcare are to be borne by the province. This process adds to the waiting time as the patient waits to be seen by a specialist who may refer the patient to yet another specialist within the province who is either able to offer the treatment or surgery or will recommend OOCC.

Health services and treatments which have been approved by out-of-country prior approval programs in different provinces and territories have included cancer treatment, diagnostic testing, high-risk bariatric surgery, residential treatment (such as for psychiatric disorders, eating disorders or substance abuse), neurosurgery, spinal surgery, and pregnancy complications.¹¹

When an application is denied, the patient may appeal that denial directly to the Ministry or to the province's Health Services Appeal and Review Board, a quasi-independent tribunal that holds public hearings as part of its adjudication.¹²

While this form of reimbursed medical tourism was not designed specifically to deal with waiting lists in Canadian provinces, it has been used for that purpose.¹³

10. Runnels & Packer, *ibid.*

11. *Ibid* at 138.

12. Runnels & Packer, *supra* note 8 at 139.

13. *Ibid* at 140.

These facts are relevant for my analysis, as I argue below that home countries have particularly strong moral obligations for government-prompted medical tourism. Especially where, as it appears, Canada does not merely passively support its citizens going abroad through reimbursing their care, but may also *cause* their need to go abroad in the first place based on funding decisions relating to health care availability domestically, its duties may be higher. These duties may entail sending Canadian patients only to foreign facilities that have taken steps to mitigate and/or ameliorate the negative impacts of medical tourism on health care for their domestic poor, paying subsidies to the local communities whose interests they may be stymieing.

II. Introduction

Medical tourism – the travel of patients who are residents of one country (the “home country”) to another country for medical treatment (the “destination country”) – represents a growing and important business. For example, by one estimate, in 2004, more than 150,000 foreigners sought medical treatment in India, a number that is projected to increase by fifteen percent annually for the next several years.¹⁴ Malaysia saw 130,000 foreign patients in the same year.¹⁵ In 2005, Bumrungrad International Hospital in Bangkok, Thailand, alone saw 400,000 foreign patients, 55,000 of whom were American (although these numbers are contested).¹⁶ By offering surgeries such as hip and heart valve replacements at savings of more than eighty percent from that which one would pay out-of-pocket in the United States, medical tourism has enabled underinsured and uninsured Americans to secure otherwise unaffordable health care.¹⁷ The title of a recent Senate hearing – “The

14. Glenn Cohen, “Protecting Patients with Passports: Medical Tourism and the Patient-Protective Argument” (2010) 95:5 Iowa L Rev 1467 at 1472 [Cohen, “Protecting Patients”].

15. *Ibid.*

16. *Ibid.*

17. See *e.g. ibid* at 1476-88, citing Arnold Milstein & Mark Smith, “Will the Surgical World Become Flat?” (2007) 26:1 Health Affairs 137 at 137, 139-40; US, *The Globalization of Health Care: Can Medical Tourism Reduce Health Care Costs?: Hearing Before the Special Committee on Aging*,

Globalization of Health Care: Can Medical Tourism Reduce Health Care Costs?” – captures the promise of medical tourism.¹⁸ US insurers and self-insured businesses have also made attempts to build medical tourism into health insurance plans offered in the United States, and states like West Virginia have considered incentivizing their public employees to use medical tourism.¹⁹ There have even been calls for Medicaid and Medicare to incentivize medical tourism for their covered populations.²⁰

Although hardly new, in recent years, the dramatic increase in the scope of the industry and the increasing involvement of US citizens as medical tourists to developing countries have made pressing a number of legal and ethical issues.²¹ While the growth of medical tourism has

109th Cong (Washington, DC: United States Government Printing Office, 2006) at 18 (Dr Arnold Milstein), online: US Government Information <<http://www.gpo.gov/fdsys/pkg/CHRG-109shrg30618/pdf/CHRG-109shrg30618.pdf>> [*The Globalization of Health Care*]; Devon M Herrick, “Medical Tourism: Global Competition in Health Care” (2007) NCPA Pol’y Rep 304 (November 2007) at 11 table 1, online: National Center for Policy Analysis <<http://www.ncpa.org/pdfs/st304.pdf>>, relying on data from Unmesh Kher, “Outsourcing Your Heart”, *Time* (21 May 2006) 44.

18. *The Globalization of Health Care*, *ibid* at 1.
19. See Cohen, “Protecting Patients”, *supra* note 14 at 1473, citing US, HB 4359, 77th Leg, 2d Spec Sess, W Va, 2006; Joe Cochrane, “Medical Meccas”, *Newsweek* (30 October 2006) 1; Mark Roth, “Surgery Abroad an Option for Those with Minimal Health Coverage”, *Post Gazette* (10 September 2006) online: Post Gazette <<http://www.post-gazette.com/life/travel/2006/09/10/Surgery-abroad-an-option-for-those-with-minimal-health-coverage/stories/200609100214>>.
20. See Cohen, “Protecting Patients”, *ibid* at 1473-74; Dean Baker & Hye Jin Rho, “Free Trade in Health Care: The Gains from Globalized Medicare and Medicaid” (2009) online: Center for Economic Policy and Research <<http://www.cepr.net/documents/publications/free-trade-hc-2009-09.pdf>>.
21. In some senses, medical tourism is a very old phenomenon. Ancient Greeks traveled to spas known as asklepiea in the Mediterranean for purification and spiritual healing, and for over two thousand years, foreign patients have traveled to the Aquae Sulis reservoir built by the Romans in what is now the British town of Bath. See Kerrie S Howze, “Note, Medical Tourism: Symptom or Cure?” (2007) 41:3 Ga L Rev 1013 at 1015-16; Anne Cearley & Penni Crabtree, “Alternative-Medicine Clinics in Baja Have History of Controversy”, *San Diego Union Tribune* (1 February 2006) A8. Moreover, in the United States, our most outstanding

represented a boon (although not an unqualified one)²² for US patients, what about the interests of those in the destination countries? From their perspective, medical tourism presents a host of cruel ironies. Vast medico-industrial complexes, replete with the newest expensive technologies to provide comparatively wealthy medical tourists hip replacements and facelifts, coexist with large swaths of the population dying from malaria, AIDS, and lack of basic sanitation and clean water. A recent New York Times article entitled “Royal Care for Some of India’s Patients, Neglect for Others,” for example, begins by describing the care given at Wockhardt Hospital in India to “Mr. Steeles, 60, a car dealer from Daphne, Ala., [who] had flown halfway around the world last month to save his heart [through a mitral valve repair] at a price he could pay.”²³ The article describes in great detail the dietician who selects Mr. Steeles’ meals, the dermatologist who comes as soon as he mentions an itch, and Mr. Steeles’ “Royal Suite” with “cable TV, a computer, [and] a mini-refrigerator, where an attendant that afternoon stashed some ice cream, for when he felt hungry later.”²⁴ This treatment contrasts with the care given to a group of “day laborers who laid bricks and mixed cement for Bangalore’s construction boom,” many of whom “fell ill after drinking illegally brewed whisky; 150 died that day.”²⁵ “Not for them [was] the care of India’s best private hospitals,” writes the article’s author; “[t]hey had been wheeled in by wives and brothers to the overstretched government-

facilities like the Mayo Clinic have long attracted medical tourists, and Middle Eastern patients, for example, have also sought care in other developed-world medical hubs, such as London.

22. As I have discussed elsewhere, medical tourism presents concerns regarding disparities in quality of care and medical malpractice recovery. See generally Cohen, “Protecting Patients”, *supra* note 14 (reviewing the risks of malpractice and care quality created by medical tourism and proposing regulations to protect patients). It is also uncertain whether the recently enacted health care reform, if fully implemented, will blunt some of the motivation to go abroad of US medical tourists currently paying out of pocket (since more will be insured), as well as whether it will result in more insurer-prompted medical tourism. See Howze, *ibid* at 1525-26, 1542-43.
23. Somini Sengupta, “Royal Care for Some of India’s Patients, Neglect for Others”, *New York Times* (1 June 2008) K3.
24. *Ibid.*
25. *Ibid.*

run Bowring Hospital, on the other side of town,” a hospital with “no intensive care unit, no ventilators, no dialysis machine,” where “[d]inner was a stack of white bread, on which a healthy cockroach crawled.”²⁶

These kinds of stark disparities have prompted intuitive discomfort and critiques in the academic and policy literatures. For example, David Benavides, a Senior Economic Affairs Officer working on trade for the United Nations, has noted that developed and developing countries’ attempts at exporting health services sometimes come “at the expense of the national health system, and the local population has suffered instead of benefiting from those exports.”²⁷ Rupa Chanda, an Indian professor of business, writes in the World Health Organization Bulletin that medical tourism threatens to “result in a dual market structure, by creating a higher-quality, expensive segment that caters to wealthy nationals and foreigners, and a much lower-quality, resource-constrained segment catering to the poor.”²⁸ While the “[a]vailability of services, including physicians and other trained personnel, as well as the availability of beds may rise in the higher-standard centres,” it may come “at the expense of the public sector, resulting in a crowding out of the local population.”²⁹ Similarly, Professor Leigh Turner suggests that “the greatest risk for inhabitants of destination countries is that increased volume

26. *Ibid.*

27. David Diaz Benavides, “Trade Policies and Export of Health Services: A Development Perspective” in Nick Drager & Cesar Vieira, eds, *Trade in Health Services: Global, Regional, and Country Perspectives* (Washington, DC: Pan American Health Organization Program on Public Policy and Health, 2002) 35 at 39, online: World Health Organization <<http://www.who.int/trade/resource/THS/en/>>.

28. Rupa Chanda, “Trade in Health Services” in Nick Drager & Cesar Vieira, eds, *Trade in Health Services: Global, Regional, and Country Perspectives* (Washington, DC: Pan American Health Organization Program on Public Policy and Health, 2002) 158 at 160, online: World Health Organization <<http://www.who.int/trade/resource/THS/en/>>.

29. *Ibid.*; see also Milica Z Bookman & Karla K Bookman, *Medical Tourism in Developing Countries* (New York: Palgrave MacMillan, 2007) (“[m]edical Tourism can thus create a dual market structure in which one segment is of higher quality and caters to the wealthy foreigners (and local high-income patients) while a lower quality segment caters to the poor ... [such that] health for the local population is crowded out as the best doctors, machines, beds, and hospitals are lured away from the local poor” at 176).

of international patients will have adverse effects upon local patients, health care facilities and economies.”³⁰ He explains that the kinds of investments destination-country governments must make to compete are in “specialized medical centres and advanced biotechnologies” unlikely to be accessed by “most citizens of a country [who] lack access to basic health care and social services.”³¹ Furthermore, higher wages for health care professionals resulting from medical tourism may crowd out access by the domestic poor.³² Thus, “[i]nstead of contributing to broad social and economic development, the provision of care to patients from other countries might exacerbate existing inequalities and further polarize the richest and poorest members” of the destination country.³³

The same point has also been made in several regional discussions: Janjaroen and Supakankunti argue that in Thailand, medical tourism threatens to both disrupt the ratio of health personnel to the domestic population and “create a two-tier system with the better quality services reserved for foreign clients with a higher ability to pay.”³⁴ Similarly, the Bookmans claim that in Cuba, “only one-fourth of the beds in CIREN (the International Center for Neurological Restoration in Havana) are filled by Cubans, and ... so-called dollar pharmacies provide a broader range of medicines to Westerners who pay in foreign currency.”³⁵ They describe a medical system so distorted by the effects of medical tourism as “medical apartheid, because it makes health care available to foreigners that is not available to locals.”³⁶ Numerous authors have made similar

30. Leigh Turner, “First World Health Care at Third World Prices’: Globalization, Bioethics and Medical Tourism” (2007) 2 *Biosocieties* 303 at 320.

31. *Ibid.*

32. *Ibid.*

33. *Ibid.* at 321.

34. Watatana S Janjaroen & Siripen Supakankunti, “International Trade in Health Services in the Millennium: The Case of Thailand” in Nick Drager & Cesar Vieira, eds, *Trade in Health Services: Global, Regional, and Country Perspectives* (Washington, DC: Pan American Health Organization Program on Public Policy and Health, 2002) 87 at 98, online: World Health Organization <<http://www.who.int/trade/resource/THS/en/>>.

35. Bookman & Bookman, *supra* note 29 at 177.

36. *Ibid.*

claims about medical tourism in India.³⁷ Similar concerns have even been raised as to medical tourism in developed countries. For example, an investigation by the Israeli newspaper Haaretz concluded, “medical tourists enjoy conditions Israelis can only dream of, including very short waiting times for procedures, the right to choose their own doctor and private rooms ... [a]nd these benefits may well be coming at the expense of Israeli patients’ care.” The investigation also suggested that allowing medical tourists to move to the front of the line on waiting lists for services meant that “waiting times for ordinary Israelis will inevitably lengthen – especially in the departments most frequented by medical tourists, which include the cancer, cardiac and in vitro fertilization units.”³⁸

Behind all of these claims – scholarly and popular – are some significant and interesting fundamental questions. How likely is medical tourism to produce negative consequences on health care access in Less Developed Countries?³⁹ If those effects occur, does the United States (or other Western countries or international bodies) have an obligation to discourage or regulate medical tourism to try to prevent such

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37. See *e.g.* Ami Sen Gupta, “Medical Tourism in India: Winners and Losers” (2008) 5:1 *Indian Journal of Medical Ethics* 4-5; Laura Hopkins et al, “Medical Tourism Today: What is the State of Existing Knowledge?” (2010) 31:2 *Journal of Public Health Policy* 185 at 194; Rory Johnston et al, “What is Known About the Effects of Medical Tourism in Destination and Departure Countries? A Scoping Review” (2010) 9:24 *International Journal for Equity in Health* 1.
38. Dan Even & Maya Zinshtein, “Haaretz Probe: Israel Gives Medical Tourists Perks Denied to Citizens”, *Haaretz* (18 November 2010) online: Haaretz.com <<http://www.haaretz.com/print-edition/news/haaretz-probe-israel-gives-medical-tourists-perks-denied-to-citizens-1.325275>>.
39. Of course, as a growing literature emphasizes, it is a mistake to fetishize health care in normative analysis instead of health, which may depend more on sanitation, housing, and social determinants than on medical services. See Norman Daniels, *Just Health* (New York: Cambridge University Press, 2008) at 79-102; Michael Marmot et al, “Contributions of Psychosocial Factors to Socioeconomic Differences in Health” (1998) 76:3 *Milbank Quarterly* 403 at 434. Although conscious of this issue, I will for the most part focus on health care access because this is the main margin in which medical tourism has been predicted to have negative effects, while acknowledging that it is the negative effects on health stemming from these diminutions in health care access that motivate the concern.

consequences? How might governments do so?

I examine those questions in this article, the first in-depth treatment focusing on the normative question of home countries' obligations.⁴⁰ In so doing, I draw on international development work on health systems and globalization, political philosophy work on international justice, and a more embryonic applied literature on the normative aspects of drug access and pricing in the developing world. While my focus is on medical tourism, this article also aims to further flesh out the intersection of health inequalities, trade, and Global Justice obligations.

I hope the analysis developed here will serve as a template for discussion of similar problems in the globalization of health care, including medical migration (that is, "brain drain"). Indeed, I see this work as a dialogue between the theory and its application. On the one hand, political theories on Global Justice can help us better understand our obligations regarding medical tourism. On the other hand, while our intuitions might suggest that some of these theories lead to predictable positions on medical tourism, their actual application to the case of medical tourism yields surprising results and unforeseen complexities, highlights areas in which the theories are underspecified, and suggests diverging paths for filling in *lacunae*. Thus, these theories of Global Justice cannot only teach us something about the concrete case of medical tourism, but medical tourism can also teach us something about these theories as applied to globalization.

More specifically, I begin in Part III by describing and distinguishing medical tourism by individuals purchasing care out-of-pocket from those whose use is prompted by insurers and governments. I then distinguish concerns about medical tourism's effect on health care access in the destination country – the focus of this article – from other concerns with

40. My focus in this article is on the obligations of home country governments and international bodies. Some of what I say may have implications for the obligations of two other groups: individual tourist patients and corporations involved in (or who incentive their covered populations to use) medical tourism, and I noted the instances where I see that relevance (*e.g.* in Nussbaum and Daniels' work). Translating ideas from political philosophy into the realms of moral philosophy or corporate social responsibility, however, is no easy task, and I make no pretension of fully doing so here.

medical tourism that I and others have discussed elsewhere. I unpack this concern as encompassing an empirical claim and a normative claim, which I examine in turn.

I begin with the empirical claim in Part IV, where I show that despite the expressions of concern of several prominent scholars and policymakers, there currently exists little empirical evidence that suggests medical tourism has adverse effects on health care access in destination countries. Nevertheless, both as a grounding for what follows and as an attempt to help formulate an empirical research project, I discuss six possible triggering conditions through which we would expect medical tourism to reduce access for the poor in destination countries.

In Part V, the heart of the paper, I turn to the normative claim and ask: assuming *arguendo* that medical tourism reduces health care access in destination countries for local populations (the empirical claim), under what conditions should such a reduction trigger obligations on the part of home countries and international bodies to regulate medical tourism or mitigate its negative effects? I demonstrate why arguments appealing to national self-interest in order to restrict medical tourism fail. I then examine three broad camps of Global Justice theory (Cosmopolitan, Statist, and Intermediate) and analyze whether they can be applied to medical tourism as grounds for these obligations.

Part VI examines how much of an overlapping consensus and divergence exists between the prescriptions of the theories in these rival camps, drawing some distinctions between kinds of medical tourism. I also discuss ways in which policymakers can use domestic and international law to translate ethical theory into reality.

A conclusion summarizes and charts some implications of my analysis for health care globalization more generally.

III. Kinds of Medical Tourism, Kinds of Ethical Concerns

Medical tourism is one part of a larger move toward the globalization of health care, a globalization that encompasses, among other things, medical migration (the brain drain), medical outsourcing (such as teleradiology), research tourism (where US-based pharmaceutical companies perform

clinical trials abroad), and the parallel trade in approved pharmaceuticals (such as purchasing drugs from Canada). At a high level, medical tourism falls into three types, each of which raises ethical questions I have outlined elsewhere: (1) medical tourism for services that are illegal in both the patient's home and destination countries (such as organ purchase in the Philippines); (2) medical tourism for services that are illegal or unapproved in the patient's home country but legal in the destination country (such as fertility, euthanasia, experimental drug, and stem cell tourism); and (3) medical tourism for services legal in both the home and destination countries.⁴¹

In this article, I focus on the last category. I divide such medical tourism by patient population into three types, each relevant for the normative analysis that follows. The first is patients paying out-of-pocket. In the United States, this typically refers to uninsured or underinsured patients using medical tourism to achieve substantial cost savings for procedures like hip replacements.⁴² A second group consists of private-insurer-prompted medical tourism. In its weakest form, insurers simply cover the service abroad without any incentive, but in a more common form, Tourism-Incentivized plans offer individuals rebates, waived deductibles, or other payment incentives for receiving treatment abroad.⁴³ For example, a plan proposed by Hannaford Brothers Supermarkets in the northeastern United States gives employees incentives to seek treatment in Singapore at Joint Commission International (JCI)-accredited hospitals.⁴⁴ A final form is government-prompted medical tourism. For example, there have been recent proposals to give US Medicare and Medicaid patients incentives to use medical tourism (with estimates of USD \$18 billion in annual savings based on ten percent of the populace taking advantage of the incentives). Another version is already in place

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41. I Glenn Cohen, "Medical Tourism: The View from Ten Thousand Feet" (2010) Hastings Center Report 11 at 11-12 [Cohen, "Medical Tourism"].
 42. Cohen, "Protecting Patients", *supra* note 14 at 1479-81.
 43. *Ibid* at 1486-88, (discussing Tourism-Incentivized, Tourism-Mandatory, and Domestic-Extra possible configurations).
 44. *Ibid* at 1486, citing Bruce Einhorn, "Hannaford's Medical-Tourism Experiment", *Businessweek* (9 November 2008) online: Businessweek <<http://www.businessweek.com>>.

in the European Union, where member states face some obligations to reimburse their citizens for treatments received in other member states.⁴⁵

Medical tourism of any of these types raises a large number of ethical and legal concerns – concerns about protecting the tourist patient from poor quality of care; the *de facto* waiver of rights to medical malpractice compensation for any resulting medical error; the dynamic effects on health care provided at home (including the possibility of regulatory races to the bottom); and the structuring of fair health insurance plans.⁴⁶ In this article, I focus on a very different set of concerns: those pertaining to potential negative effects of medical tourism on health care access for the poor in the destination country.

IV. The Empirical Claim

While concerns about effects on health care access abroad are raised by academics and policymakers discussing medical tourism, they have thus far been under-theorized. These concerns are best thought of as consisting of an empirical claim – that medical tourism diminishes health care access in the destination country, usually with a focus on its effects on the poorest residents – and a normative one – that such diminished access creates obligations on the United States and other tourist patient home countries (or international bodies, or possibly corporations) to do something about medical tourism.⁴⁷

45. See *ibid* at 1488, citing *Watts v Bedford Primary Care Trust*, C-372/04 [2006] ECR I-04325; Nicolas P Terry, “Under-Regulated Health Care Phenomena in a Flat World: Medical Tourism and Outsourcing” (2007) 29:2 *W New Eng L Rev* 421 at 437. In 2011, the EU adopted a new directive on cross-border health care codifying some of this case law and altering and adding other elements. See *e.g.* Sophie Petjean, “Council Approves Compromise with Parliament”, *Europolitics* (10 February 2011) online: Europolitics <<http://europolitics.info/>>.

46. See generally Cohen, “Medical Tourism”, *supra* note 41 discussing these issues; Cohen, “Protecting Patients”, *supra* note 14 discussing similar issues; Nathan Cortez, “Recalibrating the Legal Risks of Cross-Border Health Care” (2010) 10:1 *Yale Journal of Health Policy, Law, and Ethics* 1.

47. This should be contrasted with a different claim that although medical tourism does not harm the interests of people in the destination country, in the sense that these individuals are just as or more well-off, all things

Although, as discussed, there have been a number of more anecdotal statements and analyses offered in favor of the empirical claim, there is very little in the way of statistical evidence supporting the empirical claim. As such, this is an area where more developmental economic work would be very helpful. That said, I think it useful to identify six triggering conditions, which, when combined with substantial amounts of medical tourism, may lead to reduced access to health care for local populations and thus satisfy the empirical claim:

(1) The health care services consumed by medical tourists come from those that would otherwise have been available to the destination country poor. When medical tourists seek travel abroad for cardiac care, hip replacements, and other forms of surgery used by the destination country poor, the siphoning effect is straightforward. By contrast, the destination country poor are already unlikely to be able to access some boutique forms of treatment, such as cosmetic surgery and stem cell and fertility therapies. Thus, while medical tourism by American patients for these services would diminish access by, for example, Indian patients, it would not necessarily diminish access for poor Indian patients (which would remain steady at virtually none). Instead, it would cut into access by upper-class patients. Thus, one triggering condition focuses on whether medical tourism is for services currently accessed by destination country poor. That said, as discussed below, over time, the salience of the distinction is likely to break down, and even medical tourism for services currently inaccessible to destination country poor may siphon resources away from the poor because increased demand for services like cosmetic surgery may redirect the professional choices of graduating or practicing physicians who currently provide health care to India's poor into these niche markets. Whether that dynamic obtains would depend in part on the extent to which the destination country regulates specialty choice

being considered, it could be designed in a way that could make them even better off or have fewer negative effects along with its positive ones. *C.f.* Seana Valentine Shiffrin, "Wrongful Life, Procreative Responsibility, and the Significance of Harm" (1999) 5:1 *Legal Theory* 117 (proposing a non-comparative model where "harm" and "benefit" are two separate things, and it is wrong to impose harm without consent in order to confer an even larger benefit).

versus the extent to which health care workers can pursue the specialties most desirable to them.

(2) Health care providers are “captured” by the medical tourist patient population, rather than serving some tourist clientele and some of the existing population. Absent regulation, the introduction of a higher-paying market will likely cause health care providers to shift away from treating patients in the lower-paying market.⁴⁸ Thus, for example, Hopkins and her co-authors argue that this dynamic has taken place in Thailand, where “[a]lmost 6000 positions for medical practitioners in Thailand’s public system remained unfilled in 2005, as an increasing number of physicians followed the higher wages and more attractive settings available in private care,” and that due to medical tourism, “the addition of internal ‘brain drain’ from public to private health care may be especially damaging” for “countries such as Ghana, Pakistan, and South Africa, which lose approximately half of their medical graduates every year to external migration.”⁴⁹ This has also been the dynamic when private options are introduced into public systems, even in the developed world, although a number of jurisdictions, such as Canada and France, have tried by regulation to prevent flight to the private system.⁵⁰ Regulations that require providers to spend time in both systems are also more likely to produce positive externalities from the private to public health care

48. See Johnston et al, *supra* note 37 at 11.

49. Hopkins et al, *supra* note 37 at 194; see also Rupa Chinai & Rahul Goswami, “Medical Visas Mark Growth of Indian Medical Tourism” (2007) 85:3 Bulletin of the World Health Organization 164 (quoting Dr. Manuel Dayrit, Director, WHO’s Human Resources for Health Department, as saying, “[a]lthough there are no ready figures that can be cited from studies, initial observations suggest that medical tourism dampens external migration but worsens internal migration” at 165).

50. See Colleen M Flood, “Chaoulli’s Legacy for the Future of Canadian Health Care Policy” (2006) 44:2 Osgoode Hall LJ 273 (discussing evidence that “to the extent that prices are higher in the private sector and where specialists are free to do so, they will devote an increasing proportion of their time to private patients who are likely to have less acute or serious needs than those patients left behind in the public system” at 289); Colleen M Flood & Amanda Haugan, “Is Canada Odd? A Comparison of European and Canadian Approaches to Choice and Regulation of the Public/Private Divide in Health Care” (2005) 5:3 Health Economics, Policy and Law 319 at 320.

systems; for example, a physician who receives extra training as part of her duties in the medical tourism sector may be able to carry that training over to her time spent treating poor patients, if regulation forces her facility to treat poor patients. I discuss such possible regulation more in depth in Part VI, but it is worth noting that in medical tourism havens like India, even when such regulations are in place, many observers have been skeptical that they have been or will be enforced.⁵¹

(3) The supply of health care professionals, facilities, and technologies in the destination country is inelastic. Theoretically, if medical tourism causes increased demand for health care providers and facilities in the destination country, the country could meet such demand by increasing the supply of these things. In reality, however, even Western nations have had difficulty increasing this supply when necessary.⁵² As discussed, the need to match increased demand for the right specialties poses additional problems. In any event, investments in building capacity always entail an adjustment period. Thus, even countries that are unusually successful in increasing the size of their health care workforce to meet the demands of medical tourism will face interim shortages.

(4) The positive effects of medical tourism in counteracting the brain drain of health care practitioners to foreign countries are outweighed by the negative effects of medical tourism on the availability of health care resources. Medical migration, or brain drain, represents a significant threat

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51. See *e.g.* Gupta, *supra* note 37 (“[t]he government would have us believe that revenues earned by the industry will strengthen health care in the country. But we do not see any mechanism by which this can happen. On the contrary, corporate hospitals have repeatedly dishonoured the conditions for receiving government subsidies by refusing to treat poor patients free of cost – and they have got away without punishment. Moreover, reserving a few beds for the poor in elite institutions does not address the necessity to increase public investment in health to three to five times the present level” at 4-5); Johnston et al, *supra* note 37 at 5.
52. See Greg L Stoddart & Morris L Barer, “Will Increasing Medical School Enrollment Solve Canada’s Physician Supply Problems?” (1999) 161:8 *Canadian Medical Association Journal* 983; Abhaya Kamalakanthan & Sukhan Jackson, “The Supply of Doctors in Australia: Is There a Shortage?” University of Queensland, Discussion Paper No. 341 (2006) online: University of Queensland <http://espace.library.uq.edu.au/eserv.php?pid=UQ:8209&dsID=econ_dp_341_0506.pdf>.

to health care access abroad. For example, 61 percent of all graduates from the Ghana Medical School between 1986 and 1995 left Ghana for employment elsewhere (of those, 54.9 percent worked in the United Kingdom and 35.4 percent worked in the United States), and a 2005 study found that 25 percent of doctors in the United States are graduates of foreign medical schools.⁵³ A recent study of nurses in five countries found that 41 percent reported dissatisfaction with their jobs and one-third of those under age thirty planned on leaving to work elsewhere.⁵⁴ As Larry Gostin has put it, in the ordinary course of globalization, “[h]ealth care workers are ‘pushed’ from developing countries by the impoverished conditions: low remuneration, lack of equipment and drugs, and poor infrastructure and management,” and “[t]hey are ‘pulled’ to developed countries by the allure of a brighter future: better wages, working conditions, training, and career opportunities, as well as safer and more stable social and political environments.”⁵⁵ It is possible that for health care professionals tempted to leave their country of origin to practice in other markets, the availability of higher-paying jobs with better technology and more time with patients in the medical tourist sector of their country of origin will counteract this incentive.⁵⁶ Medical tourism may also enable the destination country to “recapture” some health care providers who left

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53. Fitzhugh Mullan, “The Metrics of The Physician Brain Drain” (2005) 353:17 *New Eng Journal of Medicine* 1810 at 1811; David Sanders et al, “Public Health in Africa” in Robert Beaglehole, ed, *Global Public Health: A New Era* (New York: Oxford University Press, 2003) 172. The cost to less developed countries and the benefit to the United States and other countries caused by the brain drain are staggering. A recent report suggested that it would have cost on average USD \$184,000 to treat each of the three million health care professionals who had migrated, such that richer nations saved \$552 billion, whereas poor nations lost \$500 million in training costs. Bookman & Bookman, *supra* note 29 at 106.
54. Linda H Aiken et al, “Nurses’ Reports on Hospital Care in Five Countries” (2001) 20:3 *Health Affairs* 43 at 45-46.
55. Lawrence O Gostin, “The International Migration and Recruitment of Nurses: Human Rights and Global Justice” (2008) 299:15 *Journal of the American Medical Association* 1827 at 1828.
56. See Matthias Helble, “The Movements of Patients Across Borders: Challenges and Opportunities for Public Health” (2011) 89:1 *Bulletin of the World Health Organization* 68 at 70 (discussing as-yet-unpublished data supporting this claim in Thailand).

years earlier, or to change brain drain into “brain circulation,” wherein home country providers leave for training abroad and return home ready to use and impart their skills to other providers in the home country.⁵⁷ But while some countries that experience medical brain drain are also developing strong medical tourism industries, many are only sources of medical brain drain and not destinations for medical tourism.⁵⁸ Thus, the creation of medical tourism hubs may actually exacerbate intra-regional medical migration.

(5) Medical tourism prompts destination country governments to redirect resources away from basic health care services in a way that outweighs positive health care spillovers. In order to compete for patients on quality and price against both the patient’s home country and other medical tourism hubs, destination countries will need to invest in their nascent medical tourism industry through, for example, direct funding, tax subsidies, and land grants.⁵⁹ Unfortunately, such funding often comes from money devoted to other health programs, including basic health care and social services,⁶⁰ and those effects are likely to be felt most strongly by the destination country poor. In other words, we need some sense of whether governments actually invest in health care services accessible by the poor (or at least do not take them away) in a counterfactual world where medical tourism is restricted. We also need to examine this dynamic as against a potential countervailing dynamic wherein medical tourism leads to a diffusion of Western medical technology or standards of practice or other health care spillovers that are beneficial to the entire

57. For discussions of these possibilities in other contexts, see *e.g.* Ayelet Shachar, “The Race for Talent: Highly Skilled Migrants and Competitive Immigration Regimes” (2006) 81:1 NYUL Rev 148 at 168.

58. Bookman & Bookman, *supra* note 29 at 105-09.

59. *Ibid* at 65-82; Turner, *supra* note 30 at 314-15, 320.

60. See Benavides, *supra* note 27 at 55; Johnston et al, *supra* note 37 (“the hiring of physicians trained in public education systems by private medical tourism facilities is another example of a potentially inequitable use of public resources. Furthermore, physicians in [low and middle income countries] who might normally practice in resource-poor environments can instead treat high-paying international patients, thereby gaining access to advanced technologies and superior facilities while receiving a higher wage” at 5-6); Turner, *supra* note 30 at 320.

patient population.⁶¹ Which dynamic wins out can only be answered on a country-by-country basis, but in India, for example, some commentators have suggested that the product of these countervailing forces has ultimately been a net negative for the destination country poor.⁶²

(6) Profits from the medical tourism industry are unlikely to “trickle down.” Successful medical tourism industries promise an infusion of wealth into the destination country, and the possibility that all boats will rise.⁶³ In practice, however, that possibility may not be realized. The reason for this might be something insidious like rampant corruption, or it may be something more benign, such as a tax system that is not particularly redistributive, or a largely foreign-owned medical sector.⁶⁴ Thus, the fact that a destination country gains economically from medical tourism (for example, in GDP terms) does not necessarily mean that those gains are shared in a way that promotes health care access (or health) among the destination poor.

Notice, as it will become relevant in the normative analysis, that many of these triggering conditions are themselves in the control of the destination country government to some extent.

As I have said before, data on the effects of medical tourism on health care access in the destination country are scarce – in many cases, they rest on anecdote and speculation – and the analysis can only be done on a country-by-country basis, which is impossible, given the current paucity of data. In countries where the triggering conditions all obtain, one would expect medical tourism to cause some diminution in access to

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61. Nathan Cortez, “International Health Care Convergence: The Benefits and Burdens of Market-Driven Standardization” (2009) 26:3 *Wis Int’l LJ* 646.
 62. See *e.g.* Hopkins et al, *supra* note 37 (“[i]n India, medical professionals are trained in highly subsidized public facilities. The annual value of these public training subsidies to the private sector where many physicians eventually work is estimated at more than USD \$100 million, at least some of which accrues to the medical tourism industry. This diverts public funds that might otherwise have gone into improving public health care for the poor – to private care for more affluent individuals” at 194).
 63. Cortez, *supra* note 61 at 693-94, citing Alain Enthoven, “On the Ideal Market Structure for Third-Party Purchasing of Health Care” (1994) 39:10 *Social Science & Medicine* 1413 at 1420.
 64. Helble, *supra* note 56 at 70.

health care for the destination country's poorest due to medical tourism; as fewer factors obtain, this becomes less likely. This list of factors is certainly not exhaustive, and there may be additional factors in particular countries that push in the other direction. While I cannot prove that this result obtains in any country, and some readers will no doubt be skeptical, the claim seems at least plausible enough to merit a normative analysis.

In the following analysis, I will merely assume we have a home-destination country pairing where the empirical claim obtains. For purposes of illustration, I will use US medical tourists traveling to India as my example.⁶⁵ From this point on, my analysis thus adopts a sort of disciplinary division of labour: I leave to development economists attempts to corroborate and further specify these triggering conditions and to show where they are satisfied. I instead focus on the normative questions about the obligations that flow from potential diminutions, and the legal and institutional design questions about how to satisfy those obligations.

V. The Normative Question

Suppose that US medical tourism to India really does reduce health care access for India's poorest residents. Does the United States (or an international body) have an obligation to do something about it? For example, does it have an obligation to try to curb medical tourism use by US citizens? In this section, I try to determine how much of an overlapping consensus there is among several rival comprehensive moral theories.

In terms of priors, I think it useful to begin with some skepticism toward the claim that there is something morally wrong with medical tourism because of its negative effects on health care access by the destination country poor. After all, medical tourism appears to involve willing providers of services (destination country physicians and facilities)

65. While I focus on US medical tourists, much of what I say can be transposed to medical tourists from other countries; the exceptions relate to some elements of US health insurance and the regulatory tools available to deal with US insurer-prompted medical tourism.

and willing consumers (home country patients, insurers, governments) pursuing an ordinarily morally unproblematic activity (providing medical services). Moreover, unlike cases such as organ sale or clinical trials in sub-Saharan Africa of drugs that will not be readily available there when approved,⁶⁶ there is no plausible claim that the (in one sense) “voluntary” seller (or buyer) is being exploited. Instead, the harm occurs from the negative externalities of reduced access to care for third parties produced from these voluntarily nonexploitive transactions. I examine four types of theories that nonetheless purport to find fault with this arrangement.

A. Self-Interest

In making the case for curbing medical tourism to policymakers, it would be most desirable to appeal to national self-interest directly and claim that restrictions on medical tourism would serve the interests of US citizens (or the home country of other tourists, but from this point forward I will merely say “US” for simplicity). Such an argument would not require subscription to any theory of global justice, nor even a particularly strong commitment to distributive justice domestically. While many philosophers might chafe at the invocation of such an egoistic theory,⁶⁷ this argumentative strategy has been employed in parallel settings: to urge, among other things, action by developed countries to reduce medical migration from developing countries (especially “poaching” practices) and the loosening of intellectual property rights to vaccines in the developing world, in attempts to increase access to essential medicines at price points within the grasp of developing world populations.⁶⁸ Might

66. See *e.g.* Jennifer S Hawkins, “Research Ethics, Developing Countries, and Exploitation: A Primer” in Jennifer S Hawkins & Ezekiel J Emmanuel, eds, *Exploitation and Developing Countries: The Ethics of Clinical Research* (New Jersey: Princeton University Press, 2008) 21 at 21-55.

67. That this kind of argument may not appeal to most Global Justice theorists does not mean they should not consider it in attempting to persuade policy-makers. As I stress repeatedly in this article, to achieve that goal, it is desirable to achieve as much of an overlapping consensus as possible between rival views.

68. See William W Fisher & Talha Syed, “Global Justice in Health: Developing Drugs for the Developing World” (2007) 40:3 UC Davis L Rev 581 at 588-91; Lawrence O Gostin, “Meeting Basic Survival Needs

the same kinds of arguments have purchase in this context?

I can think of at least four types of arguments along these lines.

First, one might press patient-protective concerns or concerns about externalities borne by our domestic health care system when medical tourist patients experience poor care abroad and need additional health care here in the United States. For example, because the *Emergency Medical Treatment and Active Labor Act*⁶⁹ requires that US hospitals provide emergency services regardless of patients' insurance status or ability to pay, US hospitals will face the costs associated with meeting additional emergency health care needs due to medical tourism that harms US patients, and will pass these costs on to other paying patients.⁷⁰ Even assuming these are valid concerns regarding medical tourism (a matter itself subject to doubt),⁷¹ the larger problem is that the cases where this particular self-interest argument might push us to curb medical tourism will map on only by coincidence, if at all, to cases posing concerns about the destination country poor's health care access. That is, there can be cases where this particular self-interest concern would urge action but there are no health care access concerns, and cases where there are health care access concerns but this particular self-interest argument is not operative. The same response applies regarding concerns about the importation of diseases (especially antibiotic-resistant strains or "super-bugs") back to developed countries due to medical tourism, as has been

of the World's Least Healthy People: Toward a Framework Convention on Global Health" (2008) 96 Geo LJ 331 at 352-63.

69. 42 USC §§1395dd(a)-(d) (2010) [*EMTALA*].

70. *Ibid.* To put the point another way, some health care may be iatrogenic. That is, it may cause harm and thus present new health care needs that did not exist before the care was provided.

71. See Cohen, "Protecting Patients", *supra* note 14 at 1523-42 (discussing patient protection). To unpack this point, even if some medical tourism is iatrogenic, it seems possible (indeed, even plausible) that on net, medical tourism saves hospitals in terms of *EMTALA* costs; that is, the number of patients with new medical needs covered by *EMTALA* and caused by medical tourism may be dwarfed by the number of patients who now avoid the need for care covered by *EMTALA*, because they instead get care through medical tourism, preventing or forestalling the need for an emergency admission. This is, of course, an empirical question, and one that would be quite difficult to definitively answer, but it seems plausible to me that this is the case.

reported in a few case studies.⁷²

One might instead adapt to medical tourism other arguments made in the health care literature for the claim that the United States (or other countries) should care about the impact of US policies or US citizens' behavior on the health of those abroad. First, given the frequency of travel by Americans (and others who visit the United States) to India, medical tourism that results in decreased access to treatment for infectious diseases might increase the risk of transmission of those diseases to Americans.⁷³ Second, because Indians are valuable to the United States as producer-exporters of cheap goods and consumer-importers of our goods, improving Indian citizens' basic health care will improve that country's development and ensure more productive trading partners and affluent markets in which to sell US-made goods.⁷⁴ Finally, one might make the more attenuated argument that improving health care access abroad may reduce immigration pressures to the United States or increase national security by reducing global terrorism.⁷⁵

Unfortunately, these arguments are not very persuasive in this context. For the infection-transmission and consumer arguments, we should arguably be more concerned about the health of the higher-Socio-Economic-Status strata of Indian society, who are more likely to travel to our shores and be better able to buy our goods. While diminishing health care access to India's poorest, medical tourism services may actually improve the health care of the wealthier strata, at least those who are able to buy into these better facilities or take advantage of the diffusion of knowledge and technology. This is not to say there are no infection

72. See E Yoko Furuya et al, "Outbreak of *Mycobacterium Abscessus* Wound Infections Among 'Lipotourists' from the United States Who Underwent Abdominoplasty in the Dominican Republic" (2008) 46:8 *Clinical Infectious Diseases* 1181; Centre for Disease Control, "Brief Report: Nontuberculous Mycobacterial Infections After Cosmetic Surgery – Santo Domingo, Dominican Republic, 2003-2004" (2004) 53:23 *Morbidity and Mortality Weekly Report* 509.

73. *C.f.* Fisher & Syed, *supra* note 68 at 588; Gostin, *supra* note 68 at 353-55.

74. *Ibid.*

75. *C.f.* Fisher & Syed, *ibid* at 590; Gostin, *ibid* at 358-61. To be clear, Fisher, Syed, and Gostin are also not particularly impressed by these arguments, even in the health care globalization contexts about which they write.

concerns – Americans traveling to India for pleasure tourism may bring diseases back with them – but that they are less salient than in other contexts.

A more serious and general objection to deploying these self-interest arguments here is that even if it is in the American self-interest to help India's poor access health care for these reasons, it will frequently be even more in its self-interest to help its own poor citizens in this regard. As I have discussed here and elsewhere, and as the Senate recognized in its own hearing, medical tourism promises to improve the health care of poor Americans even while it (by hypothesis) reduces health care access to poor Indians, and the former effect might be thought to dominate in terms of US self-interest.⁷⁶ This objection is particularly salient for medical tourism by those paying out-of-pocket or for government-prompted medical tourism. It is less forceful an objection with respect to insurer-prompted medical tourism, because if medical tourism were restricted, many of the users would continue to have access to health care; they would just pay more for it. That said, at the margins, there may be populations whose access to health care will depend on the availability of lower-priced health insurance plans with some amount of medical tourism covered or incentivized, and particular services may be excluded from insurance coverage at a given price if medical tourism is curbed.⁷⁷ For similar reasons (discussed more fully below), this objection to the self-interest argument may be less forceful for certain sub-types of medical tourism, like cosmetic surgery. I return to these two distinctions (as to insurer-prompted medical tourism and certain sub-types of procedures) repeatedly in this paper.

In sum, for most types of medical tourism, we need to go beyond

76. Cohen, "Protecting Patients", *supra* note 14 at 1523-28; Cohen, "Medical Tourism", *supra* note 41 at 11-12.

77. Cohen, "Protecting Patients", *ibid* at 1546. That said, if these insured patients are paying more for their health insurance because medical tourism is excluded, their welfare will be negatively impacted (they are losing disposable income they could spend on other items) even if their access to health insurance and therefore health care is less likely to be negatively impacted. Whether that distinction matters may depend on whether one adopts the view that health has special moral importance (a separate spheres kind of view) or not. See Daniels, *supra* note 39 at 29-78.

pure national self-interest to mount a cogent defense for why one should be concerned about medical tourism's negative effects on health care access in the destination country.⁷⁸ I consider three families of political philosophy theories that seek to do that: Cosmopolitan, Statist, and Intermediate.

B. Cosmopolitan Theories

Cosmopolitan theories share a commitment to ignoring geographic boundaries in the application of moral theory. I consider what three cosmopolitan theory types – Utilitarian, Prioritarian, and the Nussbaum/Sen Functioning/Capabilities approach (which is in some senses Sufficientarian) – would say about medical tourism. This discussion should be understood as being at the level of ideal types, because there are many variants of these theories.

Utilitarians are committed to maximizing aggregated social welfare. Cosmopolitan Utilitarians take the Millian and Benthamite slogan “each to count for one, and none for more than one,”⁷⁹ and ignore national boundaries in determining who is the “each” to be counted.⁸⁰ Bracketing complicated questions about what it is that welfare consists of,⁸¹ there

78. John Stuart Mill, “Utilitarianism” (1863) reprinted in Alan Ryan, ed, *Utilitarianism And Other Essays* (New York: Penguin Books, 1987) 272 at 336.

79. This discussion has been premised on the current volume of medical tourism or a volume one might estimate as realistic in the next decade. If, for example, a third of the American populace started using medical tourism, that effect on lost revenue for the US domestic health care system and the dynamic effects on the US health care market would pose a quite separate set of self-interest concerns. I do not investigate those hypothetical concerns here, both because the volume of medical tourism needed to make them relevant seems extremely unrealistic and because, as with the *EMTALA* cost-related concerns discussed above, the concern is quite orthogonal to diminutions in health care access by the destination country poor.

80. See Peter Singer, “Famine, Affluence, and Morality” (1972) 1:1 *Philosophy & Public Affairs* 229 at 231; Peter Singer, “The Tanner Lectures on Human Values, A Response to Martha Nussbaum” (13 November 2002) *Utilitarianism*, online: *Utilitarian Philosophers* <<http://www.utilitarianism.net/singer/by/20021113.htm>>.

81. See generally LW Sumner, *Welfare, Happiness, and Ethics* (New York:

is a *prima facie* case that Cosmopolitan Utilitarians would find medical tourism normatively problematic. As William W Fisher and Talha Syed have suggested in the context of pharmaceutical R&D spending on diseases that predominantly affect the poorest countries, the fact of diminishing marginal utility from health care gives a good *prima facie* argument on Utilitarian grounds to favor interventions for the worst-off over the better-off, even if each group is a similarly sized population. Increasing health care access is more likely to raise the welfare of the poor than it is that of comparably richer individuals.⁸² This is true even if we grant the possibility that individual utility curves vary and we lack sufficient knowledge for interpersonal comparisons of utility; as long as one makes the minimal assumption that individual utility curves are distributed randomly, moving to a more equal distribution will maximize utility as a statistical matter because there is an equal chance that a person with a given curve will lose or gain the good from the equalizing transfer. In other words, “the harm of a loss (to a well-off person with that utility function) will be outweighed by the benefit (to a worse-off person with that curve).”⁸³ A similar case can be made for interventions to curb medical tourism – for example, to invoke one of the possible triggering conditions discussed above, if medical tourism causes fewer physicians to treat the poor and produces higher infant mortality.

This case is only a *prima facie* one, and more complicated than the R&D spending case for several reasons. First, many Cosmopolitan Utilitarians are concerned with welfare, not health *per se*, so increases in wealth (and thus welfare) to all the Indian populace from medical tourism, even if accompanied by decreases to the health of the poorest, have to be factored in, as do wealth increases to Americans based on savings from medical tourism, which might muddy the waters.⁸⁴ That said, if the wealth gains are also concentrated in the most well-off, the

Clarendon Press Oxford University Press, 1996) (exploring rival definitions).

82. Fisher & Syed, *supra* note 68 at 602-05.

83. *Ibid* at 605.

84. I say “many Cosmopolitan Utilitarians” because there could also be utilitarian views that attached a special importance to health, to which this particular objection might not apply.

same diminishing marginal utility principle will tend to reduce the value of these gains. Second, out-of-pocket or government-prompted medical tourism usually improves health care access for poor Americans⁸⁵ and for middle-class Indians who can use these facilities. Thus, in fact, the relevant trade-off is not rich American versus poor Indian, but poor American and middle-class Indian versus poor Indian. If the utility curves of the poor American and poor Indian are close enough in terms of diminishing marginal utility,⁸⁶ the addition of benefits to middle-class Indians may make up the weight. For reasons similar to those discussed above, this will be less of a problem with curbs on insurer-prompted medical tourism. Third, the discussion so far has assumed we are trading off one (stylized and hypothetical) increment of health care between the domestic citizen and the medical tourist, but there is no reason to think the world will actually be so neat. It could be true that in a world with medical tourism the Indian patient loses on net only one increment of

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85. As I have noted elsewhere, we lack specific demographic information on medical tourists, but the existing evidence suggests that in the US they are largely uninsured and underinsured patients who lack better options for getting necessary health care. Cohen, “Protecting Patients”, *supra* note 14 at 1480. In part because of the funding of and strict eligibility criteria for Medicaid in the United States, many of the uninsured who are not Medicaid recipients are themselves quite poor. A 2010 Kaiser Family Foundation Report estimated that 40 percent of uninsured individuals (*i.e.* not receiving either Medicaid or private insurance) fell below the US poverty level, which was USD \$22,050 for a family of four in 2010, and 90 percent of all uninsured in America were below 400 percent of the poverty level. Henry J Kaiser Family Foundation, “The Uninsured: A Primer - Key Facts About Americans Without Health Insurance” (Washington, DC: Kaiser Family Foundation, 2010) at 5.
86. That is, of course, a big “if.” To many, it may seem plausible that even a poor American who would make use of medical tourism is quite far away from the poor Indian in terms of diminishing marginal utility. That said, as I have discussed elsewhere in greater depth, see Cohen, “Protecting Patients”, *supra* note 14 at 1472-74, 1479-81, many of the current developed-world users of medical tourism are seeking heart bypass surgeries, heart valve replacement surgeries, spinal surgeries, and cancer treatments they cannot afford to have at home. These are serious – in many cases, life-or-death – surgeries, and the inability to access them will have very large utility consequences. Thus, we ought to be careful before too quickly dismissing this issue, even if one’s prior intuitions go the other way.

health care while the American tourist gains three – for example, medical tourism might have offsetting benefits in terms of improving medical technology and practice by Indian physicians who serve the domestic population. In such a world, while medical tourism makes Indians worse off, it does so less than it makes Americans better off. Of course, the opposite could be true, in which case the argument for banning medical tourism is stronger. None of this is to argue that the Cosmopolitan Utilitarian could not oppose medical tourism, but just that there are some indeterminacies here.

Many of those indeterminacies become less pressing under Cosmopolitan Prioritarianism. Unlike Utilitarians, Prioritarians do “not give equal weight to equal benefits, whoever receives them,” but instead give more weight to “[b]enefits to the worse off.”⁸⁷ Take, for example, John Rawls’s extremely Prioritarian Difference Principle: inequalities in “primary goods” (income, wealth, positions of authority or responsibility, the social bases of self-respect, and, after prompting from Norman Daniels, health) should be allowed to persist only if they work to the greatest benefit of the least-advantaged group.⁸⁸

While, as we will see shortly, Rawls cabined the principle’s application to within the nation-state, Charles Beitz, among others, has extended it to the international sphere. Beitz identifies two attractions in doing so: (1) the desire to avoid moral arbitrariness in the distribution of primary goods – that is, “we should not view national boundaries as having fundamental moral significance”⁸⁹ – and (2) that a limitation of Rawlsian redistribution to the domestic sphere is only justifiable on an account of nations as self-sufficient cooperative schemes, a position he views as untenable in today’s world of international interdependence, where those regulating trade (World Trade Organization) and capital (International Monetary Fund and World Bank) “[impose] burdens on poor and

87. Derek Parfit, “Equality or Priority?” (1997) 10:3 Ratio 202 at 213.

88. See John Rawls, *A Theory of Justice* (Cambridge, Mass: Harvard University Press, 1971) § 46 at 300-01, § 11 at 60-61 [Rawls, “Theory”]; John Rawls, *Justice as Fairness: A Restatement* (Cambridge, Mass: Harvard University Press, 2001) § 51.5 at 172; Daniels, *supra* note 39 at 44.

89. Charles R Beitz, *Political Theory and International Relations* (Princeton, NJ: Princeton University Press, 1979) at 151.

economically weak countries that they cannot practically avoid.”⁹⁰

Beitz offers a strong and weak version of his Cosmopolitan Prioritarian thesis. The strong version is that we should apply the Rawlsian redistributive principle internationally.⁹¹ This version clearly grounds a

90. Charles R Beitz, “Justice and International Relations” (1975) 4:4 *Philosophy & Public Affairs* 360 at 374.

91. Rawls is careful in *A Theory of Justice* to limit the ambit of his Difference Principle to the “basic structure” of society: “the way in which the major social institutions distribute the fundamental rights and duties and determine the division of advantages from social cooperation,” the sources of “deep inequalities.” Rawls, “*Theory*”, *supra* note 88, § 2 at 6-7, § 41 at 229. One pertinent question in constructing a Rawlsian-style Cosmopolitan Prioritarian perspective on medical tourism is whether the concept of “basic structure” is expansive enough to reach these kinds of meso- (if not micro-) level policy decisions. To crystallize the point, one might resist the application of a Rawlsian-style Cosmopolitan Prioritarianism to the medical tourism case not because one disagrees with it as the appropriate political theory to govern the international arena, but because one believes that in global context it should be limited to issues equivalent to those “basic structure” issues to which the Difference Principle applies in the domestic context, and that setting policy on medical tourism exceeds that “basic structure.” Beitz, the most notable advocate of expanding Rawls’ domestic Prioritarianism internationally, does not discuss the “basic structure” limitation in any depth in his book and takes as the possible target of a Global Difference Principle some quite specific policies. For example, he observes that “one might argue on the grounds of distributive justice for such policies as a generalized system of preferential tariffs for poor countries and the removal of nontariff barriers for trade, or for the use of Special Drawing Rights in the International Monetary Fund as a form of development assistance.” See Beitz, *supra* note 89 at 174. In the health setting, others have followed suit, treating an issue like the pricing of pharmaceuticals in the developing world as the possible target of a Rawlsian-style Cosmopolitan Prioritarian argument. See *e.g.* Fisher & Syed, *supra* note 68 at 652-59. I think it is an open question whether these policies are ones that are properly within the ambit of Rawls’ own conception of the “basic structure,” or whether these authors are instead embracing a Rawlsian-style Cosmopolitan Prioritarianism that relaxes the basic structure constraint or adopts an expansive version of that concept. In any event, in developing a Cosmopolitan Prioritarian approach to medical tourism, I will follow Beitz and others in allowing a version of the Difference Principle to apply to somewhat less grand policy decisions, such as whether to regulate medical tourism, while noting some doubts about whether this is fully consistent with Rawls’ own vision as to the ambit of the basic structure.

normative problem in medical tourism while avoiding a potential problem faced by the Utilitarian approach – the possibility of welfare gains to Americans or middle-class Indians counterbalancing welfare losses to poor Indians – because of the extreme priority given to the worst-off, who are likely to be India’s poor in this context.⁹² By contrast, the weaker version of Beitz’s approach instructs us to apply internationally whatever distributive justice policy one adopts domestically.⁹³ Its implication for medical tourism is less clear and depends on the degree of priority given to the worst off, although it would seem to more clearly promote interventions restricting medical tourism than the Utilitarian approach.

A third Cosmopolitan approach is Sufficientarianism, according to which justice is not concerned with improving the lot of the least well-off (Prioritarianism) or achieving equality *per se* (Egalitarianism), but instead with ensuring that individuals do not fall below a particular threshold of whatever is the “currency” of distribution.⁹⁴ Although emanating from a more Aristotelian starting point, we can understand Amartya Sen and Martha Nussbaum’s approach as roughly fitting this category. In a nutshell, their approach is to discern the “functionings” central to a flourishing human life, determine the “capabilities” needed to attain those functionings, and then identify and fix natural and social disparities to raise people to threshold in those capabilities.⁹⁵ In her latest work

92. I say “likely” because it would depend in part on how “worst-off” was defined; most welfarists would define it in terms of total welfare, but a welfarist focused on health in particular might press for a focus on “sickest” rather than total welfare. Either way, I think it plausible that the poor Indian would qualify.

93. Beitz, *supra* note 89 at 174.

94. See Roger Crisp, “Equality, Priority, and Compassion” (2003) 113:4 *Ethics* 745 at 756-63; Harry G Frankfurt, “Equality as a Moral Ideal” (1987) 98:1 *Ethics* 21 at 21-25; Alexander Rosenberg, “Equality, Sufficiency, and Opportunity in the Just Society” (1995) 12:2 *Social Philosophy & Policy* 54.

95. See generally Martha Nussbaum, *Frontiers of Justice* (Cambridge, Mass: Harvard University Press, 2006) at 155-216, 273-315 [Nussbaum, “*Frontiers*”] (setting out the Capabilities approach); Martha Nussbaum, *Women and Human Development: The Capabilities Approach* (Cambridge: Cambridge University Press, 2002) at 4-14 (describing the Capabilities approach similarly); Amartya Sen, *Inequality Reexamined* (New York: Harvard University Press, 1992) at 39-53 (describing the Capabilities

on the subject, *Frontiers of Justice*, which speaks directly to the issue of international justice, Nussbaum delineates ten capabilities, two of which are central for our purposes: “Life [– b]eing able to live to the end of the human life of normal length; not dying prematurely, or before one’s life is so reduced as to be not worth living” and “Bodily Health [– b]eing able to have good health, including reproductive health.”⁹⁶ Nussbaum indicates that the responsibility to achieve the threshold on these capabilities falls at all levels: on national governments, on international bodies, and even on corporations, and the failure of one institution to meet its obligations does not reduce the obligation of the others.⁹⁷ She also makes clear that the thresholds are non-relativistic. For example, the threshold for adequate “life” or “bodily health” is the same if the citizen is American or Indian.⁹⁸

This approach offers powerful reasons why the effects of medical tourism on health care access in destination countries ought to be a matter of substantial concern. While she does not attempt to operationalise where the health or life capability threshold should be set, Nussbaum’s description of these thresholds plausibly suggests that the Indian poor fall below the thresholds due to poor health care access (among other reasons, such as lack of adequate sanitation). On her theory, it would then be the responsibility of the United States, India, international bodies, and even the hospitals, insurers, and intermediaries involved in medical tourism to try to rectify that result.

That said, in applying the Sufficientarian approach to medical tourism, some problems latent in the theory become manifest. For out-of-pocket or government-prompted medical tourism, many American users are poor and may themselves be below the threshold on life and bodily health. Consider, for example, a 1990 study suggesting that an African-American man living in Harlem was less likely to live until age sixty-five than a Bangladeshi man, and tracing this in part to lack of

approach similarly).

96. Nussbaum, “*Frontiers*”, *ibid* at 76-78.

97. *Ibid* at 171, 313-19.

98. *Ibid* at 78-81. For an application of Nussbaum’s approach to global health specifically, see Gostin, *supra* note 68 at 343-47.

health care access.⁹⁹ We may thus face a situation where we cannot raise everyone to the capability threshold, that is, a case of below-threshold tradeoffs. A number of authors have criticized Nussbaum for failing to provide guidance in such cases.¹⁰⁰ Again, this is less of a problem for insurer-prompted medical tourism, whose users will usually lie above the threshold. It may also not be a problem for restricting medical tourism for certain subcategories of treatments by Western patients that are not “health” related – cosmetic surgery and fertility tourism, for example (although whether the latter counts as “health” is a contested question),¹⁰¹ because these treatments are less important for promoting the capabilities. This is an important divergence from the Utilitarian approach, which treats all inputs into welfare equally, whether classified as health or not.

A second problem with this theory has to do with Nussbaum’s refusal to allow tradeoffs between capabilities. We may face conflicts between raising individuals to threshold on the Life/Health capabilities and raising

99. Colin McCord & Harold P Freeman, “Excess Mortality in Harlem” (1990) 322:3 *New England Journal of Medicine* 173.

100. See *e.g.* Anita Silvers & Michael Ashley Stein, “Disability and the Social Contract” (2007) 74:4 *U Chicago L Rev* 1615 at 1638; Singer, *supra* note 80; Mark Stein, “Nussbaum: A Utilitarian Critique” (2009) 50:2 *BCL Rev* 489 at 504-14. This may mean that a modified version of the Capabilities approach that breaks from Nussbaum in this regard will do better as a Cosmopolitan theory that can ground duties relating to medical tourism.

101. See *e.g.* I Glenn Cohen & Daniel Chen, “Trading-Off Reproductive Technology and Adoption: Does Subsidizing IVF Decrease Adoption Rates and Should It Matter?” (2010) 95:1 *Minn L Rev* 485 at 500-05; Daniels, *supra* note 39 (offering a theory of health tied to whether a deficit causes a “departure from normal functioning that reduces an individual’s fair share of the normal opportunity range and gives rise to claims for assistance” and finding infertility to count because it interferes with “basic functions of free and equal citizens, such as reproducing themselves biologically, an aspect of plans of life that reasonable people commonly pursue” at 59); Nussbaum, “*Frontiers*”, *supra* note 95 at 76 (including reproductive health within the “bodily health” capability). Fleshing out what is and is not penumbral to “health” and on what theory is not my focus in this article. I will, however, note that even discussing categories like “cosmetic surgery” may be too crude in the final analysis; to the extent the category encompasses both sex change operations and breast augmentation, each may call for a quite different analysis.

them to threshold on one or more of the eight other coequal capabilities we have thus far not discussed – for example “Play [– b]eing able to laugh, to play, to enjoy recreational activities” and “Senses, Imagination, and Thought, [– b]eing able to use the senses to imagine, think, and reason – and to do these things in a ‘truly human’ way, a way informed and cultivated by an adequate education.”¹⁰² If medical tourism improves recreational or educational opportunities (by increasing Indian GDP), it is unclear whether these increases to threshold in other capabilities could outweigh medical tourism’s negative effects on the “Bodily Health” and “Life Capabilities.”¹⁰³ These questions somewhat mirror those discussed as to the Cosmopolitan Utilitarian approach. One could try to alter the theory to adopt one of a series of methods of dealing with below-threshold cases: help the person who will make the biggest capability gain, help the person lowest down on the capabilities level, or maximize the number of people who are above threshold,¹⁰⁴ each of which would somewhat strengthen the case against medical tourism. Such alterations would still, however, leave open the problem of across-capability tradeoffs.

While clearly aware of these problems, Nussbaum appears resistant to altering her theory much in this regard. She makes clear that “all ten of these plural and diverse ends are minimum requirements of justice, at least up to the threshold level,”¹⁰⁵ that “the capabilities are radically

102. Nussbaum, “*Frontiers*”, *supra* note 95 at 76-77.

103. There is a separate set of issues relating to thresholds and timeframes. For example, medical tourism may in the short-term make it harder to achieve the threshold for currently existing Indian populations on these capabilities, but the development of India’s health sector and trickle-down may in the long-term raise more Indians (including not-yet-existing ones) to threshold. In part because of their complexity, see generally Louis Kaplow, “Discounting Dollars, Discounting Lives: Intergenerational Distributive Justice and Efficiency” (2007) 74:1 U Chicago L Rev 79 (discussing complications involved with intergenerational discounting); John Broome, “Should We Value Population?” (2005) 13:4 Journal of Political Philosophy 399 (discussing complications in reasoning about the interests of future generations, and in part because these are domain-general questions that almost all theories face in almost all contexts rather than specific problems for the Capabilities approach as to medical tourism, I note but largely bracket these issues here).

104. Stein, *supra* note 100 at 509-20.

105. Nussbaum, “*Frontiers*”, *supra* note 95 at 175.

non-fungible: deficiencies in one area cannot be made up simply by giving people a larger amount of another capability.”¹⁰⁶ Her “theory does not countenance intuitionistic balancing or tradeoffs among them,” but instead “demands that they all be secured to each and every citizen, up to some appropriate threshold level.”¹⁰⁷ She recognizes that “[i]n desperate circumstances, it may not be possible for a nation to secure them all up to the threshold level, but then it becomes a purely practical question what to do next, not a question of justice,” because “[t]he question of justice is already answered: justice has not been fully done here.”¹⁰⁸ That posture, however, makes her theory less useful as a tool for normative analysis of medical tourism.

With the possible exception of Beitz’s strong Cosmopolitan Prioritarian thesis, perhaps surprisingly, the other Cosmopolitan theories also face some indeterminacies and problems when faced with the case study of medical tourism. That said, I think it is fair to say that they offer a strong *prima facie* case (if not a completely certain one) for condemning some forms of it.

There are, however, two more pressing and related problems with relying too heavily on the Cosmopolitan theories to urge restrictions on medical tourism – one theoretical and one pragmatic.

The theoretical problem is that what these theories offer us is not a theory of when we are responsible for harms stemming from medical tourism, but when we ought to improve the lives of the badly-off simpliciter. In one sense, causation matters: only if restricting medical tourism causes an improvement in welfare for the worst off, the raising of health capabilities, etc., are we required to take the action. In another sense, however, causation in the historical and responsibility senses is irrelevant because it is the mere fact of the destination country’s citizens’ needs that imposes upon us the obligation to help them in whatever way we can, and not anything about medical tourism specifically. Thus, in one direction, the duties may persist even when medical tourism is eliminated or its harms are remedied in that the source of the obligation

106. *Ibid* at 166-67.

107. *Ibid* at 175.

108. *Ibid*.

is not anything we have done, but instead the destitute state of those abroad. In the other direction, once the theories' goals are met (for example, they reach the sufficient level on the capabilities, to use one variant), we do not bear an obligation (at least under distributive justice principles) to prevent medical tourism or remedy its ill-effects, even if medical tourism continues to produce significant health care deficits for the destination country poor that would not occur if it were curbed. Moreover, it is possible that other forms of aid or assistance might "cancel out" whatever negative effects medical tourism has in terms of the global cosmopolitan calculus.

To put the point another way, the problem is that the Cosmopolitan theory tells us to help those in the destination country who are badly-off by curbing medical tourism, whether or not medical tourism caused them to be badly-off; this is to be contrasted with a different kind of theory (more corrective justice in spirit) that would urge us to curb medical tourism because it causes people in the destination country to be worse off.

Further, these approaches also face what I will call a "self-inflicted wounds problem," a problem that I will return to several times in this article. These theories imply (subject to a qualification) that it is not relevant to the scope of the home country's obligation that some of the factors (discussed above) that cause medical tourism to negatively impact health care access in the destination country are within the destination country's government's control, *i.e.* that the destination country is partially responsible. The qualification is that, to the extent that we could induce the destination country to alter these facts about its self-governance, such influence would be one tool to meet our obligations under these theories. But to the extent we are unable to prompt these alterations, under the Cosmopolitan approach, our responsibility to improve the welfare and capabilities of the poor in the destination country attaches even for the elements for which their own sovereign is actually responsible.¹⁰⁹

109. Nussbaum is the most explicit of the theorists in suggesting that the responsibility to achieve the threshold on these capabilities falls at all levels – on national governments, on international bodies, even on corporations – and that the failure of one institution to meet its obligations does not reduce the obligation of the others. See Nussbaum, "*Frontiers*", *supra*

To some, these implications may seem problematic; from others, the reply will be, “It is just not that kind of theory.” More troubling, though, may be a pragmatic corollary: if we need to rely on these theories to convince public policymakers to take action on medical tourism, they threaten to prove too much. To borrow a phrase that Charles Fried has used in discussing Utilitarianism generally, all of these approaches threaten to become “oppressive in the totality of the claim they make on the moral agent”;¹¹⁰ addressing the harms caused by medical tourism is a small drop in the bucket in terms of what these theories would call upon us to do to right the balance between developed and developing countries. For starters, they would further demand that we radically increase taxes for all strata in our nation to fund large-scale water purification, housing, and other interventions in Less Developed Countries (LDCs). As Thomas Pogge has stressed, unless a theory of Global Justice is politically feasible, it is “destined to remain a philosopher’s pipe dream.”¹¹¹ It seems hard to believe that a principle as broad and demanding as the one espoused by Cosmopolitans of this sort would be compelling to US policymakers.

Again, some philosophers might chafe at this approach and say that if the Cosmopolitan approach is “right,” it matters not a lick that US political elites would never accept it. Even if we think that within the ambit of philosophy that response is correct,¹¹² Pogge is also surely

note 95 at 313-19. There are some complicated dynamic elements I gloss over here. For example, if it turned out that, because of moral hazard issues, a theory of moral obligation that did hold the destination country responsible for its own role in these health care access deficits in the long run actually improved the welfare/capabilities of the population more than one that did not – because the destination country sovereign would then have a greater incentive to clean its own house – then we might in fact adopt a system that apportioned responsibility even on these theories; however, that apportioning of responsibility would be pragmatic and instrumental, not because these theories suggests that the responsibility of the destination country diminishes that of the patients’ home country.

110. Charles Fried, *Right and Wrong* (Cambridge, Mass: Harvard University Press, 1978) at 13.
111. Thomas W Pogge, “Human Rights and Global Health: A Research Program” (2005) 36:1-2 *Metaphilosophy* 182 at 185.
112. *C.f.* David Estlund, “Human Nature and the Limits (if Any) of Political Philosophy” (2011) 39:3 *Philosophy & Public Affairs* 207 (discussing whether the fact that human nature is such that we will never do

correct that, when it comes to trying to shift public policy, these kinds of considerations are king. In any event, to find common ground with both those who would reject Cosmopolitanism as a philosophical matter and those who would reject it as a pragmatic matter, it would be desirable to show a normative obligation to correct health care access diminution from medical tourism on less demanding theories as well. I consider two sets of such theories next, Statist and Intermediate.¹¹³

C. Statist Theories

Unlike Cosmopolitans, Statists reach the conclusion that the obligations of distributive justice apply only within the nation-state and not to citizens of other nations. I discuss the arguments of two of the best-known expositors of this view, John Rawls and Thomas Nagel, before applying those arguments to medical tourism. As one might expect, justifying duties to curb medical tourism is difficult for Statist approaches. However, what one might not expect, and as I show, is that even these approaches might mandate some limited regulatory interventions grounded in the Rawlsian duty to aid burdened states and the Nagelian duty of humanitarian aid. That said, I also express some misgivings about these ways out of the problem.

Statists limit justice-based duties of redistribution to the nation-state because “[w]hat lets citizens make redistributive claims on each other is not so much the fact that they share a *cooperative* structure,” but that societal rules establishing a sovereign state’s basic structure are “coercively imposed.”¹¹⁴ Nagel clarifies that this is because for Rawls (and *contra* the

that which is called for by a political philosophy should matter for its evaluation).

113. A different response is that we need not be so philosophically pure: we can endorse Cosmopolitanism in this limited domain while rejecting it elsewhere. That is, of course, an option, but then one bears the burden of justifying why, if one accepts the principle, one should adopt it here but not elsewhere. It is not clear to me that those espousing Cosmopolitanism only for medical tourism have a good answer to this question.
114. Mathias Risse, “What We Owe to the Global Poor” (2005) 9:1-2 *Journal of Ethics* 81 at 99-100 [emphasis in original]; see also John Rawls, *The Law of Peoples* (Cambridge, Mass: Harvard University Press, 1999) at 16 [Rawls, “*Peoples*”] (making a similar argument for the Statist approach);

Cosmopolitans), the “moral presumption against arbitrary inequalities is not a principle of universal application”; rather “[w]hat is objectionable is that we should be fellow participants in *a collective enterprise of coercively imposed legal and political* institutions that generates such arbitrary inequalities.”¹¹⁵ It is the “complex fact” that in societal rules establishing a sovereign state’s basic structure “we are both putative joint authors of the coercively imposed system, and subject to its norms, i.e., expected to accept their authority even when the collective decision diverges from our personal preferences – that creates the special presumption against arbitrary inequalities in our treatment by the system.”¹¹⁶

Increasing globalization does not change the picture, say Nagel and Rawls, because “it is not enough that a number of individuals or groups be engaged in collective activity that serves their mutual advantage”; that is, “mere economic interaction does not trigger the heightened standards of socioeconomic justice.”¹¹⁷ Nor does the existence of international institutions such as the United Nations or World Trade Organization (WTO) trigger those obligations, according to Nagel, because their edicts “are not collectively enacted or coercively imposed in the name of all the individuals whose lives they affect.”¹¹⁸ That is, “[n]o matter how substantive the links of trade, diplomacy, or international agreement, the institutions present at the international level do not engage in the same kinds of coercive practices against individual agents”; it is “[c]oercion, not cooperation, [that] is the *sine qua non* of distributive justice.”¹¹⁹

Michael Blake, “Distributive Justice, State Coercion, and Autonomy” (2001) 30:3 *Philosophy & Public Affairs* 257 at 285-89 (making a similar argument for the Statist approach).

115. Thomas Nagel, “The Problem of Global Justice” (2005) 33:2 *Philosophy & Public Affairs* 113 at 127-28 [emphasis added].

116. *Ibid* at 128-29; see Blake, *supra* note 114 at 265, 289.

117. Nagel, *supra* note 115 at 138; see also Rawls, “Peoples”, *supra* note 114 at 115-19 (making a similar point).

118. Nagel, *ibid*.

119. Blake, *supra* note 114 at 265, 289. Blake goes on to qualify this somewhat by indicating that this is “not to say that coercion does not exist in forms other than state coercion. Indeed, international practices can indeed be coercive – we might understand certain sorts of exploitative trade relationships under this heading, and so a theory concerned with autonomy must condemn such relationships or seek to justify them ...

All of this seems to construct a dead end for Statist support for distributive justice-based duties in the medical tourism sector, as can be gleaned by comparing the medical tourism case to Nagel's similar analysis of immigration. Nagel argues that, while "[t]he immigration policies of one country may impose large effects on the lives of those living in other countries," this is not sufficient to "imply that such policies should be determined in a way that gives the interests and opportunities of those others equal consideration."¹²⁰ This is because "immigration policies are simply enforced against the nationals of other states; the laws are not imposed in their name, nor are they asked to accept and uphold those laws" and it is a "sufficient justification" of these policies that they "do not violate [the immigrants'] prepolitical human rights."¹²¹ In a similar vein, the medical tourism policies of home countries – whether merely permitting their citizens to purchase medical tourism out-of-pocket, permitting insurer-prompted medical tourism, or, in the extreme case of government-prompted medical tourism, creating state incentives to use medical tourism – are not being imposed in the name of destination country citizens, nor are those citizens or their governments being forced to open themselves up to medical tourism.¹²²

Nevertheless, I believe there exist in Statist theories at least two open avenues for grounding some limited obligations of home countries and international bodies to regulate medical tourism or mitigate its negative effects on health care access in destination countries.

The first avenue stems from Rawls' recognition of a duty (separate from those relating to distributive justice) to assist "burdened societies" – those whose "historical, social, and economic circumstances make their achieving a well-ordered regime, whether liberal or decent, difficult if not impossible" – to "manage their own affairs reasonably and rationally"

[But] ... only the relationship of common citizenship is a relationship potentially justifiable through a concern for equality in distributive shares." *Ibid* at 265.

120. Nagel, *supra* note 115 at 129.

121. *Ibid* at 129-30.

122. See below notes 132-48 and accompanying text for a discussion of one complication related to the General Agreement on Trade in Services.

in order to become “well-ordered societies.”¹²³ These societies “lack the political and cultural traditions, the human capital and know-how, and, often, the material and technological resources needed to be well-ordered” but, with assistance, can over time come to “manage their own affairs reasonably and rationally and eventually to become members of the Society of well-ordered Peoples.”¹²⁴ Being a well-ordered society requires having a “decent system of social cooperation,” meaning that the state secures “a special class of urgent [human] rights, such as freedom from slavery and serfdom, liberty (but not equal liberty) of conscience, ... security of ethnic groups from mass murder and genocide” and formal equality, that citizens view their law as imposing duties and obligations “fitting with their common good idea of justice” and not “as mere commands imposed by force,” and that officials believe that “the law is indeed guided by a common good idea of justice,” not “supported merely by force.”¹²⁵

Can regulation of medical tourism by patients’ home countries or international bodies be justified on this rationale? Grounding medical tourism-related obligations in this kind of duty presents four challenges.

First, there is a question of coverage. Many of the destination countries in question may not be burdened societies; India, Mexico, Thailand and Singapore, for example, may have poor populations facing deficits in health care access, but they seem to meet Rawls’ more minimal criteria for being well-ordered. Thus, these obligations will apply, at most, only to medical tourism to a subset of destination countries. That itself is not fatal – the United States (or perhaps an international body) could theoretically prevent, tax, or allow incentives for medical tourism only to some destination countries in a manner akin to the “channeling” regimes I have elsewhere discussed¹²⁶ and return to in Part VI below – but it does complicate the picture, and it may be that the same factors that make these states burdened may make them unlikely to develop robust medical tourism industries.

123. Rawls, “Peoples”, *supra* note 114 at 90, 111.

124. *Ibid* at 106, 111.

125. *Ibid* at 66-68, 79.

126. Cohen, “Protecting Patients”, *supra* note 14 at 1515-23, 1559-61.

Second, there is a problem as to the kind of aid envisioned by this duty. Rawls seems focused on institution building, and Mathias Risse suggests the duty's targets as building things like "stable property rights, rule of law, bureaucratic capacity, appropriate regulatory structures to curtail at least the worst forms of fraud, anti-competitive behavior, and graft, quality and independence of courts, but also cohesiveness of society, existence of trust and social cooperation, and thus overall quality of civil society."¹²⁷ Foreign aid by home countries to help the destination countries improve their ability to produce more medical providers, or policy aid in designing health care system regulations designed to control how much time doctors spend in the public or private system – both factors likely to contribute to diminutions in access, as discussed above – seem to fit nicely into this category and are well-supported by this approach. It is less clear that the same is true of regulation aimed at trying to prevent or make it more expensive for home country patients to travel to the destination country for medical tourism.

Third and relatedly, Rawls cautions that "well-ordered societies giving assistance must not act paternalistically, but in measured ways that do not conflict with the final aim of assistance: freedom and equality for the formerly burdened societies."¹²⁸ Again, economic aid for those abroad does not seem unduly paternalistic (unless perhaps conditioned on certain ways of spending or meeting certain conditions), but attempts by home countries or international bodies to limit the use of medical tourism by their populations (out-of-pocket, insurer-prompted, or government-prompted) when the destination country is ready to take all-comers may run afoul of this limitation. Thus, this approach may limit the type of intervention a home state government can enact regarding medical tourism.

Fourth, it is also at least possible that the Rawlsian duty to aid burdened states might actually support leaving medical tourism unregulated (or even encouraging it). Because the duty does not aim to address diminutions in health care access caused by medical tourism (nor health needs at all *per se*), but instead fostering institution building, it is

127. Risse, *supra* note 114 at 85.

128. Rawls, "Peoples", *supra* note 114 at 111.

possible that medical tourism may actually help build institutions in the destination country aiding the burdened state while diminishing health care access for the destination country poor. For example, the rise in GDP and the need for corporate accountability to support a medical tourism industry attractive to Westerners might carry with it benefits to the destination country in terms of establishing the rule of law or property rights. If so, medical tourism might itself represent aid to burdened states even while it diminishes health care access to the destination country's poor.

Thus, the Rawlsian duty to aid burdened states seems to support only duties to help build up the health care capacity of the destination country and foreign aid more generally, and then only for the sub-set of states that qualify as burdened states. Further, those duties attach only so long as the burdened state has not transitioned to a well-ordered society; once it has made that transition, these duties are satisfied even if medical tourism continues to significantly diminish health care access in the destination countries. Finally, the duty to aid burdened states is also not a perfect fit for the argument because it is at least possible for medical tourism that diminishes health care access to the poor to itself serve in building institutions and aiding burdened states, in which case it ought to be encouraged or left alone rather than prohibited. Thus, the approach justifies only a much smaller sub-set of possible interventions regarding medical tourism, but does not rule out a duty of home state action entirely.

The other avenue is Nagel's separate conception of humanitarian duties of aid. Nagel suggests that "there is some minimal concern we owe to fellow human beings threatened with starvation or severe malnutrition and early death from easily preventable diseases, as all these people in dire poverty are," such that "some form of humane assistance from the well-off to those in extremis is clearly called for quite apart from any demand of justice, if we are not simply ethical egoists."¹²⁹ Although he is self-admittedly vague, he thinks "the normative force of the most basic human rights against violence, enslavement, and coercion, and of the most basic humanitarian duties of rescue from immediate danger,

129. Nagel, *supra* note 115 at 118.

depends only on our capacity to put ourselves in other people's shoes," and speaks of obligations to relieve others, whatever their nation, "from extreme threats and obstacles to [the freedom to pursue their own ends] if we can do so without serious sacrifice of our own ends."¹³⁰ In a similar vein, Michael Blake suggests a duty to provide "access to goods and circumstances" enabling people "to live as rationally autonomous agents, capable of selecting and pursuing plans of life in accordance with individual conceptions of the good" and singles out "famine, extreme poverty, [and] crippling social norms such as caste hierarchies," as the kinds of things against which we have obligations to intervene notwithstanding the citizenship of the victim.¹³¹

Can this approach ground duties relating to medical tourism? Fisher and Syed suggest that a duty of Western countries to expand access to drugs in LDCs can be grounded in these humanitarian duties because there "is little question that millions of people are suffering and dying from contagious diseases in developing countries and that the residents of developed countries could alleviate that suffering with relative ease."¹³²

A parallel argument, however, seems somewhat harder to make in the context of medical tourism interventions. For one thing, while we lack good empirical data on the ill effects of medical tourism on health care access abroad, it is unlikely at present that it is causing "millions of people" to die in destination countries – its effects are more marginal. Of course, the millions of deaths in the drug development case are not the *sine qua non* for humanitarian duties; there may be "early death from easily preventable diseases" that curbing medical tourism might prevent. Lack of access to care is as sure a killer as is famine or lack of needed pharmaceuticals, and, over a longer time horizon, its effects may be more significant. Still, we should be cautious when specifying the level of deprivation needed to trigger these humanitarian duties since the resulting duties are not medical-tourism-specific; that is, if we decide a particular kind of deprivation is enough to trigger our duty to intervene here, we will bear a comparable duty to all citizens of that

130. *Ibid* at 131.

131. Blake, *supra* note 114 at 271.

132. Fisher & Syed, *supra* note 68 at 649.

foreign country in comparable conditions. Too expansive a conception of the humanitarian duty will result in few meaningful differences between obligations of humanitarian and distributive justice and may have significant implications for issues like our general immigration policy that Nagel (and other Statists) have rejected.¹³³ That is, if the health care deficits experienced due to medical tourism are enough to ground humanitarian duties regarding medical tourism, should we not also open our immigration doors to those suffering comparable deficits in their home countries?¹³⁴ Too expansive a conception would raise the very pragmatic and political concerns about the scope of the demands placed upon us that we aimed to avoid by seeking a non-Cosmopolitan approach.

Second, the question of whether we “could alleviate that suffering with relative ease” or “without serious sacrifice of our own ends” (to use Nagel’s terms) is more difficult in this context in ways that mirror our discussion of Cosmopolitan theories. At least for medical tourism by those paying out-of-pocket and, to a lesser extent, for some forms of government-prompted medical tourism, trying to satisfy humanitarian duties to the global poor by curbing medical tourism is more likely to come at the expense of our own poor than in the pharmaceutical case. Thus, in the exceptional case, we may face tradeoffs not only between satisfying our humanitarian duties to our own poor versus those to the poor abroad, but also between our distributive justice duties to our poor and our humanitarian duties to the destination country poor. Neglecting our duties to our own poor patients would seem to count as “serious sacrifice of our own ends,” suggesting the obligations may more clearly attach to some forms of medical tourism, including insurer-prompted medical tourism, where paying more for health insurance is less clearly a “serious sacrifice of our own ends.” Similarly, the humanitarian duty

133. Nagel, *supra* note 115 at 129-30.

134. The “without serious sacrifice of our own ends” constraint discussed in the next section might be thought to distinguish the immigration case, although Nagel at least wants to dispose of the immigration case on the threshold question of whether humanitarian duties attach (*ibid*). In any event, as I discuss in the next paragraph, there are problems with that constraint as to medical tourism as well.

approach might more easily justify curbing medical tourism for services like cosmetic surgeries that are more penumbral to health. This restriction may also limit us to interventions that do not restrict access to health care via medical tourism for our citizens but instead aid the destination country in building capacity; even that is tricky, though, for dollars spent on foreign aid could always be reallocated to improving Medicaid coverage for America's poor, to give but one example.¹³⁵

Finally, notice that, like the Cosmopolitan theories, the duty towards humanitarian aid is actually somewhat divorced from medical tourism – if we have satisfied the duty of humanitarian aid, then even if medical tourism continues to have harmful effects on the destination country we have no obligation to restrict it; if foreign citizens still remain below the

135. A different way forward, at least in the US case, would be to get at the presumptive “root” of the problem prompting much of the medical tourism trade: that too many Americans are uninsured or underinsured or lack affordable care options, and turn to medical tourism as a solution. See Cohen, “Protecting Patients”, *supra* note 14 at 1479-81. In principle, that would be a very desirable solution, but the Obama Health Care Reform, the most ambitious move in this direction in the last fifty years, has been estimated by the most recent Congressional Budget Office (CBO) scoring to leave twenty-three million nonelderly residents uninsured if and when it is fully implemented in 2019, and countless more underinsured; Letter from Douglas W Elmendorf, Dir, Cong Budget Office, to Nancy Pelosi, Speaker, US House of Representatives (18 March 2010) table 2, online: Congressional Budget Office <<http://www.cbo.gov/publication/21327>>. That reform is now under significant attack in the courts, the Congress, and in US public opinion, but even if it withstands the barrage, the bill as passed would still leave many US users of out-of-pocket medical tourism, and it is hard to conceive that there will be political will to make the necessary investments to further reduce the number of un- and underinsured in the foreseeable future. Here again is a place where it seems plausible to me that the philosophical and policy discourse split – it may be that the United States ought to deal with medical tourism by cleaning its own house first, but if we concede (as I think we should) that this is not within the political feasibility set, then we are back in a philosophically second-best world where we must ask what steps the United States should take regarding medical tourism directly. Another way of putting this point is that in a world of ideal justice, there would be no uninsured medical tourists, and these comments should be understood as speaking to the non-ideal world. *C.f.* Rawls, “*Theory*”, *supra* note 88 § 39 at 244-46.

humanitarian level after medical tourism is eliminated or its harms are remedied, we still must aid more. To the extent that one was convinced that this aspect of Cosmopolitan theories was undesirable as a ground for duties as to medical tourism, one should also be wary of the Statist humanitarian duties approach.

While, as expected, the Statist theories reject grounding duties as to medical tourism in the distributive justice obligations to those abroad, there may be some room for obligations grounded in duties to aid burdened states or provide humanitarian aid. While the former may create obligations to help build institutional capacity to deliver health care abroad or foreign aid, it will not be appropriate for many destination countries. The latter may be more promising, but if the threshold for humanitarian need is kept relatively high, as I believe it should be, home countries will owe humanitarian duties relating to medical tourism only when acting will prevent grave humanitarian disasters and when the burden on home country citizens will not be serious. As I have argued, such duties will most likely affect only cases of insurer-prompted medical tourism and medical tourism for less-essential service and may be limited to providing aid rather than curbing the home countries' citizens' medical tourism use. Further, as with the Cosmopolitan theories, I have expressed concern that these approaches generate theories about satisfying health needs, rather than about obligations stemming from medical tourism.

D. Intermediate Theories

A final set of theories seeks to position itself between the Statist and Cosmopolitan camps. I consider two such intermediate theories and their application to medical tourism: the first is put forth by Joshua Cohen and Charles Sabel, and applied to health care by Norman Daniels, and the second is put forth by Thomas Pogge. I think these are the most fertile grounds for a Global Justice-based theory of obligations to regulate medical tourism because they generate a kind of theory more appropriate for the task: one that focuses on the harms and institutions stemming from particular existing practices rather than one that focuses on the relative holdings of particular individuals at the current moment and counsels a more general reallocation of primary goods. That said, as

applied to this specific problem, the theories run into some problems.

1. Cohen, Sabel & Daniels

The Cohen, Sabel, and Daniels approach suggests the Statists are too demanding in requiring coercion as the touchstone of distributive justice principles and also too “all-or-nothing” in the deployment of those principles. Instead, these authors propose lesser duties of “inclusion” internationally, which fall short of full-blown distributive justice but are greater than the minimal humanitarian duties endorsed by Statists: the state should treat those outside of the coercive structure of the nation-state as individuals whose good “counts for something” (not nothing) even if it falls short of the full consideration a state would give its own citizens.¹³⁶

Cohen and Sabel suggest these duties of inclusion may be triggered *inter alia* by the “coercion-lite” (my term) actions of international bodies such as the WTO; that is, “[e]ven when rule-making and applying bodies lack their own independent power to impose sanctions through coercion,” they still shape conduct “by providing incentives and permitting the imposition of sanctions” and “withdrawing from them may be costly to members (if only because of the sometimes considerable loss of benefits),” such that “[i]n an attenuated but significant way, our wills – the wills of all subject to the rule making-authority – have been implicated, sufficiently such that rules of this type can only be imposed with a special justification.”¹³⁷

They offer the example of the WTO, suggesting that “[o]pting out is not a real option” because no country in the developed or developing world could really survive without participation in the WTO, and once one is in for a penny, one is in for a pound; a member country cannot pick and choose which parts of the WTO’s demands to comply with, such that “there is a direct rule-making relationship between the global

136. See Joshua Cohen & Charles Sabel, “Extra Rempublicam Nulla Justitia?” (2006) 34:2 *Philosophy & Public Affairs* 147 at 154-55; Daniels, *supra* note 39 at 351.

137. Cohen & Sabel, *ibid* at 165.

bodies and the citizens of different states.”¹³⁸ They argue that for the WTO, duties of inclusion would mean that the rulemakers are “obligated to give some weight to the reasonable concern of the rule takers (who are themselves assumed to have responsibility to show concern for the interests of their own citizens).”¹³⁹

The authors also suggest consequential rulemaking by international bodies “with distinct responsibilities,” such as the International Labor Organization (ILO), might require those bodies to adopt duties of inclusion.¹⁴⁰ More specifically, they claim that this obligation follows from three facets of the ILO: that the ILO has taken on the responsibility for formulating labour standards (geared towards eliminating child and forced labour, ending employment discrimination, promoting collective bargaining, etc.); that the ILO claims that its rulemakings have significant consequences; and that the ILO believes that, if it were to disappear, no comparable entity would emerge.¹⁴¹

Daniels adds that certain kinds of international independencies may also give rise to duties of inclusion, giving the example of medical migration (brain drain). He argues that the International Monetary Fund (IMF)’s historical requirement that countries like Cameroon make severe cutbacks in their publicly-funded health care systems in order to reduce deficits that result in poorer working conditions for medical personnel (a “push” factor), combined with the attempt by the United Kingdom and other OECD countries to recruit medical personnel from developing countries (a “pull” factor), gives rise to a duty on the part of Western countries and the IMF to address the ill effects of this migration.¹⁴² Among the methods to satisfy that obligation, he urges altering “the terms of employment in receiving countries of health workers from vulnerable countries,” compensating for “the lost training costs of these workers,” “prohibit[ing] recruitment from vulnerable countries,” and “giv[ing] aid to contributing countries in order to reduce the push factor.”¹⁴³

138. *Ibid* at 168.

139. *Ibid* at 172.

140. *Ibid* at 170-71.

141. See *ibid*.

142. See Daniels, *supra* note 39 at 337-39.

143. *Ibid*.

Can this approach be readily applied to medical tourism? One might be tempted to draw three analogies, but each of them faces problems that make the medical tourism case harder than the ones these authors have taken on.

First, one might suggest that intermediaries, and particularly medical tourism accreditors like the Joint Commission International (JCI), bear some duties to build consideration of the effects of medical tourism to a particular facility on health care access for destination country poor into their accreditation processes, in analogy to the ILO example. One might argue that the JCI is like the ILO in that it has taken on responsibility for formulating standards, it claims its rules have significant consequences (determining who gets accredited, causing facilities to alter their procedures), and perhaps if it disappeared no other institution would take its place.¹⁴⁴

On reflection, though, the analogy is problematic. The JCI's role is to accredit foreign hospitals, specifically to examine their procedures and determine whether those procedures meet relevant standards of practice.¹⁴⁵ While this might be loosely thought of as a kind of "rulemaking," the JCI does not purport to regulate the medical tourism market, let alone to weigh the advantages or disadvantages of a particular country or particular hospital opening itself up to medical tourism. The same points apply even more strongly to intermediaries who are largely for-profit entities.

Second, we might analogize to the medical migration example and say that, for patients paying out-of-pocket, the lack of affordable health

144. This last point of comparison seems dubious. Even with the JCI in place, it faces competition in accreditation, including from the International Organization for Standardization (ISO). The ISO has a less popular certification program that has been used to certify some hospitals in Mexico, India, Thailand, Lebanon, and Pakistan. See Arnold Milstein & Mark Smith, "America's New Refugees – Seeking Affordable Surgery Offshore" (2006) 355:16 *New England Journal of Medicine* 1637 at 1639. Thus, if the JCI were to disappear, there is every reason to believe others would take its place. That said, while Daniels describes the ILO as having these three characteristics, it may be that meeting the first two is sufficient to ground the duties he has in mind.

145. See Cohen, "Protecting Patients", *supra* note 14 at 1485; Cortez, *supra* note 46 at 83-84.

insurance in the US system, and its failure to prevent insurer-prompted medical tourism, drives medical tourism, much like the United Kingdom's recruitment of foreign nurses drives migration. Accepting that analogy, however, would cause the intermediate theory to lose much of its appeal. In medical tourism by patients paying out-of-pocket, we do not have the US government or international bodies directly creating push and pull factors. True, the US government has not taken steps to prevent travel to India for medical procedures – for example, by criminalizing consumption in the way it does child sex tourism abroad under the *PROTECT Act* of 2003¹⁴⁶ – but if merely not acting and following a background norm of permitting travel to consume goods and services abroad is sufficient under Daniels' intermediate theory, the theory loses much of its attraction as a middle ground between the Cosmopolitan and Statist poles because so much of the day-to-day workings of international trade will trigger obligations under the theory.

That said, it seems to me that government-sponsored medical tourism initiatives such as that considered by West Virginia and that proposed for Medicare and Medicaid would fit the medical migration analogy quite well and might create US obligations to destination countries, at least insofar as tourism is incentivized and not merely covered in a way that is cost-neutral from the point of view of the patient. Medical tourism in universal health care countries prompted by long wait times might also better fit the analogy – the failure to produce sufficient medical practitioners in the patient's home country might prompt attempts either to recruit foreign providers (brain drain) or to incentivize medical tourism. However, the propriety of that last potential analogy seems to be a closer question, and it is unclear where the stopping point is from that analogy to the (problematic) conclusion that the fundamental organization of one's domestic health care system might trigger duties of inclusion internationally based on home country patients' reactions to it.¹⁴⁷

146. 18 USC § 2423(c), (f) (2006); see also Cohen, "Protecting Patients", *supra* note 14 at 1511-16 (discussing this as a possible intervention for regulating medical tourism).

147. To put the point in an exaggerated way: suppose that the underlying principle advocated by these authors was "for any domestic policy choice

Third, one might focus on the obligations some destination countries have undertaken to open up their health care sectors to medical tourism under the *General Agreement on Trade in Services* (GATS)¹⁴⁸ and argue that it plays a “coercion-lite” role analogous to the obligations of WTO membership discussed by these authors.¹⁴⁹ While GATS imposes general obligations that apply to all WTO members, it imposes obligations relating to “market access”¹⁵⁰ and “national treatment”¹⁵¹ on countries that have explicitly elected to be bound by them. These obligations – called “specific commitments” – are made as to particular service sectors and particular modes of service (consumption abroad, cross-border supply, etc.).¹⁵² Violations of these obligations are subject to trade sanctions. Medical tourism might be implicated by a country’s specific commitment to open up its “Hospital Services” sector, which includes *inter alia* surgical, medical, ob-gyn, nursing, laboratory, radiological, anesthesiological, and rehabilitation services.¹⁵³

our country makes, be it health, education, transportation, etc., we are responsible for remediating any effects that follow, whether the conduit is changes in trade, consumption, or travel by our populace.” That would make it mysterious why they paid such careful attention to particular institutional relations, such as the ILO, TRIPS, or poaching of doctors. On this principle that analysis was superfluous, the answer was much, much simpler. I thus have serious doubts that this is what these authors had in mind. Of course, that is a matter of interpretation. Perhaps more pointedly, if this is the principle that underlies the intermediate approach, it ceases to be a distinctive middle ground between the Cosmopolitan and Statist theories that can focus on particular institutional arrangements, coercion, and interdependency. Further, such a broad principle reintroduces the pragmatic policy-oriented worry I discussed above that the intermediate approach advantageously seemed poised to avoid.

148. 15 April 1994, 33 ILM 1167 (entered into force 1 January 1995) [GATS].

149. See Patricia J Arnold & Terrie C Reeves, “International Trade and Health Policy: Implications of the GATS for US Healthcare Reform” (2006) 63:4 *Journal of Business Ethics Reform* 313 at 315; Cohen, “Protecting Patients”, *supra* note 14 at 1521, n 213.

150. GATS, *supra* note 148 at art XVI.

151. *Ibid*, art XVII.

152. *Ibid*.

153. *Ibid*, art III; see also Arnold & Reeves, *supra* note 149 at 316-18 (discussing the relationship between GATS and trade in health services); Cohen, “Protecting Patients”, *supra* note 14 at 1521, n 213 (discussing

To be sure, the analogy (and thus, duties of inclusion) will only apply to countries that have undertaken obligations under GATS to open up their health care systems. Even as to these countries, though, the theory faces the self-inflicted wounds problem. The decision to become a signatory of GATS and open up one's medical system to medical tourism is itself within the control of the destination country, so how could it give rise to duties of inclusion on the part of the other signatories? In responding to a similar objection to their WTO example, Cohen and Sable suggest the point "seems almost facetious" because "[o]pting out is not a real option (the WTO is a 'take it or leave it' arrangement, without even the formal option of picking and choosing the parts to comply with), and given that it is not, and that everyone knows it is not, there is a direct rule-making relationship between the global bodies and the citizens of different states."¹⁵⁴ This same response, however, is much less persuasive in the GATS/medical tourism context because unlike the all-or-nothing WTO agreements, the GATS specific commitment obligations are incredibly versatile, with individual states making individual commitments as to individual modes for individual sectors.¹⁵⁵ The proof is to some extent in the pudding: as WTO officials Rudolf Adlung and Antonia Carzaniga recently observed, across the board there is a "generally shallow level of [GATS-specific] commitments on health services" with "no service sector[s] other than that of education [having] drawn fewer bindings among WTO Members than the health sector."¹⁵⁶ Indeed, in 2001 across all GATS modes only forty-four members made commitments as to hospital services and only twenty-nine to services provided by nurses, midwives, etc.; and, while there are generally more commitments in LDCs, the pattern is far from uniform.¹⁵⁷ Thus, the take-it-or-leave-it, offer-you-can't-refuse type of argument relied on by Cohen, Sable, and Daniels in their discussion seems to have less traction

the relationship between GATS and medical tourism).

154. Cohen & Sabel, *supra* note 136 at 168.

155. *Ibid.*

156. Rudolf Adlung & Antonia Carzaniga, "Health Services Under the General Agreement on Trade in Services" (2001) 79:4 Bulletin of the World Health Organization 352 at 356-58.

157. *Ibid.*

here.

This difficulty may not be fatal, and one way out might be to borrow two ideas from the philosophical work done by Gopal Sreenivasan on the effect of GATS rules on national choices and how those rules restrict efforts to expand public health care. In responding to a similar self-inflicted wounds problem, Sreenivasan first suggests (though he does not fully embrace the idea) that while “[v]olunteering for treaty obligations is an exercise of sovereign authority ... sovereignty and democratic legitimacy are not the same thing,” and the issue of democratic legitimacy turns on the “kind of popular mandate [that] existed for various decisions taken in relation to the GATS.”¹⁵⁸

This would obviously rule out the validity of GATS restrictions for dictator states, but also, he suggests, call into question the validity of other less-than-democratic forms of mandate: he contrasts the way GATS was subject to the possibility of a popular referendum in Switzerland before approval with the way the US Congress ratified the agreement not as a treaty, but as ordinary legislation, and did so via approval of the Uruguay Round, in which all the terms of the agreement had to be accepted or rejected at once.¹⁵⁹ By analogy, one could argue that because some of the destination countries also ratified GATS in these less-than-democratic ways, the fact that they chose to enter GATS should not stand in the way of establishing obligations to these countries on Daniels’ intermediate theory (*i.e.* compliance with GATS should not be considered a “self-inflicted wound”). Sreenivasan himself seems understandably ambivalent about how far to take this response, and wonders whether we should instead presume a popular mandate as to ordinary legislation.¹⁶⁰

Second, and I think more confidently, Sreenivasan argues that because GATS imposes obligations in an intergenerational sense and the penalties for exiting GATS are so large, GATS should be thought of as more akin to constitutional obligations, like a Bill of Rights, than ordinary legislation. Sreenivasan’s conclusion is not that “nothing can

158. Gopal Sreenivasan, “Does the GATS Undermine Democratic Control Over Health?” (2005) 9:1-2 *Journal of Ethics* 269 at 274-75.

159. *Ibid* at 275.

160. *Ibid* at 275-76.

confer democratic legitimacy on effectively compulsory obligations that span generations,” which “would certainly be going too far”; instead, his claim is that these kinds of obligations “require special measures of democratic scrutiny in order to gain legitimacy,” such as the supermajority and dedicated referendums that are commonly required for constitutional amendments.¹⁶¹

I do not attempt to fully assess the merits of Sreenivasan’s argument here. Instead, my more limited goal is to show that, although Sreenivasan’s work is on democratic legitimacy and not international justice obligations, it is possible that Cohen, Sable, and Daniels might graft his approach (or a variant of it) onto their own theory to offer a different kind of response to the self-inflicted wounds problem in the medical tourism context; indeed, this solution, suggested by the application to this case, may be a more generalized direction in which their theory might be extended. Doing so might mean that duties of inclusion arise as to medical tourism, but only as to the subset of destination countries who have made GATS commitments impinging on their ability to resist medical tourism, that (1) are dictatorships (or perhaps without a popular mandate) or (2) have ratified GATS in ways that do not meet specified requirements for democratic legitimacy of “effectively compulsory obligations that span generations.”¹⁶²

While this may adequately deal with the “self-inflicted” wounds problem relating to GATS, several of the triggering conditions for medical tourism’s negative effects on health care access in the destination country – the supply of health care professionals, whether the system is regulated in such a way that requires professionals to spend time in both the public and private systems – are, as I stressed above, also at

161. *Ibid* at 277-79.

162. I say “might” because one might counter that the self-inflicted wounds problem is “turtles, turtles all the way down.” If these features of the destination country’s political system led to deficits in ratifying GATS, one might counter that those features are themselves “self-inflicted wounds,” within the control of the destination country. On such an argument, it would not only be the GATS-ratifying decision itself, but also the constitutional or other political structure that sets up this mechanism for ratifying treaties that would itself have to have contain the features Sreenivasan suggests are necessary for democratic legitimacy.

least partially within the control of the destination country governments. These decisions represent ordinary legislation, not the extraordinary kind relating to GATS and, in most cases, will enjoy a popular mandate of some sort.¹⁶³

Do these kinds of self-inflicted wounds not blunt the claim that home country governments or international bodies bear responsibility for deficits associated with medical tourism? Yes and no. As Daniels has persuasively argued, even countries with similar domestic policies experience significant differences in population health, such that “[e]ven if primary responsibility for population health rests with each state, this does not mean that the state has [the] sole responsibility.”¹⁶⁴ In order to clarify home countries’ obligations, we ought to try to factor out the elements of destination countries’ population health deficits caused by medical tourism that are a result of the domestic policy decisions¹⁶⁵ and then apply the Cohen, Sable, and Daniels duties of inclusion only to the remaining deficits that meet the theories’ requirements.

This ability to apportion responsibility between the destination and home countries seems like a major theoretical advantage of this approach as against the prior ones discussed. Of course, while conceptually simple to state, actually doing such apportioning would be extremely difficult in practice, and the absolute best we can practicably hope for is a rough approximation. Thus, only in instances of medical tourism where a plausible case of “coercion-lite” or other pressure can be said to give rise to a duty of inclusion will such duties attach, and only then as to the proportion of the deficits caused by medical tourism to health care access by the destination country poor that is outside the control of the destination country.

163. Again, it remains open to press the stronger version of the argument about which Sreenivasan is ambivalent – that even ordinary legislation requires a form of direct democratic or supermajoritarian check to “count” as the will of the people for international justice purposes and create a self-inflicted wound. I feel ambivalent enough about this claim (as I think Sreenivasan does) that I would not want to press this as a way of avoiding the self-inflicted wounds problem, but others may find it a more appealing approach to the issue.

164. Daniels, *supra* note 39 at 345.

165. See *ibid* at 341-45.

Even if one of these routes validly triggers a duty of inclusion on some home countries or international bodies for some sets of medical tourism, there is the further question of what that duty entails. The authors are self-admittedly somewhat vague about the contours of these kinds of duties, telling us that it is not a duty of “equal concern” or redistributive justice on the one hand, but that it requires more than mere humanitarian duties on the other, and that it requires treating individuals abroad as individuals whose good “counts for something” (not nothing) while making decisions that will impact their life.¹⁶⁶

That leaves a fair amount of room to maneuver. One could imagine the duties mandating something like “notice and comment rulemaking” in administrative law – which would merely require acknowledging that these interests were considered, but found to be outweighed¹⁶⁷ – to something approaching a weighting formula in which the welfare of those abroad is counted as .8 while those in the nation state are counted as 1 (to use purely fictional discounting factors).

In discussing the brain drain example, Daniels seems to suggest duties of inclusion should have significant bite, arguing that they might prohibit recruitment from vulnerable countries, force recruiting countries to restrict the terms they offer foreign health workers, compensate for losses suffered when health care workers are lost, or give aid to help reduce push factors.¹⁶⁸ By analogy, in the context of medical tourism, such duties could perhaps require the United States to prevent its citizens from traveling abroad, channel its patients to medical tourism facilities or countries with programs to ameliorate health care deficits that result, tax medical tourists, intermediaries, or insurers, and use that revenue as aid aimed at amelioration, or provide more general aid to build institutional health care capacity in the destination country or, more appropriately, regulate its health care sector. I return to regulatory design options in greater depth in the next Part.

166. Cohen & Sabel, *supra* note 136 at 154-55; see also Daniels, *supra* note 39 at 351 (making a similar point in the health context).

167. See *Administrative Procedure Act*, 5 USC § 553 (2000); John F Manning & Matthew C Stephenson, *Legislation and Regulation* (New York: Foundation Press, 2010) at 604-40.

168. Daniels, *supra* note 39 at 353-54.

2. Pogge

A quite different intermediate theory, to which it will be difficult to give justice in this short space, is suggested by Thomas Pogge. Pogge begins with the idea that all people have rights to a “minimally worthwhile life” and therefore require a share of minimum levels of basic goods, including health care, that are essential to a decent life – he terms such goods “human rights.”¹⁶⁹ According to Pogge’s theory, citizens of one state have an obligation to avoid “harming” citizens of another state by imposing “deficits” on their access to these human rights; that is, he argues that “[w]e are harming the global poor if and insofar as we collaborate in imposing” a “global institutional order ... [that] foreseeably perpetuates large-scale human rights deficits that would be reasonably avoided through foreseeable institutional modifications.”¹⁷⁰

Pogge applies his approach to many examples, but the closest to ours is his claim that wealthy countries have an obligation to loosen their enforcement of the intellectual property rights of pharmaceutical companies to drugs that LDCs desperately need. In this application of his approach, Pogge suggests that “[m]illions would be saved from disease and death if generic producers could freely manufacture and market life-saving drugs” in those countries.¹⁷¹ Part of his ire is focused on the Trade-Related Aspects of Intellectual Property Rights (TRIPS) Agreement, membership in which was made a condition of joining the WTO and requires members to grant twenty-year product patents on new medicines. Pogge suggests that the TRIPS Agreement, which he claims was disastrous for LDCs, “foreseeably excludes the global poor from access to vital medicines for the sake of enhancing the incentives to develop new medicines for the sake of the affluent,” and asks, “[h]ow can the imposition of such a regime be justified to the global poor?”¹⁷²

169. Thomas Pogge, *World Poverty and Human Rights* (Cambridge, Mass: Polity, 2002) at 48-49; see also Fisher & Syed, *supra* note 68 at 644-45 (discussing Pogge’s account).

170. Thomas Pogge, “World Poverty and Human Rights” (2005) 19:1 *Ethics & International Affairs* 1 at 5; see also Daniels, *supra* note 39 at 337-39 (discussing Pogge’s account).

171. Pogge, *ibid* at 6; Pogge, *supra* note 169 at 74.

172. Thomas Pogge, “Access to Medicines” (2008) 1:2 *Public Health Ethics* 73

Pogge instead proposes a tax-based fund that operates as a prize system rewarding drug companies for their products' contribution to reductions in the global burden of disease.¹⁷³

In a second example paralleling one used by Cohen, Sable, and Daniels, he claims that many WTO policies cause human rights deficits because they permit the affluent countries' "continued and asymmetrical protections of their markets through tariffs, quotas, anti-dumping duties, export credits and huge subsidies to domestic producers," and thereby "greatly [impair] export opportunities for the very poorest."¹⁷⁴ In response, Pogge suggests that the rich countries have an obligation to "[scrap] their protectionist barriers against imports from poor countries," which he claims would lower unemployment and increase wage levels in those countries.¹⁷⁵

Might the same claims hold as to medical tourism? One might say it also "foreseeably excludes the global poor from access to" health care "for the sake of enhancing" the health care access and cost savings in the West. Further, like Pogge's own examples, one could say that medical tourism is supported by the existing institutional order insofar as that order facilitates things like international travel; standard settings; the accreditation of foreign hospitals; the training and credentialing of foreign doctors in the United States and other developed countries; etc.¹⁷⁶

However, there are a few problems (or at least open questions) that become manifest through this application to medical tourism. First, what is the content of a human right to health? Or, to put it otherwise, how

at 75.

173. *Ibid* at 76-78.

174. Pogge, *supra* note 170 at 6.

175. *Ibid.* As a descriptive matter, Pogge's account of the negative effects of TRIPS is not without dissenting view. See e.g. Rachel Brewster, "The Surprising Benefits to Developing Countries of Linking International Trade and Intellectual Property" (2011) 12 *Chicago J Int'l L* 1.

176. See generally Cortez, *supra* note 46 (discussing the way these things facilitate medical tourism); Aaditya Mattoo & Randeep Rathindran, "How Health Insurance Inhibits Trade in Health Care" (2006) 25:2 *Health Affairs* 358 (presenting a similar discussion); Graham T McMahon, "Coming to America – International Medical Graduates in the United States" (2014) 350:24 *New England Journal of Medicine* 2435 (discussing the reliance on foreign doctors in the US health care system).

much health care must one have before one's human rights are being violated?¹⁷⁷ In answering this question, the theory faces a problem that parallels one we discussed for Nussbaum and Sen – if the threshold is set too low, the negative effects of medical tourism may not cause a “deficit” to the human right; if the threshold is set too high, then it will cause a deficit, but so will not allowing that tourism to go forward (given the needs of the American patients using medical tourism). Pogge has offered a response to a somewhat similar criticism by suggesting the *proviso* to his theory that “these human rights deficits must be reasonably avoidable in the sense that a feasible alternative design of the relevant institutional order would not produce comparable human rights deficits or other ills of comparable magnitude.”¹⁷⁸ But, as in our discussion of a somewhat similar *proviso* by Nagel, one might wonder what “reasonably avoidable” really means and how much of the institutional order we should feel free to redesign in a given moment. Once again, this problem seems least acute for insurer-prompted medical tourism and medical tourism for services like cosmetic surgery.

Second, Pogge has tried to avoid some of the pragmatic and political feasibility problems of the Cosmopolitan theories by trying to use a kind of act-omission distinction, with the ideas of “harm” and “imposing ... deficits.” But, as Daniels has remarked, “[i]nternational harming is complex in several ways. The harms are often not deliberate; sometimes benefits were arguably intended.” Daniels has also argued that “harms are often mixed with benefits” such that “great care must be taken to describe the baseline in measuring harm,” and the “complex story about motivations, intentions, and effects might seem to weaken the straightforward appeal of” Pogge's theory.¹⁷⁹ To illustrate: as in Pogge's examples (by hypothesis), the existence of the phenomenon of medical tourism leads to a “deficit” in one human right – health care – and one might say that medical tourism is supported by the existing

177. *C.f.* Daniels, *supra* note 39 (asking whether Pogge's human right to health is frustrated “[w]hen a country fails to meet the levels of health provided, say, by Japan, which has the highest life expectancy” at 337).

178. Thomas Pogge, *World Poverty and Human Rights: Cosmopolitan Responsibilities and Reforms* (Cambridge, Mass: Polity, 2008) at 26.

179. Daniels, *supra* note 39 at 340.

institutional order insofar as that order facilitates things like international travel, standard setting, and accreditation of foreign hospitals. But do these institutional elements “harm” the human right to health care of destination country citizens in our case?¹⁸⁰

In Pogge’s examples, we have identifiable state and international actors, chief culprits if you will, at whom he can point the finger as actors who caused the deficit in question: the WTO, the TRIPS Agreement, and those who support them.¹⁸¹ For medical tourism, by contrast, we

180. In discussing Pogge’s proposal to create a prize system to spur innovation in drugs targeting the global burden of disease, Daniels critiques whether what is going on is really “harming” versus “not optimally helping?” Daniels, *supra* note 39 at 337. A similar worry seems less apposite as to medical tourism where it is the actions of home country citizens that are setting back the interests of those abroad, assuming *arguendo* that medical tourism makes the Indian poor worse off than they would otherwise be.

181. Others writing in much the same vein as Pogge on access to essential pharmaceuticals in LDCs have emphasized similar facts about this context that strain the analogy to medical tourism and suggest the case for Global Justice obligations may be much stronger in the pharmaceutical context. For example, Outterson and Light, working on an analogy to duties to engage in easy rescue when there are special relationships, suggest several specific reasons why that analogy is applicable in the drug context: the fact that “the patent-based drug companies created the global intellectual property system and are actively preventing rescue by others” with the explicit goal of prohibiting “free trade of low-priced generics from the emerging pharmaceutical industries in developing countries” thereby having created the danger, the fact that the drug companies receive public monies and are able to block development through the patent system, and (according to these authors) the fact that that innovation rewards could be set up in such a way to make this a case of “easy rescue” wherein pharmaceutical companies would not lose much if anything from their bottom line. Kevin Outterson & David W Light, “Global Pharmaceutical Markets” in Helga Kuhse & Peter Singer, eds, *A Companion To Bioethics*, 2d ed (Malden, Mass: Wiley-Blackwell, 2009) 417 at 417-29. None of these points seems true as to the United States’ or other home countries’ involvement in medical tourism by those individuals paying out of pocket. That said, some elements (such as the use of public funds) are more analogous to government-prompted medical tourism, and some of these points (pursuit of profit-maximizing strategies that may run counter to destination-country health care access) may in appropriate cases provide reasons for subjecting medical tourism intermediaries to the same approbation these authors foist on drug companies. This latter point on corporate social responsibility raises questions beyond the scope

have a much more complex web of acts and omissions that together form the system. We have the private decisions of individual citizens in the home country to satisfy health care needs in a foreign country, which seems like causing harm, but that need may be itself caused by a state-level failure to secure universal health care, or even more indirectly by the failure to adopt more redistributive taxation approaches. What about the role played by US health insurance companies in pricing their plans that in part determines how many Americans are uninsured (which, in turn, is partially a function of the wage demands of health care workers)? We also have the background international law and trade principles allowing for free travel by citizens to foreign states and the consumption of goods and services abroad, but are those causes of deficits?¹⁸² To put the point another way, the baseline against which Pogge's concept of harm is drawn is extremely slippery as to medical tourism – a problem that legal realism has emphasized in legal discourse.¹⁸³

of this article, which is focused on governmental and intergovernmental obligations.

182. Larry Gostin has made a similar point as to these kinds of theories more generally: "National policies and globalization have benefited the rich and contributed to global health disparities, but so have many other factors. Blame for harms in the Third World, however, is hard to assess. States usually do not intend to cause harm to poor countries, and political leaders may believe they are doing good. International policies, moreover, often have mixed benefits and harms that defy any simple assignment of blame. Finally, countries themselves may have contributed to the harms due to inadequate attention to population health, excessive militarization, or simple incompetence or corruption. At bottom, reasonable people disagree as to who bears the responsibility for health inequalities and who owes a duty to right the perceived wrongs." Gostin, *supra* note 68 at 345-46.
183. It is also worth emphasizing that not every "harm" in the sense that Pogge uses the term may morally obligate us to compensate the victim. If I open up a flower shop next door to yours, and my shop siphons off your best florists by offering higher wages that causes a diminution in your business, we do not ordinarily think that I have wrongfully harmed you or that I owe you recompense for the setback to your interest. This is true even if I open my shop with the intention of driving you out of business. If this is the mechanism by which medical tourism reduces access to health care for the destination country poor (one of several of the possible mechanisms I sketched above) – that doctors who served the destination country poor instead move over to the medical tourism facility to treat their patients

All that said, I do not want to overstate the point. The subset of government-sponsored medical tourism seems to nicely parallel Pogge's own examples: this form of medical tourism has both a clear causal pathway of "harm" and easy-to-specify institutional rearrangements, such that under Pogge's view, it should give rise to obligations on home countries. How well the theory extends into medical tourism by patients purchasing out-of-pocket (or even insurer-prompted medical tourism), however, is less clear.

VI. Convergence, Divergence & Policy Prescriptions

In this article, I have tried to tackle head-on the pressing question of medical tourism and access to health care abroad. While I hope to have made some progress, part of the point has been to show how complex the issue is and how, on the philosophical side, it identifies *lacunae* and poses hard questions for many major theories.

I began by identifying the biggest unknown in the question – what effect medical tourism is actually having on health care access in the destination country – and have sought to assist the empirical project of answering that question by specifying several plausible triggering conditions through which we would expect medical tourism to reduce access to medical services for the poor in the destination country.

Assuming *arguendo* that the empirical claim that medical tourism impairs health care access by the destination country poor in some cases is satisfied, I then examined the normative question: under what conditions would a diminution in health care access by the destination country poor due to medical tourism trigger obligations on the part of home countries and international bodies? I rejected the simplest argument appealing to national self-interest in restricting medical tourism because it is implausible. I then examined three broad camps of Global Justice theory (Cosmopolitan, Statist, and Intermediate) as grounds for obligations, but

– it seems that the facility should similarly not owe recompense or remediation; if the medical tourism facility does not owe the destination country poor for this action, why should the home country whose causal role in the harm is still more attenuated? I am indebted to Nir Eyal for this suggestion.

that examination has not pointed in one clear direction. I have expressed a preference for the approach of the Intermediate theories because they try to offer us a theory of obligations stemming from medical tourism, rather than a more general theory of what we owe to those abroad quite divorced from medical tourism. In particular, the institutional-focused approach of Cohen, Sable, and Daniels seems to me an extremely fertile way forward in this area, though I have suggested reasons why its actual application to this case study might suggest a more restricted set of obligations than that championed by many of the commentators (academic and popular) discussed in the introduction.

Taking a step back, what can we say about the larger landscape of Global Justice theories, access to health care, and medical tourism? While I think a true overlapping consensus or incompletely theorized agreement between these different theories eludes us in this area, I do think it is fair to say we can identify two “central tendencies” among the group of theories: insurer-prompted medical tourism and government-prompted medical tourism are the areas where the argument that states and international bodies have a moral obligation to intervene is the strongest, for two different (but on some theories also overlapping) reasons. The case for curbing insurer-prompted medical tourism is stronger because preventing these services is less likely to expose the state’s own citizens to deficits in health care access,¹⁸⁴ which would be in tension with the same concerns regarding those abroad. Similar reasoning suggests that there is a greater obligation to restrict medical tourism for inessential services or services that are more penumbral to the concept of health (such as cosmetic surgery and, on some accounts, fertility tourism). The case for intervening in government-prompted medical tourism is stronger because there is a fairly direct causal tie between the state’s action and the deficits caused by medical tourism (which matter on the intermediate theories). Claims of an obligation on the part of the home country government or international bodies to do something about medical tourism by those

184. To be sure, as I cautioned above, even restricting insurer-prompted medical tourism poses some risk of diminution in access domestically; it is just that it appears to pose less of that risk such that the case for intervention is concomitantly stronger.

purchasing essential services out-of-pocket seem concomitantly weaker.

Beyond these central tendencies, however, there is a fair amount of divergence among the theories in picking out which circumstances give rise to obligations (*e.g.*, only medical tourism to “burdened states”? Only medical tourism to states whose method of ratifying GATS seems suspect?) and whether there are limits on the means by which those obligations can be met (only foreign aid, targeted or otherwise, or more paternalistic attempts to control the flow of home countries’ patients as well?). The Nagelian conception of humanitarian aid might be thought of as a floor on which these other theories can add, but, as I have shown above, its demands are somewhat independent of medical tourism and instead stem from the existence of desperate need, regardless of its causal relation to medical tourism.

In any event, my ambition here has been to lay out the terrain of Global Justice theories, their application to medical tourism, and the problems that arise from that application.¹⁸⁵ Going further and deciding the exact content of those obligations requires choosing between these rival theories and filling many of the *lacunae* I have identified in their application. Although I have made some tentative suggestions here and there, I have not attempted that task in this paper. Instead, my goal has been to open a dialogue between moral and political theorists and those making on-the-ground policy prescriptions relating to medical tourism’s negative effects on the health of the poor in the destination country.

My own tentative conclusion is that there is a more persuasive case for restricting insurer-and government-prompted medical tourism, and medical tourism for services that are inessential or more in the penumbra of “health.” By contrast, due to concerns about health care access in the home country, I find less convincing the case for restricting medical tourism for those purchasing essential health services out-of-pocket, especially when this represents these individuals’ best way of getting these services.¹⁸⁶

185. While my own theoretical preferences lean towards the Cohen, Sable, and Daniels approach as the most useful approach in this area, I have tried to maintain a relatively Catholic attitude towards the different contenders so as to pave the way for those more drawn to one of the rival accounts.

186. One lingering concern with that conclusion is that it seems to “reward”

Interestingly, that ordering mirrors my conclusions on the policy side as to the ease by which home states can implement policies to curb medical tourism of different varieties, as I have suggested in other work on medical tourism.¹⁸⁷

For government-prompted medical tourism, the United States could, by regulation or legislation, restrict facilities or countries to which it sends patients to those with health care access guarantees or amelioration plans. It could also leave the market unregulated but dedicate foreign aid to destination countries based on the volume of medical tourism to particular regions. Of course, in so doing, it would have to rely on foreign sovereigns to spend aid appropriately or devise a system whereby nongovernmental organizations (NGOs) are given the aid or monitor its spending. As long as such policies did not result in significantly longer waiting times or fewer procedures covered, the effect on health care access for the US poor would be small.

For insurer-prompted medical tourism, the United States could by state or federal insurance regulation prevent sending patients to facilities or countries without health access amelioration plans.¹⁸⁸ The United

the “bad” countries that have not secured universal health care in their home state, and thus have given more of their domestic poor the incentive to go abroad. Of course, it is beyond cavil that countries like the United States that have failed to secure truly universal health care have not failed to do so in order to be able to send their poor abroad for medical tourism without acting unjustly, but that does not seem an adequate response. Here are two that may be more (if not entirely) satisfying. First of all, to repeat something I said earlier, *supra* note 135, in a world of ideal justice, the United States would have achieved universal health care, but we are faced with a very different world and are asking what obligations we can realistically impose upon it under the circumstances. Second, while we may be “rewarding” the “bad” states, we also want to avoid “punishing” their poor citizens who lack better options than medical tourism.

187. See Cohen, “Protecting Patients”, *supra* note 14 at 1506-17, 1544-46. For a more in-depth discussion of the tools and drawbacks for regulating medical tourism, including extensive discussion of home country, destination country, and multilateral possibilities for regulations, see I Glenn Cohen, “How To Regulate Medical Tourism” [unpublished, archived at Virginia Journal of International Law Association] [Cohen, “How to Regulate”].
188. *C.f. ibid* at 1544-46. But see *supra* note 51 and sources cited therein for skepticism as to how well such regulation is actually enforced in a

States could also (in addition or separately) tax insurers by their volume of medical tourism and redistribute those sums towards health care access amelioration in the destination country. This would mirror to some extent the UNITAID scheme; UNITAID is an NGO aimed at scaling up access to treatment for HIV/AIDS, malaria, and tuberculosis, primarily for people in low-income countries. A large share of its funding (72 percent) stems from twenty-nine supporting countries (including France and Chile) that have voluntarily chosen to impose on airlines departing from their countries a tax on departing passenger tickets collected by the airlines set by the country – for example, France imposes a €1 and €10 tax on domestic economy, and a €4 and €40 tax on departing international flights, respectively.¹⁸⁹ One might also think about this in analogy to the use of taxes on tobacco products to offset some of the costs those products impose on the health care system.

It is much harder to regulate the behavior of US medical tourists paying out-of-pocket. Even here, though, we do have some options. The United States could hypothetically render illegal some forms of medical tourism (compare the *PROTECT Act*, making it a crime to engage in child sex while abroad), or render less attractive some forms of medical tourism (for example, by exempting them from the tax deduction available for qualifying medical expenses), but as I have said before, I worry that these regulatory interventions are either too draconian or not terribly effective.¹⁹⁰ The United States could also tax intermediaries and use the revenue to support health care access in LDCs (in a way similar to that discussed above) or try to force JCI to build health care access into accreditation standards. Less paternalistically, the United States or international bodies could create a separate third-party labeling or accreditation standard that audits facilities and informs tourists of how attentive a facility is to health care access concerns regarding the local population, as Nir Eyal has proposed under the moniker “Global Health Impact Labels” in analogy to Fairtrade Coffee.¹⁹¹ I have some

destination country such as India.

189. About UNITAID online: UNITAID <<http://www.unitaid.eu>>.

190. Cohen, “Protecting Patients”, *supra* note 14 at 1511-15.

191. Nir Eyal, “Global Health Impact Labels” in Ezekiel Emanuel & Joseph Millum, eds, *Global Justice in Bioethics* (Oxford: Oxford University Press,

doubts about how effective these labels are likely to be, since medical tourism patients are likely to choose facilities based on quite different and much more important priorities (for example, location of service, quality of doctor, and price) than coffee drinkers, though to be fair, this is an empirical question. Finally, foreign aid is always a possibility.

These are, for the most part, unilateral strategies focused on what steps medical tourist patients' home states could take. Destination country and multilateral strategies are also possible, but for reasons I have discussed in greater depth elsewhere, these seem less feasible.¹⁹²

Destination country governments can tax medical tourism providers and redistribute the proceeds to pay for health care access for the poor, regulate the behavior of their physicians and impose requirements that they spend certain amounts of their time serving domestic rather than foreign patients, require a uniform reimbursement rate or limit the disparities, etc. In destination countries where certificates or other licensure is required in order to build a new hospital or expand an existing one, the government can limit the number of entrants into the medical tourism market that exist or extract commitments (such as those pertaining to providing care for indigents) from the facilities. There are many other possible interventions, and the exact details will vary country by country, depending on their existing domestic health care regulation.

However, to the extent medical tourism offers an influx of foreign capital to the destination country and its costs occur mostly to the destination country poor (many of whom may be somewhat disenfranchised in the political system), there is a clear conflict of interests between those who regulate and those who are burdened by medical tourism. Even when these regulations are formally put in place, there is no guarantee destination country governments will enforce them or that the regulations will be much more than a paper tiger, as several commentators have suggested regarding medical tourism in India.¹⁹³

2012) 241.

192. Cohen, "How to Regulate", *supra* note 187.

193. See *e.g.* Johnston et al, *supra* note 37 at 1; Gupta, *supra* note 37; see also Chinai & Goswami, *supra* note 49 (discussing the Confederation of Indian Industry certification system for medical tourist facilities that requires hospitals "to limit the charges to foreigners as part of a dual

Turning to the multilateral approach, we have thus far not seen multilateral trade agreements pertaining to trade in health services, even in the places where such agreements would seem most natural. While the United States has pushed for more harmonization of the health care systems covered by the North American Free Trade Act (NAFTA), those calls have thus far been resisted by Canada and Mexico.¹⁹⁴ While the European Union has the most comprehensive regulatory regime for trading health services in the world – requiring *inter alia* national health insurance systems in member states to cover treatments in other member states, and mutual recognition of the credentials of doctors, nurses, and pharmacists – the World Health Organization (WHO) has concluded that “there has been little progress in developing a common regulatory framework for health services or in establishing common standards of training and practice,” and stated that “[r]egulation of professional practice in health care remains very different across the member countries.”¹⁹⁵

Although it is in theory possible for the WHO to make rules governing medical tourism through the powers granted to it by the International Health Regulations, I share with others skepticism that this is a likely way forward – importantly, it would mean straying a fair amount from the International Health Regulations’ origins and its purpose, the prevention of disease migration.¹⁹⁶ Similarly, the multiple references to a human right to health in the UN Charter, International Covenant on Economic, Social, and Cultural Rights, WHO constitution, and elsewhere have thus far resulted in remarkably little international health care regulation,¹⁹⁷ and given the various powerful pro-medical tourism

pricing system that offers domestic patients lower prices,” but noting that “even these lower prices are too high for the vast majority of India’s 1.1 billion population” at 164-65).

194. Nathan Cortez, “Patients Without Borders: The Emerging Global Market for Patients and the Evolution of Modern Health Care” (2008) 83:1 Ind LJ 71 at 128.
195. *Ibid*, quoting Rupa Chanda, “Trade in Health Services”, WHO Communication on Macroeconomics and Health, (2001) Working Paper Series, 1, 73, Paper No WG 4:5.
196. See Gostin, *supra* note 68 at 375-81.
197. See *Universal Declaration of Human Rights*, GA Res 217A(III), UNGAOR, 3rd Sess, Supp No 13, UN Doc A/810, (1948) 71; *International Covenant on Economic, Social, & Cultural Rights*, 16

constituencies, regulation restraining the medical tourism industry seems unlikely as a starting place for such an approach. Gostin has proposed a Framework Convention on Global Health, of which medical tourism could certainly play a part, but as he recognizes, there are formidable obstacles to achieving this goal, such that middle-or short-term action of this sort seems unlikely.¹⁹⁸

VII. Conclusion: From Medical Tourism to Health Care Globalization

A number of authors in both the popular and academic literature have expressed concern about the effects of medical tourism on access to health care for the poor of the destination country and have claimed that this is a normative problem calling for regulatory intervention. In this article, I have broken down this claim into its empirical and normative components and put pressure on both. On the empirical side, I have noted the current absence of evidence for diminutions in health care access by the destination country poor due to medical tourism, and tried to specify triggering conditions that could be further studied by developmental economists under which this diminution would be most likely. Assuming *arguendo* that such negative effects occur, I then examined the normative question of destination country governments and international bodies' obligations as to medical tourism having such effect. I canvassed Cosmopolitan, Statist, and Intermediate theories, and suggested ways in which application of these theories to medical tourism highlights gaps and indeterminacies, as well as reasons why some of these theories may not be good fits for this kind of applied ethics inquiry, and built on existing discussions of pharmaceutical pricing and medical migration. I have tried to map divergences and convergences between these theories, and tentatively conclude that the claim for Global Justice obligations stemming from medical tourism is strongest (but not without problems) for insurer-and government-prompted medical tourism and

December 1966, 999 UNTS 302, S Exec Doc D 95-2 1978; *Constitution of the World Health Organization preamble*, 22 July 1946, 14 UNTS 185, art 1, 62 Stat 2679; Gostin, *supra* note 68 at 381.

198. Gostin, *supra* note 68 at 383-91.

for tourism for inessential services, such as cosmetic surgeries, while it is quite weak for medical tourism by those paying out-of-pocket for essential services. Finally, I have outlined the types of regulatory policy levers available to developed countries and international bodies to seek to remedy deficits in destination country health care access due to medical tourism.

While my focus has been on medical tourism, as I suggested above, I think the discussion here has some important implications for analysis of other manifestations of the globalization of health care, and indeed, perhaps, for globalization more generally. Here are six tentative lessons I think the work I have done in this article might teach us in shaping future analyses.

First, at the highest level, while it is somewhat philosophically “impure,” I think the method of analysis provided here is useful, especially for work aimed at policymakers. The empirical and normative approaches are jointly necessary in establishing the need for action. More subtly, within the normative sphere, it is useful to consider both more and less demanding theories of Global Justice and to map their convergences and divergences; even if one thinks some of these theories are “too stingy” or “get it wrong,” they are useful for persuading policymakers and other audiences that one need not be a full-blown Cosmopolitan (with all the implications that would mean) in order to justify some actions. Thus, in medical migration (the medical brain drain), it is helpful to show, for example, that even on the narrower Statist approaches, the duty to aid burdened states may establish obligations to engage in institution-building so as to educate providers and increase capacities; on the Cohen, Sabel, and Daniels Intermediate approach, the existence of rulemaking bodies with some claim of dominion over the field (the ILO, according to Daniels) and the international interdependence fostered by push and pull factors may ground the need for action; and on the Poggean approach, the more that migration is thought of as the unjust “taking” of doctors, the more easily obligations to avoid or mitigate that activity can be understood as flowing from an obligation to avoid “harming” a “human right” to health.

Second, I think that the national self-interest arguments for

Western governments intervening in medical tourism are also weak in other instances of health care globalization. For example, I think such arguments suffer similar deficits as to medical migration. To adapt those arguments: even assuming *dubitante* that patients in the country where migrating doctors go (the “receiving country”) suffer indirectly because these new physicians provide lower quality care – or there is an increase in disease transmission to the receiving countries because of the depletion of providers in the sending country (the country from which the doctors migrate), or the sending country’s citizens are less able to purchase our goods due to their poorer health caused by migration, or migration increases immigration pressure from sending countries or national security threats to receiving countries – these negative effects are likely outweighed by the self-interested benefits of migration for the receiving country. Thus, just as with medical tourism, it seems as though we will need some form of Global Justice theory to ground obligations to intervene.

Third, the cleavage I have introduced between types of Global Justice theories has broader application to other instances of health care globalization and globalization more generally. The Cosmopolitan theories and the duty of humanitarian aid under Statist theories do not offer us a theory of when we are responsible for harms stemming from medical tourism, medical migration, or other forms of globalization, but instead a theory of when we ought to improve the lives of the badly-off simpliciter. Let me illustrate with medical migration. Again, in one sense, causation matters: only if restricting migration causes an improvement in the well-being of those in the sending country (up to a capability threshold, up to the threshold of humanitarian needs, or in the interest of increasing welfare, depending on the theory) are we required to take the action. In another sense, however, causation in the historical and responsibility senses is irrelevant because it is the mere fact of the other country’s citizens’ needs that imposes upon us the obligation to help them in whatever way we can, and not anything about migration and its effects specifically. Thus, in one direction, the duties may persist even when migration is halted or its harms are remedied in that the source of the obligation is not anything we have done, but instead the destitute state of

those abroad. In the other direction, once the theories' goals are met, we do not bear an obligation (at least under distributive justice principles) to prevent migration or remedy its ill effects, even if migration continues to produce significant health care deficits for the destination country poor that would not occur if it were curbed. Moreover, it is possible that other forms of aid or assistance might "cancel out" whatever negative effects migration has in terms of the global Cosmopolitan calculus.

In effect, these theories tell us to help those in the sending country who are badly-off by curbing or mitigating the effects of medical migration, regardless of whether that migration caused them to be badly off; this is to be contrasted with a different group of theories (such as several variants of the Intermediate approach) that would urge us to curb medical migration because it causes people in the sending country to become worse off. This distinction does not make the latter group of theories "better" than the former, but it does suggest they may be better suited at answering questions about the Global Justice implications of a particular manifestation of globalization (such as medical tourism or migration) as opposed to questions of redistribution between nations at the highest level of generality.

Fourth, my analysis here draws attention to the "self-inflicted wounds" problem that is endemic in attempts to address Global Justice concerns regarding negative impacts of globalization as well as ways to deal very directly with this concern. Again, to use medical migration as an example, there are ways in which some sending countries might increase the supply of health care providers to mitigate migration's negative effects but do not do so because of the lobbying efforts of members of the profession seeking to protect their wages by reducing supply. Moreover, there are ways in which some of these sending countries might implement programs that help them retain more providers in the face of the pull of recruiting countries, not only by improving employment conditions (easy to recommend, hard to implement), but through mechanisms like conditional scholarships that require a number of years of in-country service as a condition for forgiving student loans for medical school.¹⁹⁹

199. See *e.g.* Delanyo Dovlo & Frank Nyongator, "Migration by Graduates of the University of Ghana Medical School: A Preliminary Rapid Appraisal"

Especially on the Intermediate theories of Global Justice, the fact that a sending country in principle has these interventions available but in practice does not use them ought not to completely immunize receiving countries from Global Justice obligations, but it should also not be completely ignored in the calculus. Rather, we ought to try to factor out the elements of the sending country's population health deficits caused by medical migration that are a result of the domestic policy decisions and then apply the obligations of Global Justice to only the remainder of deficits.

As to one more specific variant of the "self-inflicted wounds" problem relating to obligations to open up one's service sector to medical tourism undertaken as a GATS signatory, I have offered an analysis that could equally be employed as to other kinds of treaty obligations relating to trade – a recurring problem as to Global Justice analysis of globalization. To the extent the obligations under these treaties span generations and are effectively compulsory due to their penalties for defection or exit, I have suggested that they might count as self-inflicted wounds reducing other countries' Global Justice obligations only insofar as these treaties meet heightened requirements for democratic legitimacy such as referenda rather than the standards of ordinary legislation.

Fifth, the analysis here has emphasized that medical tourism is a heterogeneous practice and that its different constituent forms (government-prompted, insurer-prompted, out-of-pocket, etc.) may lead to different Global Justice analyses. I have also suggested we need to pay careful attention to who benefits in the home country from medical tourism, and their counterfactual care and welfare if the practice is stymied. The same seems true as to other manifestations of health care globalization. Again, let me use medical migration to illustrate. Just as I have suggested that there is a greater obligation to restrict medical tourism for inessential services or services that are more penumbral to the concept of health (such as cosmetic surgery), it seems to me that medical

(1999) 3:1 Human Resources For Health Development Journal 40; Nir Eyal & Till Bärnighausen, "Conditioning Medical Scholarships on Long Future Service: A Defense" [unpublished, archived at Virginia Journal of International Law Association].

migration is most problematic when it would recruit sending country physicians to provide services that are inessential or penumbral to health in the receiving country. This might, for example, serve as a basis for limiting the recruiting of less developed sending country physicians for US (or Canadian or other) cosmetic surgery (or other) medical residency programs, but not residencies in other specialties. It might also lead us to allow recruiting of foreign physicians only for underserved areas in the receiving country and not more generally.

I have also argued that the case for intervening in government-prompted medical tourism is stronger because there is a fairly direct causal tie between the state's action and the deficits caused by medical tourism (which matter on the Intermediate theories). Similarly, there may be a stronger argument for intervention in medical migration in cases where a receiving country's governmental health care system – such as the National Health Service (NHS) in Britain, or the individual provinces in Canada – are the ones directly recruiting physicians from places like Ghana, as opposed to cases involving recruitment by individual private hospitals.²⁰⁰ To be sure, there are many ways in which this analogy is inexact. Unlike individual patients traveling abroad for health care, with hospitals recruiting foreign physicians, we are still dealing with institutions, and thus the Intermediate theories are better-poised to impose duties upon them. Moreover, since governmental health care systems tend to achieve better domestic distributive justice by ensuring universal coverage, there may be something worrying about penalizing them in terms of Global Justice in the analysis as compared to more privatized systems, although perhaps not if that universal coverage is attained through improper

200. The Canadian provinces are single-payers, but the doctors are individual contractors, not employees of the provinces, and hospitals may be publicly or privately owned. In the British National Health Service, by contrast, physicians in general practice are capitated employees, while specialty physicians are salaried employees of the National Health Service (NHS), and hospitals are primarily publicly owned. See *e.g.* Deborah J Chollett, "Health Financing in Selected Industrialized Nations: Comparative Analysis and Comment" excerpted in Mark A Hall et al, *Health Care Law and Ethics*, 7th ed (New York: Aspen Publishers, 2007). I leave it to other work to consider whether these differences between the two systems may be relevant in the analysis.

physician recruitment from less developed countries.

Again, I do not aim for what I have said here to provide a final analysis of Global Justice issues in medical migration, let alone other forms of health care globalization or globalization more generally. Instead, I have aimed to show how my analysis of these issues in regards to medical tourism helps us identify the right questions to ask as to the larger field of health care globalization, and perhaps globalization generally.

'Orphaned' Transplantable Organs: Law, Ethics, and Ownership

Remigius N Nwabueze*

The legal status of an organ, in the period between its extraction from the body of a donor and its implantation in the body of a recipient, is unclear. In that period, the excised organ might be said to be orphaned because of its ambiguous custodial and proprietary status, and a host of activities might take place which could jeopardise its safety or viability for transplantation. For instance, what happens if the organ was lost or damaged in transit? Not inconceivably, a thief might snatch the organ from the possession of the transplant team; a transplant surgeon could use the organ for the treatment of their relative or close friend, a celebrity, or an influential political figure, instead of transplanting the organ into the properly selected and designated recipient contrary to the established allocation criteria. The excised organ might be damaged maliciously by a third party, say, an enemy of the proposed recipient who was bent on frustrating the recipient's only means of receiving a life-saving treatment. Further, a live donor might change their mind on donation to the potential recipient after the organ has already been extracted.

While these scenarios raise an interesting mix of legal, ethical, political and social questions, a fundamental enquiry that permeates the whole gamut of issues engendered by the hypothetical above is the question of ownership and proprietary entitlement to an excised (orphaned) organ. Accordingly, this article interrogates the question of proprietary control or ownership of an orphaned organ.

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I. Introduction

The legal status of an organ,¹ in the period between its extraction from the body of a donor and its implantation in the body of a recipient, is unclear.² In that period, the excised organ might be said to be *orphaned* because of its ambiguous custodial and proprietary status. Recently, Kowal deployed a similar conceptualisation to capture the ethical ambiguity shrouding the problematic use of indigenous Australian DNA samples collected many decades ago for medical and scientific research, which are now stored away in institutional freezers around Australia.³ She

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1. An organ is defined as a “differentiated and vital part of the human body, formed by different tissues, that maintains its structure, vascularisation and capacity to develop physiological functions with an important level of autonomy.” Human Tissue Authority, *Code of Practice 2: Donation of Solid Organs for Transplantation* (UK: Department of Health, 2013) at Glossary, online: Human Tissue Authority <<http://www.hta.gov.uk/legislationpoliciesandcodesofpractice/codesofpractice.cfm>> [*HTA, Code of Practice 2*].
 2. Similarly, the Nuffield Council on Bioethics observed that there is “uncertainty around the legal status of materials that are donated for transplantation: for example, the status of an organ that is being treated prior to transplantation.” Nuffield Council on Bioethics, *Human Bodies: Donation for Medicine and Research* (London: Nuffield Council on Bioethics, 2011) at para 7.21, online: Nuffield Council on Bioethics <<http://www.nuffieldbioethics.org/project/donation>>.
 3. Emma Kowal, “Orphan DNA: Indigenous Samples, Ethical Biovalue and Postcolonial Science” (2013) 43:4 *Social Studies of Science* 577.

considers such DNA samples to be *orphaned* because of their separation from the underlying affective networks, in that both the sources and the scientific collectors or guardians of the samples are no longer traceable.⁴ However, analytical commentaries on the question of orphaned organs are generally few and far between. Yet, in the context of donation and transplantation of organs, the resolution of a significant range of legal liability issues depends on the appropriate legal characterisation of an *orphaned* organ.

In that penumbral period within which an organ is orphaned, a host of activities might take place which could jeopardise the safety or viability of the organ for transplantation. Pertinently, the Nuffield Council on Bioethics has drawn attention to the increasingly complex transactions and multiple intermediaries involved in the process of organ donation and transplantation,⁵ which not only highlights the central role played in the process by organisations and organisational structures, but also points to “the added complexities in the form of ... liabilities and obligations that may arise where donated material is transformed, banked or otherwise handled as a commodity by successive intermediaries.”⁶ For instance, the prevailing organ allocation criteria and donor-recipient matching result in a particular case might warrant the transportation of an excised organ across local, regional, state or national boundaries. But what happens if the organ was lost or damaged in transit? Not inconceivably, a thief might snatch the organ from the possession of the transplant team; a transplant surgeon could use the organ for the treatment of their relative

4. *Ibid* at 589.

5. Similar complexities and transactional variability are also evident in the biobanking arena and use of excised body parts for research. See Bronwyn Parry, “Entangled Exchange: Reconceptualising the Characterisation and Practice of Bodily Commodification” (2008) 39:3 *Geoforum* 1133. See also Nils Hoppe, *Bioequity – Property and the Human Body* (Farnham: Ashgate Publishing, 2009) at 25-26.

6. Nuffield Council on Bioethics, *supra* note 2 at para 1.31.

or close friend,⁷ a celebrity,⁸ or an influential political figure,⁹ instead of transplanting the organ into the properly selected and designated recipient contrary to the established allocation criteria. It might also be the case that the excised organ was maliciously damaged by a third party,¹⁰ say, an enemy of the proposed recipient who was bent on frustrating the recipient's only means of receiving a life-saving treatment. Further, and quite imaginatively, a live donor might change their mind on donation to the potential recipient after the organ has already been extracted.¹¹

While these scenarios raise an interesting mix of legal, ethical, political and social questions, which are often quite difficult to segregate,¹²

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7. While Norrie suggested that such a surgeon could be held liable "for abuse of his position," he did not specify the cause of action or the basis for such a legal liability. Kenneth M Norrie, "Human Tissue Transplants: Legal Liability in Different Jurisdictions" (1985) 34:3 ICLQ 442 at 467.
 8. Consider the controversy surrounding the liver transplant received by the legendary American baseball star, Mickey Mantle, who stayed on the waiting list for only two days. Peter Gorner & Peter Baniak, "Mantle's New Liver: A Question of Ethics: Experts Find No Favoritism After Speedy Transplant", *Chicago Tribune* (9 June 1995) 3N.
 9. Also, consider the controversy surrounding the heart-liver transplant to Governor Casey of Pennsylvania in 1993 – he received his transplant after waiting for only twenty-four hours on the list. Claudia Coates, "Casey's Quick Transplant Renews Ethics Debate: Medicine: Pennsylvania governor got heart and liver within 24 hours of getting on list, under guidelines giving priority to those who need multiple organs", *Los Angeles Times* (25 July 1993). See generally Phyllis Coleman, "'Brother, Can You Spare A Liver?' Five Ways To Increase Organ Donation" (1996) 31:1 Val U L Rev 1.
 10. This compares to the US case of *US v Arora*, 806 F Supp 1091 (Md Dist Ct 1994), where a scientist employed by the US government destroyed human cells cultured by his colleague as an acute expression of the animosity existing between the two. The US government succeeded in a conversion action against the wrongdoer.
 11. This might be well taken care of by an excellent informed consent procedure, in which the donor is informed, and agrees, that they can no longer change their mind after a particular point had been reached in the procedure; this point might be defined differently by others and could be fixed, for instance, at the point of extraction from the donor, at the commencement of the recipient's surgical procedure, or after implantation in the recipient.
 12. Childress observed that "[o]rgan allocation policy involves a mixture of ethical, scientific, medical, legal, and political factors, among others."

a fundamental enquiry that permeates the whole gamut of issues engendered by the hypothetical above is the question of ownership and proprietary entitlement to an excised (orphaned) organ. Put differently, who owns or should exercise proprietary control over an orphaned organ? Interestingly, Nelson observed that the “question of how viable human organs ought to be categorized remains tricky,” mainly because “organs aren’t fully property, as they cannot be sold. Nor are they fully public goods, as society may not use them at will.”¹³ Similarly, Childress observed that it “took me some time to discern that our debates about ‘equitable access’ and ‘equitable allocation’ were, in part, debates about who ‘owns’ donated organs.”¹⁴ In the same vein, Cronin and Price, after suggesting that the debate on directed and conditional organ donation could be resolved on the basis of donor ownership or control, observed that the question of ownership was “no longer an issue that can be skirted around.”¹⁵ However, the paucity of judicial and academic commentaries on that question belies the increasing recognition of its criticality in potentially resolving the conundrum highlighted in the hypothetical above.

It might be, as Cronin and Douglas have suggested, that the “complexities of transplantation appear to have discouraged litigation. Few, if any, judicial rulings or comments exist,” meaning that the “law of organ donation is rather unsatisfactory.”¹⁶ As if in anticipation of this problem, Lord Justice Rose observed, in *R v Kelly*,¹⁷ that an excised organ that has a use or significance beyond its mere existence, such as where it is “intended for use in an organ transplant operation,” might be regarded

James F Childress, “Putting Patients First in Organ Allocation: An Ethical Analysis of the U.S. Debate” (2001) 10:4 Cambridge Quarterly of Healthcare Ethics 365 at 365.

13. James L Nelson, “Trusts and Transplants” (2005) 5:4 American Journal of Bioethics 26 at 27.
14. Childress, *supra* note 12 at 366.
15. Antonia J Cronin & David Price, “Directed Organ Donation: Is the Donor the Owner?” (2008) 3:3 Clinical Ethics 127 at 130.
16. Antonia J Cronin & James F Douglas, “Non-Standard Kidneys For Transplants: Clinical Margins, Medical Morality, and the Law” (2013) 21:3 Med L Rev 448 at 458.
17. [1999] QB 621 (CA).

as property.¹⁸ Unfortunately, the facts in *R v Kelly* did not require Rose LJ to resolve the question of title to an excised organ, as it was sufficient for that case to hold that the scientifically preserved anatomical specimens belonged to the Royal College of Surgeons, through the work or skill exception,¹⁹ and, therefore, those specimens were capable of being stolen under the *Theft Act*.

Accordingly, this article interrogates the question of proprietary control or ownership of an orphaned organ: does it belong to the donor, the donee, the state or community, or the potential recipient? Also, what are the justifications for the proprietary control exercised by the owner of an orphaned organ? In that sense, the concern here is not about devising an effective framework for increasing the supply of transplantable organs,²⁰ nor is it generally about negligent liability arising from the transfer of defective organs or performance of a transplantation procedure.²¹ It should also be stated that the focus is on the law of England and Wales, though relevant comparisons have been made to comparable jurisdictions.

II. Donor's Proprietary Entitlement

Is an orphaned organ the property of the donor? If it is, the donor should retain certain rights over the organ and, in addition, be subject to certain liabilities in relation to the organ. The following analysis requires a distinction between living and cadaveric donors since different considerations apply to each category.

18. *Ibid* at 631.

19. The origin of the exception is the Australian High Court case of *Doodeward v Spence*, (1908), 6 CLR 406 (HCA) [*Doodeward*] (establishing ownership of a cadaver or a part of cadaver through transformative work on it).

20. However, for a regulated market framework for increasing organ supply, see James S Taylor, *Stakes and Kidneys: Why Markets in Human Body Parts are Morally Imperative* (Farnham: Ashgate Publishing, 2005); for retaining the current altruistic approach, see Debra Satz, *Why Some Things Should Not Be For Sale: The Moral Limits of Markets* (New York: Oxford University Press, 2010); for a hybrid of altruism and limited market, see Michele Godwin, *Black Markets: The Supply and Demand of Body Parts* (New York: Cambridge University Press, 2006).

21. Norrie provides a good analysis of that aspect. See Norrie, *supra* note 7.

A. Cadaveric Donor's Entitlement

Analysis of the cadaveric donor's proprietary entitlement should begin with the *Human Tissue Act 2004*²² which regulates cadaveric organ donation in England, Wales and Northern Ireland; the Act established the Human Tissue Authority as the regulatory body. In Scotland, however, cadaveric donation is regulated by the *Human Tissue (Scotland) Act 2006*,²³ and the Human Tissue Authority established under the 2004 Act helps to administer the 2006 Act.²⁴ Both statutes contain fairly similar provisions, with the difference that while the 2004 Act uses the language of *consent* as its overall and fundamental regulatory principle, the 2006 Act uses the language of *authorisation* for cadaveric donation. The focus here is on the 2004 Act.

The 2004 Act is a product of scandal relating to the unauthorised removal, use and storage of cadaveric paediatric tissues and body parts in England,²⁵ prompting Mason and Laurie to say that it was “born under the wrong star.”²⁶ A brief overview of the scandal is necessary, not only to unpack the moral, ethical and legal underpinnings of the 2004 Act, but also to illuminate the proprietary analysis undergirded by the 2004 Act. It all started with a public inquiry, chaired by Sir Ian Kennedy, into children's heart surgery at the Bristol Royal Infirmary.²⁷ In the course of that inquiry, Professor RH Anderson, a professor of Morphology at the Hospital for Sick Children, London (Great Ormond St Hospital),

22. (UK), c 30 [2004 Act].

23. (UK), Asp 4.

24. See JK Mason & GT Laurie, *Mason & McCall Smith's Law & Medical Ethics*, 9th ed (Oxford: Oxford University Press, 2013) at 581.

25. For a discussion of the scandal and the litigation that followed it (*AB v Leeds Hospital NHS*, [2004] EWHC 644 (QB)), see Remigius N Nwabueze, “Interference with Dead Bodies and Body Parts: A Separate Cause of Action in Tort?” (2007) 15 Tort Law Review 63.

26. Mason & Laurie, *supra* note 24 at 581.

27. Bristol Royal Infirmary Inquiry, *The Report of the Public Inquiry into Children's Heart Surgery at the Bristol Royal Infirmary 1984-1995: Learning from Bristol* (London: Stationery Office, 2001); see also the Interim Report published by the inquiry: Bristol Royal Infirmary Inquiry, *Interim Report - Removal and Retention of Human Material* (London: Stationery Office, 2000).

testified and commented on the benefits of heart collections for research and study. He particularly commended the excellent collection of hearts at the Royal Liverpool Children's NHS Trust in Alder Hey hospital; this triggered another inquiry into the removal, use and storage of cadaveric organs at Alder Hey, chaired by Michael Redfern, QC.²⁸ The Redfern inquiry heard evidence relating to the emotional distress suffered by the parents of the deceased children when they learned that some parts of their children's bodies were removed, used or retained without their consent. For instance, one of the parents testified that "[i]t feels like body snatching. The hospital stole something from me. They have taken us back 11 years in our healing process."²⁹ Other parents expressed similar anguish: "[t]hey gave me skin and bone back"; "Alder Hey stole 90% of my child"; "I feel devastated. I am wondering how much of her body was left"; and "I have learnt to live with my daughter's death and now I have found out that they removed her heart. It is like losing her all over again."³⁰ However, other parents were not as much opposed to the removal and use of their deceased children's tissues as they were opposed to the failure of the hospital authorities to study those tissues. For instance, a parent lamented: "[s]tudying her brain would help explain why her brain did not form properly and it might help treat the next child born with a similar condition. Unfortunately her brain has not been studied. Instead it sits in a jar in a storeroom somewhere."³¹ In short, the Redfern Report catalogued a series of deception on the part of the medical authorities, in part engendered by the lack of transparency and insufficient disclosure procedures adopted for post-mortem examinations carried out on the deceased children.³² As a result, there was significant public distrust of the medical system and healthcare professionals.³³

Importantly, the Redfern inquiry observed that the practice of

28. The House of Commons, *The Royal Liverpool Children's Inquiry* (London: Stationery Office, 2001).

29. *Ibid* at 19.

30. *Ibid*.

31. *Ibid*.

32. *Ibid* at 22-23.

33. Margaret Brazier, "Retained Organs: Ethics and Humanity" (2002) 22:4 LS 550 at 556.

unauthorised removal, use or retention of cadaveric tissues was facilitated by the ambiguous provisions of the *Human Tissue Act 1961*.³⁴ The 1961 Act, which was then the relevant legislation, enabled a hospital in lawful possession of a dead body to remove its tissues or organs for research or transplantation, even when it was not known to the hospital that the deceased or their family objected to the removal, use or storage of the body part. Thus, under the 1961 Act, it was not clear whether the hospital should be proactive and seek or obtain the consent of the deceased's families, where the deceased did not express wishes in that regard prior to their deaths, or whether it was the burden of the deceased's families to make conscious efforts to register their objection to cadaveric donation. Among other things, therefore, the Redfern inquiry recommended the repeal of the *Human Tissue Act 1961*, and the promulgation of new legislation that would make explicit consent the cornerstone requirement for the removal, use and storage of cadaveric tissues and body parts. The government accepted this recommendation, and accordingly the 2004 Act was enacted. It contains seven scheduled purposes, including organ donation and transplantation, which can only be performed with the prior consent of a specified person.³⁵ Thus, consent is the conceptual framework upon which the superstructure of the 2004 Act rests.

Under the 2004 Act, an organ might be retrieved from the body of a deceased person in two situations.³⁶ First, where the deceased consented to donation during his or her lifetime, the organ could be lawfully removed by the transplant team without reference to the deceased's family.³⁷ In practice, however, organ retrieval authorities endeavour to inform the family of the deceased about the donation, and are unlikely to

34. (UK), c 54.

35. 2004 Act, *supra* note 22, s 1.

36. Note that the *Human Tissue Act 2004* does not govern coronial activities. In circumstances where coronial jurisdiction is triggered, such as the sudden and unexplained death of a person, the Coroner is entitled to the lawful possession or custody of the deceased for the purposes of coronial inquiry, and might therefore order the anatomical examination of the deceased and authorise the removal of any organ of the deceased that bears on the cause of death. See generally John Jervis et al, *Jervis on the Office and Duties of Coroners*, 12th ed (London: Sweet & Maxwell, 2002).

37. HTA, *Code of Practice 2*, *supra* note 1 at para 95.

proceed with the donation against the family's objection.³⁸ Second, where the deceased's prior wishes about donation are not known, their family might be contacted with a view to ascertaining what the deceased's wishes were, or might have been,³⁹ and if positive, the family would be asked to consent to donation.⁴⁰ Thus, going by the history and express provisions of the 2004 Act, it is clear that a deceased donor is empowered to exercise significant control and decisional authority over the use of their organs.⁴¹ Control power of this sort over one's organs qualifies as a proprietary interest. Interestingly, this sort of psychological aspect of property has been highlighted by the Nuffield Council on Bioethics, by observing that the concept of ownership can be "used with a broader moral resonance," in the sense that "when people talk about 'owning' their bodies or body parts, even if they use the language of property, their primary concern is with *control* over those materials."⁴²

A control-based property right, that is, "a person's position as the primary arbiter over what is to be done with a thing,"⁴³ acutely expresses the title holder's personhood and promotes their autonomy.⁴⁴ The ability to isolate and particularise the control elements of property, as analysed

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38. *Ibid* at para 99. See also Sonya Norris, *Organ Donation and Transplantation in Canada* (Ottawa: Library of Parliament, 2009) at 14, online: Parliament of Canada <<http://www.parl.gc.ca/Content/LOP/researchpublications/prb0824-e.htm>>.
39. For a detailed discussion of the family's fallibility in predicting the deceased's wishes regarding donation, as well as the role of families in cadaveric organ donation, see TM Wilkinson, *Ethics and the Acquisition of Organs* (Oxford: Oxford University Press, 2011) at 64-79.
40. HTA, *Code of Practice 2*, *supra* note 1 at paras 98, 100.
41. But this power could be significantly undermined by the family's (practical) power of veto, which, as Wilkinson observed, might conflict with the deceased's posthumous personal sovereignty. See Wilkinson, *supra* note 39 at 76-79.
42. Nuffield Council on Bioethics, *supra* note 2 at para 5.18 [emphasis in the original].
43. John Christman, "Distributive Justice and the Complex Structure of Ownership" (1994) 23:3 *Philosophy & Public Affairs* 225 at 231 [Christman, "Distributive Justice"].
44. Margaret J Radin, "Property and Personhood" (1982) 34 *Stan L Rev* 957. For an interesting criticism of Radin, see Neil Duxbury, "Do Markets Degrade?" (1996) 59:3 *Mod L Rev* 331.

above, has been facilitated by the bundle of rights theory's disaggregation of property.⁴⁵ For instance, the bundle of rights theory projects *property* as an indefinite bundle of sticks, in which each stick represents a separate and protectable proprietary interest.⁴⁶ The greatest accumulation of such sticks, qualitatively and quantitatively, amounts to ownership.⁴⁷ However, Christman has argued that *full ownership*, in the sense of comprising all the sticks in the bundle, is neither possible nor justifiable on the basis of the Lockean natural rights theory of property, because Locke's theory embeds positive duties to others, entailing equal rights to the share of resources, which countervails the idea of full ownership.⁴⁸ For this reason, Christman has suggested that there is no unified or monolithic concept of ownership; rather, ownership is comprised of two congeries (or a bipartite package) of sticks in the bundle of rights concept of property,⁴⁹ and thus, there is "no *conceptual* reason to understand ownership only as the full set of liberal rights."⁵⁰ Nevertheless, a single stick or lesser collection of sticks not approximating to ownership is still protectable as a proprietary interest,⁵¹ even when not coextensive with the stick of alienation.

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45. Grey provides an excellent analysis of the fragmentation of property. TC Grey, "The Disintegration of Property" in JR Pennock & JW Chapman, eds, *Property, Nomos 22* (New York: New York University Press, 1980) at 69-85.
46. SR Munzer, *A Theory of Property* (Cambridge: Cambridge University Press, 1990) at 23 (however, Christman disagreed with this view, arguing that *property* is better normatively seen as a collection of rights that fall into two categories of *control* and *income* rights). Christman, "Distributive Justice", *supra* note 43 (thus, Christman suggested that a single stick in the bundle of property rights, considered individually and in isolation from the bipartite groups of property rights, does not carry much normative importance).
47. GP Wilson, "Jurisprudence and the Discussion of Ownership" (1957) 15:2 Cambridge LJ 216 at 222.
48. John Christman, "Can Ownership Be Justified By Natural Rights?" (1986) 15:2 Philosophy & Public Affairs 156.
49. John Christman, "Self-Ownership, Equality, and the Structure of Property Rights" (1991) 19:1 Political Theory 28 at 37.
50. Christman, "Distributive Justice", *supra* note 43 at 229 [emphasis in original].
51. Grey in Pennock & Chapman, *supra* note 45.

The bundle of rights theory of property is exemplified by Honoré's classic work on ownership,⁵² in which he listed eleven standard incidents of ownership, all or congeries of which might be recognised by a mature legal system as constituting ownership.⁵³ More interestingly, Honoré's list serves to highlight some of the individual sticks in a bundle of property rights; these include an owner's management right – that is, the right to control the use of a particular resource. Apparently, this right is coextensive with the statutory requirement for *inter vivos* consent to cadaveric donation under the 2004 Act. Put differently, by making lawful cadaveric donation dependent on the *inter vivos* or pre-mortem consent of a donor, the 2004 Act has imbued donors with (control-based) proprietary interests in their excised organs. Envisioning a similar analytical strategy for the US, Robertson observed that there were no third party rights to a donated cadaveric organ that could supersede the wishes of the donor because “the donor's autonomy is fundamental, and ... the organs are hers until she donates them.”⁵⁴ As could be surmised from the above quotation, the only question that remains to be considered is when the donor's proprietary interest could be understood as exhausted or transferred to a potential recipient: is it at the point of extraction of the organ, or at any point up to implantation into the body of the recipient? This question requires an interrogation of the law of gifts, which, for completeness, is fully examined below in connection

52. Wall argued that Honoré's framework is incomplete unless coupled with trespassory rules, especially the trespassory rules developed by Guido Calabresi & A Douglas Melamed, “Property Rules, Liability Rules, and Inalienability: One View of the Cathedral” (1972) 85:6 Harv L Rev 1089; Jesse Wall, “The Legal Status of Body Parts: A Framework” (2011) 31:4 Oxford J Legal Stud 783. For a criticism of Wall, arguing that trespassory rules are remedial or compensatory, rather than normative, see Remigius N Nwabueze, “Body Parts in Property Theory: An Integrated Framework” (2014) 40:1 Journal of Medical Ethics 33. Nwabueze's view also resonates with Getzler's. Joshua Getzler, “Theories of Property and Economic Development” (1996) 26:4 Journal of Interdisciplinary History 639 at 660.

53. AM Honoré, “Ownership” in AG Guest, ed, *Oxford Essays in Jurisprudence* (New York: Oxford University Press, 1961) 107.

54. Christopher Robertson, “Who Is Really Hurt Anyway? The Problem of Soliciting Designated Organ Donations” (2005) 5:4 American Journal of Bioethics 16 at 17.

with living donations. It suffices to say that significant policy and pragmatic considerations would infuse any answer to the question above. Meanwhile, and consistent with the analysis below on the delivery of gifts, it is suggested that a cadaveric donor's gift is effective to transfer a proprietary interest to the recipient when the organ is retrieved from the donor with the intention of transplanting it to a recipient already selected from the waiting list, according to the prevailing allocation criteria,⁵⁵ or to a recipient specified by the donor (in systems that permit directed cadaveric donation).

A view favouring the proprietary entitlement of a cadaveric donor is bound to impact significantly on a wide-range of issues relating to organ donation and transplantation. For instance, consider the current public policy on organ procurement and allocation in England, which generally prohibits a *directed* or *conditional* donation of organs of deceased persons.⁵⁶ Such a policy would be gravely undermined by the recognition of the deceased donors' proprietary interests, since it would enable them to determine the specific beneficiary of donated organs, or the destination of the organs. Similarly, a proprietary interest would empower donors to attach certain lawful conditions to the use of their

55. Generally, a recipient is selected from the relevant waiting list before a donated organ is excised from the cadaveric donor. See Institute of Medicine, *Organ Procurement and Transplantation: Assessing Current Policies and the Potential Impact of the DHHS Final Rule* (Washington, DC: National Academy Press, 1999) at 115.

56. A *directed* donation occurs when an organ is donated for the benefit of a specific person. A donation is *conditional* when it is meant for the use of a class defined by race, religion or similar factors. The policy prohibiting directed and conditional cadaveric donation was enunciated following a scandalous donation of a deceased relative's organ subject to the condition that it be used for Caucasians only. Department of Health, *An Investigation into Conditional Organ Donation* (London: Department of Health, 2000); for a severely limited exception to the prohibition, see Department of Health, *Requested Allocation of Deceased Donor Organ* (London: UK Health Administrations, 2010). See generally Antonia J Cronin & James F Douglas, "Directed and Conditional Deceased Donor Organ Donations: Laws and Misconceptions" (2010) 18:3 Med L Rev 275 [Cronin & Douglas, "Directed and Conditional"]; Shaun D Pattinson, "Directed Donation and Ownership of Human Organs" (2011) 31:3 LS 392.

donated organs.⁵⁷ While no view is taken here on the propriety of such an outcome (as it is not the focus of this article), the point is that it would jeopardise the current criteria for organ donation based on altruistic and unconditional donation,⁵⁸ and organ allocation based on clinical factors, such as the relative urgency of a potential recipient's medical needs, and the probability of a successful transplantation outcome. Nevertheless, a proprietary approach in favour of the donor creates legal certainty and would help to resolve some of the conundrum highlighted in the introduction. For instance, the estate of the deceased should be able to sue for the loss of an orphaned organ, or damage to it. Similarly, the theft of an excised organ could be the subject of a criminal prosecution since the organ would qualify as property belonging to the deceased. In addition, the deceased's estate could maintain an action in conversion against the unauthorised use or malicious destruction of the organ. But as with rights, liabilities also are bound to follow. Thus, the estate of the donor could (potentially) be sued for various issues in connection with the donation, such as the withdrawal of the organ in violation of the recipient's settled expectations or reliance on the donation; the donor's estate could also be sued where the organ turned out to be infectious due to contamination by an undisclosed disease.⁵⁹

B. Justification of Cadaveric Donor's Proprietary Entitlement

While the proprietary approach above provides a neat solution and framework of analysis for the hypothetical in the introduction of this article, it still begs the question of justification. In other words, why should the deceased donor be the owner of an orphaned organ?⁶⁰ What

57. This view is supported by both Cronin & Douglas, *ibid*; Pattinson, *ibid*.

58. Alasdair Maclean, "Organ Donation, Racism and the Race Relations Act" (1999) 149 New LJ 1250 at 1250-52.

59. The issue arose, but was not litigated, in *Ravenis v Detroit General Hospital*, 234 NW (2d) 411 (Mich App Ct 1975), where the defendant-hospital transplanted to the claimants infected corneas harvested from a deceased donor. While the donor was not sued, the defendant was held liable to the claimants in negligence.

60. Nor, arguably, should the organ belong to the deceased's family. Note that Wilkinson has argued persuasively that the deceased's family interest in an

are the moral, ethical and legal justifications for vesting such proprietary entitlement in the deceased donor? In the wake of the Alder Hey and Royal Liverpool Infirmary scandals discussed earlier, there was a collective sense of morality in England and Wales that the removal, use and storage of cadaveric organs (and other body parts) must be based on prior consent from the deceased, the deceased's designated representative, or a family member of the deceased. Arguably, this moral consensus not only inspired the public policy enshrined in the 2004 Act; it also justifies the recognition of a cadaveric donor's proprietary interest. For Harris, however, the requirement of the deceased's consent to donation serves no ethical function and misconstrues the role ordinarily played by consent in the context of healthcare treatment, such as the promotion of a patient's agency and ability to make an informed choice.⁶¹ In other words, consent safeguards a person's right to self-determination: the right to determine what should be done to one's body.⁶² Thus, Harris argued that, as the dead have no autonomy, their consent to donation was generally irrelevant,⁶³ implying that the recognition of a cadaveric donor's proprietary interest would be ethically unjustifiable.

However, a deceased donor's proprietary interest in an excised organ could be justified on the basis of posthumous autonomy. For instance, Wilkinson argued that the concept of *personal sovereignty*, the idea that a person should be able to run their own life, extends beyond biological life.⁶⁴ In other words, certain interests survive death; a phenomenon Harris acknowledged as *persisting critical interests*, although he went ahead to argue that such interests are generally weak and must give way to an overriding public interest, such as the use of cadaveric organs.⁶⁵ A set back of posthumous interests engenders harm, albeit to the person

organ does not rest on any freestanding right of the family in relation to the organ (that is, in their own right), although the family could vindicate any distress they suffered where retrieval was done without their consent. Wilkinson, *supra* note 39 at 66-70.

61. John Harris, "Law and Regulation of Retained Organs: The Ethical Issues" (2002) 22:4 LS 527 at 531.
62. *Canterbury v Spence*, 464 F (2d) 772 at 780 (DC Cir 1972).
63. Harris, *supra* note 61 at 534-38.
64. Wilkinson, *supra* note 39 at 44.
65. Harris, *supra* note 61 at 534-35.

who is now dead, that is, the *ante-mortem person*.⁶⁶ Sperling provides a stronger defence of posthumous interests in his suggestion that they should be protected as legal rights when such interests “accord with some significant moral attributes characterizing the dead.”⁶⁷ Thus, he observed that although a person might be dead, they nonetheless continue to exist symbolically in the minds, thoughts and language of other existing creatures.⁶⁸ Similarly, McGuinness and Brazier argued that the dead is not just a deceased person, but remains in our minds, as the case may be with our father, mother, brother, sister or friend.⁶⁹ In essence, posthumous interests recognise “one’s symbolic existence.”⁷⁰ These sorts of interests have been recognised in the area of testamentary disposition; thus, a person’s interest in the distribution of their property after death is recognised and protected through laws and statutes on wills. For similar reasons, Brazier deployed this analogy, along with religious and cultural factors, to argue for the legal recognition of a deceased person’s burial wishes.⁷¹ A few cases are beginning to respond positively to posthumous interests by way of recognising the burial wishes of a deceased person.⁷²

In *Burrows v HM Coroner for Preston*, one of the issues was whether the wishes of the deceased (a young man who committed suicide while in a penitentiary) regarding cremation should be recognised. Justice Cranston observed that “[o]ne thing is clear, that in as much as our domestic law says that the views of a deceased person can be ignored it is

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66. See generally Joel Feinberg, *Harm to Others* (New York: Oxford University Press, 1984); Wilkinson, *supra* note 39 at 34-35.
 67. Daniel Sperling, *Posthumous Interests: Legal and Ethical Perspectives* (Cambridge: Cambridge University Press, 2008) at 84. For a similar argument, see Heather Conway, “Dead, But Not Buried: Bodies, Burial and Family Conflicts” (2003) 23:3 LS 423 at 433.
 68. Sperling, *ibid* at 40-41.
 69. Sheelagh McGuinness & Margaret Brazier, “Respecting the Living Means Respecting the Dead Too” (2008) 28:2 Oxford J Legal Stud 297.
 70. Sperling, *supra* note 67 at 41.
 71. Brazier, *supra* note 33 at 564-65.
 72. *Buchanan v Milton*, [1999] 2 FLR 844 (FamD); *X v Federal Republic of Germany*, [1981] 24 DR 137; *Burrows v HM Coroner for Preston*, [2008] EWHC 1387 (QB) [*Burrows*]. See Remigius N Nwabueze, “Legal Control of Burial Rights” (2013) 2:2 Cambridge Journal of International Comparative Law 196.

no longer good law.”⁷³ The outcome in *Burrows*, which gave effect to the wish of the deceased, is arguably in dissonance with the orthodox legal doctrine that “[t]he dead have no rights and can suffer no wrongs.”⁷⁴ Hence, in *Ibuna v Arroyo*,⁷⁵ Justice Smith refused to attribute interests or rights to a dead body “as if it has some independent right to be heard which is in effect what Cranston J is saying.”⁷⁶ Unsurprisingly, therefore, Norrie argued that the taking of an organ from the deceased, even without consent or in the face of an express refusal of such consent by the deceased person, while morally wrong and even criminally punishable, could not ground the surgeon’s civil liability.⁷⁷ Moreover, based on Getzler’s suggestion that control-based proprietary entitlements attract the expressive justificatory theory of property, geared towards enhancing the personhood and autonomy of the entitlement holder,⁷⁸ it is obvious that such a framework cannot avail the deceased because the dead, on the orthodox view, has no autonomy.

In sum, these justificatory difficulties may discourage the recognition of a cadaveric donor’s proprietary entitlement in an excised organ. Consequently, the analysis turns on the proprietary entitlement of the live donor.

C. Live Donor’s Entitlement

In the case of an excised organ from a live donor, awaiting transplantation or use, the question is whether the organ should be considered the property of the live donor. Of course, the *Human Tissue Act 2004* regulates live donation, under which it is an offence to remove an organ from a live donor with the intention of using it for the purposes of transplantation contrary to the provisions of the Act.⁷⁹ An offence would be committed under the Act, for example, upon giving or receiving a payment for organ

73. *Burrows*, *ibid* at para 20.

74. *R v Ensor* (1887), 3 TLR 366 at 367, Stephen J. See also, *Silkwood v Kerr-McGee Corporation*, 637 F (2d) 743 (10th Cir 1980).

75. [2012] EWHC 428 (Ch).

76. *Ibid* at para 50.

77. Norrie, *supra* note 7 at 461.

78. Getzler, *supra* note 52.

79. 2004 Act, *supra* note 22, s 33.

donation (other than for necessary expenses), or non-compliance with the necessary consent requirements. Live donation could be *directed*, in the case of genetic or emotional relationships, and also *directed and altruistic*, such as when the donor and recipient are brought together through a social networking website.⁸⁰ In such cases, assessment by an Independent Assessor⁸¹ and consent of the Human Tissue Authority Transplant Approval Team are required.⁸² In the absence of an established relationship of some sort, live donation should be altruistic, non-directed and unconditional, in which case consent of the Human Tissue Authority is required – after the donation has been approved by a Panel set up for that purpose by the Human Tissue Authority.⁸³ Thus, as in the case of a cadaveric donor above, and for the reasons stated therein, the *Human Tissue Act 2004* has vested in live donors significant control over the use of their excised organs, which arguably amounts to a proprietary interest.

Such control powers offer good justification for vesting property interest in an orphaned organ in the live donor. Furthermore, on the basis of the work or skill exception, Cronin and Douglas suggested that organs donated for clinical transplantation should be viewed as the property of the donor because “[e]xtensive skills have been applied to them to make them suitable for transplantation. These include not only surgical removal and preparation, perfusion with preserving fluid and sterile cold storage, but also the establishment of recipient compatibility by means of tissue typing and cross-matching procedures.”⁸⁴ The work or skill exception was more famously enunciated by the Australian High Court in *Doodeward v Spence*, where the claimant sued to recover possession of a double-headed stillborn foetus seized from him by the police. Chief Justice Griffith held that a “human body, or a portion of a human body, is capable by law of becoming the subject of property” when, by lawful exercise of work or skill, “it has acquired some attributes differentiating it from a mere corpse awaiting burial.”⁸⁵ Thus, this exception anticipates

80. HTA, *Code of Practice 2*, *supra* note 1 at para 27.

81. *Ibid* at paras 34, 60-64.

82. *Ibid* at paras 39, 66.

83. *Ibid* at para 38.

84. Cronin & Douglas, “Directed and Conditional”, *supra* note 56 at 287.

85. *Doodeward*, *supra* note 19 at 414.

a more substantial transformative work, which makes it inapplicable to transplantable organs, whose utility lies in the preservation of their original state.⁸⁶

In the same vein, Hardcastle observed that the work or skill exception is a conceptual derivation from the Roman law's doctrine of *specificatio*, which determines the proprietorship of a *new* object produced from a different thing.⁸⁷ He opined that the "work or skill exception is a misguided application of the specification doctrine because often the work performed is for preservation purposes and does not result in the creation of a new thing."⁸⁸ Moreover, the exception usually applies in favour of the provider of the work or skill (here, the transplant team), rather than the source or donor of the organ,⁸⁹ although this could be remedied by considering the transplant team as having applied their skill to the organ as an agent of the donor.⁹⁰

Apart from the potential justification of a live donor's proprietary entitlement based on the work or skill exception, it is possible to agree with Rose LJ's inference, in *R v Kelly*, that a donor's proprietary interest in his or her organ is created upon its detachment from the donor's body with the *intention* of it being used for the purpose of transplantation.⁹¹ This sort of *intention-plus* argument for the justification of a property

86. For this reason, the exception was not applied in *Dobson v North Tyneside Health Authority*, [1997] 1 WLR 596 (CA), where the deceased's brain was merely fixed in paraffin. Also, while the Court of Appeal, in *Yearworth v North Bristol NHS Trust*, [2009] EWCA Civ 37 [*Yearworth*], observed that the work or skill exception was potentially applicable to sperm samples of the claimants that were negligently preserved in a liquid nitrogen, it preferred to base the claimants' proprietary interests on their right to control the use of their sperm samples extracted and stored for their benefit.

87. Rohan J Hardcastle, *Law and the Human Body: Property Rights, Ownership, and Control* (Oxford: Hart Publishing, 2007) at 135-42.

88. *Ibid* at 142.

89. Brazier, *supra* note 33 at 563.

90. This was the approach of the Australian case of *In re Mark Edwards*, [2011] NSWSC 478, involving proprietary interests in stored sperm samples.

91. *R v Kelly*, *supra* note 17; but this approach creates difficulties where the source has not stated any intention as to the use of the separated material. See Hardcastle, *supra* note 87 at 152-53.

right was, again, used by the Court of Appeal in *Yearworth* when it held that the claimants, from whom negligently damaged sperm samples originated, had property rights in their sperm samples because the “sole object of the ejaculation of the sperm was that, in certain events, it might later be used for their benefit.”⁹² More liberally, Penner⁹³ and Hardcastle have suggested that a source’s (or donor’s) proprietary interest should become extant on the detachment of the body part, whether or not accompanied with an intention as to use, and that the separated body part should be considered the property of the source.⁹⁴

In addition, a sound justificatory framework for the live donor’s ownership of an excised organ could be based on the principles of dignity and right to bodily integrity. Although these principles protect the *person* rather than their separated body parts, Hardcastle has observed that “[r]ecognising that property rights are created on detachment represents a natural extension of the right to bodily integrity”, and that “[i]t would seem inconsistent if the act of detachment changed biological materials from material fully protected by the law into material receiving no legal protection whatsoever.”⁹⁵ This sort of dignitarian justificatory framework resonates with Christman’s analysis of property as constituted, in part, by a collection of control rights which facilitate the holder’s psychological control over their environment and conduces to the development of their self-concept and promotion of their autonomy;⁹⁶ something that Getzler categorises as an expressive theory of property.⁹⁷ Thus, the live donor’s proprietary interest in an excised organ is reasonably justifiable. Additional support could also be inferred from some of the decided cases.

*Moore v Regents of the University of California*⁹⁸ is an interesting example. In this well-known case, Moore’s tissues were surreptitiously harvested by his physicians under the guise of a post-operative splenectomy

92. *Yearworth*, *supra* note 86 at para 45.

93. JE Penner, *The Idea of Property in Law* (Oxford: Oxford University Press, 1997) at 111.

94. Hardcastle, *supra* note 87 at 145-50.

95. *Ibid* at 147.

96. Christman, “Distributive Justice”, *supra* note 43.

97. Getzler, *supra* note 52 at 641.

98. 271 Cal Rptr 146 (Sup Ct 1990) [*Moore*].

procedure. Moore succeeded in his action for breach of informed consent, but the majority rejected his action for conversion. In his concurring and dissenting judgement, however, Justice Broussard observed that Moore's "right to determine, prior to the removal of his body parts, how those parts would be used after removal" qualified as a property right, which was infringed by the defendants and, thus, remediable in conversion.⁹⁹ To emphasize Moore's proprietary entitlement to his excised body parts, Broussard J delineated a hypothetical scenario where "[i]f, for example, another medical center or drug company had stolen all of the cells in question from the UCLA Medical Center laboratory and had used them for its own benefit, there would be no question but that a cause of action for conversion would properly lie against the thief."¹⁰⁰ Thus, Broussard J thought that this hypothetical put Moore's proprietary entitlement beyond doubt.

Similarly, while *Greenberg v Miami Children's Hospital Research Institute*¹⁰¹ and *Washington University v Catalona*¹⁰² both involved body parts donated for research, their propositions extrapolate to the organ donation context. In *Greenberg*, the claimants, parents of children suffering from Canavan disease and charitable research foundations that support research on Canavan disease, provided tissues and body parts, as well as funding, to the defendant-scientists in order to facilitate the defendants' research on Canavan disease. The research collaboration was fruitful, leading to the isolation and patenting of the Canavan gene, and the development of prenatal testing for the disease. However, the patent was obtained without the knowledge of the claimants, who alleged that the defendants' licensing practice had the effect of defeating the claimants' intention which was to make the prenatal testing generally available. In *Catalona*, Professor Catalona had assisted the Washington University in developing a biorepository, using tissues donated by his cancer patients and research participants, as well as tissues from the patients of his colleagues. However, Washington University objected to his claim

99. *Ibid* at 168.

100. *Ibid*.

101. 264 F Supp (2d) 1064 (Fla D 2003) [*Greenberg*].

102. 437 F Supp (2d) 985 (Mo D 2006) [*Catalona*], aff'd 490 F (3d) 667 (8th Cir 2007) [*Catalona*, 8th Cir].

when he got a professional appointment at Northwestern University and sought to leave with some of the tissues in the biorepository, with the consent of the sources.

While the claimants in both of these cases brought several causes of action, the concern here is on the courts' treatment of the claimants' conversion claims, touching on their proprietary entitlement to separated body parts. In dismissing the claimants' causes of action in *Greenberg* (except for the action for unjust enrichment), Justice Moreno observed that "the property right in blood and tissue samples ... evaporates once the sample is voluntarily given to a third party."¹⁰³ In the same vein, in *Catalona*, Justice Limbaugh "found the research participant to be a 'donor' who had parted with any semblance of ownership rights once their biological materials had been excised for medical research."¹⁰⁴ The United States Court of Appeals, Eighth Circuit, affirmed the decision of Limbaugh J in *Catalona*, on the ground that the research participants had practically made a gift of their bodily tissues to the biorepository.¹⁰⁵ Thus, by anchoring the decisions in both cases on the legal concept of a gift, the courts implied that the claimants in *Greenberg*, and the research participants in *Catalona*, had proprietary interests in their excised body parts, at least initially, since you cannot make a gift unless it is yours to give in the first place.¹⁰⁶ This suggests that a live donor possesses proprietary interest in their excised organ, which remains extant until validly transferred to a third party. Before considering the legal requirements for such a transfer, it is useful to look at two additional interesting cases.

In the Canadian case of *Urbanski v Patel*,¹⁰⁷ the claimant's daughter had only one kidney due to congenital defect; however, the kidney was accidentally removed during an exploratory surgical procedure, due to the mistaken belief of the surgeon that the kidney was an ovarian cyst. To

103. *Greenberg*, *supra* note 101 at 1075.

104. *Catalona*, *supra* note 102 at 997.

105. *Catalona*, 8th Circuit, *supra* note 102.

106. For a fuller discussion of the proprietary implications of both cases, see Remigius N Nwabueze, "Donated Organs, Property Rights and the Remedial Quagmire" (2008) 16:2 Med L Rev 201 at 218-21 [Nwabueze, "Remedial Quagmire"].

107. 84 DLR (3d) 650 (Man QB) [*Urbanski*].

save his daughter who was left without any kidneys, the claimant donated one of his kidneys. Unfortunately, although the transplant operation was competently performed, it was not successful and the kidney had to be removed three days later. The claimant's daughter succeeded in an action for negligence against the hospital for the loss of her only kidney. The claimant joined in the suit in his own right, alleging that the defendant's negligence caused him to lose one of his kidneys. Justice Wilson agreed with the claimant and awarded damages on the ground that it was reasonably foreseeable that the defendant's negligence which led to the loss of the claimant's daughter's kidney would cause the claimant to offer one of his kidneys to his daughter.¹⁰⁸

While *Urbanski* was entirely based in negligence rather than property law,¹⁰⁹ it is suggested that the successful outcome, as well as the claimant's standing to bring the action, was facilitated by the intuitive recognition of his proprietary interest in the excised kidney; an interest that was kept alive by the failed transplant, in the sense of preventing a complete transfer of the claimant's separated kidney to his daughter. *Sirianni v Anna*¹¹⁰ renders this view more compelling. *Sirianni's* facts closely mirror those of *Urbanski*. Just as in *Urbanski*, the claimant's son in *Sirianni* had only one kidney due to congenital defects. That kidney was, unfortunately, mistakenly removed in a surgical procedure. Consequently, the claimant volunteered her kidney, which was successfully implanted in her son. The claimant then brought an action, alleging that the defendant's negligence in treating her son caused her to lose one of her kidneys. Justice Ward held that the claimant had not stated a viable cause of action, and that her son's (separate) action in negligence could not be extended to her, because her donation was a voluntary and independent act done with full knowledge of the consequences. Accordingly, Ward J observed that the "premeditated, knowledgeable and purposeful act of this plaintiff in donating one of her kidneys to preserve the life of her son did not extend or reactivate the consummated negligence of these defendants."¹¹¹

108. *Ibid* at paras 104-06.

109. Negligence was probably the only relevant cause of action in the circumstances.

110. 55 Misc (2d) 553 (NY Sup Ct 1967) [*Sirianni*].

111. *Ibid* at 556.

Interestingly, in *Urbanski*, Wilson J distinguished *Sirianni* on the ground that it was decided in the 1960s, when transplantation procedure had not become routine and, therefore, could not be reasonably foreseeable in medical accidents involving the loss of a kidney.¹¹² I suggest, however, that the outcome in *Sirianni* was dictated by the successful transplant operation in that case, on the basis of which ownership of the claimant's excised organ had been completely transferred to her son. As the claimant no longer had an extant interest in her separated organ, it was difficult for her to ground her case on any recognisable cause of action. Ward J may have had this in mind when he asked: "[s]tripped of emotionalism, the issue here is, does a cause of action exist in favour of a donor of a human organ against the defendants who removed vital organs from the donee in a negligent manner?"¹¹³ In essence, both *Urbanski* and *Sirianni* suggest that a live donor enjoys proprietary interest in an excised organ which has not yet been lodged in the body of a recipient.

D. Effect of a Live Donor's Gift

The analysis above suggests that the ownership of an excised organ vests in its source, the live donor. However, having made a *gift* of it, the critical question becomes when that gift could be said to have taken effect so as to exhaust or transfer the live donor's proprietary interest to the donee. Recall that this question was also put forward in connection with the cadaveric donor, where I raised the issue of whether the effective moment of transfer was at the point of extraction, implantation or somewhere in-between. In essence, a live donor remains the owner of an orphaned organ until a valid transfer has taken place. This requires a legal analysis of gifts.

*Bowman v Secular Society Ltd*¹¹⁴ is a classic case on the validity of gifts. The claimant (the testator's next of kin) challenged a bequest to the corporate defendant on the ground that its objects or purposes were subversive of Christianity, though not criminal, in the sense of being punishable under the common law of blasphemy. The claimant argued

112. *Urbanski*, *supra* note 107 at paras 101-03.

113. *Sirianni*, *supra* note 110 at 554-55.

114. [1917] AC 406 (HL) [*Bowman*].

that with Christianity being part of the law of England, the defendant's purposes amounted to a denial of or an attack on Christianity, which rendered the gift unenforceable for being contrary to public policy. However, with a gift approach that deemphasized the nature of the defendant's purposes, Lord Parker expounded on the tripartite requirements as to the validity of gifts. First, there must be certainty as to the subject matter of the gift; second, the "donor must have the necessary disposing power over, and must employ the means recognized by common law as sufficient for the transfer of, the subject-matter;"¹¹⁵ and third, the "donee must be capable of acquiring the subject-matter."¹¹⁶ When these conditions are satisfied, the "property in the subject-matter of the gift passes to the donee, and he becomes the absolute owner thereof and can deal with the same as he thinks fit."¹¹⁷ It should be added that while Lord Parker's second condition above implies the presence of donative intention,¹¹⁸ the third condition implies the requirement of donee's acceptance.¹¹⁹ In that sense, and in light of Hill's very clear exposition on the topic, *Bowman* should be taken as evincing a two-sided analysis of gift, in contradistinction to an equally contending one-sided analysis of gifts, in which a gift is taken to be validly constituted by the unilateral act of the donor, subject to the donee's right of repudiation.¹²⁰

A live donor's gift of an excised organ potentially satisfies *Bowman's* conditions above. The only possible doubt relates to when the *transfer* (in condition two above) could be said to have been effectuated. Transfer of chattels by gift usually takes effect upon delivery.¹²¹ If, analogically, an excised organ intended for transplantation was categorised as a chattel,¹²²

115. *Ibid* at 436.

116. *Ibid*.

117. *Ibid*.

118. *Re Ridgway* (1885), 15 QBD 447.

119. Jonathan Hill, "The Role of the Donee's Consent in the Law of Gift" (2001) 117 Law Q Rev 127.

120. *Ibid*.

121. Duncan Sheehan, *The Principles of Personal Property Law* (Oxford: Hart Publishing, 2011) at 53.

122. Such a possibility looms large with the characterisation of an embryo as a chattel by an Alberta court in *CC v AW*, 2005 ABQB 290 ("[t]he remaining fertilized embryos remain her property. They are chattels that can be used as she sees fit" at para 25). However, the controversial

the question becomes when the organ could be said to have been *delivered*. In the law of gifts, delivery is an analytically torturous concept.¹²³ The clearest form of delivery is actual delivery, the physical or manual transfer of the object of the gift to the donee. This method of delivery is impossible in gifts of choses in action;¹²⁴ parental gifts to young children;¹²⁵ gifts of bulky objects;¹²⁶ gifts of property in faraway places; gifts of a symbol of title (such as a key to a house);¹²⁷ or gifts of objects already in the possession of the donee.¹²⁸ Hence exceptions were made for symbolic or constructive delivery.¹²⁹ Two theories underpin the requirement of delivery. The first trenches on the historical school of thought, which hypothesized that delivery was a relic of the historical requirement that the transfer of seisin in any property was not recognisable unless there was a change of possession.¹³⁰ On the basis of this theory, delivery is not indispensable, and not a fundamental requirement of the law of gift, because it is a mere historical accident. However, Sheehan has affirmed the necessity for the requirement of delivery, observing that “English law has been reluctant to allow even the clearest words of gift to override the need for an unequivocal change of possession.”¹³¹ On the other hand,

nature of such characterisations is put into bold relief by Justice Arabian’s concurring judgement in *Moore*, *supra* note 98 (“[p]laintiff has asked us to recognize and enforce a right to sell one’s own body tissue *for profit*. He entreats us to regard the human vessel – the single most venerated and protected subject in any civilized society – as equal with the basest commercial commodity. He urges us to commingle the sacred with the profane. He asks much” at 164).

123. Some dated, but historically relevant, analyses of the subject include: Frederick W Maitland, “The Mystery of Seisin” (1886) 2 Law Q Rev 481; Frederick Pollock, “Gifts of Chattels Without Delivery” (1890) 6 Law Q Rev 446; Samuel Stoljar, “The Delivery of Chattels” (1958) 21 Mod L Rev 27.
124. *Milroy v Lord* (1862), 4 De GF & J 264 (CA in Ch).
125. *Jones v Lock* (1865), 1 Ch App 25.
126. *In Re Cole*, [1964] Ch 175 (CA).
127. *Wrightson v McArthur and Hutchinson*, [1921] 2 KB 807.
128. *In Re Stoneham*, [1919] 1 Ch 149.
129. Sheehan, *supra* note 121 at 54-55. See also Patrick Rohan, “The Continuing Question of Delivery in the Law of Gifts” (1962) 38:1 Ind LJ 1 at 7-8 [Rohan, “Delivery in the Law of Gifts”].
130. Rohan, “Delivery in the Law of Gifts”, *ibid* at 4.
131. Sheehan, *supra* note 121 at 55.

the second theory of delivery emphasizes its functionality, rather than the manual tradition; this includes the need to protect a donor against the enforcement of rash or impulsive promises of gift, the evidentiary advantage of having witnesses of the gift, and the prevention of fraud.¹³² Thus, delivery should be adjudged to have taken place whenever these functions are satisfied, whether or not accompanied by a physical transfer of the gift. In practice, however, the cases on gifts do not fit neatly into any of the two theories above, hence the courts' approaches have been rather eclectic.¹³³

All of the above means that the delivery of an excised organ could be actual or symbolic. However, actual delivery by the live donor is not practically possible since the organ has to be extracted after the live donor had been physically immobilised by the administration of anaesthetic agents. Also, the excised organ is usually taken into the immediate possession of the transplant team for lodgement in the recipient. While this difficulty could be met by construing the transplant team as agents of the live donor for the purpose of actual delivery, it is more plausible to hold that delivery in the transplantation context is effected symbolically. Thus, the intention to donate, coupled with extraction of the organ, should be regarded as effecting the delivery of a live donor's excised organ to the recipient.¹³⁴ In essence, the recipient of a live donation becomes (thanks to Lord Parker in *Bowman* above) the "absolute owner"¹³⁵ of a donated organ from the moment the organ is extracted from the donor.¹³⁶ Consequently, it is the designated recipient of an excised organ that should exercise legal rights in relation to the organ.

Before examining the recipient's proprietary interest in detail, it remains to put aside the often unstated assumption that any property

132. Rohan, "Delivery in the Law of Gifts", *supra* note 129 at 4-6.

133. *Ibid.*

134. This is consistent with Rohan's suggestion that delivery should be taken to be complete where an overt act accompanies the expression of a donative intent. *Ibid* at 18.

135. *Bowman*, *supra* note 114 at 436, 440.

136. Pattinson makes a suggestion to the contrary, observing that the transfer of proprietary interests to the recipient takes place only after implantation of the organ in the recipient. However, Pattinson did not discuss the law of gifts. Pattinson, *supra* note 56 at 407.

right in an excised organ vests in the state and, thus, the state is entitled to distribute donated organs on the grounds of efficiency and justice.

III. State Ownership or Entitlement to Donated Organs

Although not given much dialogue, it is often assumed that altruistically donated cadaveric organs belong to the state – local, provincial, regional, or national government (as the case may be); thus, such organs constitute a national resource, a sort of community property. Quite often, this sort of argument is used to justify the state's exclusive control over organ donation and allocation criteria. For instance, Prottas observed that both the federal and state governments in the US became increasingly involved in the organ transplantation process because of the belief that the “organs were not the property of the physician procuring them but of the public at large.”¹³⁷ For the same reason, Zink and colleagues argued that the “only body that is qualified to determine who will receive donated organs in a fair and ethical manner is the medical community.”¹³⁸ In the same way, Nelson suggested that “we ought to move closer toward seeing such organs as communal resources.”¹³⁹

While this presumption of state ownership is generally common and strong, its provenance is not entirely clear. Cronin and Price have suggested that the idea of state ownership of donated organs might be based on the questionable no-property rule for cadavers, in the sense that parts of cadavers suitable for transplants might be taken into the possession and ownership of professionals as first possessors, on behalf of society. The authors, however, concluded that the “[n]otions of collective property in body parts are anathema to most liberal societies.”¹⁴⁰ The issue was much more seriously debated in the US, especially in the mid-2000s; the immediate context of the debate was the proprietary status of UNOS (United Network of Organ Sharing) in relation to donated

137. Jeffrey Prottas, *The Most Useful Gift: Altruism and the Public Policy of Organ Transplants* (San Francisco: Jossey-Bass Publishers, 1994) at 18.

138. Sheldon Zink et al, “Examining the Potential Exploitation of UNOS Policies” (2005) 5:4 *American Journal of Bioethics* 6 at 10.

139. Nelson, *supra* note 13 at 27.

140. Cronin & Price, *supra* note 15 at 129.

cadaveric organs. Particularly, the debate was focused on whether UNOS could override a donor's wishes regarding the designation or direction of their organ.¹⁴¹ Truog rightly observed that the debate hinged on the "question of whether transplantable organs should be considered personal property or a societal resource."¹⁴² Truog argued that legal distinctions are commonly made between the living and the dead, and that such differentiations sometimes justify the invasion of the body of the dead for public purposes (such as forensic autopsy), although such invasions are not permissible in the case of a living person. For that reason, Truog opined that "organs obtained from cadaveric donors should be regarded as a societal resource;"¹⁴³ as such, only a limited direction of the donor should be allowed. In the same vein, Childress argued that cadaveric organs are a national or community resource and, thus, they should be allocated based on efficiency and utilitarian considerations, rather than extraneous factors, such as the accident of geography.¹⁴⁴ Cohen, however, disagreed on the conceptualisation of cadaveric organs as a public resource;¹⁴⁵ he observed that donated "cadavaric organs do not belong to UNOS. UNOS is given custody and control of organs."¹⁴⁶ Thus, he suggested that UNOS is a trustee that should remain faithful to its responsibilities by respecting the conditions placed on donated organs by the donors. In part, the weakness of the argument for state ownership of donated organs is the incontrovertible fact that property in the organ, as shown above, is vested in the donor, at least initially. The burden, therefore, is on the proponents of state ownership to show how the organ has suddenly transmogrified to state ownership.

Furthermore, an altruistically donated organ is usually meant for the benefit of a potential recipient on the waiting list, rather than as a gift to the state. In that sense, the organ might be considered as the property

141. Note that the US *Uniform Anatomical Gift Act* permits the designation of recipients of cadaveric organs.

142. Robert D Truog, "Are Organs Personal Property or a Societal Resource?" (2005) 5:4 *American Journal of Bioethics* 14 at 14.

143. *Ibid* at 15.

144. Childress, *supra* note 12.

145. Lloyd R Cohen, "UNOS: The Faithless Trustee" (2005) 5:4 *American Journal of Bioethics* 13.

146. *Ibid* at 13.

of a potential recipient on the waiting list, subject to the state's *power* to select the actual recipient according to the established allocation criteria. Consequently, the state is neither an *owner* nor a *trustee* of donated organs, but a *donee* of power. Describing the state as a trustee would inadvertently recognise it as the legal owner of an organ, albeit without beneficial content. As a donee of power, however, the state is empowered to select a recipient in order to complete the transfer to that recipient; before the state exercises its power of selection, the right of action in relation to the organ belongs to the donor. Since the state is, however, in physical possession of the organ before implantation in the recipient, it might wish to vindicate such possessory interests in the event of an unauthorised interference. This approach resonates with the observation of the Nuffield Council on Bioethics that an excised organ intended for transplantation should be "conceptualised as being in the 'custodianship' of third parties," which should include "rights of possession and use, but only for the purposes envisaged in the original consent."¹⁴⁷ Thus, the Nuffield Council on Bioethics implies that the state has custody and possession, but not ownership of donated organs.

IV. Entitlement of the Recipient

As analysed above, the *delivery* of an excised organ has the effect of vesting the proprietary interest in the recipient. Thus, the potential recipient, rather than the donor, is the appropriate person to seek legal remedies for any unlawful or unauthorised interference with an excised organ. This conclusion engages the interesting case of *Colavito v New York Organ Donor Network*,¹⁴⁸ which is more fully discussed elsewhere.¹⁴⁹

In *Colavito*, the deceased's wife made a directed donation of her late husband's kidneys to Colavito, a long-time family friend who was suffering from end stage renal disease. The kidneys were retrieved from the deceased in a New York hospital, and were intended to be air-lifted

147. Nuffield Council on Bioethics, *supra* note 2 at para 7.21.

148. 356 F Supp (2d) 237 (NY D 2005) [*Colavito*], *aff'd* 438 F (3d) 214 (2d Cir 2006) [*Colavito*, 2d Cir 2006]; *Colavito v New York Organ Donor Network*, 8 NY (3d) 43 (NY Ct App 2006) [*Calavito*, Ct App], *aff'd* 486 F (3d) 78 (2d Cir 2007) [*Colavito*, 2d Cir 2007].

149. Nwabueze, "Remedial Quagmire" *supra* note 106 at 209-16.

to Miami, Florida, for lodgement in Colavito. Under the relevant New York statute, however, Colavito was only entitled to one kidney at a time, so only the left kidney was taken to him. Minutes before the transplant surgery, Colavito's doctor discovered that the left kidney was irreparably damaged; he therefore made an immediate request for the right kidney from the New York hospital, but was told that the right kidney had already been allocated to another patient whose transplant operation was then in progress. Eventually, histo-compatibility test results showed that the kidneys were histo-incompatible with Colavito's anti-bodies; thus, the transplant could not have taken place in any event. Nevertheless, Colavito sued for conversion, fraud and breach of statutory duties, though the conversion claim is the most relevant here. The District Court dismissed Colavito's conversion claim on the ground that there was no property right in the dead body of a human being or parts of it.

On appeal, the US Court of Appeals, Second Circuit, observed that the cases supporting the no-property rule in the human body were utterly anachronistic, and that those cases could not anticipate the modern revolution in biomedical technology and its application to body parts. Moreover, the Second Circuit observed that those earlier cases were mainly concerned about claimants whose only injury sounded in emotional distress, in contradistinction to Colavito, who suffered a real deprivation through the loss of an organ. Thus, the Second Circuit certified certain questions to the New York Court of Appeals, which returned a negative answer, observing that under the New York organ donation statute "it is enough to say ... that plaintiff, as a specified donee of an incompatible kidney, has no common-law right to the organ."¹⁵⁰ When the matter came back again to the Second Circuit, it agreed with the New York Court of Appeals, adding that "as a matter of law ... Colavito could not have derived a medical benefit from the organ and did not 'need' it."¹⁵¹

More importantly, *Colavito's* case demonstrates an implicit acceptance by the courts adjudicating the matter that Colavito, as the specified recipient of an excised kidney, was the owner thereof and, thus, was competent to bring the claim for conversion. Unsurprisingly, the

150. *Colavito*, Ct App, *supra* note 148 at 53.

151. *Colavito*, 2d Cir 2007, *supra* note 148 at 81.

District Court described the donated kidneys as “Mr Colavito’s kidneys,” although it confusingly added that they “are not property.”¹⁵² Similarly, Justice Sack of the US Court of Appeals, Second Circuit, observed that while Colavito’s right of action could be supported under the relevant New York statute on organ donation, his proprietary interests in the kidney could be grounded in his common law rights by analogy to the beneficiary of a trust of the benefit of a covenant, a concept that does not rely on the doctrine of consideration or privity of contract.¹⁵³ Furthermore, *Colavito* provides support for the view that the *delivery* of a donated organ takes place at the point where the organ is excised with the intention of transplanting it to a specified recipient.

V. Conclusion

Considerable legal liability issues may arise in connection with an excised organ in the period between its extraction from the donor and implantation in the recipient. Where the organ is stolen, damaged, maliciously destroyed, or used without authority, one of the questions that would arise is that of ownership; in other words, whose organ is it and who can sue for the damage or unlawful interference with it?

What has been done above is to provide a tiered analysis of the ownership of orphaned organs and its justificatory underpinnings. The issue is one that is bound to increase in importance in light of both the general shortage of transplantable organs and further improvements in transplantation technology. Accordingly, it is suggested that after delivery the proprietary interests in an excised organ vests in the designated or selected recipient. Delivery takes place after the organ has been excised with the intention of lodging it in the body of a designated or specified recipient. Thus, the recipient is empowered to sue for any interference with an orphaned organ. Before delivery, however, the donor remains the owner, and should be able to exercise his or her ownership rights or control over the organ. Furthermore, the state is neither the owner nor trustee of donated organs, but, as a custodian thereof, the state might wish

152. *Colavito*, *supra* note 148 at 244.

153. *Colavito*, 2d Cir 2006, *supra* note 148 at 228. For enunciation of the principle, see *Fletcher v Fletcher* (1864), 67 ER 564 (Ch).

to vindicate its possessory interests. In this way, the current proprietary gaps surrounding an excised organ are closed, and its orphaned status is eliminated.

Informal Care and Private Law: Governance or a Failure Thereof?

Brian Sloan*

The provision of care for elderly and disabled people is an issue of enormous public importance, particularly in the context of an ageing population. There is currently much discussion, in light of the UK Government's attempts to implement an approximation of the Dilnot Commission's recommendations on care funding, about the provision of formal care for those who require it and how it should be funded. But care recipients, and ultimately wider society, continue to rely heavily on care provided informally (i.e. in the absence of a legal duty) in the home. Many of the people providing such care suffer significant financial and health-related disadvantages as a result of their responsibilities, though in principle some are able to seek (in addition to limited support from the state) a form of 'compensation' from their care recipients via a private law claim.

This paper asks whether private law remedies for carers, such as those remedies identified and to an extent advocated in the author's recent monograph, Informal Carers and Private Law, are inevitably related to an inadequacy of state support for carers and care recipients and a failure to properly grapple with the issue of care on the part of government and society. It evaluates the alternative proposition that such remedies are normatively appropriate irrespective of the level of state provision of care or state support for informal carers.

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- I. INTRODUCTION
 - II. THE SOCIAL POLICY CONTEXT OF INFORMAL CARE IN ENGLAND
 - III. JUSTIFYING A PRIVATE LAW APPROACH TO INFORMAL CARE
 - IV. CONCLUSION
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I. Introduction

The world's population is ageing.¹ In Canada, for example, the number of citizens who are aged 65 or over is expected to double between 2011 and 2036, and around 25 per cent of the population is expected to be in that category by 2051.² In the United Kingdom, similarly, 23 per cent of the population is projected to be aged 65 or older by 2035, while only 18 per cent will be under 16 by then.³ One of the most important questions in social policy is therefore how to allocate the burdens of funding and providing care for the increasing number of people who will require it in the decades to come. In England, there is currently much discussion about the Government's attempts to implement an approximation of the Dilnot Commission's recommendations on the Funding of Care and Support, which concern the provision of formal social care for those who require it.⁴ The funding question forms part of

1. See *e.g.* Axel Börsch-Supan, Karsten Hank & Hendrik Jürges, "A New Comprehensive and International View on Ageing: Introducing the 'Survey of Health, Ageing and Retirement in Europe'" in Peter A Kemp, Karel Van den Bosch & Lindsey Smith, eds, *Social Protection in an Ageing World* (Antwerp: Intersentia, 2008) 3.
2. Employment and Social Development Canada, "Canadians in Context – Aging Population" (Ottawa: HRSDC, 2014), online: Employment and Social Development Canada <<http://www4.hrsdc.gc.ca/.3ndic.1t.4r@-eng.jsp?iid=33>>.
3. Office for National Statistics, *Older People's Day 2011* (UK: Office for National Statistics, 2011) at 1, online: Office for National Statistics <http://www.ons.gov.uk/ons/dcp171778_235000.pdf>.
4. Commission on Funding of Care and Support, *Fairer Care Funding – The Report of the Commission on Funding of Care and Support* (UK: Commission on Funding of Care and Support, 2011), online: Independent Living in Scotland <http://www.ilis.co.uk/uploaded_files/dilnott_report_the_future_of_funding_social_care_july_2011.pdf>.

an overhaul of the whole system of adult social care,⁵ and the legislation eventually known as the *Care Act 2014*⁶ will bring about what has been described as “the biggest change in the law governing the operation of care and support in England since the *National Assistance Act 1948*.”⁷

The focus of this paper, however, is on the *informal* carer, who provides care services in the absence of any contractual or other legal duty to do so. In particular, it concerns the use of private law remedies, *i.e.* the outcomes of a claim by the carer against the care recipient, or more likely her estate, in order to support, compensate or reward the carer. It does not discuss particular private law remedies in detail. Much of that work was undertaken in my recent monograph, *Informal Carers and Private Law*,⁸ in which I evaluated property law, family property law, succession law, and unjust enrichment as potential sources of remedies for a carer from a comparative common law perspective. Rather, the purpose of this article is to consider the normative question of whether private law remedies for the carer can be justified in general, with a particular concentration on the English policy context but an awareness that private law approaches to care have been taken in several other jurisdictions including Canada.

This article begins by sketching the social policy context in which the informal carer operates in England.⁹ It then examines the scope for

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5. See *e.g.* Law Commission of England & Wales, *Adult Social Care* (London: Stationery Office, 2011), online: Law Commission <http://lawcommission.justice.gov.uk/docs/lc326_adult_social_care.pdf>.
 6. (UK) c 23 [*Care Act*]; Bill 168, *Care Bill* [HL], 2013-2014 sess, 2013, (3rd reading 11 March 2014). (The Bill received its first reading in the House of Commons, having passed through the House of Lords, in October 2013, which received royal assent on 14 May 2014).
 7. House of Lords & House of Commons Joint Committee on the Draft Care and Support Bill, *Draft Care and Support Bill: Report* (London: Stationery Office, 2013) at para 41, online: United Kingdom Parliament <<http://www.publications.parliament.uk/pa/jt201213/jtselect/jtcare/143/143.pdf>>.
 8. Brian Sloan, *Informal Carers and Private Law* (Oxford: Hart Publishing, 2013).
 9. While England and Wales constitute a legal system for many purposes (including relevant private law claims), social care is a devolved matter for which the Welsh Assembly is responsible. See *e.g.* the *Social Services and Well-being (Wales) Act 2014* (UK), anaw 4 (which received royal assent on 1 May 2014).

a private law approach to rewarding, supporting, or compensating the informal carer. The aim is to consider whether the justification for such remedies is dependent upon an absence of proper governance of the care issue by the state. An alternative thesis, which I tentatively advance in this article, is that private law remedies could be justified independently of the quality of state provision for care or carers, and represent an aspect (albeit a small one) of appropriate governance of the issue. It is not contended, however, that it is legitimate for the state to rely solely on the availability of private law remedies in order to abdicate its governance responsibilities relating to the care conundrum. As Martha Fineman correctly argues, a societal response to the plight of the carer is not merely a matter of empathy or altruism, but of the preservation of society itself.¹⁰

II. The Social Policy Context of Informal Care in England

In broad contrast to health care provided under the National Health Service, many care recipients in England have to pay for formal social care on a means-tested basis.¹¹ Social care vitally “supports people of all ages with certain physical, cognitive or age-related conditions in carrying out personal care or domestic routines.”¹² As things stand before the full implementation of the *Care Act*, those care recipients with assets worth over £23,250 must fund their own social care and receive no financial state support in order to do so.¹³ The relevant assets can include a home

10. Martha A Fineman, *The Autonomy Myth: A Theory of Dependency* (New York: New Press, 2004) [Fineman, *The Autonomy Myth*]. See also e.g. Jonathan Herring, *Caring and the Law* (Oxford: Hart Publishing, 2013) [Herring, *Caring and the Law*].

11. See generally Commission on Funding of Care and Support, *supra* note 4. *C.f.* the duty contained in *Care Act* [HL], *supra* note 6, s 3(1) (which would require a local authority to “exercise its functions under [the relevant Part of the Act] with a view to ensuring the integration of care and support provision with health provision and health-related provision” in certain circumstances).

12. Commission on Funding of Care and Support, *ibid* at 4.

13. *Ibid* at 11. See e.g. *National Assistance (Assessment of Resources) Regulations 1992*, SI 1992/2977.

if no dependant is living in it.¹⁴ Local authorities are placed under a duty to recover payments covering residential care that they have provided in certain circumstances,¹⁵ and they also have a power to charge for non-residential services including personal care.¹⁶ A charge on the care recipient's home is one method by which a local authority can recover its costs.¹⁷

The Dilnot Commission recommended that the maximum lifetime contribution towards care expected of any one individual should be capped at £35,000, and that “the asset threshold for those in residential care beyond which no means-tested help is given should increase.”¹⁸ The Government has agreed with the principles espoused by the Dilnot Commission, though clearly not the proposed figures. It has been announced that a cap of £72,000 for those of state pension age and over will be implemented in England in 2016.¹⁹ The Government has also made a commitment that, by virtue of a universal deferred payment scheme, no-one will have to sell her home during her lifetime in order to pay for care.²⁰ While the currently anticipated cap is lower than the £75,000 cap originally proposed by the Government (with the difference being funded partly by a freeze in inheritance tax thresholds),²¹ either cap would still be more than double that proposed by the Dilnot Commission. The cap's narrow focus on care itself also means that it is not thought to include the cost of food or renting a room in a care

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14. Commission on Funding of Care and Support, *ibid* at 11.
 15. *National Assistance Act*, 1948 (UK), 11 & 12 Geo VI, c 29, s 22.
 16. *Health and Social Services and Social Security Adjudications Act 1983* (UK), c 41, Part VII. See *e.g. R v Somerset County Council, ex parte Harcombe*, (1997) 96 LGR 444 (QB).
 17. See *e.g. Campbell v Griffin*, [2001] EWCA Civ 990.
 18. Commission on Funding of Care and Support, *supra* note 4 at 5.
 19. Department of Health, *Caring for our Future: Consultation on Reforming What and How People Pay for their Care and Support* (UK: Department of Health, 2013) at para 22, online: GOV.UK <<https://www.gov.uk/government/consultations/caring-for-our-future-implementing-funding-reform>> [Department of Health, *Caring for our Future*].
 20. *Ibid* at para 26.
 21. “Social Care Cost Cap and Flat-Tier Pension Brought Forward”, *BBC News* (17 March 2013) online: BBC News <<http://www.bbc.co.uk/news/uk-politics-21820719>>.

home,²² and many of the details will be left to statutory instruments rather than being contained in the *Care Act* itself.²³

Moreover, despite the Government's intention to introduce a national minimum eligibility threshold for care and support in England, the actual level of provision of social care will remain considerably subject to the discretion of local authorities,²⁴ and again the details will be contained in secondary legislation.²⁵ Many such local authorities are struggling to provide adequate services in the current economic climate.²⁶ What is more, a close reading of private law cases suggests that the extent to which some care recipients will resist state involvement in their affairs should not be under-estimated,²⁷ and many such recipients will want to stay in their own homes at all costs, notwithstanding the extent of their care needs.

It seems, therefore, that English society will continue to rely on the vital work of the *informal* carer, even in the context of a reformed social care system. The Government has accepted this, and given informal carers the perhaps dubious compliment that the latter “embody the spirit of the Big Society,”²⁸ which has been described as “[a] society in which power and responsibility have shifted: one in which ... individuals and communities have more aspiration, power and capacity to take decisions and solve problems themselves, and where all of us take greater

22. Department of Health, *Caring for our Future*, *supra* note 19 at para 25.

23. *Care Act*, *supra* note 6, s 15. See Department of Health, “Closed consultation: Updating our care and support system: draft regulations and guidance” (UK: Department of Health, 2014), online: GOV.UK <<https://www.gov.uk/government/consultations/updating-our-care-and-support-system-draft-regulations-and-guidance>>.

24. See *e.g.* House of Lords & House of Commons Joint Committee on the Draft Care and Support Bill, *supra* note 7 at paras 189-91. Compare *Care Act*, *supra* note 6, ss 18, 19.

25. *Care Act*, *ibid*, s 13.

26. See *e.g.* Age UK, *Care in Crisis: What's Next for Social Care?* (UK: Age UK, 2012), online: Age UK <http://www.ageuk.org.uk/Documents/EN-GB/Campaigns/care_in_crisis_2012_policy_report.pdf?dtrk=true>.

27. See *e.g.* *Special Trustees for Great Ormond Street Hospital for Children v Rushin, Re Morris, decd*, [2000] EWHC J0419-21.

28. Department of Health, *Recognised, Valued and Supported: Next Steps for the Carers Strategy* (UK: Department of Health, 2010) at 3, online: GOV.UK <http://dera.ioe.ac.uk/1972/1/dh_122106.pdf>.

responsibility for ourselves, our communities and one another.”²⁹ The Organisation for Economic Co-operation and Development, for its part, has said that informal care provided in the home is the most important source of care from a global perspective.³⁰

Before proceeding further, it is necessary to consider in more detail what is meant by the phrase “informal carers.” Definitions are of course fraught with difficulties.³¹ One attempt is to say that “[a] carer spends a significant proportion of their life providing unpaid support to family or potentially friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems.”³² Crucially, definitions of “informal carer” are at least intended to exclude carers for able-bodied children,³³ and it is worth noting that there have been interesting discussions about the status of carers for *disabled* children and carers who are themselves children.³⁴ The 2011 census data indicate that there are 5.8 million informal carers in England and Wales,³⁵ as compared to the 5.2 million recorded by the 2001 census.³⁶ Meanwhile, the representative organisation, Carers UK, estimates that 60 per cent of people will become a carer at some point

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29. The Commission on Big Society, *Powerful People, Responsible Society: The Report of the Commission on Big Society* (London: ACEVO, 2011) at para 1.4, online: ACEVO <<http://www.acevo.org.uk/document.doc?id=1515>>.
 30. Organisation for Economic Co-operation and Development, *Long-term Care for Older People* (Paris: OECD Publishing, 2005) at 15.
 31. See e.g. Herring, *Caring and the Law*, *supra* note 10 at 13-26.
 32. Department of Health, *Carers at the Heart of 21st-Century Families and Communities: “A Caring System on your Side. A Life of your Own”* (UK: Department of Health, 2008) at 19 [Department of Health, *21st-Century Families and Communities*].
 33. *C.f.* Jonathan Herring, “Where are the Carers in Healthcare Law and Ethics?” (2007) 27:1 LS 51 at 52.
 34. House of Lords & House of Commons Joint Committee on the Draft Care and Support Bill, *supra* note 7 at paras 245-56.
 35. Office for National Statistics, News Release, “More than 1 in 10 Providing Unpaid Care as Numbers Rise to 5.8 Million” (15 February 2013), online: Office for National Statistics <http://www.ons.gov.uk/ons/dcp29904_300542.pdf>.
 36. Office for National Statistics, “Focus on Health: 2004 Edition” (UK: Office for National Statistics, 2004) at 10, online: Office for National Statistics <<http://www.ons.gov.uk/ons/rel/disability-and-health-measurement/focus-on-health/2004-edition/index.html>>.

in their lives.³⁷ The opportunity costs of caring can be very high: it has been claimed that UK carers lose an average of £11,000 per year due to their caring responsibilities,³⁸ and significant health problems often arise as a result of those same responsibilities.³⁹ Conversely, informal care has been described as the “invisible pillar” of the welfare state,⁴⁰ and the total amount of informal care provided in the UK has been valued at £87 billion per year.⁴¹

English law does make some attempt to provide state support for carers themselves, as distinct from helping the care recipients for whom they care.⁴² For example, the *Carers (Recognition and Services) Act 1995*⁴³ granted carers the right to an assessment of their ability to provide care when a local authority is ascertaining a care recipient’s need for more formal community care. The *Carers and Disabled Children Act 2000*⁴⁴ made the right to an assessment independent of the care recipient’s assessment, and gave local authorities powers to provide services for carers, before the *Carers (Equal Opportunities) Act 2004*⁴⁵ placed local authorities under a duty to inform carers of their rights under the previous two Acts, and

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37. Carers UK, “Facts about Carers 2012” (London: Carers UK, 2012) at 2, online: Carers UK <http://www.carersuk.org/media/k2/attachments/Facts_about_carers_Dec_2012.pdf>.
38. House of Commons Work and Pensions Committee, *Valuing and Supporting Carers: Fourth Report of Session 2007-08*, Volume 1 (London: Stationery Office, 2008) at para 102, online: United Kingdom Parliament <<http://www.publications.parliament.uk/pa/cm200708/cmselect/cmworpen/485/485i.pdf>>.
39. Department of Health, *21st-Century Families and Communities*, *supra* note 32 at 100-20; The Princess Royal Trust for Carers, *Always On Call, Always Concerned: A Survey of the Experiences of Older Carers* (UK: Princess Royal Trust for Carers, 2011), online: Carers Trust <https://www.carers.org/sites/default/files/always_on_call_always_concerned.pdf>.
40. Sophie Moullin, *Care in a New Welfare Society: Unpaid Care, Welfare and Employment* (London: Institute for Public Policy Research, 2007) at 7.
41. Lisa Buckner & Sue Yeandle, *Valuing Carers: Calculating the Value of Unpaid Care* (London: Carers UK, 2007).
42. See generally Luke Clements, *Carers and their Rights: The Law Relating to Carers*, 5th ed (London: Carers UK, 2012) and see *e.g.* Herring, *Caring and the Law*, *supra* note 10 at 122-27.
43. (UK), c 12.
44. (UK), c 16.
45. (UK), c 15.

required consideration of the carer's employment, training, and housing needs as part of the assessment. Analogously with the provision of social care itself, however, Jonathan Herring has criticised the fact that such statutory provisions are "largely permissive, authorizing local authorities to provide ... services ... rather than dictating that they must."⁴⁶

As well as rights relating to flexible working and non-discrimination extended to carers in the employment context,⁴⁷ there is limited direct financial support available for carers in England.⁴⁸ A carer's allowance is a limited benefit payable to a person who spends at least 35 hours per week caring for someone who is herself in receipt of certain benefits related to illness or disability,⁴⁹ though it has been criticised for its inadequacy.⁵⁰ There is also the possibility that a care *recipient* could use the Direct Payments scheme to acquire the means to pay an informal carer in lieu of social care provided by the local authority, effectively transforming the care into a "care worker."⁵¹ A significant current limitation, however, is that a Direct Payment recipient is often prohibited from purchasing services from spouses, civil partners, or people living with the recipient as such, or from close relatives living in the same household.⁵²

The Department of Health has said that the *Care Act* is intended, *inter alia*, to place carers on an equal footing with care recipients in regards to its fundamental principle that the purpose of the social care system is the well-being of the individual,⁵³ even if the Explanatory Notes to the Act

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46. Jonathan Herring, *Older People in Law and Society* (Oxford: Oxford University Press, 2009) at 102 [Herring, *Older People*].
47. See e.g. Rachel Horton, "Care-giving and Reasonable Adjustment in the UK" in Nicole Busby & Grace James, eds, *Families, Care-Giving and Paid Work: Challenging Labour Law in the 21st Century* (Cheltenham: Edward Elgar, 2011) 137; Herring, *Caring and the Law*, *supra* note 10 at 247-58.
48. Herring, *Caring and the Law*, *ibid* at 120-22.
49. "Carer's Allowance", online: GOV.UK <<https://www.gov.uk/carers-allowance>>.
50. Herring, *Older People*, *supra* note 46 at 100-01.
51. *Health and Social Care Act 2001* (UK), c 15, s 57. See e.g. Clare Ungerson, "Whose Empowerment and Independence? A Cross-National Perspective on 'Cash for Care' Schemes" (2004) 24:2 *Ageing & Society* 189.
52. Clements, *supra* note 42 at para 5.40.
53. House of Lords & House of Commons Joint Committee on the Draft Care and Support Bill, *supra* note 7 at paras 78-79. See *Care Act*, *supra* note 6, s 1.

make clear that the principle “is not intended to be directly enforceable as an individual right.”⁵⁴ Specific reforms aimed at carers include the removal of the previous requirement that a carer either does or intends to provide regular and substantial care before his needs can be assessed by the local authority.⁵⁵ As Herring points out, however, while “[t]here is much to be welcomed” in the proposals embodied in the Act, “at the end of the day it will be the levels of funding which are key, rather than legislative structure.”⁵⁶ Given this and the general fears expressed about funding and care earlier in this section, the next section of the article considers an alternative “private law” approach to supporting informal care.

III. Justifying a Private Law Approach to Informal Care

The previous section of the article has demonstrated that there is currently some state support for informal carers in England, and they should benefit both directly and indirectly from a reformed social care system to an extent. But the important question for present purposes is whether we can nevertheless justify a *private law* approach to supporting, compensating, or rewarding the carer, perhaps as an attempt to redress the financial or health difficulties that the carer has suffered due to the responsibilities he has undertaken. For example, it could be asked whether the carer should be able to claim a share of the care recipient’s estate. While my monograph did grapple with this normative question,⁵⁷ I ultimately decided that because private law remedies for carers were in fact available in limited circumstances on various bases including the equitable doctrine of proprietary estoppel,⁵⁸ the English *Inheritance (Provision for Family*

54. Care Act 2014: Explanatory Notes (London: Stationery Office, 2014) at para 57, online: Legislation.gov.uk <http://www.legislation.gov.uk/ukpga/2014/23/pdfs/ukpgaen_20140023_en.pdf>.

55. Compare *Carers (Recognition and Services) Act 1995*, *supra* note 43, s 1(1)(b), and *Care Act*, *supra* note 6, s 10(3).

56. Herring, *Caring and the Law*, *supra* note 10 at 143.

57. See *e.g.* Sloan, *supra* note 8 at 12-20.

58. See *e.g.* *Jennings v Rice*, [2002] EWCA Civ 159 and Sloan, *supra* note 8 at 30-90; *c.f. ibid* at 91-120 for an argument that a statutory solution

*and Dependants) Act 1975*⁵⁹ and equivalent legislation elsewhere,⁶⁰ the cases in which this occurred were worthy of rationalisation and analysis irrespective of the state support question.

Given that the system of state support in England is likely to remain stretched for the foreseeable future, it may nevertheless become necessary to use private law remedies in order to adequately support and encourage informal care for elderly and disabled people where appropriate resources exist on the part of care recipients. This is particularly true in light of fears that the availability of informal care will be reduced in the years to come.⁶¹ Mika Oldham therefore pragmatically advocates a system of “successional priority” for informal carers, which would give them a prioritised right of provision from the care recipient’s estate.⁶² It is telling that when reviewing my monograph, Herring rather humbly contrasts my own “modest” private law-oriented proposals that he considers “realisable and carefully tailored to fit within current legal approaches,”⁶³ with the “tendency for those writing in this area to insist we need nothing less than a complete change in the way we see the world and organise law.”⁶⁴

An unjust enrichment lawyer might say that the carer is a “risk-taker” who has freely chosen to confer a benefit on the care recipient and should not, for that reason alone, expect payment after the event.⁶⁵ Indeed, the

modelled upon the New Zealand *Law Reform (Testamentary Promises) Act 1949*, no 33 would be preferable to the uncertainty and controversy caused by the judicially-developed estoppel doctrine in England.

59. (UK), c 63.

60. See *e.g. Graham v Murphy*, [1997] 1 FLR 860 (Ch) and Sloan, *supra* note 8 at 136-205.

61. See *e.g. Caring Choices, The Future of Care Funding: Time for a Change* (London: King’s Fund, 2008) at 17, online: The King’s Fund <<http://www.kingsfund.org.uk/publications/future-care-funding>>.

62. Mika Oldham, “Financial Obligations within the Family – Aspects of Intergenerational Maintenance and Succession in England and France” (2001) 60:1 CLJ 128 at 173–77. See Sloan, *supra* note 8 at 14-20 for discussion.

63. Jonathan Herring, “Informal Carers and Private Law” (2013) 35:4 J Soc Wel & Fam L 503 [Herring, “Informal Carers”].

64. *Ibid.*

65. See *e.g. Andrew S Burrows*, “Free Acceptance and the Law of Restitution” (1988) 104 LQR 576; Paul S Davies, “Risk in Unjust Enrichment” (2012) 20 RLR 57; Sloan, *supra* note 8 at 124-25. See also Jeroen

law of unjust enrichment has not yet proved fertile ground for claims by carers (and other people in “domestic” relationships in England and Wales).⁶⁶ But the Canadian courts, tending to focus on the absence of “juristic reasons” for an enrichment⁶⁷ distinct from the English “unjust factor” approach,⁶⁸ have been prepared to uphold claims by carers using that area of the law.⁶⁹ Moreover, even if the care provided is by definition informal and not the subject of contractual remuneration in a technical sense, Fineman has argued that the choice to care “occurs within the constraints of social conditions, including history and tradition.”⁷⁰ Writing from a US perspective, she fails to see why most of the costs of care should be borne by carers themselves rather than being distributed amongst the true beneficiaries of care, whether institutional or individual. If it is necessary to provide a private means of support for carers who are genuinely in need of encouragement, it also seems unjust to deny such private law remedies to those who do not require such an inducement, but do suffer disadvantages. Even in the context of entirely altruistic friendship-based relationships, John Eekelaar is content that a succession-based claim on the death of one of the parties would “fit in with the values of friendship.”⁷¹

A further question that causes difficulty, however, is whether any

Kortmann, *Altruism in Private Law: Liability for Nonfeasance and Negotiorum Gestio* (Oxford: Oxford University Press, 2005) at ch 11 for a general discussion of private law remedies for “good Samaritans” in English Law.

66. See e.g. *Cook v Thomas*, [2010] EWCA Civ 227; *Walsh v Singh*, [2009] EWHC 3219 (Ch); Sloan, *supra* note 8 at 121-39; Sarah Nield, “Testamentary Promises: A Test Bed for Legal Frameworks of Unpaid Caregiving” (2007) 58:3 NILQ 287 at 294-98.
67. See e.g. *Kerr v Baranow*, 2011 SCC 10 at paras 31-32, Cromwell J.
68. *Banque Financière de la Cité v Parc (Battersea) Ltd* (1998), [1999] 1 AC 221 (HL) at 227, Lord Steyn; c.f. Peter Birks, *Unjust Enrichment*, 2d ed (Oxford: Clarendon Press, 2005).
69. See e.g. *Clarkson v McCrossen*, [1995] 6 WWR 28 (BCCA); c.f., e.g. *Brennan v Gardy Estate*, 2011 BCSC 1337. For discussion, see Sloan, *supra* note 8 at 129-34; Rosalyn Wells, “Testamentary Promises and Unjust Enrichment” (2007) 15 RLR 37.
70. Fineman, *The Autonomy Myth*, *supra* note 10 at 41.
71. John Eekelaar, *Family Law and Personal Life* (Oxford, Oxford University Press, 2007) at 48.

justification for a private law approach *depends* on the failure of the state to provide adequate support for care and carers. It could be argued that in a perfect society, the state would provide adequate support such that any justification for private law remedies that previously existed immediately falls away. It could also be said that, given the anxiety about the amount that individuals should have to pay towards the cost of *formal* care, it would be very difficult to justify imposing additional liability in respect of *informal* care on care recipients.

But it is not clear that things are really as simple as that. Many scholars are quite content to say that there should be some sort of redistribution of property following the end of a marriage or civil partnership,⁷² in spite of the potential availability of state benefits for the parties to the relationship.⁷³ Indeed, one of Lady Hale's concerns about the greater enforceability of pre-nuptial agreements in England, expressed in her dissenting speech in *Radmacher v Granatino*,⁷⁴ was that an economically stronger party could use such an agreement to "cast the burden of supporting her husband onto the state" rather than undertaking the burden herself.⁷⁵ When evaluating the English Law Commission's proposals for an equivalent redistributive scheme for *unmarried* cohabitants,⁷⁶ Simone Wong has argued that there is "no logical reason to limit access to the law to only couple-based relationships,"⁷⁷ even if she emphasised the distinctive

72. See e.g. Jonathan Herring, *Family Law*, 6th ed (Harlow: Pearson, 2013) at 212-19.

73. For an argument that financial support should be a matter of public liability rather than private law, see Kevin J Gray, *Reallocation of Property on Divorce* (Abingdon, UK: Professional Books, 1977) at 302-34. See also Lucinda Ferguson, "Family, Social Inequalities, and the Persuasive Force of Interpersonal Obligation" (2008) 22:1 IJLPF 61 (for a useful discussion of the appropriate respective roles of public and private law in this context from a Canadian perspective).

74. [2010] UKSC 42.

75. *Ibid* at para 190.

76. Law Commission of England and Wales, *Cohabitation: The Financial Consequences of Relationship Breakdown* (UK: Law Commission, 2007), online: GOV.UK <https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/228881/7182.pdf>.

77. Simone Wong, "Caring and Sharing: Interdependence as a Basis for Property Redistribution" in Anne Bottomley & Simone Wong, eds, *Changing Contours of Domestic Life, Family and Law: Caring and Sharing*

nature of the commitment in such conjugal couple-based relationships in later work,⁷⁸ and even though a lot of informal care self-evidently takes place *within* couple-based relationships.

Moreover, testamentary freedom is already limited in English law through its allowing a wide range of individuals to claim discretionary provision out of a deceased person's estate under the *Inheritance (Provision for Family and Dependents) Act 1975*,⁷⁹ some of whom are carers,⁸⁰ and it might legitimately be asked why a carer for that person should not be specifically recognised as a potential family provision claimant in his own right, particularly where a such a person has a need for future maintenance comparable to that of other possible claimants as a result of his caring. The specific inclusion of caring relationships in such legislation is not a fanciful suggestion, but already occurs in several parts of Australia, for example.⁸¹ Analogously with the widely accepted view on divorce-based claims, under the current law of family provision on death, English courts are generally reluctant to attach a great deal of significance to the availability of state support for an applicant when evaluating his claim.⁸²

(Oxford: Hart Publishing, 2009) 49 at 54. *C.f.* the Commission's own conclusion in an earlier project that "[i]t is not possible ... to devise a statutory scheme for the ascertainment and quantification of beneficial interests in the shared home which can operate fairly and evenly across the diversity of domestic circumstances which are now to be encountered," see Law Commission of England and Wales, *Sharing Homes: A Discussion Paper* (UK: Law Commission, 2002) at 85, online: Law Commission <http://lawcommission.justice.gov.uk/docs/Sharing_Homes_Discussion_Paper.pdf>, which led it to exclude non-conjugal caring relationships from its cohabitation project, see Law Commission of England and Wales, *Cohabitation: The Financial Consequences of Relationship Breakdown: A Consultation Paper* (UK: Law Commission, 2006) at para 9.136, online: Law Commission <http://lawcommission.justice.gov.uk/docs/cp179_Cohabitation_Consultation.pdf>. See Sloan, *supra* note 8 at 206-08 for discussion.

78. Simone Wong, "Shared Commitment, Interdependency and Property Relations: A Socio-legal Project for Cohabitation" (2012) 24:1 CFLQ 60 at 74-75.

79. *Supra* note 59.

80. See *e.g.* Sloan, *supra* note 8 at 136-205.

81. See generally *ibid*; see also *Adult Interdependent Relationships Act 2002*, SA c A-4.5 and *Wills and Succession Act 2010*, SA c W-12.2, ss 72(b)(ii), 88.

82. See *e.g.* *Re E, E v E*, [1966] 2 All ER 44 (Ch); *Re Collins, decd*, [1990]

Perhaps it is possible to go as far as to say that private property redistribution is *more* readily justifiable in the case of a genuine caring relationship rather than a marriage or couple-based relationship *per se*, since a true caring relationship confers a vital benefit, by definition. In other words, a caring relationship is not necessarily a status-based relationship like marriage or civil partnership, in relation to which the English courts are to some extent content merely to assume that there is a justification for a redistribution of property rights when a relationship breaks down by virtue of a “partnership” model,⁸³ but arguably provides more benefits to society *per se* than some of those status-based relationships. Recognition of this notion would take us closer to the focus on the “carer-dependant” paradigm that Fineman (at least at one time) considered vital for family law⁸⁴ and, in Maxine Eichner’s words, change “the basis of entitlement ... to desert.”⁸⁵

Public opinion may jeopardise such principled thinking. There is at least some evidence that a significant portion of the population is uncomfortable with the idea of linking care and private rewards,⁸⁶ and care must be taken that people are not allowed to fall unknowingly into relationships generating rights and obligations without good reason.⁸⁷ There is, moreover, a converse risk that the recognition of

Fam 56 at 61-62, Hollings J; *Ilott v Mitson*, [2011] EWCA Civ 346 at para 75, Arden LJ.

83. See in particular *Miller v Miller; McFarlane v McFarlane*, [2006] UKHL 24, concerning the use of the courts’ powers to redistribute property under the *Matrimonial Causes Act 1973* (UK), c18, Part II; and see *e.g.* Lisa Glennon, “Obligations Between Adult Partners: Moving from Form to Function?” (2008) 22:1 IJLPF 22 at 40.

84. See Shazia Choudhury & Jonathan Herring, *European Human Rights and Family Law* (Oxford: Hart Publishing, 2010) at 426, and Herring, *Caring and the Law*, *supra* note 10 at 187-233 for discussion. *C.f.* Martha A Fineman, “The Vulnerable Subject: Anchoring Equality in the Human Condition” (2008) 20:1 Yale JL & Feminism 1.

85. Maxine Eichner, “Dependency and the Liberal Polity: on Martha Fineman’s The Autonomy Myth” (2005) 93:4 Cal L Rev 1285 at 1291.

86. See *e.g.* Karen Rowlingson, “Attitudes to Inheritance: Focus Group Report” (Bath: University of Bath, 2004), but *c.f.*, *e.g.* Deirdre G Drake & Jeanette A Lawrence, “Equality and Distributions of Inheritance in Families” (2000) 13:3 Social Justice Research 271.

87. See *e.g.* Nicola Peart, “De Facto Relationships (or Maybe Not) in New

caring relationships facilitating property redistribution, *inter alia*, could be manipulated to undermine equality-oriented legislation aimed at conjugal same-sex couples.⁸⁸ It is nevertheless significant that although Fineman herself advocates for greater *state* support of the carer, she also accepts that care recipients “owe an individual debt to their individual caretakers,” which exists alongside a broader societal debt owed to those carers.⁸⁹

It is not my intention to argue here that private law should be the predominant means of support for carers, that a claim should be available in every situation, or that a carer should automatically be paid out of the care recipient’s resources as though he had been providing formal social care for her. Indeed, in many cases a claim will be impossible simply because the care recipient has lived or died with insufficient assets, particularly in light of the formal care costs considered above.⁹⁰ Moreover, we should not seek to encourage the state to regard private law as the major mode of governance in relation to care, and Susan Boyd and Claire Young rightly express concern from a Canadian perspective that the recognition of a variety of relationships can cause governments to “offload responsibility onto those private relationships, resulting in more expectations being made of those relationships in terms of taking care of ‘their own.’”⁹¹

It is also legitimate to quibble about important details of any private law claim by a carer, as I did in my monograph, and specifically about questions such as: should the claim be dependent on a promise made by

Zealand” (2008) IFL 113.

88. See *e.g.* Lisa Glennon, “Displacing the ‘Conjugal Family’ in Legal Policy – A Progressive Move?” (2005) 17:2 CFLQ 141 (which includes analysis of Canadian developments such as Law Commission of Canada, *Beyond Conjuality: Recognizing and Supporting Close Personal Adult Relationships* (2001) in this regard); Sloan, *supra* note 8 at 206-16. *C.f.* Herring, “Informal Carers”, *supra* note 63 at 505.
89. Fineman, *The Autonomy Myth*, *supra* note 10 at 48.
90. See *e.g.* Lorna Fox O’Mahony, *Home Equity and Ageing Owners: Between Risk and Regulation* (Oxford: Hart Publishing, 2012) at 32-37.
91. Susan B Boyd & Claire FL Young, “From Same-Sex to No Sex?: Trends Towards Recognition of (Same-Sex) Relationships in Canada” (2003) 1:3 Seattle Journal for Social Justice 757 at 784.

the care recipient to the carer?;⁹² what should be the basis for relief?;⁹³ how should the “carer” be precisely defined?; should claims be actively restricted to the time after the care recipient has died?;⁹⁴ or how should the carer’s claim be weighed against those of non-caring but dependent family members?⁹⁵ This article simply suggests that a normative justification for supporting care using private law can be found, and that it does not necessarily depend fully on inadequate state support for care in the true sense.

IV. Conclusion

I hope I have provided some food for thought in this article. Of course, whatever the lofty aims of the *Care Act*, it seems unlikely that we will ever live in that perfect society where the state will provide fully adequate support for carers and care recipients. In the imperfect context, private law could well come increasingly to the fore, and the question posed in this article may never really have to be posed by policymakers in an undiluted form. While private law should never be used to allow the state to abdicate its responsibility to ensure that care is supported, a normative justification for a private law approach to the issue can nevertheless be found. As a closing question, readers may wish to consider why society might be more comfortable about private redistribution of property in respect of *some* socially useful relationships than others.

92. See *e.g.* Sloan, *supra* note 8 at 21-23, 239-43.

93. See *e.g. ibid* at 24-25, 244-45.

94. Compare *ibid* at 136-205, 206-16.

95. See *e.g. ibid* at 206-16.

Dementia, Decision-Making, and the Modern (Adult) Guardianship Paradigm: *Bentley v Maplewood Seniors Care Society*

Margaret Isabel Hall*

This paper considers the meaning of decision-making, including substitute decision-making, for persons with dementia. The paper discusses the historical development of adult guardianship, from the King's stewardship of the property of "fools" and "lunatics" to the modern mechanisms of substitute decision-making, and the relationship between substitute decision-making and a particular ideal of autonomy. The paper concludes with a discussion of Bentley v Maplewood Seniors Care Society, a case concerning the present choices of a woman with dementia, the decisions set out in the "living will" she drafted many years earlier (prior to dementia), and the decisions made by the woman's (purported) representatives on her behalf. The case invites us to consider whether the decisions of the former, mentally capable self can ever trump the choices of the current self with dementia.

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I. Introduction

The case of *Bentley v Maplewood*¹ raises a number of profound questions about the nature of self in dementia, the nature and significance of “decisions” and “decision-making,” and the role of substitute decision-makers (including the former self through an advance directive) *vis-à-vis* the person with dementia. What is the nature of consent for an individual with advanced dementia, who departs in dramatic physical and mental ways from the norm (including his or her former “normal” self), and how can it be recognised? Should consent ever be separated from decision-making and if so, why and under what circumstances? What are the ethical implications of enabling a former self to make life terminating decisions on behalf of a fundamentally changed present self? What is the role of the individual’s representative in this situation? As Ronald Dworkin would have it (see discussion, *infra*), should a person’s prior (intellectual) decision override contrary (embodied) behaviour by the present self-with-dementia? What is “decision-making” and why does it matter?

This article considers the issues raised by the *Bentley* case, as they both illustrate and challenge the modern adult guardianship paradigm.

1. 2014 BCSC 165 [*Bentley*].

II. Autonomy Through Decision-Making: The Modern Adult Guardianship Paradigm

The modern adult guardianship paradigm is predicated on a particular theory about autonomy, individualism, decision-making, and the relationship between them. “Decision” (for the purposes of this theory) refers to a specific kind of choice, a “conclusion or resolution reached after consideration”;² *mere* choices are not decisions. A conclusion arrived at through this process of consideration (*because* it has been arrived at through this process) is understood to be the person’s “own” free, and therefore autonomous, decision. Control of one’s own decisions and decision-making process is essential to one’s identity as an individual; the individual, in turn, tends to make the kind of decision that is consistent with his or her identity. The ability to make a different out-of-character kind of decision, however, for whatever reason, is integral to personal freedom and must be respected.

In this account, the ability to carry out the *process* of decision-making is essential to both autonomy and individual identity. “Mental” or “decision-making capacity” (sometimes referred to as competence) refers to this ability. The *content* of decisions arrived at through this process is irrelevant so long as one is capable of making a “real” decision about the matter at hand: “[t]he right knowingly to be foolish is not unimportant; the right to voluntarily assume risks is to be respected. The State has no business meddling with either. The dignity of the individual is at stake.”³ Autonomy in this sense (as exercised through autonomous decision-making) is a core legal value, long recognised by the common law and equity (through the doctrines of undue influence and duress)⁴ and protected by the right to life, liberty and security of the person guaranteed by section 7 of the *Canadian Charter of Rights and Freedoms*.⁵

2. Oxford Dictionaries, *sub verbo* “decision”, online: Oxford Dictionaries <<http://www.oxforddictionaries.com/definition/english/decision>>.
3. *Koch (Re)* (1997), 33 OR (3d) 485 (Gen Div) at para 17, Quinn J.
4. Which recognize that, in certain factual situations, an otherwise mentally capable person’s ability to make free decisions may be overborne.
5. *R v Morgentaler*, [1988] 1 SCR 30 at 171, Wilson J, concurring (the majority agreed with Justice Wilson on this point); *Canadian Charter of Rights and Freedoms*, Part I of the *Constitution Act, 1982*, being Schedule B

Consent refers to a particular type of decision; to allow something that would otherwise be un-allowed. As with other kinds of decisions, the person who does not have the mental capacity required to consent cannot, truly, consent. The doctrine of informed consent⁶ is premised on the idea that a person cannot make her “own” “real” decision about a matter if she lacks the information she needs to understand the choice involved, and the implications of making it.

The person who is identified as unable to carry out the decision-making process (as lacking mental or decision-making capacity) poses a problem for this account. On the one hand, to hold a person to the consequences of a decision that is not really her “own” seems unfair. On the other hand, making decisions *for* that person negates her identity as autonomous.

The modern guardianship paradigm appears to resolve this problem through the mechanisms of substitute and supported decision-making. Substitute decision-making enables the autonomy of the person whose decision-making processes are impaired by enabling her substitute to effect the decisions she *would have made* if able to do so. The substitute is not a replacement; he or she operates as a kind of decision-making amanuensis, effecting decisions that “really” belong to the other. Proceeding on the basis that persons generally make decisions like those they have made in the past, the substitute is able to maintain the identity of the individual by perpetuating this kind of consistent decision-making. Supported decision-making is a variation on this idea, providing a less intrusive mechanism for enabling autonomous decision-making.⁷ The objective in both cases is the same: to enable the individual to formulate and express his or her “own” decisions and to have those decisions recognized and enforced by the law.

The theoretical account outlined above is a story; a story about how people think and about how they behave. It is a story which resonates, profoundly, with broader cultural and political values. But, however

to the *Canada Act 1982* (UK), 1982, c 11.

6. *Malette v Shulman* (1990), 72 OR (2d) 417 (CA).

7. The supported decision-making model was developed within the developmental disability community, for whom the “substitute” model is much less coherent (there being no former “competent” identity to perpetuate).

attractive the narrative, it is not real. It is a social construct, and its application, to be justified, depends on its workability:

If ideas, meanings, conceptions, notions, theories, systems are instrumental to an active reorganization of the given environment, to a removal of some specific trouble and perplexity, then the test of their validity and value lies in accomplishing this work. If they succeed in their office, they are reliable, sound, valid, good, true. If they fail to clear up confusion, to eliminate defects, if they increase confusion, uncertainty and evil when they are acted upon, then are they false. Confirmation, corroboration, verification lie in works, consequences ... By their fruits shall ye *know* them.⁸

III. Historical Context: Situating the Modern Paradigm

The modern adult guardianship paradigm is the most recent iteration of a very old concept: that a public obligation of some kind is owed to persons whose processes of thought and mind are seen to create or exacerbate vulnerability.

The English system of guardianship, from which the Canadian system derives, originated sometime before the 13th century as a personal obligation of the King.⁹ The obligation was limited to the protection and stewardship of property, and distinguished between “idiots” or “fools” (individuals never having possessed the mental ability required to manage their property) and “lunatics” or *non compos mentis* (those losing this ability as adults). *Non compos mentis* individuals were treated by the law

8. J Dewey, *Reconstruction in Philosophy* (Boston: Beacon Press, 1948) at 156 [emphasis in original].

9. The obligation is first mentioned in, although apparently not created by, the *Statute De Prerogativa Regis* in the late thirteenth century. Doug Surtees provides an excellent summary of the murky origins of the Crown’s jurisdiction, which replaced the feudal arrangement whereby the Lord of the Manor assumed control of the property of persons of “unsound mind.” This assertion of Kingly jurisdiction has been explained as a response to abuses of this power committed by the lords, or, alternatively, as part of the general extension of centralised Crown jurisdiction during this period; D Surtees, “How Goes the Battle? An Exploration of Guardianship Reform” (2012) 50:1 *Alta L Rev* 115. Prior to assumption by the King at some point during the reign of Edward I (1272- 1307); see also Lawrence B Custer, “The Origins of the Doctrine of *Parens Patriae*” (1978) 27:2 *Emory LJ* 195 at 195.

as if they could regain mental capacity in the future (whether or not they currently enjoyed “lucid” moments) and, accordingly, the Crown was required to manage the property of such a person on that person’s behalf, taking no profits. Having “once lived his life on an equal mental footing with others ... there was always that glimmer of hope that he would do so again,”¹⁰ and should a lunatic regain lucidity (either permanently or episodically) his property and profits would be returned. The property of fools, on the other hand, who would never regain capabilities they had never enjoyed, was managed on behalf of the Crown. The profits from their estates became the king’s property, subject only to the king’s duties to provide the incapable individual with the necessities of life, not commit waste or destruction, and to pass the estate to any heirs upon death.

The Crown’s “power of administration” over the property of both lunatics and fools was delegated personally to the Lord Chancellor (and, later, to the Lord Justices of Appeal in Chancery), as opposed to the equitable jurisdiction of the Chancellor regarding children. Over time, however, it appears that this power of administration developed in practice into something like an equitable jurisdiction, “[by] virtue of [the Chancellor’s] general power, as holding the great seal, and keeper of the King’s conscience.”¹¹ Also over time, the property of fools came to be managed according to the same standards as the property of lunatics, and the *de facto* distinction between the two categories withered away. No precise moment or mechanism through which this change took place is apparent; Professor Surtees, in his account, directs the reader to Blackstone’s comment that “the ‘clemency of the crown and pity of juries’ gradually assimilated the condition of idiots to that of lunatics.”¹² In a similar way, over time and with no marked turning point, the Crown

10. Louise Harmon, “Falling Off the Vine: Legal Fictions and the Doctrine of Substituted Judgment” (1990-91) 100:1 Yale LJ 1 at 16.

11. *Ibid* at 19, citing Joseph Story, *Commentaries on Equity Jurisprudence: as Administered in England and America*, 12th ed (Boston: Little Brown, 1877) at 608.

12. Surtees, *supra* note 9 at 117; see also Sarah Burningham, “Developments in Canadian Adult Guardianship and Co-Decision Making Law” (2009) 18 Dal J Leg Stud 119.

(through the Chancery) assumed responsibility for the personal care and wellbeing of both lunatics and fools, in addition to property stewardship (although personal responsibilities were most often in fact carried out by families).

The core tenets of the modern adult guardianship paradigm began to take shape with the *Imperial Lunacy Act* of 1890.¹³ First, a new unified category of the “mentally infirm” removed altogether the archaic distinction between lunatics and idiots. Second, the Act effectively privatised the formerly public obligation, setting out procedures for appointing an agent to manage the property of the infirm.¹⁴ Third, by permitting the use of medical evidence (provided through affidavit) in place of a full judicial inquiry, the Act effectively medicalised the guardianship process; although both the declaration of disorder/incapacity justifying guardianship and the appointment of a guardian remained the responsibility of the court (with the exception of “statutory guardianship” where applicable¹⁵) medical evidence of decision-making capacity is virtually always determinative.

Substitute decision-making had been introduced earlier in the 19th century in the case of *Ex parte Whitbread*¹⁶ as a means of allowing the law to effect what could not otherwise be done: to make a distribution of property from the estate of a wealthy “lunatic” to his impecunious, but competent, relative.¹⁷ Such a distribution, with the court taking the private property of one person for the benefit of another, conflicted with the core liberal legal value of private property ownership. It would also

13. 53 & 54 Vict c 5.

14. Burningham, *supra* note 12.

15. “Statutory guardianship” refers to the mechanism whereby the Public Guardian or Trustee (or analogous body depending on the language of the jurisdiction) may be appointed as guardian of property or estate through medical evidence only. The process in British Columbia (originally developed to apply where an individual had been institutionalised) allows for the Public Guardian and Trustee to be appointed as guardian of estate on the basis of a Certificate of Incapacity issued by the director of a Provincial mental health facility or psychiatric unit designated for this purpose under the *Mental Health Act*, RSBC 1996, c 288 and/or under the *Patients Property Act*, RSBC 1996, c 349.

16. 35 Eng Rep 878 (Ch 1816) [*Ex Parte Whitbread*].

17. Harmon, *supra* note 10.

appear to have been prohibited by the court's mandate (as descended from the King's obligation) to preserve the lunatic's estate in his or her interests.¹⁸ The "fiction" of substitute decision-making allowed the court to "discover what the lunatic himself probably would have done" and carry out those "probable desires" through the adoption of an "internal, subjective point of view."¹⁹ According to this fiction, the gift to the niece was "really" in her uncle's interest because it was "really" what he would have decided to do had he been mentally capable of making that decision. The closeness of the family relation together with "[e]vidence of the lunatic's former intentional states" were essential to this exercise.²⁰

These 19th century innovations – privatization, medicalization, and substitute decision-making – comprise the conceptual core of the modern adult guardianship paradigm. All three are connected to, and dependent upon, one another. The substitute decision-making model has come to define adult guardianship in terms of both purpose (as a response to impaired decision-making) and function (the implementation of autonomous decision-making mechanisms). The legal requirement of "finding" decision-making impairment (as a pre-requisite to appointing a substitute or supportive decision-maker) has, in turn, enhanced medical control over the process. Medically produced evidence of decision-making capacity, presented in hard and scientific language of the "bio-fact,"²¹ is seldom questioned by legal decision-makers when legal decision-makers

18. *Ibid* ("[T]he Court... has nothing to consider but the situation of the Lunatic himself, always looking to the probability of his recovery, and never regarding the interest of next of kin" at 22, citing Lord Eldron's judgment in *Ex Parte Whitbread*, *supra* note 16). The jurisdiction of the Courts, descended from the King's delegation of his personal responsibility to the Lord Chancellor, developed into something like an equitable jurisdiction "by virtue of [the Chancellor's] general power, as holding the great seal, and keeper of the Kings conscience." *Ibid* at 19, referring to Story's *Commentaries on Equity Jurisprudence as Administered in England and America* (12th ed, 1877) 608. See also Surtees, *supra* note 9.

19. Harmon, *supra* note 10 at 22.

20. *Ibid* at 25.

21. See discussion in Margaret Isabel Hall, "Mental Capacity in the (Civil) Law: Capacity, Autonomy and Vulnerability" (2012) 58:1 McGill LJ 61 at 71-74.

are involved in the process.²² The increasing privatization of the once public guardianship process through the rise of the enduring power of attorney and other “personal planning” instruments such as health directives (in British Columbia, the representation agreement) has made the involvement of the courts increasingly less likely. These private instruments provide for the individual him or herself to appoint a remedial decision-maker of some kind (substitute or supportive) without public oversight, a “least interventionist” alternative. Within the conceptual framework of the substitute decision-making model, the friend or family member appointed through a private process is best placed to know the individual’s “prior intentional states” and to effect the decision that individual *would have made* if able to do so. The result of these processes has been a dwindling of the public/legal role in the guardianship process, and a transformation (in accordance with the liberal conceptualization of liberty and individualism) of the old idea that a public obligation of some kind is owed to persons whose processes of thought and mind are seen to create or exacerbate vulnerability to harm.

The rise of the advanced directive expands on, and in a sense perfects, these processes, directly enforcing the individual’s “former intentional state” regarding a particular kind of decision – decisions about health care – without the need for a third person intermediary or amanuensis. Within the limited scope of decisions to which it applies, the advanced directive maximizes autonomy by enabling the individual to directly effect his or her own “real” decisions, regardless of decision-making capacity, up to the point of death. The process is a legal one only to the extent that it is enabled by legislation, and the private nature of the advance directive as a direct exchange between individual and physician is intended to construct, in so far as possible, a “normal” medical decision (as if the patient were any other “normal” decision-competent individual).

IV. Situating Dementia: Margo’s Story

Harmon discusses at some length how the doctrine of substitute decision-making came to provide the basis for “substitute” health care

22. See Glyn Davies & Lesley Taylor, “Private Committeeship in British Columbia: A Study of Due Process” (1989) 8:1 Can J Fam L 185.

decision-making on behalf of developmentally disabled persons. The fiction lost all coherence in this context, according to Harmon; unlike the wealthy, lunatic uncle in the *Ex Parte Whitbread* case, there could be no evidence of such a person's "former intentional state" from which to draw conclusions about what he or she *would have done*. Indeed, there was no former "real" self on whose behalf the substitute could act; the real self was the present self. Harmon provides several examples of purportedly "substitute" decisions that were dramatically *contra* the interests of the (present-self) individuals on whose behalf they had been made.²³ Harmon argues that substitute decision-making operated in this context as a blatant and self-serving fiction, employed for the purpose of benefitting (through organ transplant, for example, and the refusal of life saving treatments) other persons at the expense of the incapable individual.²⁴

Dementia poses other difficulties for the substitute decision-making model. In one sense (and unlike the developmentally disabled person) the person with dementia falls into the category of persons formerly characterised as lunatics, for whom evidence of former intentional states can be found. Unlike the lunatic (in the archaic distinction), however, there is no "glimmer of hope" that the individual with dementia will be restored to her or his former self. Indeed the very nature of dementia entails the progressive movement away from that former self, ending in death. Is this process a loss of self (the "living death" or zombie trope) or a changed self? And if the substitute decision model (in all of its modern iterations) works as a mechanism for enacting the "would-have-been" "real" decisions of the individual, how does that mechanism protect the autonomy of an individual with no or little current connection to that past self?

Ronald Dworkin and Rebecca Dresser have both considered this question through the story of Margo, a woman with Alzheimer's disease whose story was originally told by Andrew Firluk in a *Journal of*

23. These developments comprise the focus of her article.

24. And the incoherence of substitute decision-making may be a key reason for the development of supportive decision-making by and on behalf of the developmentally disabled community (and the relative incoherence of supported decision-making in the context of dementia).

the America Medical Association column called “A Piece of my Mind.”²⁵ Firlik describes Margo as “undeniably one of the happiest people I have known,” absorbed in reading and re-reading of her novel and painting abstracts in warm and rosy colours:

There is something graceful about the degeneration [Margo’s] mind is undergoing, leaving her carefree, always cheerful. Do her problems, whatever she may perceive them to be, simply fail to make it to the worry centers of her brain? How does Margo maintain her sense of self? When a person can no longer accumulate new memories as the old rapidly fade, what remains? Who is Margo?²⁶

In his response to Margo’s story, Ronald Dworkin considers the following moral and ethical dilemma: what if Margo, prior to her mental “degeneration,” had expressed a desire to have her life ended in the event that she developed Alzheimer’s disease?²⁷ Dworkin concludes that Margo’s previous wishes should be honoured regardless of Margo’s current contented state of mind. Honouring Margo as an autonomous being, in Dworkin’s account, requires honouring her interest in “living her life in character,” a “critical” interest of higher value than the mere “experiential” interests all humans enjoy as sentient beings (the taste of delicious food; listening to agreeable sounds). Those with the mental capacity to do so construct their identity as autonomous beings through the choices they make throughout their lives; the autonomous character of “Ronald Dworkin” is the outcome of this process, and “Ronald Dworkin” has a critical interest in constructing and maintaining this autonomous self. Acting in Margo’s best interests requires maintaining the autonomous self that Margo constructed while she was capable of doing so; once Margo loses the capacity to, effectively, change her storyline, there is no one else qualified to do that on her behalf, and the most accurate information

25. AD Firlik, “Margo’s Logo” (1991) 265:2 *The Journal of the American Medical Association* 201. The immediate concern of both Dworkin and Dresser is substitute decision-making in the context of health treatment – specifically, end of life decision-making, extending to euthanasia. The essential terms of the argument apply to the workability and moral justification of substitute decision-making generally in the dementia context, however.

26. *Ibid* as cited in Rebecca Dresser, “Dworkin on Dementia: Elegant Theory, Questionable Policy” (1995) 25:6 *Hastings Center Report* 32 at 32.

27. R Dworkin, *Life’s Dominion: An Argument about Abortion, Euthanasia, and Individual Freedom* (New York: Alfred A Knopf, 1993).

available resides in Margo's previously expressed wishes (a time when she was still "Margo" and still able to make the kinds of decisions that would determine who "Margo" would be – in Dworkin's scenario, "Margo" would *not* be a woman with dementia). If Margo did not leave instructions before losing the capacity to do so, according to Dworkin, "the law should so far as possible leave decisions in the hands of [her] relatives or other people close to [her] whose sense of [her] best interests [in Dworkin's sense of maintaining Margo's autonomous character]... is likely to be much sounder than some universal, theoretical, abstract judgment."²⁸

Rebecca Dresser has responded to and rejected Dworkin's argument on the basis (in her terms) of either "wisdom or morality."²⁹ Prior to developing dementia, Dresser notes, it is highly doubtful that Margo had any real understanding of what her lived experience of dementia would be (apart from the mainstream narrative of "horrifying disease"). More fundamentally, Dresser writes, "Dworkin assumes that Margo the dementia patient is the same person who issued the earlier requests to die, despite the drastic psychological alteration that has occurred."³⁰ That assumption is not self-evident, and the morality of imposing the will of a now disappeared self onto the life of a current and existing self is problematic,³¹ either directly (as through an advance directive) or through the "substitute" decisions of a guardian.

28. *Ibid* at 213.

29. Dresser, *supra* note 26 at 34; see also Rebecca Dresser, "Missing Persons: Legal Perceptions of Incompetent Patients" (1994) 46:2 Rutgers L Rev 609.

30. *Ibid* at 35.

31. See also James Lindemann Nelson & Hilde Lindemann Nelson, eds, *Meaning and Medicine: A Reader in the Philosophy of Health Care* (New York: Routledge, 1999) at 47-56; Allen Buchanan, "Advance Directives and the Personal Identity Problem" (1988) 17:4 Philosophy and Public Affairs 277; Seana Valentine Shiffrin, "Autonomy, Beneficence, and the Permanently Demented" in Justine Burley, ed, *Dworkin and His Critics: With Replies by Dworkin* (Malden, MA: Blackwell Publishing, 2004) 195.

V. *Bentley v Maplewood Seniors Care Society*

Bentley v Maplewood Seniors Care Society engages, implicitly, with the fundamental questions of consent and autonomy which substitute decision-making appears to resolve, and the extent to which that (apparent) resolution loses coherence in the context of dementia.³² What is the relationship between autonomy, the self-with-dementia, and the former self? Are the decisions of the former self “real” (the result of reflection and, through that process, the deliberate adoption of identity) in a way that the choices of the self-with-dementia are not? Is it a betrayal of that real self (and therefore an abnegation of the individual’s true autonomy) to prefer and give effect to the choices of the self-with-dementia? What are the obligations of a substitute decision-maker in this situation?

The case concerned Margot Bentley, a resident at the Maplewood care facility. Mrs. Bentley had been diagnosed as suffering from advanced Alzheimer’s disease. Mrs. Bentley is described in the case as having “very few physical movements,” “occasionally rub[bing] the back of her hand, arm, or face” with “[h]er eyes ... closed much of the time. She has not spoken since 2010. She does not indicate through her behaviour that she recognizes her family members or any other person.”³³ The British Columbia Supreme Court agreed with an assessment carried out by a hospice care physician that Mrs. Bentley was not dying, “[d]espite her cognitive and physical disabilities”; if the petitioners’ application was granted she would die from starvation or dehydration, rather than from any effect of Alzheimer’s disease.³⁴

32. Oxford Dictionaries, *sub verbo* “dementia”, online: Oxford Dictionaries <<http://www.oxforddictionaries.com/definition/english/dementia>>. “Dementia” here refers to “[a] chronic or persistent disorder of the mental processes caused by brain disease or injury and marked by memory disorders, personality changes, and impaired reasoning” and includes, but is not limited to, Alzheimer’s. The *Bentley* case concerns an individual with Alzheimer’s, but the issues raised by the case apply to dementia more broadly.

33. *Supra* note 1 at para 18.

34. *Ibid* at para 33.

Staff at Maplewood “assisted” Mrs. Bentley with eating and drinking by:

[P]lacing a spoon or glass on her lower lip. When she opens her mouth to accept nourishment or liquid, the care attendant places the nourishment or liquid in her mouth and Mrs. Bentley swallows it. When she keeps her mouth closed despite being prompted, the care attendant will try again. If she keeps her mouth closed despite a couple of attempts, the care attendant makes no attempt to force her to accept nourishment or liquid.³⁵

Conflicting medical evidence was provided regarding Mrs. Bentley’s apparent “choice” to participate in the spoon feeding. A hospice palliative care physician who assessed Mrs. Bentley concluded she was “clearly” (if non-verbally) “choos[ing] to eat.”³⁶ An assessment of Mrs. Bentley’s decision-making capacity was also carried out by an Incapacity Assessor with the Office of the Public Guardians and Trustee. The assessor agreed that Mrs. Bentley was choosing to eat, and found that her behaviour (opening her mouth in response to dessert after refusing the final portion of her dinner) conveyed Mrs. Bentley’s choices about *what* food to eat. Although Mrs. Bentley “does not make eye contact or appear to respond in other ways when people try to interact with her” she did “grasp the hands of people who speak to her” and “convey[ed] when she is in pain by moaning and tightening her facial muscles.”³⁷ Mrs. Bentley’s condition was described by her GP, in contrast, as “a vegetative state.”³⁸ In the opinion of the GP “any response Mrs. Bentley has when she is prompted with a spoon or glass is ‘a reflex and is not indicative of any conscious decision about whether to eat or not’ ... [s]he does not function mentally in any discernible way.”³⁹

Mrs. Bentley, through her litigation guardian,⁴⁰ together with her husband and daughter, now sought a declaration from the Court that Maplewood stop the spoon feeding. Maplewood, the Fraser Health Authority (“FHA”), the Province of British Columbia (the “Province”), and the intervenor, Euthanasia Prevention Coalition of British Columbia

35. *Ibid* at para 19.

36. *Ibid* at para 24.

37. *Ibid* at para 27.

38. *Ibid* at para 22.

39. *Ibid*.

40. Mrs. Bentley’s litigation guardian was also her daughter.

argued that to stop giving Mrs. Bentley nourishment or liquids would cause her discomfort and bring about her death through dehydration and starvation, constituting neglect within the meaning of the *Adult Guardianship Act*,⁴¹ and possibly violating several criminal laws, including the prohibition against assisted suicide.

The petitioners argued that a “statement of wishes” written and signed by Mrs. Bentley in 1991 required Maplewood to stop providing her with liquids and nutrition, either directly as an “advanced directive” or through the substitute decision-making authority it conferred on them as her “representatives.” The statement of wishes provided that:

If at such a time the situation should arise that there is no reasonable expectation of my recovery from extreme physical or mental disability, I direct that I be allowed to die and not be kept alive by artificial means or “heroic measures”; that “no nourishment or liquids” be provided; and that “[i]n the event that mental deterioration is such that I am unable to recognize the members of my family, I ask that I be euthanized.”⁴²

The statement of wishes also designated Mrs. Bentley’s husband as her “proxy for the purpose of making medical decisions on my behalf in the event that I become incompetent and unable to make such decisions for myself” and her daughter as alternative proxy.⁴³ A second, undated “statement of wishes” was subsequently found providing that:

If the time comes when I can no longer communicate, this declaration shall be taken as a testament to my wishes regarding medical care. If it is the opinion of two independent doctors that there is no reasonable prospect of my recovery from severe physical illness, or from impairment expected to cause me severe distress or render me incapable of rational existence, then I direct that I be allowed to die and not be kept alive by artificial means such as life support systems, tube feeding, antibiotics, resuscitation or blood transfusions: any treatment which has no benefit other than a mere prolongation of my existence should be withheld or withdrawn, even if it means my life is shortened.⁴⁴

The specific reference to “nourishment or liquids” was omitted in this second statement. The petitioners argued that this second statement nevertheless did not contradict the first, and in fact reinforced it.

Advance directives were not provided for in legislation in British

41. RSBC 1996, c 6.

42. *Supra* note 1 at para 5.

43. *Ibid.*

44. *Ibid* at para 9.

Columbia until September 2011;⁴⁵ representation agreements were not provided for until 2000.⁴⁶ The petitioners argued that Mrs. Bentley intended her statement of wishes to operate as a “living will” (although no such instrument was legally recognised in British Columbia at the time) and that the statement should now be treated as having effectively created *both* an advance directive and a representation agreement.⁴⁷ As an advance directive, the “statement of wishes” required Maplewood to stop feeding Mrs. Bentley. As a representation agreement, the statement required Mrs. Bentley’s representatives – her husband and then her daughter – to ensure that her wishes were carried out, therefore entitling them to demand an end to the spoon feeding.

The Court disagreed, on several bases. If the statement of wishes *were* to be treated as creating an advance directive, it was not clear that the refusal of “artificial means and heroic measures,” followed in the “statement of wishes” by a list of items including “nourishment or liquids,” was intended as a refusal of “heroic and artificial” *methods* of providing nourishment and liquids (such as tube feeding) or a refusal of liquid and nourishment *per se*. The “consensus in the medical community” (as attested to by a medical ethicist) was that “assistance with oral nutrition and hydration is neither artificial nor heroic.”⁴⁸ A health care provider could not obtain consent from an advance directive where “the instructions in an adult’s advance directive are so unclear that it cannot be determined whether the adult has given or refused consent to the health care,”⁴⁹ as in this case.

In any event, the “statement of wishes” was not an advance directive for several reasons. Advance directives and representation agreements

45. *Health Care (Consent) and Care Facility (Admission) Act*, RSBC 1996 c 181, Part 2.1 [*HCCCFA Act*].

46. *Representation Agreement Act*, RSBC 1996, c 405 [*RA Act*].

47. See *Health Care Consent Regulation*, BC Reg 20/2000, s 15: although legislation introducing advance directives was not proclaimed in British Columbia until 2011, “written instructions made by a capable adult as described in that section are deemed to be advance directives if made and executed in accordance with sections 19.4 and 19.5 of the Act, as if those sections had been in force at the time the written instructions were made.”

48. *Supra* note 1 at para 111.

49. *HCCCFA Act*, *supra* note 45, s 19.8(1)(b).

are fundamentally different documents: an advanced directive cannot appoint a substitute decision-maker (as this document purported to do). Furthermore, advance directives can only direct *health* care decisions; the spoon feeding in this case was not “health care,” but “personal care.” More invasive methods of feeding such as tube feeding could be characterized as “health care,” but spoon feeding could not. The Court noted also Maplewood’s argument that the *Residential Care Regulations* (applying to nutrition, assistance with eating, and meal plans for adults living in assisted living and care settings) required that Mrs. Bentley be provided with liquid and nutrition.⁵⁰

Of course, personal care also requires consent. In British Columbia, the *Representation Agreement Act*⁵¹ sets out the mechanisms for appointing a substitute decision-maker for both personal and health care where a person is unable to consent.⁵² There is no mechanism for creating a personal care advance directive, although a representative must consider the “previous intentional states” or wishes of the person on whose behalf he or she is acting and follow those wishes unless there are compelling reasons to do otherwise. Two kinds of representation agreements are available: a section 7 agreement (which can be made by a person with relatively lower mental capacity and which confers a more limited scope of decision-making authority on the representative)⁵³ and a section 9

50. See *Residential Care Regulations*, BC Reg 96/2009, ss 66-67. The Regulations specify that a “licensee [Maplewood in this case] must ensure that each person in care receives adequate food to meet their personal nutritional needs, based on Canada’s Food Guide and the person in care’s nutrition plan”; that “a licensee must ensure that fluids are provided to persons in care in sufficient quantity and variation to meet the needs and preferences of the persons in care”; and that “a licensee must provide each person in care with ... eating aids, personal assistance or supervision, if required by a person in care who has difficulty eating, or the nutrition plan of a person in care.”

51. *Supra* note 46, s 1.

52. “Personal care” is defined in the *RA Act*, *ibid* to include matters respecting “the shelter, employment, diet and dress of an adult” (the emphasis is provided in the case), “participation by an adult in social, educational, vocational and other activities, contact or association by an adult with other persons, and licences, permits, approvals or other authorizations of an adult to do something.”

53. See *ibid*, s 7. A section 7 representative can also carry out financial

agreement (which authorises the representative “to do anything that the representative considers necessary in relation to the personal care or health care of the adult,” including giving or refusing consent to “health care necessary to preserve life.”)⁵⁴ Within these parameters the person making the agreement can confer more or less decision-making authority on the representative. If Mrs. Bentley had wanted to create a *de facto* representation agreement conferring personal decision-making authority on her “proxies,” she would have done so.

The petitioners argued that the statement of wishes should be construed as a representation agreement (presumably a section 9) and that their designation as “proxies” effectively appointed them as Mrs. Bentley’s health care and/or personal care substitute decision-makers.⁵⁵ If the statement *were* read as creating a representation agreement, however, it purported to appoint the two proxies as health care decision-makers only (“to serve as my proxy for the purpose of making medical decision on my behalf in the event that I become incompetent and unable to make such decisions for myself”⁵⁶) with no mention of personal care. The authority to make one kind of decision could not be taken to imply the other and the statement could not be construed as conferring decision-making authority regarding personal care.

Most significantly, however, even if the “statement of wishes” could operate as either an advance directive or a representation agreement (or both), the Court concluded that Mrs. Bentley was capable of consenting to the spoon feeding and that, through her behaviour, she *did* consent to it.⁵⁷ The existence and content of any advance directive or representation

management for the individual (a person who is not capable of appointing a power of attorney may appoint a section 7 representative).

54. *Ibid*, s 9.

55. Although the *RA Act* came into force in 2000 and the Statement of Wishes was completed in 1991, s 39 of that *Act* provides that “[a]n agreement that was made before this Act authorized the making of a representation agreement, and would have been a valid representation agreement if, at the time the agreement was made, this Act had authorized the making of a representation agreement, is valid and is deemed for all purposes to have been made under this Act.”

56. *Supra* note 1 at para 101.

57. The fact that Mrs. Bentley could not, currently, communicate as she did previously did not indicate an inability to consent; indeed, the *RA*

agreement she may have put in place was therefore irrelevant. The extent to which Mrs. Bentley's current consent contradicted any previously expressed wishes was also irrelevant:

It is entirely possible that the decisions Mrs. Bentley predicted she would make for herself in the future through her "proxies" and as set out in her statements of wishes are different than the decisions she is currently making. All adults are entitled to change their mind subsequent to creating written instructions, which is one of the risks associated with written instructions for the future. This Court must consider the possibility that Mrs. Bentley's previously expressed wishes are not valid in the face of her current consent.⁵⁸

Mrs. Bentley's current consent must be respected, and the spoon feeding continued.

VI. Conclusion

Mrs. Bentley's husband and daughter told the Court that they could "no longer see in Mrs. Bentley the active and creative person that they knew as their wife and mother,"⁵⁹ characterizing her as "vegetative."⁶⁰ She appeared to no longer recognize her family members, and could not speak. The "Margo Bentley" the petitioners knew had ceased to exist. That Margo, they now argued, deserved to have her autonomous voice heard and respected; the apparent choices of Mrs. Bentley's self-with dementia were not real decisions but reflexes. The Court disagreed.

Importantly, that conclusion was not justified on the basis that Mrs. Bentley's choices were in any way the product of a deliberate process of consideration. There is no reference in the judgment to the extent of her decision-making or mental capacity, only to her choices as indicated by her behaviours. The Court's decision implies that this process – that "decision-making capacity" – is not, in fact, the essential factor here; that where a living human being indicates an embodied choice, that choice must be respected as "real" regardless of the intellectual process

Act, Adult Guardianship Act, and HCCCFA Act all include provisions indicating that an adult is presumed to be mentally capable and that difficulties with communication are not to be interpreted as indicating a diminishment of mental capacity.

58. *Supra* note 1 at para 54.

59. *Ibid* at para 56.

60. *Ibid* at para 57.

that produced it. The petitioners may be right, in other words, to the extent that Mrs. Bentley's current "consent" to the spoon feeding is not a decision (in the way that her "statement of wishes" is an expression of decisions). But those prior decisions do not override Mrs. Bentley's current choice in this context. It is right that embodied choices, even in the absence of rational decision-making processes, should determine what does and does not happen regarding the "personal care" of one's body.

The case has been widely discussed in the media as a "right to die" and "dying with dignity" case. The Vancouver Sun reported that "Bentley has been in a vegetative state since late 2011. Since then the family has pleaded for adherence to the living will. Her case has gained national attention and The Vancouver Sun has received many letters from readers, almost all of them outraged that the nursing home is not respecting Mrs. Bentley's wishes."⁶¹ According to the Globe and Mail, Margo Bentley, a former nurse,

was determined not to die a slow, lonely, frightful death like so many of her patients. So she planned ahead. Bentley wrote a living will, one that clearly stated that, when her time came, she did not want heroic measures taken to keep her alive. She also discussed the issue with her children, fully and openly, and they were in agreement.⁶²

Bentley did everything right. Yet today, the 82-year-old, who is in the final stages of dementia, is being kept "alive" against her wishes and those of her family. And the B.C. Supreme Court says that's okay.

How could this happen?

When will the wishes of patients finally and rightfully take precedence over the paternalistic prurience of the medico-legal establishment? When will we stop torturing people in the name of legalistic hair-splitting and fully embrace essential principles such as having treatment choices and death with dignity?⁶³

61. Tiffany Crawford, "Right-to-die: Fraser Health says it has a legal obligation to spoon-feed vegetative patient", *The Vancouver Sun* (12 September 2014) online: The Vancouver Sun <<http://www.vancouver.sun.com>>.

62. Andre Picard, "Margot Bentley case shows our health care system values its bureaucracy over its patients", *The Globe and Mail* (10 February 2014) online: The Globe and Mail <<http://www.theglobeandmail.com>>.

63. *Ibid.*

The public discourse around the Margo Bentley case essentially (if implicitly) adopts Ronald Dworkin's position regarding Firlík's "Margo." It demonstrates, powerfully, the cultural entrenchment of the modern adult guardianship paradigm, as a means of carrying the "real" self forward despite the embodied manifestation of the self-with-dementia. The dominant discourse that both constructs and surrounds dementia (the "living death" after the loss of self) is of a piece with these cultural values and beliefs (and, therefore, with the substitute decision-making model that is congruent with them). The decision of the British Columbia Supreme Court in *Bentley* provides an alternative account of the self-with-dementia as an *alternate* self (as opposed to non-self) that is capable of making choices of a certain kind; those choices look and almost certainly *are* different in kind from the decisions of the "normal" unimpaired self, and arrived at through different mental processes, but this difference does not negate their meaning. The implications of this account are potentially far-reaching, as society prepares for the "rising tide" of dementia.⁶⁴

Bentley shows the court and the medical players – what the *Globe and Mail* refers to as the "medico-legal establishment"⁶⁵ – effectively exercising a public guardian-like role *vis-à-vis* Margo Bentley (although of course neither is acting as her actual guardian) in contravention of those who would assume that role in their private capacity (as Mrs. Bentley's representatives or through enforcement of an advance directive). "Guardian-like" here refers not to the legislated mechanisms of guardianship but to the old idea referred to at the beginning of this article, of which the modern adult guardianship paradigm is merely the latest (but almost certainly not the final) iteration: that a public obligation of some kind is owed to persons whose processes of thought and mind are seen to create or exacerbate vulnerability to harm.

The modern idea (or paradigm)⁶⁶ of adult guardianship as a response

64. Alzheimer Society of Canada, *Rising Tide: The Impact of Dementia on Canadian Society*, Alzheimer Society of Canada (2010), online: Alzheimer Society of Canada <<http://www.alzheimer.ca>>.

65. Picard, *supra* note 62.

66. The Oxford English Dictionary, *sub verbo* "paradigm", online: Oxford Dictionaries <<http://www.oxforddictionaries.com/definition/english/paradigm>>. "Paradigm" is defined as "a world view underlying the theories

to impaired decision-making is just that – an idea, neither natural nor inevitable. “Ideas are ... tools- like forks and knives and microchips- that people devise to cope with the world in which they find themselves,” and “their survival depends not on their immutability but on their adaptability.”⁶⁷

The *Bentley* case suggests that the self-with-dementia needs a response of a different kind, a departure from the modern adult guardianship paradigm and from the theoretical hegemony of the decision.

and methodology of a particular scientific subject.”

67. Louis Menand, *The Metaphysical Club* (New York: Farrar, Strauss and Giroux, 2001) at xi.

Courts, Challenges, and Cures: Legal Avenues for Patients with Rare Diseases to Challenge Health Care Coverage Decisions

Sarah Burningham*

This paper examines the legal tools that may be available to patients with rare diseases seeking to compel Canadian governments to provide funding for required or desired treatments. In making health care coverage decisions, governments must decide whether to extend funding to cover potentially expensive treatments that benefit relatively few people, particularly when those treatments are experimental. If particular treatments are not covered by health insurance, patients with rare diseases may turn to the courts with claims based in constitutional, human rights, administrative, international or tort law, in an effort to compel the government to provide funding. Strategies that employ the courts in this way are unlikely to be successful, as courts tend to defer to government on these types of policy-driven decisions.

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I. Introduction

Canadian patients with rare diseases may face unanticipated barriers in pursuit of treatment. Given the plethora of diagnostic challenges associated with rare diseases, patients may go undiagnosed or misdiagnosed for years.¹ If and when they are correctly diagnosed, effective treatment may not exist, as characteristics of rare diseases may render the study of these illnesses and the development of medication difficult or unprofitable.² Even if treatment is available, it may not

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1. Erik Tambuyzer, “Rare Diseases, Orphan Drugs and their Regulation: Questions and Misconceptions” (2010) 9 *Nature Reviews Drug Discovery* 921 at 921; Paola Pierucci et al, “A Long Diagnostic Delay in Patients with Hereditary Haemorrhagic Telangiectasia: A Questionnaire-Based Retrospective Study” (2012) 7:33 *Orphanet Journal of Rare Diseases* (epub).
 2. Erika F Augustine, Heather R Adams & Jonathan W Mink, “Clinical Trials in Rare Disease: Challenges and Opportunities” (2013) 28:9 *Journal of Child Neurology* 1142; Tambuyzer, *ibid* at 922; John Forman et al, “The Need for Worldwide Policy and Action Plans for Rare Diseases” (2012) 101:8 *Acta Paediatrica* 805 at 805. Drug developers have tended to neglect rare diseases, opting to focus on developing medications for more common diseases, though many countries have introduced policies and legislation intended to stimulate research in this area: Samir Gupta, “Rare Diseases: Canada’s ‘Research Orphans’” (2012) 6:1 *Open Medicine* e23 at e23-e26; Abbas H Panju & Chaim M Bell, “Policy Alternatives for Treatments for Rare Diseases” (2010) 182:17 *Canadian Medical Association Journal* E787; Mae Thamer, Niall Brennan & Rafael Semansky, “A Cross-National Comparison of Orphan Drug Policies: Implications for the US Orphan Drug Act” (1998) 23:2 *J Health Pol* 265.

be covered by the public health care system and the cost may put the treatment out of reach for many patients.³

The recent controversy surrounding the drug eculizumab (brand name Soliris) provides a helpful example. The drug was approved by Health Canada as treatment for two rare diseases: paroxysmal nocturnal hemoglobinuria (PNH) and atypical hemolytic uremic syndrome (aHUS).⁴ The drug, with a price tag of about half a million dollars every year for each patient, is very expensive.⁵ The Canadian Drug Expert Committee, which makes suggestions to provinces regarding which drugs should be covered by their health insurance plans, recommended in both cases that the drug not be funded. In the case of PNH, the Committee believed the cost was too high, and in the case of aHUS, the Committee doubted the efficacy of the drug.⁶ In 2011, the provincial governments coordinated to cover Soliris for PNH.⁷ However, provincial health plans, for the most part, do not cover Soliris for aHUS.⁸ As this case demonstrates, patients with rare diseases may face agonizing uncertainty and disappointment about the scope of coverage. Coverage of a particular

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3. Media reports frequently feature personal stories of patients in need of medication not covered by the public system. See *e.g.* Sarah O'Donnell, "Family Wins Drug-Cost Coverage", *Edmonton Journal* (13 August 2013) A1; Joanne Laucius, "Rare Condition Could Leave 12-year-old a Drug Orphan", *Ottawa Citizen* (5 August 2013) online: Ottawa Citizen <<http://www.ottawacitizen.com>>; "North Vancouver Man Denied Life-Saving Drug", *CBC News* (10 April 2011) online: CBC News <<http://www.cbc.ca/news>>.
 4. Health Canada, "Product Monograph: Soliris (eculizumab)" (25 May 2009), online: Health Canada <<http://www.hc-sc.gc.ca>>; Laucius, *ibid.* An estimated 90 people in Canada have PNH: Sam Cooper, "Drug-Funding Agreement Gives Rare Disease Patients New Hope", *Edmonton Journal* (26 July 2011) A2.
 5. Laucius, *supra* note 3.
 6. Canadian Drug Expert Committee, "CDEC Final Recommendation: Eculizumab: (Soliris – Alexion Pharmaceuticals Inc.) New Indication: Atypical Hemolytic Uremic Syndrome" (18 July 2013), online: Canadian Agency for Drugs and Technologies in Health <<http://www.cadth.ca>>; Canadian Expert Drug Advisory Committee, "CEDAC Final Recommendation: Eculizumab: (Soliris – Alexion Pharmaceuticals Inc.) Indication: Paroxysmal Nocturnal Hemoglobinuria" (19 February 2010), online: Canadian Agency for Drugs and Technologies in Health <<http://www.cadth.ca>>.
 7. Cooper, *supra* note 4.
 8. Laucius, *supra* note 3 (it appears that Soliris may be covered for aHUS in Quebec).

medication may be extended only to certain groups of patients and denied to others. Furthermore, a “coverage patchwork” may develop across the country, leading to a situation where a particular medication is publicly funded in one province but not covered in adjacent provinces.⁹

This paper focuses on health care access challenges faced by patients with rare diseases. A disease is a “rare disease” if it affects only a small segment of the overall population, typically defined as 1 in 2,000 people.¹⁰ Although individual rare diseases affect only a small number of people, over 5 per cent of the total population has a rare disease.¹¹

As the above example of Soliris illustrates, in a publicly funded health care system like Canada’s, hard questions arise: Which treatments should be covered, and for whom? Who should pay for people with rare diseases to receive expensive drugs? How should governments choose to allocate scarce health resources? This paper will not provide a normative answer to these questions. Rather, it focuses on a different, yet related, problem that arises after these questions have been answered and funding decisions have been implemented: Do patients with rare diseases who are denied public health insurance coverage for desired treatments have recourse to the courts?

This paper reviews legal mechanisms available to patients with rare diseases who seek to establish entitlement to publicly funded medical treatment. It begins with an overview of how coverage decisions are made in Canada’s public health care system. This is followed by a consideration of different legal avenues – constitutional, administrative, human rights, international, and tort – and an assessment of their potential for success.

Throughout the following discussion, one issue that arises repeatedly is the efficacy of the medication in question. Sometimes the treatment sought by patients will be proven to be effective and, in the case of a drug, approved by Health Canada. At other times, patients may seek

9. Jamie R Daw & Steven G Morgan “Stitching the Gaps in the Canadian Public Drug Coverage Patchwork? A Review of Provincial Pharmacare Policy Changes from 2000 to 2010” (2012) 104:1 Health Policy 19; Wendy J Ungar & Maciej Witkos, “Public Drug Plan Coverage for Children Across Canada: A Portrait of Too Many Colours” (2005) 1:1 Healthcare Policy 100.

10. Gupta, *supra* note 2 at e23.

11. *Ibid* at e26.

unproven or unapproved¹² treatments or drugs.¹³ While many of the legal issues pertinent to these two circumstances overlap, the latter situation presents unique challenges. For example, if there is no scientific evidence establishing that a particular drug is an effective treatment for a particular disease, then the patient seeking access to that drug may be unable to satisfy his or her burden to prove the requisite elements of the claim. The issue of how medical efficacy may affect the outcome of a particular claim is addressed when germane to the discussion below.

II. Overview of Health Care Coverage Decision-Making

As a condition of federal subsidy under the *Canada Health Act*,¹⁴ provincial health insurance plans must cover “medically required” “physician services”¹⁵ and “medically necessary” “hospital services.”¹⁶ The contours of “medically necessary” – and thus what services must be covered – are not fleshed out in the federal act or in the provincial health acts which establish and operationalize provincial health care

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12. Under schemes set up by the provinces and the federal government, patients are able to obtain unapproved drugs in certain circumstances. A detailed description of these processes and the decision-making that occurs under them is outside the scope of this paper. For more information, see Timothy KS Christie, Marianne Harris & Julio SG Montaner, “Special Access Denied: A Case Study of Health Canada’s Special Access Program” (2006) 2:2 Health Policy 27; Health Canada, “Special Access Programme – Drugs”, online: Health Canada <http://www.hc-sc.gc.ca/dhp-mpps/acces/drugs-droguessapfs_pasfd_2002-eng.php>.
 13. See Simon Day, “Evidence-Based Medicine and Rare Diseases” in Manuel Posada de la Paz & Stephen C Groft, eds, *Rare Diseases Epidemiology: Advances in Experimental Medicine and Biology*, vol 686 (New York: Springer, 2010) 41 (“most new experimental treatments sadly do not work – or, even if they do work, their overall benefit-risk balance is not positive” at 44).
 14. RSC 1985, c C-6 [CHA].
 15. *Ibid*, s 2.
 16. *Ibid*.

themes.¹⁷ Despite the fertile academic literature on this issue,¹⁸ case law exploring and developing the term is sparse, leading to the rather unhelpful conclusion that “medically necessary” hospital and physician services are those that governments ultimately decide to cover under their public insurance plans.¹⁹

Given that these decisions are not based on legislative guidelines, it is important that patients who intend to challenge the scope of public health care coverage understand how these decisions are made. The manner of decision-making varies greatly depending on the sort of service in issue.²⁰ Coverage for physician services, for example, is determined through “negotiation between a provincial government and

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17. Colleen M Flood, Mark Stabile & Carolyn Tuohy, “What Is In and Out of Medicare? Who Decides?” in Colleen M Flood, ed, *Just Medicare: What’s In, What’s Out, How We Decide* (Toronto: University of Toronto Press, 2006) 15 at 17; Timothy Caulfield, “Wishful Thinking: Defining Medically Necessary in Canada” (1996) 4 Health LJ 63 at 67 [Caulfield, “Wishful Thinking”].
 18. See e.g. Caulfield, “Wishful Thinking”, *ibid*; Louise R Sweatman & Diane Woollard, “Resource Allocation Decisions in Canada’s Health Care System: Can These Decisions Be Challenged in a Court of Law” (2002) 62 Health Policy 275; Cathy Charles et al, “Medical Necessity in Canadian Health Policy: Four Meanings and...a Funeral?” (1997) 75:3 The Milbank Quarterly 365 at 370; Flood, Stabile & Tuohy, *ibid*; Commission on the Future of Health Care in Canada, *Medically Necessary: What is it, and Who Decides?* (Ottawa: 2002), online: Canadian Foundation for Healthcare Improvement <<http://www.cfhi-fcass.ca/Home.aspx>>; Donna Greschner, “Charter Challenges and Evidence-Based Decision-Making in the Health Care System: Towards a Symbiotic Relationship” in Colleen M Flood, ed, *Just Medicare: What’s In, What’s Out, How We Decide* (Toronto: University of Toronto Press, 2006) 42; Sara Rosenbaum et al, “Who Should Determine When Health Care is Medically Necessary?” (1999) 340 The New England Journal of Medicine 229. See also the Honourable Michael JL Kirby, *The Health of Canadians – The Federal Role: Final Report* (Ottawa: The Standing Senate Committee on Social Affairs, Science and Technology, 2002), online: Parliament of Canada <<http://www.parl.gc.ca>>.
 19. Flood, Stabile & Tuohy, *supra* note 17 at 16-18; Colleen M Flood & Michelle Zimmerman, “Judicious Choices: Health Care Resource Decisions and the Supreme Court of Canada” in Jocelyn Downie & Elaine Gibson, eds, *Health Law at the Supreme Court of Canada* (Toronto: Irwin Law, 2007) 25 at 29-30; Caulfield, “Wishful Thinking”, *supra* note 17 at 63-67, 74-77; Kirby, *ibid* at Vol 6, Part VIII, Chapter 17; Mel Cousins, “Health Care and Human Rights after Auton and Chaoulli” (2009) 54:4 McGill LJ 717 at 719.
 20. Flood, Stabile & Tuohy, *supra* note 17 at 17.

its respective medical association.”²¹ By way of contrast, the process of decision-making for drug coverage tends to be more formalized.²² Under the terms of the *Canada Health Act*, provinces must fund “drugs ... administered in the hospital”²³ and may (partially or fully) cover other prescription drugs as well.²⁴ Provincial drug coverage decisions are steered by the recommendations of the Common Drug Review, which bases its advice on reviews of efficacy and a cost-benefit analysis.²⁵

Once a coverage decision is made, the ability of patients to challenge the decision is limited. Some provinces provide internal review mechanisms, whereby health department employees can review coverage decisions in response to patient requests.²⁶ In certain provinces, administrative tribunals may be authorized to decide matters that touch on public health care funding.²⁷ For example, administrative boards play

21. *Ibid.*

22. *Ibid.*

23. *CHA*, *supra* note 14, s 2.

24. Kirby, *supra* note 18 at Vol 6, Part IV, Chapter 7.

25. Canadian Agency for Drugs and Technologies in Health, “About the Common Drug Review” (2015), online: CADTH <<http://www.cadth.ca>> (“[t]he CADTH Common Drug Review ... is a pan-Canadian process for conducting objective, rigorous reviews of the clinical effectiveness and cost-effectiveness, as well as reviews of patient input for drugs”). See also Pan-Canadian Oncology Drug Review, “About the pan-Canadian Oncology Drug Review” (2011), online: pCODR <<http://www.pcodr.ca>>. For information on the process of drug approval and price setting, see Amir Attaran, “Take Your Medicine?: The Risk of Patient-Led Legislation in Canada’s Medicine Access System” (2009) 3:1 McGill JL & Health 3 at 5; Steven Morgan et al, “Breadth, Depth and Agreement among Provincial Formularies in Canada” (2009) 4:4 Healthcare Policy e162; Natalie de Paulsen, “The Regulatory Gap: Off-Label Drug Use in Canada” (2005) 63:2 UT Fac L Rev 183 at 189. See also *Food and Drug Regulations*, CRC c 870, s C.08.004; *Patented Medicines Regulations*, SOR/94-688; *Patent Act*, RSC 1985, c P-4, ss 79-103; Ontario Ministry of Health and Long-Term Care, “How Drugs Are Approved: Funding Decisions” (27 June 2012), online: Ontario Ministry of Health and Long-Term Care <<http://www.health.gov.on.ca>>.

26. Flood, Stabile & Tuohy, *supra* note 17 at 22-29; Nola M Ries & Timothy Caulfield, “Accountability in Health Care and Legal Approaches” (3 May 2004), Health Care Accountability Paper prepared for the Canadian Policy Research Networks (Ottawa, Ontario) at 12, online: Canadian Policy Research Networks <http://www.cprn.org/documents/28717_en.pdf>.

27. Flood & Zimmerman, *supra* note 19 at 34-35; Flood, Stabile & Tuohy, *supra* note 17 at 23-25.

a key role in determining whether residents will be reimbursed for health care costs incurred out-of-province.²⁸ If these internal mechanisms are not successful, patients may seek the intervention of the courts through a variety of avenues, a review of which forms the remaining body of this paper.

III. Legal Mechanisms to Challenge Health Care Coverage Decisions

A. The *Charter*

In the years immediately following the adoption of the *Charter*,²⁹ some scholars suggested that it should be interpreted so as to provide protection for socio-economic rights, including the right to health care.³⁰ Such an interpretation would provide fertile ground to argue that the right to access particular therapies fell within its ambit. However, *Charter* claims seeking health care entitlements have been mostly unsuccessful to date.³¹

Patients with rare diseases seeking to use the *Charter* to challenge health care coverage decisions have two potential avenues of argument. First, patients could argue that their section 7 “right[s] to life, liberty and security of the person” are unjustifiably infringed by legislation that limits access to medical services.³² Second, patients could argue that the government failed to live up to obligations created by either section 7 or section 15 of the *Charter*.³³

Using the first avenue, patients may argue that legislation which removes or narrows medical options available to them contravenes

28. Flood, Stabile & Tuohy, *supra* note 17 at 25.

29. *Canadian Charter of Rights and Freedoms*, Part I of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (UK), 1982, c 11.

30. See *e.g.* Martha Jackman, “The Protection of Welfare Rights under the Charter” (1988) 20:2 *Ottawa L Rev* 257; Martha Jackman, “Charter Review as a Health Care Accountability Mechanism in Canada” (2010) 18 *Health LJ* 1 at 15, 20 [Jackman, “Charter Review”].

31. Cousins, *supra* note 19 at 721; Colleen M Flood, Lance Gable & Lawrence O Gostin, “Introduction: Legislating and Litigating Health Care Rights Around the World” (2005) 33:4 *JL Med & Ethics* 636 at 638.

32. Ries & Caulfield, *supra* note 26 at 1-2, 8-9.

33. *Ibid* at 3.

section 7 of the *Charter*.³⁴ This avenue contemplates legislation which expressly prohibits patients from obtaining certain treatments or medical services, such as the kind of legislation that was at issue in *Chaoulli*.³⁵ In that case, a Quebec statute provided that patients could not obtain private health insurance for medical services available within the public health care system.³⁶ A patient challenged the constitutionality of this legislation, arguing that the lengthy “delays resulting from waiting lists”³⁷ in the public health system combined with removal of the option to obtain private insurance negatively impacted his health and thus infringed his section 7 rights to life and security of the person. Three of the justices of the Supreme Court of Canada agreed, finding further that the legislation was arbitrary and thus inconsistent with the principles of fundamental justice.³⁸ One justice preferred to decide the case under the Quebec *Charter of Human Rights and Freedoms*³⁹ and the three remaining justices upheld the provision under the Canadian *Charter*.⁴⁰

Patients with rare diseases will find *Chaoulli* of limited help, however, as their access to health care is impeded not by legislation that prohibits them from accessing certain services, but rather, by government inaction (*e.g.* not paying for necessary medical treatments or procedures). What is needed, from the perspective of patients with rare diseases, is a hook on which government obligation to fund treatment can be hung. The approach discussed below provides a more promising means to fashion such a hook.

34. *Ibid* at 9-12. See *e.g.* *R v Morgentaler*, [1988] 1 SCR 30; *Rodriguez v British Columbia (Attorney General)*, [1993] 3 SCR 519; *Jane Doe v Manitoba*, 2004 MBQB 285, rev'd by 2005 MBCA 109.

35. *Chaoulli v Quebec (Attorney General)*, 2005 SCC 35 [*Chaoulli*]; Ries & Caulfield, *supra* note 26 at 10-11.

36. *Ibid* at para 2.

37. *Ibid*.

38. *Ibid* at para 104.

39. RSQ c C-12.

40. As many scholars have noted, it is unclear exactly how *Chaoulli* will impact constitutional claims to health care, given the split decision. The decision has also received negative commentary. See *e.g.* Jennifer Llewellyn, “A Healthy Conception of Rights? Thinking Relationally About Rights in a Health Care Context” in Jocelyn Downie & Elaine Gibson, eds, *Health Law at the Supreme Court of Canada* (Toronto: Irwin Law, 2007) 57 at 77.

In theory, governmental obligation may be created by either sections 7 or 15 of the *Charter*. In practice, however, courts have shied away from recognizing positive obligations under section 7 of the *Charter*. The Supreme Court of Canada has stated that “[t]he *Charter* does not confer a freestanding constitutional right to health care.”⁴¹ And, lower courts have similarly dismissed suggestions that the government is in violation of section 7 when it declines to cover the costs of a particular medical treatment.⁴²

Patients with rare diseases must then look to section 15 and the right to equality to establish any funding obligation. A section 15 analysis requires a court to ask: “(1) Does the law create a distinction based on an enumerated or analogous ground? (2) Does the distinction create a disadvantage by perpetuating prejudice or stereotyping?”⁴³ As the Supreme Court has observed, “[t]he focus of the inquiry is on the actual impact of the impugned law, taking full account of social, political, economic and historical factors concerning the group” and “involves looking at the circumstances of members of the group and the negative impact of the law on them.”⁴⁴

Accordingly, a patient with a rare disease must establish that the refusal to pay for a particular medical service draws a “distinction [that] create[s] a disadvantage.”⁴⁵ The patient may point to the fact that the health care scheme created by federal and provincial legislation draws a distinction between insured and non-insured services, leading to differential treatment between patients whose medical care is covered and those whose medical care is not. The patient may further point to the fact that some of those in the latter group will include patients with rare diseases. It is not obvious on the face of the scheme that the distinction is drawn on the basis of an enumerated or analogous ground – in this

41. *Chaoulli*, *supra* note 35 at para 104. See also *Gosselin v Québec (Attorney General)*, 2002 SCC 84.

42. See *Flora v Ontario Health Insurance Plan*, 2008 ONCA 538 [*Flora*]; Cousins, *supra* note 19 at 721-26.

43. *Quebec (Attorney General) v A*, 2013 SCC 5 at para 324 [*Quebec v A*]; *R v Kapp*, 2008 SCC 41 at para 17 [*Kapp*]; *Withler v Canada (Attorney General)*, 2011 SCC 12 at para 30 [*Withler*].

44. *Withler*, *ibid* at paras 37, 39.

45. *Ibid* at para 30.

case, rare disease or disability – as both those with rare diseases and those without rare diseases are denied funding if the service in issue is not covered by the public system.

However, the law protects individuals from discrimination that, while not obvious on the face of the statute in question, is apparent following deeper and more probing scrutiny of the statute.⁴⁶ If, on closer examination, it becomes apparent that patients with rare diseases are disproportionately denied funding for medical services or disproportionately affected by denial of funding, then differential treatment is established. Such a conclusion may be reached by evidence illustrating how insufficient financing negatively impacts patients with rare diseases; patients may demonstrate that, without government funding, they cannot afford the treatment in issue, and, without that treatment, their pain and suffering is increased or their life expectancy shortened. On this point, if the scientific evidence is inconclusive on the matter of a therapy's effectiveness, patients seeking these experimental treatments may be unable to tender compelling evidence that their physical pain is increased by the denial of coverage for that treatment. However, that is not the end of the matter, as these patients could underscore the emotional burden of being denied hope that experimental treatments offer. To establish that the law "create[s] a disadvantage by perpetuating prejudice or stereotyping," patients with rare diseases may point to the economic disadvantage they shoulder by paying out-of-pocket for medical expenses. This burden increases the economic hardship on patients who may already be off work as a result of illness. Being denied access to treatment may also add to the sense of exclusion and stigmatization already experienced by patients with rare diseases.⁴⁷

If an infringement is established, the burden shifts to the government to prove that the breach can be justified under section 1 of the *Charter*.⁴⁸

46. *Egan v Canada*, [1995] 2 SCR 513 (“[a]dverse effect discrimination occurs when a law, rule or practice is facially neutral but has a disproportionate impact on a group because of a particular characteristic of that group” at 586-87).

47. See e.g. Fatma Ilknur Cinar et al, “Living with Scleroderma: Patients’ Perspectives, a Phenomenological Study” (2012) 32:11 *Rheumatology International* 3573 at 3576.

48. *R v Oakes*, [1986] 1 SCR 103.

An infringement is defensible if the legislative objective is “pressing and substantial,” the chosen course is rationally connected to that objective, the injury to the right is small, and the infringement is proportionate to the benefit and effect of the impugned law.⁴⁹ In the context of a section 15 challenge by a claimant with a rare disease, several factors will be relevant. At the section 1 stage, courts tend to show deference to government decisions that require balancing multiple and varied interests or allotting limited resources.⁵⁰ Health care coverage decisions appear to be the sort of decision that will generally attract deference. Because courts require that the government establish an evidential basis for its impugned action,⁵¹ a government will not simply be able to assert that its action achieves health care objectives and meets the other section 1 requirements without furnishing evidence.⁵² However, as von Tigerstrom points out, it may be challenging for courts to evaluate the evidence put forward by the government: Are purported financial worries genuine or is cost used to shield a discriminatory decision?⁵³ And when does cost justify a decision not to cover a certain treatment? Must it be too expensive for the public system to absorb, or is it enough that the government has decided to fund procedure x over treatment y, both being equally medically effective?⁵⁴

Two Supreme Court of Canada cases will be relevant to any claim brought under section 15.⁵⁵ In *Eldridge v British Columbia*,⁵⁶ the Court found that the failure of hospitals to provide sign-language services for hearing-impaired patients was a violation of section 15.⁵⁷ In finding that the government’s decision constituted discrimination, Justice La Forest

49. *Ibid.*

50. See e.g. *Irwin Toy Ltd v Quebec*, [1989] 1 SCR 927 at para 74.

51. See e.g. *Chaoulli*, *supra* note 35.

52. Ries & Caulfield, *supra* note 26 at 6.

53. Barbara von Tigerstrom, “Human Rights and Health Care Reform: A Canadian Perspective” in Timothy A Caulfield & Barbara von Tigerstrom, eds, *Health Care Reform and the Law in Canada: Meeting the Challenge* (Edmonton: University of Alberta Press, 2002) 157 at 171.

54. Ries & Caulfield, *supra* note 26 at 7-8.

55. See also *Shulman v College of Audiologists and Speech Language Pathologists of Ontario* (2001), 155 OAC 171 (SC) (holding that the decision to remove a particular service from the public insurance plan did not violate s 15).

56. [1997] 3 SCR 624.

57. *Ibid.*

for the Court noted:

In order to receive the same quality of care, deaf persons must bear the burden of paying for the means to communicate with their health care providers, despite the fact that the system is intended to make ability to pay irrelevant ... Once it is accepted that effective communication is an indispensable component of the delivery of medical services, it becomes much more difficult to assert that the failure to ensure that deaf persons communicate effectively with their health care providers is not discriminatory.⁵⁸

One could conceivably argue that patients with rare diseases who do not obtain necessary treatment are not receiving “the same quality of care” as those patients with or without rare diseases who have access to publicly funded treatments.

However, patients with rare diseases may find it difficult to establish an infringement of section 15 given the Supreme Court’s decision in *Auton v British Columbia*.⁵⁹ In that case, families unsuccessfully argued that the government’s failure to provide therapy for their autistic children was discriminatory under section 15. In reaching its decision, the Court reviewed the provincial set-up, which distinguished between “core services” and “non-core services,” the first being those made available by physicians and hospitals, and the second being those performed by other health care professionals and insured only if so stipulated in the regulations.⁶⁰ The Court held that the therapy, being a “non-core service” provided by professionals not designated under the regulations, was not “a benefit provided by law”⁶¹ as there was no legislative entitlement to it.⁶² The Court observed that “the legislative scheme does not promise that any Canadian will receive funding for all medically required treatment,”⁶³ apparently even if the treatment is “essential to the health and medical treatment of an individual.”⁶⁴ The Court also dismissed the suggestion that “the scheme itself [was] discriminatory,”⁶⁵ finding that it

58. *Ibid* at paras 71-72.

59. 2004 SCC 78 [*Auton*]; Flood, Stabile & Tuohy, *supra* note 17 at 29.

60. *Auton, ibid* at paras 30-37.

61. *Ibid* at paras 37, 47.

62. *Ibid* at paras 34-38.

63. *Ibid* at para 35.

64. *Ibid* at para 13.

65. *Ibid* at para 39.

was designed and intended to cover only some, not all, medical services.⁶⁶ Thus, “exclusion of particular non-core services cannot, without more, be viewed as an adverse distinction based on an enumerated ground.”⁶⁷ As the Court’s conclusions in *Auton* make clear, the rigors of a section 15 analysis will not be lessened even in the case of patients who argue that access to treatment is necessary for their health and wellbeing.

Further, the Court held that once the position of the claimants in *Auton* was evaluated alongside the “appropriate comparator group” (*e.g.* persons without a “mental disability” desiring beneficial but novel medical services), “differential treatment either directly or by effect [was] not established”⁶⁸ as the evidence did not indicate that the government gave additional consideration to or was more likely to grant applications for unproven therapies made by persons in the comparator group.⁶⁹ Given the narrow characterization of the “comparator group” in *Auton*, the case would seem to preclude reliance on section 15 by persons seeking unproven treatments which are not included in the existing public insurance scheme, in the absence of evidence that other groups receive coverage for unproven therapies at greater rates. This reading of the case has significant implications for patients with rare diseases, given that many rare diseases have no treatment and thus a significant number of patients may desire to access unproven therapies.⁷⁰

66. *Ibid* at para 43.

67. *Ibid*.

68. *Ibid* at para 58.

69. *Ibid* at paras 58-62.

70. M Ian Phillips, “Gene, Stem Cell, and Future Therapies for Orphan Diseases” (2012) 92:2 *Clinical Pharmacology & Therapeutics* 182 (“currently only ~5% of the approximately 7,000 rare diseases have therapies” at 182). Anecdotal stories suggest that some patients with rare diseases place their hopes in unproven therapies. See *e.g.* Katie Nelson, “Aidan Seeger, 6, needs help to fight rare brain disorder that destroys nerve cells”, *New York Daily News* (27 June 2011) online: *New York Daily News* <<http://www.nydailynews.com/new-york/brooklyn/aidan-seeger-6-fight-rare-brain-disorder-destroys-nerve-cells-article-1.125738>>; Nicole Service, “Parents hope experimental treatments will conquer daughter’s rare illness”, *Daytona Beach News Journal* (14 November 2008) 1C. See also Matilda Anderson, Elizabeth J Elliott & Yvonne A Zurynski, “Australian Families Living with Rare Disease: Experiences of Diagnosis, Health Service Use and Needs for Psychosocial Support” (2013) 8:22 *Orphanet Journal of Rare Diseases* (epub) (some participants “perceiv[ed] a] lack of access to drugs used overseas but not

Also relevant is the decision of the Nova Scotia Court of Appeal in *Cameron v Nova Scotia*.⁷¹ In that case, an infertile couple claimed that omission of ICSI from the provincial health plan discriminated on the basis of disability, as the plan covered IVF treatment for couples who suffered only from female infertility and thus did not require ICSI.⁷² The Court agreed that the policy was discriminatory, holding that denial of access to Medicare (“a cornerstone of social programs in Canada”⁷³) reinforced the “vulnerability”⁷⁴ and ostracism of infertile couples.⁷⁵ However, the Court found that the infringement was saved under section 1 of the *Charter*. As part of the section 1 analysis, the majority of the Court emphasized the importance of the purpose of the exclusion, namely ensuring “the best possible health care coverage to Nova Scotians in the context of limited financial resources.”⁷⁶

Based on *Auton* and *Cameron*, it seems that patients bringing a section 15 challenge to establish that a government has an obligation to fund a particular treatment will face an uphill battle, as courts generally show great deference to decisions of this nature. However, that hill may be mounted in a case with the right set of facts, a strong evidential foundation establishing discrimination, and weak government arguments at the justification stage. Additionally, equality jurisprudence appears to be undergoing transformation.⁷⁷ As the Supreme Court further develops section 15 doctrine and principles – by, for example, moving away from the “comparator group” analysis – the likelihood of success of this type of claim increases. After all, the “comparator group” was one of the stumbling blocks in *Auton*. Without the “comparator group” hurdle, it will be easier for a claimant with a rare disease seeking unproven medication to establish the existence of “differential treatment.”

Even if a *Charter* challenge is not successful, there may be merit in

approved in Australia” at 6).

71. (1999), 204 NSR (2d) 1 (CA), Chipman JA (Pugsley JA concurring); separate concurring judgment delivered by Bateman JA.

72. *Ibid* at paras 170-72.

73. *Ibid* at para 206.

74. *Ibid* at para 194.

75. *Ibid* at paras 177-208.

76. *Ibid* at paras 218, 225-45.

77. *Kapp*, *supra* note 43; *Withler*, *supra* note 43; *Quebec v A*, *supra* note 43.

bringing such a claim. For example, *Charter* challenges hold government actors accountable by compelling them to produce evidence justifying their actions and decisions in the health care realm.⁷⁸ Of course, these benefits need to be balanced against the potential costs (in terms of both money and time) of *Charter* litigation.⁷⁹

B. Administrative Law

Patients with rare diseases may also consider using administrative law processes and procedures to challenge coverage decisions. Like *Charter* litigation, administrative law obliges governments to account for their actions and ensures that institutional decision-making is done in a fair and impartial manner.⁸⁰ Administrative law may be preferable to *Charter* litigation, as it tends to be quicker and less expensive.

As noted above, some provincial administrative tribunals, like Ontario's Health Services Review and Appeal Board,⁸¹ have limited authority to weigh in on health coverage decisions. For example, the Appeal Board can determine whether persons who contest denial of insurance are indeed covered under the provincial Act.⁸² The board is also empowered to make decisions on reimbursement for health care expenses incurred outside of Canada.⁸³ However, the scope of the board's

78. Jackman, "Charter Review", *supra* note 30; Ries & Caulfield, *supra* note 26; von Tigerstrom, *supra* note 52 at 178.

79. Flood, Stabile & Tuohy, *supra* note 17 at 29.

80. Flood & Zimmerman, *supra* note 19 at 27.

81. *Health Insurance Act*, RSO 1990, c H.6, ss 20(1), 21; *Ministry of Health and Long-Term Care Appeal and Review Boards Act, 1998*, SO 1998, c 18, Sch H, ss 5, 6; Ries & Caulfield, *supra* note 26 at 12.

82. *Health Insurance Act*, *ibid*, s 20(1).

83. *Ibid*; RRO 1990, Reg 552, s 28.4(2) provides:

Services that are rendered outside Canada at a hospital or health facility are prescribed as insured services if,

(a) the service is generally accepted by the medical profession in Ontario as appropriate for a person in the same medical circumstances as the insured person;

(b) the service is medically necessary;

(c) either,

(i) the identical or equivalent service is not performed in Ontario, or

(ii) the identical or equivalent service is performed in

jurisdiction is limited, and it has no general authority to evaluate coverage decisions.⁸⁴

In addition to these administrative mechanisms, a patient may turn to the courts for judicial review of either the substantive decision (*i.e.* the decision to cover (or not) a particular medical service) or the process used to make that decision. Under the principles of administrative law, government decision-makers must act within the ambit of power bestowed upon them by statute and they must act in a way that is sufficiently fair and transparent.⁸⁵

As discussed above, coverage decisions are made by numerous government actors, acting pursuant to statutory authority. Generally, coverage decisions are made by the provincial cabinet and Minister of Health, regional health boards, and other officials within the provincial health department.⁸⁶ Judicial review is concerned with whether these

Ontario but it is necessary that the insured person travel out of Canada to avoid a delay that would result in death or medically significant irreversible tissue damage; (d) in the case of a hospital service or a service rendered in a health facility described in clause (a) of the definition of “health facility” in subsection (1), the service, if performed in Ontario, is one to which the insured person would be entitled without charge pursuant to section 7 in the case of an in-patient service or section 8 in the case of an out-patient service; and (e) in the case of an in-patient service, in Ontario, the insured person would ordinarily have been admitted as an in-patient of a public hospital to receive the service.

See *RS v Ontario (Health Insurance Plan)*, 2005 CanLII 77249 (ON HSARB), 05-HIA-0148 (finding that sought treatment was experimental and thus not covered); *Flora*, *supra* note 42 (upholding decision of the board to deny reimbursement for experimental, life-saving treatment received outside of the country; provincial health care scheme does not cover all medical treatment, even if life-saving); *Stein v Quebec (Regie de l'Assurance-maladie)*, [1999] RJQ 2416 (SC) (overturning board's decision to deny reimbursement for the cost of life-saving medical treatment received out of country; decision not consistent with the purposes of health care scheme).

84. Flood, Stabile & Tuohy, *supra* note 17 at 24-25.
85. *Crevier v AG (Québec)*, [1981] 2 SCR 220; *Baker v Canada (Minister of Citizenship and Immigration)*, [1999] 2 SCR 817; *Dunsmuir v New Brunswick*, 2008 SCC 9 [*Dunsmuir*].
86. Katherine Cherniawsky, “Enforcement of Health Care Rights and Administrative Law” (1996) 4 Health LJ 35 at 45-46.

bodies have properly acted within their jurisdiction and thus each case will require a detailed analysis of the governing statute and the action purportedly taken under it.⁸⁷ General principles are canvassed below, but, of course, the old caveat rings particularly true in the context of administrative law: the outcome depends on the particular facts of the case.⁸⁸

In *Lexogest Inc v Manitoba*,⁸⁹ the Manitoba Court of Appeal found that the Manitoba Health Services Commission acted outside its jurisdiction by setting up a funding policy which covered abortion services if they were provided in hospitals, but not if they occurred in other health centres.⁹⁰ While the Commission had legislative sanction to determine which services would be covered, it could not exercise this power arbitrarily.⁹¹

The Ontario High Court of Justice in *Re Koonar*,⁹² dismissed an application brought by physiotherapists who sought review of the decision of the provincial health department to deny insurance coverage for their services.⁹³ The Court found that “[t]he extent of that insurance was a policy decision, a legislative decision which is not subject to review.”⁹⁴

In another case, following a decision by a government official to withdraw a particular drug from availability through the Special Access Programme (which provides an exceptional means for patients to access unapproved drugs), patients sought review on the grounds that the official acted outside the scope of his statutory authority.⁹⁵ The Federal Court agreed, holding that the official had, by limiting his decision in advance and in a manner not consistent with the legislative purpose, unlawfully

87. Sweatman & Woollard, *supra* note 18 at 283; Cherniawsky, *ibid* at 47.

88. Sweatman & Woollard, *ibid*; Cherniawsky, *ibid*.

89. *Lexogest Inc v Manitoba (Attorney General)* (1993), 85 Man R (2d) 8 (CA).

90. *Ibid*.

91. *Ibid*, per Helper JA (Philp JA concurring). See also *British Columbia Civil Liberties Association v British Columbia (Attorney General)* (1988), 49 DLR (4th) 493 (BCSC); *contra PEI (Minister of Health and Social Services) v Morgentaler* (1996), 144 Nfld & PEIR 263 (PEISC(AD)).

92. *Re Koonar and Minister of Health* (1982), 133 DLR (3d) 396 (Ont HCJ).

93. *Ibid*.

94. *Ibid* at para 14.

95. *Delisle v Canada (Attorney General)*, 2006 FC 933.

fettered the broad discretion granted to him under the statute.⁹⁶

With that background set out, it is apposite to turn to the particular situation at hand, namely, an administrative-based challenge to a government decision to exclude from its insurance plan a treatment desired by a patient with a rare disease. First, a patient may consider challenging the procedure used to make the impugned decision. At common law, administrative actors owe a duty of procedural fairness to individuals whose rights or interests are affected by specific, individualized decisions.⁹⁷ No duty is owed for general, policy decisions.⁹⁸ Most often, decisions about which medical services should be funded will be policy decisions, involving the apportionment of resources among competing groups, and thus no duty of procedural fairness will attach. In some cases, a duty of procedural fairness may be owed to an individual if the decision is sufficiently particular to that individual. This would likely be the case for a patient who requests reimbursement for out-of-province treatment. While the content necessary to satisfy the duty of procedural fairness varies from case to case, it may require that the affected individual be given an opportunity to respond or to submit evidence for the decision-maker's consideration. However, as noted, for the most part, patients with rare diseases who as a group seek coverage for medications are likely not owed administrative procedural fairness protections. The government may, on its own initiative and without legal compulsion, seek input from patients with rare diseases in making health care coverage decisions, and indeed, certain processes have been recently put in place to facilitate public participation in these types of decisions.⁹⁹

Second, a patient may challenge the substantive decision to include or exclude medical services from public insurance plans, by, for example,

96. *Ibid* at paras 125-28, 167-69.

97. *Martineau v Matsqui Disciplinary Board*, [1980] 1 SCR 602; *Cardinal v Director of Kent Institution*, [1985] 2 SCR 643; *Knight v Indian Head School Division No 19*, [1990] 1 SCR 653.

98. *Canada v Inuit Tapirisat*, [1980] 2 SCR 735.

99. For a comment on how procedural fairness fared under the Common Drug Review, see Attaran, *supra* note 25 at 13-14. Since publication of Attaran's article, the Common Drug Review has created a mechanism to enable patient involvement: Canadian Agency for Drugs and Technologies in Health (CADTH), "Patient Input" (2013), online: CADTH <<http://www.cadth.ca>>.

arguing that the decision-maker erred in giving weight to irrelevant considerations or misconstrued relevant evidence. A court must determine the governing standard of review, being either “correctness” (whereby the court embarks on a fresh assessment of the matter) or “reasonableness” (the more deferential standard, which asks “whether the decision falls within a range of possible, acceptable outcomes which are defensible in respect of the facts and law”).¹⁰⁰ If a board is granted considerable discretion under its enabling statute and it is deciding a question within its domain of expertise, its judgment will often be shown deference by the reviewing court.¹⁰¹ This will frequently be the case for health coverage decisions, as many statutes grant power to administrative actors in general terms which impute significant discretion to the body in question.¹⁰² However, as noted above, outcomes in administrative law depend heavily on the context and the statute in issue, and thus the matter will turn on the particulars of the statute.

C. Human Rights Legislation

Canadian human rights legislation guarantees protection from discrimination in the provision of public services.¹⁰³ Patients with rare diseases may seek to use human rights legislation to contest decisions that have the effect of denying them access to health care services. While it appears that no recorded cases have considered human rights legislation

100. *Dunsmuir*, *supra* note 85 at para 47.

101. *Sweatman & Woollard*, *supra* note 18 at 283; *Maple Lodge Farms v Government of Canada*, [1982] 2 SCR 2; Cherniawsky, *supra* note 86 at 60-61.

102. *Sweatman & Woollard*, *ibid*; Cherniawsky, *ibid*.

103. See *e.g.* *Human Rights Code*, RSBC 1996, c 210, s 8(1):

- A person must not, without a bona fide and reasonable justification,
- (a) deny to a person or class of persons any accommodation, service or facility customarily available to the public, or
 - (b) discriminate against a person or class of persons regarding any accommodation, service or facility customarily available to the public because of the race, colour, ancestry, place of origin, religion, marital status, family status, physical or mental disability, sex, sexual orientation or age of that person or class of persons.

See also Claire Mummé, “At the Crossroads in Discrimination Law: How the Human Rights Codes Overtook the *Charter* in Canadian Government Services Cases” (2012) 9 *JL & Equality* 103 at 104.

in the context of patients with rare diseases seeking treatment, this avenue has been successful in analogous situations, and thus a review of cases sheds light on how courts may decide claims brought by patients with rare diseases.

Human rights legislation has been successfully relied upon by transpersons seeking public insurance coverage for sex reassignment surgery. In *Waters v British Columbia*,¹⁰⁴ the BC Human Rights Tribunal found that the provincial health plan, which paid for vaginoplasty for transwomen but did not cover the whole cost of phalloplasty for transmen, was discriminatory.¹⁰⁵ Similarly, in *Hogan v Ontario*,¹⁰⁶ a majority of the Ontario Human Rights Tribunal held that the government's decisions to remove sex reassignment surgery from the list of funded services and not to extend stop-gap funding to cover the claimants who were in the midst of the procedure was a violation of the *Human Rights Code*,¹⁰⁷ as the government had not established it was incapable of accommodating this group of claimants.¹⁰⁸ The majority carefully noted that the government retained the power to make coverage decisions and to remove therapies from coverage.¹⁰⁹ But, in this case, it was unacceptable for the government to "pull the plug" on claimants who were well into the process.¹¹⁰

In two recent cases, male patients argued that provincial insurance plans, by covering screening for breast and uterine cancer but not covering screening for prostate cancer, discriminated on the basis of sex. The complaint was dismissed in both cases. In *Armstrong v British Columbia*,¹¹¹ the BC Court of Appeal upheld the conclusion of the adjudicator who found that the coverage decision was not related to sex,

104. *Waters v BC (Ministry of Health Services)*, 2003 BCHRT 13.

105. *Ibid* at paras 180-85.

106. *Hogan v Ontario (Minister of Health and Long-Term Care)*, 2006 HRTO 32 at paras 383, 389-465 [*Hogan*]. See also *May v Ontario (Minister of Health and Long Term Care)*, 2011 HRTO 2179; *C v BC (Ministry of Health)*, 2012 BCHRT 47.

107. *Ontario Human Rights Code*, RSO 1990, c H.19.

108. *Hogan*, *supra* note 106 at paras 99, 106-09, 120.

109. *Ibid* at para 7.

110. *Ibid* at para 120.

111. *Armstrong v British Columbia (Ministry of Health and Long-Term Care)*, 2010 BCCA 56, leave to appeal refused [2010] SCCA No 128.

but rather based on medical efficacy, as prostate cancer screening, unlike breast and uterine cancer screening, was not proven to be effective.¹¹² Similarly, in *Cochrane v Ontario*,¹¹³ the Ontario Human Rights Tribunal found that the evidence did not prove that prostate cancer screening increased survival rates and thus, like in *Armstrong*, efficacy – not sex – was the motivation for the decision.¹¹⁴ In both cases, the adjudicative body tied coverage decisions to evidence of efficacy, perhaps cementing a requirement that coverage decisions be evidence-based. If the approach in *Armstrong* and *Cochrane* is followed in the future, it seems unlikely that courts will order that the government pay for experimental treatments that lack at least some evidence of medical efficacy.

The BC Human Rights Tribunal similarly focused on evidence of efficacy in *Turnbull v British Columbia*.¹¹⁵ Under the provincial health plan, venous angioplasty was not covered for multiple sclerosis (MS), but was covered for other conditions.¹¹⁶ Turnbull argued that this constituted discrimination on the basis of disability, because the treatment would be covered if he had a different disease instead of MS.¹¹⁷ The fact that the treatment was novel and untried for MS factored heavily into the tribunal's decision to dismiss the complaint.¹¹⁸

In the well-known case of *Canada v Buffett*,¹¹⁹ however, Buffett successfully argued that the failure of the Canadian Forces to pay for in *intra*-cytoplasmic sperm injection (ICSI) for male service members while paying for *in vitro* fertilization (IVF) for female service members constituted discrimination on the basis of sex and disability.¹²⁰

Also relevant are decisions related to the obligation of governments to fund special programming for children with disabilities. In *Moore v British*

112. *Ibid* at para 33.

113. *Cochrane v Ontario (Minister of Health and Long-Term Care)*, 2010 HRTO 1477.

114. *Ibid* at paras 22, 24.

115. *Turnbull v British Columbia (Ministry of Health Services)*, 2011 BCHRT 324.

116. *Ibid* at para 89.

117. *Ibid* at para 77.

118. *Ibid* at paras 80-88, 96-98.

119. *Canada (Attorney General) v Buffett*, 2007 FC 1061.

120. *Ibid* at paras 48-64. See also Susan Krashinsky, "Funding Fertility: The Fight to Have Treatments Covered", *The Globe & Mail* (19 August 2009) online: Globe & Mail <<http://www.theglobeandmail.com>>.

Columbia,¹²¹ the Supreme Court of Canada found that the province acted discriminatorily when it abolished special programming that benefited a child with a mental disability.¹²² The Court rejected the assertion by the province and the school district that their action was necessary to tackle a “budgetary crisis,”¹²³ as “the cuts were disproportionately made to special needs programs”¹²⁴ and no consideration was first given to other ways in which the financial crisis could be resolved.¹²⁵ Extrapolating principles from this decision to the health care context, it would seem that, while budgetary considerations can justify delisting or excluding medical services from coverage, patients with rare diseases must not bear the brunt of financial constraints. In other words, governments cannot justify coverage decisions based on economic arguments if those decisions disproportionately impact patients with rare diseases.

As this brief review highlights, individuals have had mixed success in using human rights legislation to challenge governmental resource allocation decisions. For patients with rare diseases to make use of this tool, they must “demonstrate *prima facie* discrimination ... [by] show[ing] that they have a characteristic protected from discrimination under the [relevant human rights] Code; that they experienced an adverse impact with respect to the service; and that the protected characteristic was a factor in the adverse impact.”¹²⁶ Their efforts in this regard will be furthered by the types of arguments and evidence recounted under the discussion of section 15 of the *Charter*. In order to establish that “the protected characteristic was a factor in the adverse impact,”¹²⁷ patients may need to present evidence that the sought treatment is likely to be effective. If they are unable to do so, they may fail to prove that the impugned decision was in fact made on the basis of disability, rather than on the grounds that the therapy is not scientifically proven.

121. *Moore v British Columbia (Education)*, 2012 SCC 61 [*Moore*]. See also *Newfoundland and Labrador v Sparkes et al*, 2004 NLSCTD 16.

122. *Moore*, *ibid* at para 48.

123. *Ibid* at para 53.

124. *Ibid* at para 51.

125. *Ibid* at paras 50-53.

126. *Ibid* at para 33.

127. *Ibid*.

The government then has the onus of proving that denial of funding is justified and may argue that budgetary constraints and the high cost of orphan drugs warrant the impugned action or decision. However, as the Supreme Court of Canada stated in *Moore*, “accommodation is not a question of ‘mere efficiency’, since ‘[i]t will always seem demonstrably cheaper to maintain the status quo and not eliminate a discriminatory barrier’.”¹²⁸ The budgetary circumstances must be such that funding cannot reasonably be extended to cover the requested therapy without causing serious difficulties for the government. Given the exceptionally high cost of some orphan drugs, the government may be able to establish that it could not reasonably afford to cover these treatments. It should be noted, however, that data from Europe suggests that fees paid for orphan drugs constitute only a small fraction of the overall health budgets of many countries.¹²⁹ Further, if the cost of the treatment is minor, the court may reject the government’s assertion that covering the cost of therapies for patients with rare diseases would be an unreasonable burden.

D. International Law

International covenants affirm that facilitating access to health care is a crucial component in attaining the overall wellbeing of all people. By way of example, the *Universal Declaration of Human Rights* states that “[e]veryone has the right to a standard of living adequate for the health and wellbeing of himself and of his family, including ... medical care.”¹³⁰ Similarly, Article 12 of the *International Covenant on Economic, Social and Political Rights* (ICESPR) recognizes “the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.”¹³¹ Parties to the Covenant commit to “achieving progressively

128. *Ibid* at para 50, citing *Council of Canadians with Disabilities v VIA Rail Canada*, 2007 SCC 15 at para 225.

129. Carina Schey, Tsveta Milanova & Adam Hutchings, “Estimating the Budget Impact of Orphan Medicines in Europe: 2010-2020” (2011) 6:62 *Orphanet Journal of Rare Diseases* (epub) (“the cost [of orphan drugs], as a pro-portion of total pharmaceutical expenditure, is likely to plateau between 4%-5%” at 9). See also Tambuyzer, *supra* note 1.

130. *Universal Declaration of Human Rights*, GA Res 217(III), UNGAOR, 3d Sess, Supp No 13, UN Doc A/810, (1948), Art 25(1).

131. *International Covenant on Economic, Social and Cultural Rights*, 16 December

the full realization” of this right, including “[t]he creation of conditions which would assure to all medical service and medical attention in the event of sickness.”¹³²

Canada is a party to the ICESPR and thus has obligations under international law to fulfill the commitments made under that treaty. The ICESPR has not found its way into domestic implementing legislation, however. Thus, while it cannot ground a claim by a patient with a rare disease in Canadian courts, it does form part of the background in which judicial interpretation of domestic legislation in, say, an administrative or *Charter* case, occurs.¹³³ The impact of international covenants is succinctly explained in a report to Parliament:

[W]hile unincorporated treaties do not necessarily alter Canadian domestic law, they can and do influence its interpretation. A common law doctrine, which applies in Canada, holds that in interpreting legislation, courts should presume that Parliament intended to legislate in a manner consistent with its international treaty obligations ... [I]t is clear that the courts can make use of international human rights law in interpretation.¹³⁴

Accordingly, patients with rare diseases cannot directly rely on the guarantees contained in international treaties. However, patients would be well advised to emphasize Canada’s international obligations if bringing claims under domestic legislation or the *Charter*, particularly given the generous scope of some provisions in international documents. For example, if the benchmark set out in the ICESPR were adopted by Canadian courts, then entitlement to many medical services would likely follow. These services would include therapies that are necessary to extend life or ease pain, and also, arguably, experimental therapies that, while unproven, are reasonably anticipated by patients to have some positive effects. The latter category is suggested on the basis of the stress,

1966, 993 UNTS 3, Can TS 1976 No 46 (entered into force 3 January 1976, accession by Canada 19 May 1976), Art 12.

132. *Ibid*, Arts 2, 12(1), 12(2)(d).

133. von Tigerstrom, *supra* note 52 at 160.

134. Standing Senate Committee on Human Rights, chaired by the Honourable Raynell Andreychuk, *Promises to Keep: Implementing Canada’s Human Rights Obligations* (Ottawa: Parliament of Canada, 2001), online: Parliament of Canada <<http://www.parl.gc.ca/Content/SEN/Committee/371/huma/rep/rep02dec01-e.htm>>.

disappointment and feelings of hopelessness associated with denial of funding for treatment (and thus, in effect, denial of treatment if costs make it unattainable). These emotional responses should be taken into account when considering what services are necessary in order for patients to achieve the “highest attainable standard of physical and mental health” as provided for by the ICESPR.

E. Tort Law

Tort law is another potential tool for patients seeking funding for desired medical services. This section addresses the issue of whether a patient who is unable to access treatment as a result of a government’s refusal to fund that treatment could claim against the government on grounds of negligence. This question considers the matter of resource allocation at the macro-level (*i.e.* the policy phase where “big picture” resource allocation decisions are made), as well as at the micro-level (*i.e.* everyday, individual decisions about how to make use of and expend resources). The discussion thus far has focused on legal claims brought to challenge the decision of governments or government actors, not individual physicians, though they too make a type of resource allocation decision at a patient’s bed-side when they decide whether to administer treatment.¹³⁵ This section of the paper considers whether individual physicians and other health care providers who refuse to provide treatment in order to conserve system resources could be liable if the patient then suffers harm.¹³⁶ In other words, can physicians rely on what Caulfield calls the “cost-containment defence”?¹³⁷

At the macro-level of resource allocation, what use can be made of tort law to contest allocation decisions? In a recent review of Canadian jurisprudence, Lorian Hardcastle identifies several types of claims that may be brought against the government: claims for mishandling pandemics; claims related to system management failures; and claims for

135. See *e.g.* Timothy A Caulfield, “Malpractice in the Age of Health Care Reform” in Timothy A Caulfield & Barbara von Tigerstrom, eds, *Health Care Reform and the Law in Canada: Meeting the Challenge* (Edmonton: University of Alberta Press, 2002) 11 at 13, 21-24 [Caulfield, “Malpractice”].

136. *Ibid* at 24-26. See also Sweatman & Woollard, *supra* note 18.

137. Caulfield, “Malpractice”, *supra* note 135 at 24.

deaths caused by long wait times.¹³⁸ A brief review of some of these cases is in order before a discussion of the probability that patients with rare diseases will succeed with system-level negligence claims.

The Ontario Court of Appeal has struck claims brought by patients and health care professionals who argued that the province failed to protect them and to manage the hospital system properly after they contracted communicable diseases.¹³⁹ The Court soundly rejected the plaintiffs' arguments in *Eliopoulos Estate v Ontario (Minister of Health and Long-Term Care)*, observing:

[T]o impose a private law duty of care on the facts that have been pleaded here would create an unreasonable and undesirable burden on Ontario that would interfere with sound decision-making in the realm of public health. Public health priorities should be based on the general public interest. Public health authorities should be left to decide where to focus their attention and resources without the fear or threat of lawsuits.¹⁴⁰

Similarly, the Quebec Court of Appeal dismissed an application for the certification of a class action brought by cancer patients who accused the government and hospitals of negligently delaying their treatment.¹⁴¹ The clear policy nature of the decision did not warrant allowing the claim to proceed.¹⁴²

In contrast, the Ontario Court of Appeal in *Heaslip Estate v Mansfield Ski Club*¹⁴³ declined to strike the claim of plaintiffs who argued that the government acted negligently by failing to send air-based medical support to transport an injured teenager, contrary to the government's own guidelines.¹⁴⁴ The Court believed that the situation fell within the

138. Lorian Hardcastle, "Government Tort Liability for Negligence in the Health Sector: A Critique of the Canadian Jurisprudence" (2012) 37:2 Queen's LJ 525 at 546.

139. *Williams v Ontario*, 2009 ONCA 378 at para 7; *Jamal Estate v Scarborough Hospital*, 2009 ONCA 376 at para 9; *Abarquez v Ontario*, 2009 ONCA 374 at para 23; *Laroza Estate v Ontario*, 2009 ONCA 373 at para 5; *Henry Estate v Scarborough Hospital*, 2009 ONCA 375; Hardcastle, *supra* note 138 at 546-47.

140. (2006), 82 OR (3d) 321 (CA) at para 33 [*Eliopoulos Estate*]; Hardcastle, *supra* note 138 at 546-47.

141. *Cilinger v Quebec*, [2004] RJQ 2943 (CA); Hardcastle, *supra* note 138 at 548.

142. *Cilinger*, *ibid* at para 16.

143. 2009 ONCA 594 [*Heaslip*].

144. *Ibid* at paras 1, 2, 17, 23-28, 31, 35; Hardcastle, *supra* note 138 at 548.

pre-existing class of duties which entailed liability if “a public authority ... negligent[ly] fail[ed] to act in accordance with an established policy where it is reasonably foreseeable that failure to do so will cause physical harm to the plaintiff.”¹⁴⁵ The Court added that a duty could be found on an *Anns* negligence analysis.¹⁴⁶ The Court distinguished the type of government decisions that are immune from liability due to policy considerations from the claim before it, as this claim was “based upon the negligent failure to respond to a specific request for a service that is being provided under an established policy” rather than a challenge to the development of general policy.¹⁴⁷

This review of cases suggests that tort law is not a promising prospect for patients with rare diseases who seek to challenge government health care allocation decisions. As Hardcastle notes, many of these cases are decided at the duty stage, and courts have been unwilling to find the requisite proximity between the plaintiffs and the defendant governments or hospitals which is necessary to base a duty of care.¹⁴⁸ Chief Justice McLachlin explained the proximity requirement in *Hill v Hamilton-Wentworth Regional Police Services Board* as follows:

The most basic factor upon which the proximity analysis fixes is whether there is a relationship between the alleged wrongdoer and the victim, usually described by the words “close and direct”. This factor is not concerned with how intimate the plaintiff and defendant were or with their physical proximity, so much as with whether the actions of the alleged wrongdoer have a close or direct effect on the victim, such that the wrongdoer ought to have had the victim in mind as a person potentially harmed. A sufficiently close and direct connection between the actions of the wrongdoer and the victim may exist where there is a personal relationship between alleged wrongdoer and victim. However, it may also exist where there is no personal relationship between the victim and wrongdoer.¹⁴⁹

Undoubtedly, government decisions about what medical services to fund or not fund will deeply and significantly impact some individuals. However, it seems unlikely that courts would expect the government to

145. *Heaslip*, *supra* note 143 at para 21.

146. *Ibid* at paras 23-31.

147. *Ibid* at para 29.

148. Hardcastle, *supra* note 138 at 554, 556-58.

149. 2007 SCC 41 at para 29 [*Hill*]. See also *Cooper v Hobart*, 2001 SCC 79 at paras 23-26, 32 [*Cooper*].

have individual patients “in mind” as “person[s] potentially harmed.” In a general sort of way, the government will expect that its decisions in the health care realm will affect people’s lives, but, generally, it will not anticipate the specific harms that may result or the particular persons (or groups of persons) that will be impacted. Unlike in *Hill*, where police were found to be adequately proximate to an individual suspect to ground a duty of care, no patient is “singled out”¹⁵⁰ or “particularized”¹⁵¹ when the government makes general health coverage decisions. The government is dealing with – to use the language from *Hill* – “the universe of all potential”¹⁵² patients.

Even if plaintiffs establish proximity, a court may find that the duty should be abrogated for policy reasons under the second branch of the *Anns* test.¹⁵³ In *Hill*, McLachlin CJC explained that “the final stage of *Anns* is concerned with ‘residual policy considerations’ which ‘are not concerned with the relationship between the parties, but with the effect of recognizing a duty of care on other legal obligations, the legal system and society more generally’.”¹⁵⁴ For example, under the “residual policy consideration” criterion, a court should ask whether there is “potential for conflict between a duty of care in negligence and other duties owed by”¹⁵⁵ the government, such as, “duties [owed] to the public at large.”¹⁵⁶ This concern motivated the Ontario Court of Appeal in *Eliopoulos Estate* (discussed above) to hold that “impos[ing] a private law duty ... would create an unreasonable and undesirable burden ... that would interfere with sound decision-making in the realm of public health.”¹⁵⁷ Courts are likely to find that duties to individual persons are inconsistent with the government’s overarching responsibility to provide a cost-effective, reliable and fair health care system. Courts will thus “negate” the duty on the basis of policy-related worries that the imposition of such an

150. *Hill, ibid* at para 33.

151. *Ibid.*

152. *Ibid.*

153. Hardcastle, *supra* note 138 at 555-570; *Cooper, supra* note 150 at para 38.

154. *Hill, supra* note 149 at para 31, citing *Cooper, ibid* at para 37.

155. *Hill, ibid* at para 48.

156. *Ibid* at para 130.

157. *Eliopoulos Estate, supra* note 140 at para 33.

obligation would unduly interfere with the government's discretion to allocate resources in a manner it believes best meets the needs and expectations of all Canadians.

Additionally, it must be noted that, pursuant to the Supreme Court's decision in *Just*,¹⁵⁸ governments are not liable for "true policy decisions"¹⁵⁹ that "involve or are dictated by financial, economic, social or political factors or constraints."¹⁶⁰ Health care coverage decisions, as they involve resource distribution and financial wrangling, are likely the type of decision for which a government will not be liable.

Thus, for patients with rare diseases, the policy hurdles to establishing a duty of care will be difficult to overcome. A patient would need to establish that the impugned decision is in fact an "operational decision" which executes established policy.¹⁶¹ One could attempt to characterize the decision to deliver accessible, high-quality health care a "policy decision" and choices about individual services "operational decisions" made in the course of realizing that policy. This approach may avoid running afoul of the Supreme Court's observation that, "[a]s a general rule, decisions concerning budgetary allotments for departments or government agencies will be classified as policy decisions,"¹⁶² because funding (or not funding) individual services may not implicate larger budgetary decisions if the "operational decisions" are made by "lower level"¹⁶³ actors within the parameters – including ultimate financial constraints – of the policy. That is, the decision regarding how much money to allocate to overall health spending may be a "policy decision" immune from liability, but, provided the budget is not exceeded, decisions about how to spend that money (on treatment x and not treatment y) may be "operational decisions." However, based on Canadian case law,¹⁶⁴ this approach, in

158. *Just v British Columbia*, [1989] 2 SCR 1228 [*Just*].

159. *Ibid* at 1239.

160. *Ibid* at 1242, citing *Sutherland Shire Council v Heyman* (1985), 60 ALR 1 (HCA). See also Sweatman & Woollard, *supra* note 18 at 287.

161. *Just*, *supra* note 159 at 1239-40.

162. *Ibid* at 1245.

163. *Ibid* at 1243 ("a true policy decision may be made at a lower level provided that the government agency establishes that it was a reasonable decision in light of the surrounding circumstances").

164. See *e.g.* *Gosselin v Moose Jaw* (1997), 155 DLR (4th) 374 paras 15-25 (SKCA);

so far as it seeks to challenge listing and delisting decisions, is unlikely to find favour before the courts unless and until courts perceive “money decisions” to be operational ones.

Turning to micro-level decision-making, physicians and other medical service providers are unlikely to escape liability for malpractice by arguing that fiscal restraints justified their decision not to provide a particular service.¹⁶⁵ In *Law Estate v Simice*,¹⁶⁶ the British Columbia Supreme Court rejected the physician’s defence that he did not send the patient for a CT scan because of monetary restrictions.¹⁶⁷ The Court noted: “if it comes to a choice between a physician’s responsibility to his or her individual patient and his or her responsibility to the medicare system overall, the former must take precedence in a case such as this.”¹⁶⁸ The Court observed that the physical harm to the patient is “far greater than the financial harm” to the system.¹⁶⁹

This line of reasoning will be useful if a patient with a rare disease is denied an expensive treatment by a physician on the basis of cost considerations. However, it is unclear whether this scenario is common¹⁷⁰ and thus *Simice* may not be particularly helpful for patients with rare diseases.

A lawsuit pursued against an individual physician will require consideration of whether the physician has met the requisite standard of care, which is assessed in comparison to “the conduct of a prudent

Gobin v British Columbia, 2002 BCCA 373 at para 44.

165. Caulfield, “Malpractice”, *supra* note 135 at 24.

166. (1994), 21 CCLT (2d) 228 (BCSC).

167. *Ibid* at para 28.

168. *Ibid*.

169. *Ibid*; Caulfield, “Malpractice”, *supra* note 135 at 25-26.

170. But see *e.g.* Ezekiel J Emanuel & Andrew Steinmetz, “Will Physicians Lead on Controlling Health Care Costs?” (2013) 310:4 *Journal of the American Medical Association* 374 (“85% [of participant doctors] strongly or moderately agreed that trying to contain costs is the responsibility of every physician” at 375). For discussion on whether costly therapies can justifiably be denied on the basis of resource shortages, see *e.g.* Dominic Wilkinson, “Which Newborn Infants are Too Expensive to Treat? Camosy and Rationing in Intensive Care” (2013) 39:8 *Journal of Medical Ethics* 502; Dyfrig Hughes, “Rationing of Drugs for Rare Diseases” (2006) 24:4 *Pharmacoeconomics* 315.

and diligent doctor in the same circumstances.”¹⁷¹ The efficacy of the sought drug may be relevant at this stage of the analysis. If, for example, the drug is experimental and unproven, a defendant physician can more easily establish that he or she acted “in accordance with the conduct of a prudent and diligent doctor in the same circumstances,”¹⁷² by arguing that his or her peers would be cautious about administering medication without the belief that the drug has at least some chance of benefiting the patient. The fact that the patient has a rare disease – and not a common illness – may also be relevant to the determination of whether the health care provider has fallen below the standard of care. Some lower courts have found that the rare nature of an illness militates in favour of a finding that the defendant met the applicable standard, as physicians in the same setting with the same experience would not recognize the unusual disease.¹⁷³

Even if claims against individual health care providers were likely to be successful, it should be added that tort law challenges to individual decision-makers may not be ideal from the perspective of patients with rare diseases as a group, as the individualized outcome in tort cases does not necessarily lead to the larger, policy change desired by many patients. As Caulfield notes:

[T]ort law is not the best tool for effectuating health care reform. Malpractice lawsuits are determined on a case-by-case basis. They focus on the rights and legal duties of individual physicians and patients. And while the principles of tort law obviously have social utility, such as the compensation of patients who are injured by negligence, the rights and duties of patients and physicians are rarely subordinated to the needs of the broader health care system.¹⁷⁴

While an individual patient may win his or her case, the larger group of patients is still left without access to treatment.

171. *Ter Neuzen v Korn*, [1995] 3 SCR 674 at para 33.

172. *Ibid.*

173. *Hancock Estate v Hanton* (2003), 344 AR 221 at paras 56, 84-93 (ABQB); *Grennan Estate v Reddoch*, 2002 YKCA 17 at paras 36, 48-49; *Shannahan v Johnson*, 2010 BCSC 700 at para 76.

174. Caulfield, “Malpractice”, *supra* note 134 at 12.

IV. Conclusion

This paper has discussed legal avenues that patients with rare diseases may pursue if they are dissatisfied with health care coverage decisions. Each of these avenues has distinct merits and obstacles. For example, *Charter* litigation is ideal for effecting policy change and may be embraced by plaintiffs who seek “big picture” change. However, it can be complicated, costly, and drag on for years. Tort law, administrative law, and human rights law offer individualized outcomes, and thus, while policy change is possible if the government is persuaded during or following litigation to amend its approach, these avenues will not necessarily result in increased funding or new approaches to decision-making.

A common theme running through this review of cases is the policy-heavy component of health care allocation decisions. One can expect that, in response to all types of claims, the government will put forward a defence which emphasizes the policy character of the decision. Policy aspects may be used to justify *Charter* infringements, militate against the finding of a duty of care, exempt decisions from procedural fairness requirements, and tilt the standard of judicial review to the deferential “reasonableness” standard. Courts frequently articulate the belief that policy making is best left to the government. Thus, health care coverage decisions, infused with policy and financial considerations, are seen to be in the government’s wheelhouse. Judicial deference means that for patients with rare diseases it will be difficult to use the above legal avenues to establish an entitlement to funding for a particular medical service.¹⁷⁵ Deference is not absolute however; courts will intervene to ensure compliance with the Constitution or to correct a discriminatory decision. Whether a case is likely to be successful ultimately comes down to the individual facts of the case.

Before choosing litigation, patients with rare diseases should be aware that these sorts of claims may impact decision-making in unintended ways. As Ries and Caulfield observe:

175. Flood & Zimmerman, *supra* note 19 at 27 (Flood and Zimmerman suggest that, because coverage decisions are often unsystematic and arbitrary, courts should not be quick to accept these decisions).

[S]ome of these mechanisms may undermine accountability by pushing complex policy decisions into courtrooms where attention will necessarily focus on the circumstances of individual litigants, perhaps to the exclusion of broader consideration of competing demands on public resources. In addition, successful claims may accord greater status to certain therapies by enshrining public funding for them as a fundamental human or constitutional right. As a result, governments may be compelled to reallocate funds to those specific services and reduce financial support for other programs or services that have not been the subject of litigation.¹⁷⁶

Patients with rare diseases are not one “group” of patients, but many groups of patients with different health care needs. While patients who share an illness may understandably seek to “constitutionalize” funding for a particular treatment, this may not be the optimal approach once the welfare of all patients with rare diseases is taken into account. Thus, in addition to the practical hurdles discussed in this paper, strategic choices may deter patients from using the court system.

On the other hand, litigation has benefits. If successful, patients may free themselves from financial hardship and associated stresses and worries. Further, even if a claim does not prevail in court, taking legal action may prompt governments to re-consider resource allocation decisions in the health sector, especially if lawsuits are combined with political pressure brought by patient groups.¹⁷⁷ Thus legal mechanisms, even if unlikely to be successful, may be useful tools for patients with rare diseases seeking funding for medical treatments. Ultimately, patients must weigh the advantages and disadvantages of litigation, determine their ideal outcomes, assess their probability of success, and consider the possible consequences of the suit before they decide to pursue a claim. If they decide to proceed, this paper has offered a brief summary of the legal mechanisms available to them.

176. Ries & Caulfield, *supra* note 26 at 33.

177. *Ibid* at 9.

Canada's Refugee Health Law and Policy from a Comparative, Constitutional, and Human Rights Perspective

Ruby Dhand* & Robert Diab**

*Under the Interim Federal Health Program (IFHP), Canada has provided healthcare coverage for immigrants in financial need, including refugees, for over half a century. Until recently, the program provided migrants with comparable coverage to that available to Canadians on social assistance. In 2012, the government amended the IFHP to significantly reduce coverage for certain classes of migrants, including some on the basis of their country of origin, and removed coverage from others altogether. This article briefly describes the changes in migrant healthcare coverage in Canada, and compares it with analogous coverage in the United States, the United Kingdom, and Australia. The comparison demonstrates that Canada's recent changes to healthcare coverage fall below a common standard of coverage in these comparator countries. The paper then explores arguments made for and against the constitutionality of the revised IFHP in *Canadian Doctors for Refugee Care v Canada*, and the consistency of the plan with Canada's obligations under international human rights law. The authors contend that despite the reluctance of courts thus far to recognize a positive duty on the part of the state to provide health benefits as a means of protecting Charter rights, facets of this case present unique and compelling reasons for doing so. Finally, the paper argues that restoring coverage to levels prior to 2012 would bring Canada in closer conformity to the values and principles expressed in various international human rights treaties.*

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I. Introduction

Following the Second World War, Canada began to offer healthcare coverage for certain groups of immigrants brought to Canada with government assistance. It did so through a series of orders in council that gradually expanded the scope of coverage to all classes of immigrants who could not afford coverage independently.¹ Coverage for migrants in the early stages of their arrival has thus been generally provided not through provincial healthcare plans but through what has become known as the Interim Federal Health Program (IFHP).²

Until 2012, the program provided refugees, refugee claimants, and other migrants with comparable coverage to that available to Canadians

contributions as research assistants.

1. The history of the program is explored in greater detail in Part II.
2. As explored below, for certain periods, provincial and territorial health plans have offered coverage for certain classes of migrants that overlapped with eligibility under the IFHP.

receiving social assistance.³ This included coverage for non-emergency hospital and doctor visits, vaccines and other preventive medicine, and basic dental and eye care. In June of 2012, the government amended the IFHP to significantly reduce coverage for certain classes of refugees and refugee claimants, including some on the basis of country of origin.⁴ The government also removed coverage from other categories of migrants altogether.⁵ Coinciding with this, Parliament passed a series of legislative amendments to the process for refugee determination under the *Immigration and Refugee Protection Act*,⁶ with a more expeditious means of resolving claims by migrants from certain “Designated Countries of Origin” that had higher historical rates of failed claims.⁷

Under the revised 2012 IFHP, those previously eligible for a wide range of basic health benefits have been divided into four tiers of coverage, with all but 14 percent of those eligible for coverage now placed in the three lower tiers.⁸ Those in the first tier continue to enjoy coverage previously available, while those in the second tier are covered for visits to doctors or hospitals only if the matter is “of an urgent or essential

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3. Government of Canada, “Health care – Refugees”, online: Citizenship and Immigration Canada <<http://www.cic.gc.ca/english/refugees/outside/arriving-healthcare.asp>> [“Health care - Refugees”].
 4. *Order Respecting the Interim Federal Health Program, 2012*, SI/2012-26, (2012) C Gaz II, online: Justice Laws Canada <<http://laws-lois.justice.gc.ca/eng/regulations/SI-2012-26/FullText.html>>. The order was registered on April 25, 2012 and came into force on June 30, 2012.
 5. *Ibid.*
 6. SC 2001, c 27 [IRPA].
 7. Bill C-31, *Protecting Canada’s Immigration System Act*, 1st Sess, 41st Parl, 2012 (assented to 28 June 2012) [Bill C-31]. For an overview of the amendments in Bill C-31, see Government of Canada, “Protecting Canada’s Immigration System”, online: Citizenship and Immigration Canada <<http://www.cic.gc.ca/english/refugees/reform.asp>>.
 8. Government of Canada, “Interim Federal Health Program: Summary of Benefits”, online: Citizenship and Immigration Canada <<http://www.cic.gc.ca/english/refugees/outside/summary-ifhp.asp>> [“Summary of Benefits”]. The proportion of claimants in each tier is documented in the Memorandum of the Attorney General of Canada and Minister of Citizenship and Immigration, at paras 13-15 [Respondents’ Memorandum] in *CDRC, CARL, Garcia, Rodriguez et al v Canada (AG and MCI)*, Federal Court file T-356-13 [*CDRC et al v Canada*]; the trial level decision in this case is explored in more detail below.

nature,”⁹ and for medicine or vaccines “only if needed to prevent or treat a disease that is a risk to public health or to treat a condition of public safety concern.”¹⁰ Those in the third tier are provided the same coverage as those in the second tier with the exception that hospital and doctor visits are covered not where urgent or essential but only where necessary to “diagnose or treat a disease posing a risk to public health or to treat a condition of public safety concern.”¹¹ Failed claimants and migrants awaiting a pre-removal risk assessment are now placed in a fourth tier in which previous eligibility under the IFHP has been removed altogether (*i.e.* even if they suffer a condition that poses a risk to public health or safety).¹² The new scheme allows for discretionary coverage in individual cases, but limits their placement in this instance to either the second or third-tier of coverage. The new framework thus entails an effective withdrawal of coverage for most forms of preventive and, in many cases, emergency care for some 86 percent of migrants who previously enjoyed coverage.

Part II of this article briefly explores the history and scope of the IFHP, and then describes the changes in Canada's migrant healthcare coverage and their practical impact. Part III compares Canada's coverage with analogous plans in the United States, the United Kingdom, and Australia. Drawing on this overview, we argue that while various impediments to healthcare can be found in these other jurisdictions, for the most part, Canada's revised plan falls below a common standard of coverage among these comparator countries.

In Part IV, we explore the constitutionality of the revised IFHP and its consistency with Canada's obligations under international human rights law. We do so by exploring arguments raised in an action brought by two individual immigrants directly affected by the changes, along with the Canadian Association of Refugee Lawyers and Canadian Doctors for Refugee Care (the Applicants).¹³ Among the central issues in this case is whether the decision to remove coverage from certain classes of migrants

9. “Summary of Benefits”, *ibid.*

10. *Ibid.*

11. *Ibid.*

12. *Ibid.*

13. *CDRC et al v Canada*, *supra* note 8.

violates sections 7, 12, and 15 of the *Canadian Charter of Rights and Freedoms*,¹⁴ and if so whether the decision constitutes a reasonable limit on those rights under section 1. In making these claims, the Applicants invited the Court to depart from a growing body of case law in which courts have resisted recognizing a positive state duty under the *Charter* to provide a benefit essential for security of the person or for survival, including healthcare.¹⁵ The Applicants relied in part on the Supreme Court's affirmation in *Gosselin v Quebec*¹⁶ that the *Charter* might be applied in this way under "special circumstances." In July 2014, Mactavish J of the Federal Court rendered a decision at the trial level, dismissing the section 7 claim, but finding the revised IFHP scheme contrary to sections 12 and 15, and not a reasonable limit on those rights under section 1 of the *Charter*.¹⁷ Setting out an overview of this decision, we highlight relevant factual findings under sections 12 and 15 that are likely to frame the reconsideration of the case on appeal. We also argue that in dismissing the section 7 claim, Mactavish J failed to recognize facets of the present case that distinguish it from earlier case law on the question of a positive duty under section 7. For reasons to be explored, we suggest that the present facts come closer than earlier case law to presenting the "special circumstances" that the majority in *Gosselin* contemplated as necessary to justify the imposition of a positive duty under section 7. Finally, the

14. Part I of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (UK), 1982, c 11 [*Charter*].

15. These include *Masse v Ontario (Ministry of Community and Social Services)* (1996), 134 DLR (4th) 20 (Div Ct) [*Masse*], leave to appeal to CA refused, [1996] OJ No 1526 (QL), leave to appeal to SCC refused, [1996] SCCA No 373; *Clark v Peterborough Utilities Commission* (1995), 24 OR (3d) 7 (Gen Div), appeal dismissed as moot (1998), 40 OR (3d) 409 (CA); *Auton (Guardian ad litem of) v British Columbia (AG)*, 2004 SCC 78 [*Auton*]; *Grant v Canada (Attorney General)* (2005), 77 OR (3d) 481 (SC) [*Grant*]; *Wynberg v Ontario* (2006), 82 OR (3d) 561 (CA) [*Wynberg*]; *Sagharian v Ontario (Education)*, 2008 ONCA 411 [*Sagharian*]; *Flora v Ontario Health Insurance Plan*, 2008 ONCA 538 [*Flora*]; *CCW v Ontario Health Insurance Plan* (2009), 95 OR (3d) 48 (Div Ct) [*CCW*]; *Tanudjaja v Attorney General (Canada) (Application)*, 2013 ONSC 5410 [*Tanudjaja*].

16. *Gosselin v Quebec (Attorney General)*, 2002 SCC 84 [*Gosselin*].

17. *Canadian Doctors For Refugee Care v Canada (Attorney General)*, 2014 FC 651 [*Canadian Doctors*].

paper briefly examines relevant international human rights law that may assist in a *Charter* analysis of the issues raised in this case.

II. Nature of the Change to Refugee Health Coverage

A. Context for the Program

To place the nature and import of the recent changes to refugee health coverage into context, we begin with a brief overview of the origins and scope of Canada's healthcare scheme for immigrants before 2012.¹⁸

The Interim Federal Health Program can be traced to a 1946 Order in Council that authorized medical coverage for some 4,000 ex-members of the Polish Armed Forces whom the federal government had selected for assistance with immigration.¹⁹ In 1949, through a further order, the government extended coverage to immigrants generally, authorizing the Department of Citizenship and Immigration "to pay hospital accounts and maintenance expenses of immigrants who may become suddenly ill after being admitted at the port of entry and prior to their arrival at destination, in such cases where immigrants lack the financial resources to bear these expenses themselves."²⁰ In 1952, the plan was extended to cover the costs of "medical and dental care, hospitalization, and any expenses incidental thereto" not only to indigent immigrants in need of care upon entry or arrival at destination, but also to those waiting for work placements to begin.²¹ And in 1957, a further order amended the scheme to extend coverage more generally to "a person who at any time is subject to Immigration jurisdiction or for whom Immigration

18. The following account draws upon a summary of the origins of the IFHP in *Toussaint v Canada (Attorney General)*, 2010 FC 810 at paras 31-39 [*Toussaint*]; Memorandum from Canadian Doctors for Refugee Care et al, at paras 4-17 [Applicants' Memorandum] in *CDRC et al v Canada*, *supra* note 8; Mactavish J's decision in *Canadian Doctors*, *ibid* at paras 32-56.

19. *Toussaint*, *ibid* at para 32, citing Order in Council PC 1946-3112 of July 23, 1946.

20. *Ibid* at para 34, citing Order in Council PC 1949-41/3888 of August 4, 1949.

21. *Ibid* at para 35, citing Order in Council PC 1949-4/3263 of June 6, 1952.

authorities feel responsible.”²² The 1957 order would continue to be the primary authority for the program rather than being entrenched in later immigration or healthcare legislation.²³

Prior to 2012, the program offered immigrants a level of health coverage roughly equivalent to that provided to citizens or permanent residents on social assistance.²⁴ This included coverage for hospital and doctor visits and prescriptions, as is generally the case under provincial plans; but it also covered certain dental procedures and limited eye care, as in some plans for those receiving social assistance.²⁵ In these latter respects, it offered benefits not available to working citizens or permanent residents under most provincial plans. Coverage was also meant to last for a limited and short duration, until a person began working or obtained eligibility under provincial or territorial programs.²⁶

Until 1995, the bulk of IFHP funding was spent on care for “indigent landed immigrants,” but this began to shift in 1995 to “refugee claimants, refugees, and others in humanitarian need.”²⁷ In 1995 and 1996, Ontario and Quebec, respectively, ceased to provide coverage for refugee claimants under their plans.²⁸ This caused not only a shift in the balance of funding between refugees and non-refugees, but also a significant rise in the number of qualified persons falling within the scope of the IFHP.²⁹ In 1999, the scope of coverage under the plan was further extended to include applicants seeking a Pre-Removal Risk Assessment and victims of human trafficking.³⁰ By 2012, the program serviced a

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22. *Ibid* at para 36, citing Order in Council PC 1957-11/848 of June 20, 1957.
 23. Respondents’ Memorandum, *supra* note 8 at para 10.
 24. Applicants’ Memorandum, *supra* note 18 at para 10; “Health care - Refugees”, *supra* note 3.
 25. Respondents’ Memorandum, *supra* note 8 at para 8, relying upon the Affidavit of Sonia Le Bris, sworn August 29, 2013, Acting Director of Migration Health Policy and Partnerships, Health Branch, CIC at paras 7-13 [Le Bris Affidavit].
 26. *Ibid*.
 27. *Ibid* at para 12, citing Le Bris Affidavit at paras 18-21.
 28. *Ibid*.
 29. *Ibid*.
 30. *Ibid*.

larger number of immigrants (some 126,000 persons, by one estimate),³¹ and also covered them for a longer average period – close to three years in the government's estimate.³² The cost of reimbursement to hospitals, doctors, and other providers, along with medication and other fees rose significantly. In 1996-97, the IFHP cost \$18 million and by 2011-12 it was \$83 million.³³

Yet, as litigants challenging the validity of changes to the scheme have noted, from a broader perspective, the cost of the program was relatively low. It carried an annual per-capita cost of \$552 or roughly 10 percent of the annual per capita cost of healthcare for Canadians of \$5,401.³⁴ The Applicants also note that the \$83 million cost of the program comprises “only 4/100ths of one percent of total health expenditures in Canada, or about 60 cents per taxpayer per year.”³⁵

Prior to changes in 2012, the IFHP provided the same suite of coverage to various classes of immigrants, including pending, successful, and *failed* refugee claimants, along with government and privately sponsored refugees, and those awaiting a pre-removal risk assessment. Coverage lasted until a person became eligible under a provincial plan or departed from Canada.³⁶ However, as the government has indicated in the course of litigation, the earlier IFHP did not apply to persons without status in Canada, or to persons with failed or abandoned or ineligible claims who had not sought a pre-removal risk assessment. On this basis, the government has argued that the 2012 revision to the IFHP did not *introduce* a distinction in terms of coverage among migrants.

31. Applicants' Memorandum, *supra* note 18 at para 14, citing the Affidavit of Allison Little Fortin, sworn August 29, 2013, Director of the IFHP, Health Branch, CIC at para 8 [Little Fortin Affidavit].

32. Respondents' Memorandum, *supra* note 8 at para 13, citing Little Fortin Affidavit at para 75 and Le Bris Affidavit at para 39.

33. *Ibid.*

34. Applicants' Memorandum, *supra* note 18 at para 8, citing the Affidavit of Mitchell Goldberg at para 18.

35. *Ibid.*, citing Le Bris Affidavit at para 39.

36. *Ibid.* at para 7, citing Government of Canada, “Audit of the Control Framework for the Interim Federal Health Program” (2004), online: Citizenship and Immigration Canada <<http://www.cic.gc.ca/english/resources/audit/ifh.asp>>.

B. Changes to the IFHP in 2012

By an order in council on April 25 of 2012, which came into effect on June 30, 2012, the government shifted its policy with respect to coverage significantly.³⁷ Coverage would now be tiered, placing immigrants into four categories, with those in the second and third tiers losing many of the benefits and services they enjoyed earlier, and those in the fourth losing all. In response to criticism of the new scheme, the government passed an order in council on June 18, 2012, restoring some benefits to persons in the second and third tier.³⁸ What follows summarizes the current plan.³⁹

The first tier of coverage, referred to in the government documentation as “Expanded Health-Care Coverage,” applies to government-assisted refugees, privately sponsored refugees who receive income support through the Resettlement Assistance Program (or its Quebec equivalent), and to victims of human trafficking for the duration of the period in which they hold a “Temporary Resident Permit.”⁴⁰ Persons in this group receive the equivalent level of coverage to what the program offered to all immigrants prior to 2012. This includes hospital and doctor services; laboratory, diagnostic, and ambulance services; and also “supplemental health benefits,” such as prescribed medications, limited dental and vision care, prosthetics, home care, and psychological counselling. As the government’s brief in the current *Charter* challenge notes, this tier of coverage extends to 14 percent of IFHP beneficiaries.⁴¹

The second tier, titled “Health Care Coverage,” applies to privately sponsored refugees not receiving government income support (or the bulk of privately sponsored refugees), and “Other Protected Persons,”⁴² until they qualify for provincial or territorial coverage. “Other Protected Persons” include refugee claimants not from a Designated Country of

37. *Order Respecting the Interim Federal Health Program*, *supra* note 4.

38. *Order Amending the Order Respecting the Interim Federal Health Program*, PC 2012-945, (2012) C Gaz II (of 28 June 2012).

39. “Summary of Benefits”, *supra* note 8.

40. *Ibid.*

41. Respondents’ Memorandum, *supra* note 8 at para 35, citing Little Fortin Affidavit at paras 47-55.

42. “Summary of Benefits”, *supra* note 8.

Origin (see below for the definition); refugees whose claims have been accepted; immigration detainees; and persons who have received a positive Pre-Removal Risk Assessment. This tier provides the following services “only if of an urgent or essential nature”: hospital, physician, or nurse services; laboratory, diagnostic and ambulance services; and medication or vaccine “only if needed to prevent or treat a disease that is a risk to public health or to treat a condition of public safety concern.”⁴³ As a result, persons in this group are no longer covered in the ordinary course for prescription medication including insulin, anti-epileptics, anti-asthma or psychiatric medication.⁴⁴ The government’s factum notes that 62 percent of all IFHP beneficiaries (*i.e.* of persons in the first three tiers) fall within this category.⁴⁵

The third tier is comprised of refugee claimants from a “safe” or Designated Country of Origin (DCO)⁴⁶ and rejected claimants.⁴⁷ Persons in this group receive what is termed “Public Health or Safety Health-Care Coverage,” which provides the same coverage as in the second tier except that whereas in that category, the listed services aside from medications and vaccines (*i.e.* hospital and doctor visits, diagnostic and ambulance services) are covered only where they are of “an urgent or

43. *Ibid.*

44. Applicants’ Memorandum, *supra* note 18 at para 10.

45. Respondents’ Memorandum, *supra* note 8 at para 36, citing Little Fortin Affidavit at paras 56-61.

46. Following amendments in Bill C-31 to the *Immigration and Refugee Protection Act* in June 2012, the Minister may designate a source country to be “safe,” triggering an accelerated process for determining refugee claims, along with the tiered health coverage described above. See s 58 of Bill C-31, *supra* note 7, amending s 12 of Bill C-11, *An Act to Amend the Immigration and Refugee Protection Act and the Federal Courts Act*, 3rd Sess, 40th Parl, 2010 (assented to 29 June 2010). Thirty-seven countries have been deemed safe, including Hungary and Mexico – which are, as the Applicants in this case note, a source of significant numbers of refugee claimants in recent years.

47. A rejected claimant is defined as a person whose claim has been rejected by the Immigration and Refugee Board and whose right to judicial review and appeal of that right have been exhausted: Government of Canada, “Information Sheet for Interim Federal Health Program Beneficiaries”, online: Citizenship and Immigration Canada <<http://www.cic.gc.ca/english/refugees/outside/ifhp-info-sheet.asp>>.

essential nature,” here both medicine or vaccines *and* other health services are provided “only if needed to diagnose, prevent or treat a disease posing a risk to public health or to diagnose or treat a condition of public safety concern.”⁴⁸ This category entails no coverage for preventive care, and no medication or services except where a condition poses a risk to public health or safety. Thus, it excludes coverage for any disorder that is non-communicable, including diabetes, asthma, epilepsy, heart conditions, trauma, blood infections, non-violent psychoses, and pregnancy.⁴⁹ Twenty-four percent of IFHP beneficiaries are within this category.⁵⁰

Finally, a fourth group comprises refugee claimants who have withdrawn or abandoned their claims or have not been found eligible to make a claim, along with applicants for a pre-removal risk assessment without a valid claim. Prior to June of 2012, persons in this group were covered by the IFHP while awaiting the outcome of a pre-removal risk assessment (PRRA).⁵¹ They now receive no coverage under the IFHP, even if their condition poses a risk to public health or safety.⁵²

To be clear as to the nature of the difference between the plan before and after the June 2012 changes, it might help to consider a common practical scenario. Both before and since 2012, refugee claims brought by migrants from certain DCO countries such as Mexico and Hungary have been refused in a number of cases, but at least some have been successful.⁵³ Thus, for example, prior to 2012, if a pregnant woman were to arrive from a DCO country with a valid and compelling claim for asylum, she would receive coverage for routine visits to a doctor for pre-natal care and medicine. Today, falling under the third tier of coverage, she would not be covered for routine visits or medicine, given that she

48. “Summary of Benefits”, *supra* note 8.

49. Applicants’ Memorandum, *supra* note 18 at para 10.

50. Respondents’ Memorandum, *supra* note 8 at para 37, citing Little Fortin Affidavit at paras 62-70.

51. Applicants’ Memorandum, *supra* note 18 at para 10.

52. “Summary of Benefits”, *supra* note 8; Applicants’ Memorandum, *ibid*; Respondents’ Memorandum, *supra* note 8 at para 26, citing Little Fortin Affidavit at para 82.

53. The DCO category is premised on a higher rate of failed claims from these countries, but not on an absolute rate of failure or a prohibition on claims from DCO migrants.

does not suffer from a potentially communicable disease or a condition that poses a danger to public safety.

But even once a finding is made at the Immigration and Refugee Board that a pregnant woman from a DCO is a successful refugee claimant, she would only move up to the second tier of coverage. Thus, she would still not be covered for a *routine* visit to a doctor or for medication, since the second tier covers visits only of an “urgent or essential nature,” and medicine only where it is necessary to treat a communicable disease or a condition that poses a danger to public safety. In short, the plan removes coverage for many *preventive* forms of medicine that are necessary to address matters short of emergencies but critical for life or security of the person.

In responding to the constitutional challenge to the changes to the IFHP, the government questioned the severity of the situation in which persons in the lower three tiers now find themselves. Citing the availability of a range of provincial social welfare programs, such as Ontario Works, and significant numbers of community health centres that provide free health services, the government suggested that the loss of IFHP coverage can often be addressed by other means.⁵⁴ It also cited evidence that a number of provinces had expanded their healthcare plans in response to the IFHP reforms, including Quebec, which provides affected persons much of what was reduced under the 2012 reforms.⁵⁵ And in the last resort, the Respondents noted that emergency medical care at any hospital is available to everyone in Canada unconditionally.⁵⁶

54. Respondents' Memorandum, *supra* note 8 at paras 40-41, citing Little Fortin Affidavit at paras 89-92, 94.

55. *Ibid* at para 44.

56. *Ibid* at para 44, citing Little Fortin Affidavit at para 92. Note, however, that in the 2011 Federal Court of Appeal decision in *Toussaint v Canada (Attorney General)*, 2011 FCA 213 at para 59 [*Toussaint Appeal*], the Crown disputed whether the exclusion of an undocumented migrant from coverage under the IFHP deprived access to emergency care on the basis that “in Ontario, where the appellant lives, hospitals cannot deny emergency medical treatment to anyone, when to do so would endanger life”: *Public Hospitals Act*, RSO 1990, c P 40. Yet, at the trial level, Justice Zinn had found, *supra* note 18 at para 91, that “the applicant’s exclusion from IFHP coverage has exposed her to a risk to her life as well as to long-term, and potentially irreversible, negative health consequences,”

In the Federal Court's decision in *Canadian Doctors*, Mactavish J accepted the Appellants' contention that these various sources remain inadequate to address the critical needs of many migrants.⁵⁷ Refugee claimants generally do not qualify for provincial healthcare plans due to residency requirements and varying definitions of residency in provincial legislation.⁵⁸ Some refugee claimants, failed claimants, and Pre-Removal Risk Assessment applicants are eligible for provincial social assistance, but these provide supplemental benefits (medication, dental and eye care) rather than the comprehensive care normally provided under primary provincial healthcare plans.⁵⁹ Moreover, due to sponsorship undertakings, privately-sponsored refugees are precluded from obtaining social assistance for a year after their arrival, and claimants from Designated Countries of Origin are not eligible for a work permit for the first 180 days in Canada.⁶⁰ In other words, it is not clear how many refugees are expected to address a lack of coverage for critical or emergency assistance.

Justice Mactavish held that, in a broader sense, the government's position on alternative sources of care "takes no account of the extreme human cost incurred as individuals search for sources of potentially life-saving medical care."⁶¹ Many claimants face language barriers or have limited education, posing further impediments to access.⁶² Justice Mactavish was also critical of the assumption that community health centres or refugee centres could function as a surrogate for the wide range of walk-in care that would otherwise have been available under the IFHP,

amounting to a deprivation of security of the person under section 7. The Federal Court of Appeal upheld this finding at para 66, despite overturning the lower court decision on other grounds. See below for further discussion of both decisions.

57. *Canadian Doctors*, *supra* note 17 at paras 261-99.

58. Applicants' Memorandum, *supra* note 18 at para 15 (see *e.g.* the definition of "residency" in section 1.1 of RRO 1990, Reg 552 of Ontario's *Health Insurance Act*, RSO 1990, c H6 [Regulation 552], the definition of "resident" in section 1 of the British Columbia *Medicare Protection Act*, RSBC 1996, c 286 and the definition of "deemed residency" in section 2 of the *Medical and Health Care Services Regulation*, BC Reg 426/97).

59. Applicants' Memorandum, *supra* note 18 at para 15.

60. *Ibid.*

61. *Canadian Doctors*, *supra* note 17 at para 263.

62. *Ibid* at para 266.

given the “severely restricted” medical assistance typical in these essentially charitable institutions.⁶³ She also noted that neither emergency care nor the limited coverage available through social assistance could provide for a wide range of preventive care through routine doctor visits, prenatal care, or diagnostic tests.⁶⁴ Finally, the availability of discretionary coverage was also a poor substitute for a range of reasons that include the exclusion in such cases of coverage for medication, the inability to address emergency situations, the confusion surrounding knowledge of how to apply, and the general uncertainty as to whether one could obtain discretionary coverage.⁶⁵

III. Refugee Health Coverage in a Comparative Perspective

Before examining the merits of the revised IFHP in terms of the *Charter* and Canada's obligations under international human rights law, in this section we briefly survey the extent of coverage in the United States, the United Kingdom, and Australia. The overview demonstrates that while migrants face obstacles to healthcare coverage or treatment in these comparator countries, with one exception, Canada's revised IFHP falls below a basic level of coverage common to each of them for both refugee claimants and failed or non-status migrants.

A. The United States

Healthcare services are provided to refugees and asylum seekers through the Office of Refugee Resettlement, which is overseen by the federal Department of Health and Human Services.⁶⁶ The Office administers

63. *Ibid* at para 273.

64. *Ibid* at paras 277-81.

65. *Ibid* at paras 287-93.

66. US migration law distinguishes “refugees” from “asylees.” Refugees are individuals who seek asylum status from outside of the United States, while asylees do so from within. We refer to both in what follows as “refugee claimants.” For a summary of the benefits available through programs administered by the Office of Refugee Resettlement, see US, Office of Refugee Settlement, “Fact Sheet: ORR BENEFITS-AT-A-GLANCE”, online: An Office of Administration for Children & Families <http://www.acf.hhs.gov/sites/default/files/orr/orr_fact_sheet_benefits_

the Refugee Medical Assistance program to claimants, regardless of their status for up to eight months. This federally-funded program provides coverage from the time a claimant enters the United States and meets the requirements to file a claim, or is granted status by either US Citizenship and Immigration Services or the Office of Refugee Resettlement.⁶⁷

Under the Refugee Medical Assistance program, refugee claimants are provided access to emergency and non-emergency care found “medically necessary.”⁶⁸ Once coverage under the program expires, those who meet immigration status requirements under the *Affordable Care Act*⁶⁹ have access to Medicaid, the Children’s Health Insurance Program,⁷⁰ and other healthcare coverage options.⁷¹ “Mandatory benefits” under the federal Medicaid program provide refugee claimants with coverage that includes “inpatient and outpatient hospital services; early, periodic, screening, diagnostic and treatment services, nursing facility services; home health services, physician services; [and] rural health services.”⁷²

The United States thus offers a higher level of basic healthcare coverage to refugee claimants than Canada does, and it also does so without distinction on the basis of country of origin. Moreover, in

at_a_glance.pdf>.

67. “Access to Care” (2011), online: Refugee Health Technical Assistance Center <<http://refugeehealthta.org/access-to-care/>>.
68. See State Letter #04-12 from Nguyen Van Hanh, PhD, Director, Office of Refugee Resettlement (18 June 2004) to State Refugee Coordinators, National Voluntary Agencies, and Other Interested Parties, filed 30 June 2008, effective 1 August 2008.
69. *The Patient Protection and Affordable Care Act*, Pub L No 111–148, 124 Stat 119 (2010), and the *Health Care and Education Reconciliation Act of 2010*, Pub L No 111–152, 124 Stat 1029 (2010), collectively are referred to as the *Affordable Care Act [ACA]*; s 1411(a)(1) of the *ACA* (eligibility for the health insurance “exchanges” and the related affordability tax credits).
70. The Children’s Health Insurance Program was reauthorized by the *Children’s Health Insurance Program Reauthorization Act of 2009*, Pub L No 111-3, 123 Stat 8 at 214.
71. Office of Refugee Settlement, “Health Insurance – Beyond the First Eight Months”, online: An Office of Administration for Children & Families <<http://www.acf.hhs.gov/programs/orr/health>>.
72. Centers for Medicare & Medicaid, “Medicaid Benefits”, online: Medicaid.gov <<http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Medicaid-Benefits.html>>.

contrast to migrants in Canada's fourth tier under the IFHP who now receive no coverage even in cases of emergency, undocumented migrants in the US not eligible for Medicaid or the Children's Health Insurance Program may still access emergency medical care under the *Emergency Medical Treatment and Active Labor Act*⁷³ until their medical condition is "stabilized."⁷⁴ "[C]omprehensive primary care"⁷⁵ services are also available to these migrants on a sliding fee through Federally Qualified Community Health Centres and Migrant Health Centres, which are not-for-profit, but federally funded organizations.⁷⁶

A further significant element in US coverage for migrants concerns the care extended to pregnant women and children regardless of immigration status. Under the *Children's Health Insurance Program Reauthorization Act*,⁷⁷ persons in this category enjoy coverage for "mandatory benefits"⁷⁸ under Medicaid but also optional benefits such as therapy, counseling, immunizations and family planning.⁷⁹

There is, therefore, no equivalent in US law to the third or fourth categories of Canada's IFHP, which limit DCO and Rejected Refugee Claimants to coverage for services necessary to "diagnose, prevent or treat a disease posing a risk to public health or to diagnose or treat a condition of public safety concern"⁸⁰ – or, in the case of migrants who have withdrawn or abandoned refugee claims or are awaiting a pre-removal risk assessment, no coverage at all.

B. United Kingdom

In the United Kingdom, healthcare coverage for refugees and asylum-

73. 42 USC § 1395dd (1986).

74. *Ibid.*

75. Michael K Gusmano, "Undocumented Immigrants in the United States: U.S. Health Policy and Access to Care" (3 October 2012), online: The Hastings Centre <<http://www.undocumentedpatients.org/issuebrief/health-policy-and-access-to-care/#refmark-16>>.

76. *Ibid.*

77. *Supra* note 70.

78. *Ibid.*

79. *Ibid.*

80. "Summary of Benefits", *supra* note 8.

seekers is administered by the National Health Service (NHS).⁸¹ The NHS Constitution specifies the “rights and responsibilities” of the NHS, along with its guiding principles. Among the key principles relevant here is one that states that “[a]ccess to NHS services is based on clinical need, not an individual’s ability to pay. NHS services are free of charge, except in limited circumstances sanctioned by Parliament.”⁸² Healthcare coverage is provided to refugees and asylum claimants awaiting determination of their claims, and includes both routine medical care through clinical or hospital visits and specialist care, along with medicine, dental, and eye care.⁸³ However, the Court of Appeal for England and Wales has held that failed claimants are deemed not to pass the ordinary residence test that triggers eligibility for healthcare coverage in the UK, nor are they to be considered exempt from charges for care when they spend more than a year in the UK.⁸⁴

In May of 2014, the government passed Bill 110, the *Immigration Act 2014*, which made a series of revisions to healthcare coverage for migrants.⁸⁵ The government claims that changes are necessary in light of challenges it has faced in recovering service charges for Secondary Medical Care services for undocumented migrants – services that are offered by medical specialists for acute healthcare conditions.⁸⁶ The bill

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81. UK, Department of Health, *The NHS Constitution: The NHS belongs to us all* (2013), online: National Health Service <<http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Pages/Overview.aspx>>.
82. *Ibid* at 3.
83. “The National Health Service, Information Leaflet”, online: National Archives <http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4122698.pdf>.
84. *R(YA) v Secretary of State for Health*, [2009] EWCA Civ 225.
85. (UK), c 22; see also Home Office, “Immigration Act 2014”, online: GOV.UK <<https://www.gov.uk/government/collections/immigration-bill>>.
86. UK, Home Office, *Controlling Immigration – Regulating Migrant Access to Health Services in the UK: Consultation document*, online: GOV.UK <https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/226744/consultation-health.pdf> [*Controlling Immigration – Regulating Migrant Access*]; see also UK, Home Office, *Immigration Bill, Factsheet: Overview of the Bill*, online: GOV.UK <https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/249251/>

also seeks to deter illegitimate claimants by limiting access to healthcare in an analogous fashion to the revised IFHP in Canada.⁸⁷ Portions of the law yet to come into force will charge undocumented migrants, denied refugee claimants, and short-term visitors (defined as those in the UK for less than six months) for healthcare services.⁸⁸ However, the NHS has indicated in its “implementation plan” that:

[T]reatment which is considered by clinicians to be **immediately necessary (which includes all maternity treatment)**, must never be withheld from chargeable patients, even if they have not paid in advance ...

Treatment which is not immediately necessary, but is nevertheless classed as **urgent** by clinicians, since it cannot wait until the overseas visitor can return home, should also be provided, even if a payment or deposit has not been secured. Providers are nonetheless strongly encouraged to obtain a deposit ahead of treatment deemed urgent if circumstances allow. However, if this proves unsuccessful, the treatment should not be delayed or withheld for the purposes of securing payment.⁸⁹

Thus, by contrast to Canada, no urgent medical care or maternity treatment is to be withheld due to coverage issues. Though, as with Canada, routine visits to doctors or hospitals, and other forms of preventive care, are soon to be withdrawn from sizable numbers of migrants.

C. Australia

As in Canada and the United Kingdom, migrants and refugee claimants in Australia are eligible for certain levels of healthcare coverage depending on their refugee status or visa category.⁹⁰ Pursuant to the *Migration*

Overview_Immigration_Bill_Factsheet.pdf>.

87. *Controlling Immigration – Regulating Migrant Access*, *ibid* at 1.

88. *Ibid*; UK, Home Office, *Immigration Bill, Factsheet: National Health Service* (clauses 33-34), online: GOV.UK <https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/249315/Factsheet_08_-_Health.pdf>.

89. UK, Department of Health, *Visitor & Migrant NHS Cost Recovery Programme: Implementation Plan 2014-2016* (Crown Copyright, 2014) at 5, online: GOV.UK <https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/329789/NHS_Implementation_Plan_Phase_3.PDF> [emphasis in the original].

90. Australian Government, Department of Immigration and Border Protection, “Medicare”, online: Department of Immigration and Border Protection <<http://www.immi.gov.au/Help/Pages/health/medicare.aspx>>

Regulations 1994,⁹¹ coverage is provided through the Humanitarian Program for Refugees, which is overseen by the Department of Immigration and Citizenship.⁹² The program has two distinct sections: offshore resettlement (providing refugee protection for those applying from overseas) and onshore protections (providing refugee protection for those applying within Australia).⁹³ After the application process, individuals who are granted a “protection visa,” “refugee visa” or “special humanitarian visa”⁹⁴ are able to access Medicare.⁹⁵ This includes primary and secondary healthcare services (*i.e.* referrals to specialists) that are also available to Australian citizens and permanent residents.⁹⁶ Early health assessments, interventions and trauma services are also accessible to these individuals.⁹⁷

Asylum claimants are eligible to apply for Medicare within six months of their arrival in Australia. Migrants without status who have been in Australia longer than six months, were denied refugee status, or entered Australia unlawfully are not entitled to Medicare, unless certain exceptions apply.⁹⁸ These include applicants who are unaccompanied

[“Medicare”].

91. (Cth).

92. *Ibid*; Department of Immigration and Border Protection, *Australia’s Humanitarian Program* (Information Paper 2014-2015), online: Department of Immigration and Border Protection <<http://www.immi.gov.au/media/publications/refugee/ref-hum-issues/pdf/humanitarian-program-information-paper-14-15.pdf>> [*Humanitarian Program*].

93. *Humanitarian Program, ibid.*

94. Australian Medical Students’ Association (AMSA), “Refugees, Asylum Seekers and Internally Displaced Persons”, online: AMSA <<http://agh.amsa.org.au/student-centre/gh-factsheets/refugees-asylum-seekers-and-internally-displaced-persons>> [“Refugees, Asylum Seekers and Internally Displaced Persons”]; “Medicare”, *supra* note 90.

95. “Refugees, Asylum Seekers and Internally Displaced Persons”, *ibid.*

96. *Migration Regulations 1994, supra* note 91.

97. *Ibid*; Ignacio Correa-Velez, Sandra M Gifford & Sara J Bice, “Australian health policy on access to medical care for refugees and asylum seekers” (2005) 2:23 *Australia and New Zealand Health Policy* 23.

98. Department of Immigration and Border Protection, *Assistance for Asylum Seekers in Australia* (Fact Sheet 62), online: Department of Immigration and Border Protection <<http://www.immi.gov.au/media/fact-sheets/62assistance.htm>>; Correa-Velez, Gifford & Bice, *ibid.*

minors, the elderly, or families with children under 18.⁹⁹ Australian law thus excludes coverage from certain classes of migrants, but offers a more generous and humane set of exceptions.

IV. Constitutional and Human Rights Concerns

In *Canadian Doctors For Refugee Care v Canada*,¹⁰⁰ Mactavish J entertained a series of arguments against the constitutional validity of the revised 2012 IFHP and its consistency with Canada's obligations under international human rights law. In what follows, we briefly describe the circumstances of the individual applicants and the grounds of their challenge. We then focus our analysis on Mactavish J's treatment of the *Charter* arguments and of international human rights law. Our primary intention here is twofold. One is to argue that while the Court declined to find a violation of section 7, the challenge on this ground was not adequately addressed – with the Court overlooking facets of this case that distinguish it from earlier invitations to find a positive duty under section 7 in the healthcare context. The second point is to highlight ways in which the Court's decision offers a novel resolution to the constitutional claims through its analysis under sections 12 and 15.

The individual Applicants in the case are two individuals, Daniel Garcia Rodriguez and Hanif Ayubi.¹⁰¹ Rodriguez is a failed refugee claimant, though his spouse – who was a successful claimant – had been in the process of sponsoring him for permanent residence at the time the application was filed. As a failed claimant, Rodriguez was placed in the third tier of IFHP care, depriving him of coverage for an urgent operation in August of 2012 to repair a detached retina.¹⁰² Prior to the July changes, the operation would have been covered. His doctor wrote the Ministry

99. Department of Immigration and Border Protection, *Bridging E Visas for Illegal Maritime Arrivals* (Fact Sheet 65), online: Department of Immigration and Border Protection <<http://www.immi.gov.au/About/Pages/media/fact-sheet-65.aspx>>.

100. *Supra* note 17.

101. Along with Rodriguez and Ayubi, the application was brought by two advocacy groups: the Canadian Association for Refugee Lawyers and Canadian Doctors for Refugee Care. See *ibid.*

102. Applicants' Memorandum, *supra* note 18 at para 20.

of Immigration seeking discretionary coverage on the basis that further delay would risk blindness, but the Ministry declined on the grounds that Rodriguez was in Canada illegally.¹⁰³ Doctors performed the surgery on August 20th to avoid further risk, recovering only a fraction of the cost.¹⁰⁴

Ayubi, the other Applicant, came to Canada from Afghanistan in 2001, made an unsuccessful claim for refugee status, but remained in Canada due to a moratorium on removals to Afghanistan. As a type 1 diabetic, he had been receiving insulin and medical care prior to 2012, but lost coverage for medicine under the revised scheme and could not afford either the necessary insulin or the blood tests to monitor his condition. He sought and was eventually granted discretionary IFHP coverage for medical services but not for medication. As the Applicants' memoranda of argument noted, "he is being kept alive on free samples of insulin obtained by a community health centre due to the charity of the drug manufacturer."¹⁰⁵ The government argued that the IFHP is entirely discretionary or *ex gratia* and not grounded in any statutory obligation, rendering the decision of whether to continue funding it – and to what degree – purely a matter of policy.¹⁰⁶ For the Applicants, the program may have begun as an *ex gratia* program, but over the passage of time, it ceased to be one by virtue of the embrace of a national publically funded healthcare system for citizens, residents, and in some cases foreigners – together with treaty obligations under international human rights law that prohibit discriminatory treatment of refugees among other non-

103. *Ibid.*

104. *Ibid.*; Respondents' Memorandum, *supra* note 8 at para 50 (the Respondents concede that Rodriguez was eligible for only "public health and public safety" coverage beginning in August of 2012, but note that he became eligible for Ontario's Health Insurance Plan in November of that year).

105. Applicants' Memorandum, *supra* note 18 at para 22 (the memorandum also indicates that Ayubi requires other medication that he is not receiving and that the insulin he does receive gratuitously does not always match his prescription).

106. Backgrounder to the *Order Respecting the Interim Federal Health Program, 2012*, *supra* note 4 (appended to the Order), cited in Applicants' Memorandum, *supra* note 18 at para 36; Respondents' Memorandum, *supra* note 8 at para 70.

citizens.¹⁰⁷ The Applicants also argued that the 2012 revisions to the IFHP were *ultra vires* because the prerogative of the federal executive in the fields of immigration and healthcare had been extinguished due to the passage of the *Canada Health Act (CHA)*¹⁰⁸ and the *Immigration and Refugee Protection Act (IRPA)*.¹⁰⁹ As the Ontario Court of Appeal held, “once a statute occupies ground formally occupied by the prerogative, the prerogative goes into abeyance. The Crown may no longer act under the prerogative, but must act under and subject to the conditions imposed by the statute.”¹¹⁰ In this case, the Applicants contended, the passage of *IRPA* and the *CHA* extinguished any remaining prerogative over refugee healthcare “expressly or by necessary implication.”¹¹¹ The government’s response to this second claim was that neither statute at issue deals *in particular* with healthcare for immigrants and refugees, and therefore Crown prerogative in this area may only be extinguished by explicit legislative directive or by necessary implication of the *words in the statute*.¹¹²

Justice Mactavish took issue with both parties’ positions. The IFHP was neither entirely *ex gratia*, nor had the prerogative been extinguished.¹¹³ Since it was created, it had given rise to obligations to pay healthcare providers who had agreed to provide coverage under the plan. And due to the lack of federal legislation addressing the question of healthcare to refugees, claimants, or failed claimants, “the Crown’s prerogative power

107. Applicants’ Memorandum, *supra* note 18 at para 36 (see the discussion below of Article 7 of the Refugee Convention of 1951, and other obligations under international law).

108. RSC, 1985, c C-6 [*CHA*].

109. *Supra* note 6; Applicants’ Memorandum, *supra* note 18 at para 38.

110. *Black v Canada (Prime Minister)* (2001), 199 DLR (4th) 228, cited in Applicants’ Memorandum, *supra* note 18 at para 44.

111. Applicants’ Memorandum, *supra* note 18 at para 45.

112. In support of this latter proposition, the Respondents cite section 17 of the *Interpretation Act*, RSC 1985, c I-21: “[n]o enactment is binding on Her Majesty or affects Her Majesty or Her Majesty’s rights or prerogatives in any manner, except as mentioned or referred to in the enactment.” They also cite *Khadr v Canada (AG)*, 2006 FC 727 (in which Phelan J surveyed Canadian and English authority on the point, concluding that Crown prerogative “can only be abolished or exhausted by clear words in a statute or by necessary implication from words in a statute” at para 91).

113. *Canadian Doctors*, *supra* note 17 at paras 394-402.

to spend in an area not addressed by statute remains intact,” rendering the 2012 orders in council *intra vires*.¹¹⁴ However, this did not relieve the government from judicial scrutiny over modifications to the program, including *Charter* conformity.¹¹⁵ Although Mactavish J dispensed with the Applicants’ section 7 claim, she found violations of sections 12 and 15 of the *Charter*, and held that they were not reasonable under section 1. We consider each section in turn.

A. Section 7

Section 7 guarantees everyone in Canada “the right to life, liberty, and security of the person and the right not to be deprived thereof except in accordance with the principals of fundamental justice.”¹¹⁶ The Applicants in *Canadian Doctors* had argued that changes to the IFHP had deprived them of rights to life and security of the person, and that they had done so in a manner that was contrary to the principles of fundamental justice for being arbitrary and grossly disproportionate to the government’s stated intentions.¹¹⁷ The rights were violated because the withdrawal of coverage had rendered affected migrants unable to pay for critical care, placing them at risk of serious illness or death, and subjecting them to “severe psychological distress.”¹¹⁸ Justice Mactavish agreed with the Respondents’ submission that the Applicants’ claim was tantamount to asserting a positive obligation on the part of the government to provide healthcare funding (or some essential social benefit) under section 7 – a claim that several courts have thus far resisted. Relying primarily on a series of decisions that include *Flora*¹¹⁹ and *Toussaint*,¹²⁰ which dismissed attempts to assert a positive right to healthcare under section 7, Mactavish J conceded that rights to life and security of the person may be engaged by the facts before the Court, but suggested that the weight of authority prevents the Court in this case from making the finding that those rights

114. *Ibid* at para 401.

115. *Ibid* at para 402.

116. *Charter*, *supra* note 14.

117. Applicants’ Memorandum, *supra* note 18 at paras 86-97.

118. *Canadian Doctors*, *supra* note 17 at para 499.

119. *Flora*, *supra* note 15.

120. *Toussaint Appeal*, *supra* note 56.

have been deprived.¹²¹

Yet Mactavish J's decision on the issue of section 7 fails to address a broader argument that the Applicants sought to advance in this case – an argument that may be best addressed at the appellate level, and perhaps at the Supreme Court of Canada in particular. The argument was that the facts in this case present a unique set of circumstances that may constitute the closest approximation to what the Supreme Court contemplated in *Gosselin v Quebec (Attorney General)*¹²² when it first articulated the possibility that section 7 may, in “special circumstances,” give rise to a positive duty on the part of the state. While Mactavish J distinguished the facts at bar from those in earlier Supreme Court decisions including *Chaoulli*¹²³ and *PHS Community*,¹²⁴ she discerned no substantive difference between the present case and a series of other cases in which litigants sought the recognition of a duty to provide an essential benefit under section 7.¹²⁵ To make clear how this case can be distinguished from the facts in those earlier decisions, and why it may meet the *Gosselin* test in ways that earlier cases have failed to, we begin by briefly revisiting the Supreme Court's considerations in *Gosselin*.

In decisions preceding *Gosselin*, without holding so explicitly, the Supreme Court had contemplated the possibility that section 7 might protect “economic rights fundamental to human life or survival.”¹²⁶ Dicta in other cases had also expressed a reluctance on the part of individual members of the court to read section 7 too restrictively; for example, in *Singh v Minister of Employment and Immigration*,¹²⁷ Justice Wilson cited a Law Reform Commission of Canada paper for the assertion that “the right to security of the person means not only protection of one's physical integrity, but the provision of necessities for its support.”¹²⁸ *Gosselin*

121. *Canadian Doctors*, *supra* note 17 at para 497.

122. *Supra* note 16.

123. *Chaoulli v Quebec (Attorney General)*, 2005 SCC 35 [*Chaoulli*].

124. *Canada (Attorney General) v PHS Community Services Society*, 2011 SCC 44 [*PHS Community* or *Insite*].

125. *Canadian Doctors*, *supra* note 17 at paras 547-58.

126. *Irwin Toy Ltd v Quebec (Attorney General)*, [1989] 1 SCR 927 at 1003.

127. [1985] 1 SCR 177.

128. *Ibid* at 207. For other examples, see the discussion in Martha Jackman, *The Implications of Section 7 of the Charter for Health Care Spending in*

involved a challenge to the constitutionality of a differential funding scheme under Quebec's social assistance legislation, giving rise to the issue of whether section 7 guaranteed a minimal level of social assistance to safeguard the right to life or security of the person by providing for basic needs. In declining to recognize this claim on the facts before the Court, McLachlin CJC, writing for the majority, explicitly affirmed the broader possibility that section 7 could form the basis for a positive state duty to protect rights to life and security of the person.

As the Chief Justice noted, much of the prior jurisprudence had suggested that section 7 was only meant to guard against a deprivation of life, liberty, or security of the person that occurs as a result of a person's "interaction with the justice system and its administration."¹²⁹ But in McLachlin CJC's view, section 7 need not be applied in such narrow terms: "[a]n adjudicative context might be sufficient" to implicate section 7, she stated, but the Court had "not yet determined that one is necessary."¹³⁰ Even if section 7 does apply to cases where the administration of justice is not implicated, it would remain to be decided whether section 7 should protect *economic* rights essential for survival. Put otherwise, the Court would have to decide whether section 7 places a positive obligation on the state to "ensure that each person enjoys life, liberty or security of the person."¹³¹

The Chief Justice affirmed that it might, asserting that "[o]ne day s. 7 may be interpreted to include positive obligations."¹³² Invoking Lord Sankey's dicta in *Edwards v Attorney-General for Canada*,¹³³ she held that "the *Canadian Charter* must be viewed as 'a living tree capable of growth and expansion within its natural limits'."¹³⁴ The Chief Justice provided a first step in this direction by setting out a framework for assessing a claim for a breach of section 7 based on a positive state obligation to provide for

Canada (Ottawa: Commission on the Future of Health Care in Canada, 2002) at 5 [Jackman, *The Implications of Section 7*].

129. *New Brunswick (Minister of Health and Community Services) v G(J)*, [1999] 3 SCR 46 at para 65, cited in *Gosselin*, *supra* note 16 at para 77.

130. *Gosselin*, *ibid* at para 78.

131. *Ibid* at para 79.

132. *Ibid* at para 82.

133. [1930] AC 124 [*Edwards*].

134. *Gosselin*, *supra* note 16 at para 82, citing *Edwards*, *ibid* at 136.

some essential benefit. An applicant must demonstrate:

(1) that the legislation affects an interest protected by the right to life, liberty and security of the person within the meaning of s. 7; (2) that providing inadequate benefits constitutes a “deprivation” by the state; and (3) that, if deprivation of a right protected by s. 7 is established, this was not in accordance with the principles of fundamental justice.¹³⁵

Despite a powerful dissent by Arbour J, who was disposed to move in this direction in *Gosselin* itself (with L'Heureux-Dube J concurring), McLachlin CJC held that the facts in that case were not sufficient to meet the test she set out, but wrote:

I leave open the possibility that a positive obligation to sustain life, liberty, or security of the person may be made out *in special circumstances*. However, this is not such a case. The impugned program contained compensatory ‘workfare’ provisions and the evidence of actual hardship is wanting. The frail platform provided by the facts of this case cannot support the weight of a positive state obligation of citizen support.¹³⁶

The majority in *Gosselin* thus affirmed the possibility that the provision of inadequate benefits could constitute a *deprivation* under section 7 – and on this basis, section 7 could compel the state to provide an essential benefit.¹³⁷ But it would require “special circumstances” and “evidence

135. *Ibid* at para 75.

136. *Ibid* at para 83 [emphasis added].

137. In her dissenting opinion, Arbour J held that “every suitable approach to *Charter* interpretation, including textual analysis, purposive analysis, and contextual analysis, mandates the conclusion that the section 7 rights of life, liberty and security of the person include a positive dimension” at para 357. She thus read section 7 to include two distinct parts: “a free-standing right to life, liberty and security of the person” (at para 386) and a right not to be deprived of those rights except in accordance with the principles of fundamental justice. She also held, however, that where the state fails to fulfill its positive obligation to provide for life, liberty, or security of the person by inaction – rather than by a law or action that “curtails” one of these rights – it is not necessary to engage in an analysis of whether the state’s inaction was contrary to fundamental justice, but only to assess whether the violation could be justified under section 1. In this case, she found that “a minimum level of welfare is so closely connected to issues relating to one’s basic health (or security of the person), and potentially even to one’s survival (or life interest), that it appears inevitable that a positive right to life, liberty and security of the person must provide for it” at para 358. The violation could not be justified under section 1.

of actual hardship” compelling enough to support the obligation. The groundwork was therefore laid for the finding of a positive state duty under section 7, but significantly, what McLachlin CJC had in mind by the phrase “special circumstances” remained unclear. *Gosselin* invited future courts to entertain constitutional challenges to deprivations of coverage for essential services, but offered no guidance as to when the test of “special circumstances” is made out.

Despite this ambiguity at the core of *Gosselin*, later courts have moved slowly in the direction of fulfilling its promise. A number of cases have held that (a) state involvement that *hinders* access to healthcare engages section 7, (b) the hindrance amounts to a deprivation, and in some cases, (c) the deprivation is contrary to the principles of fundamental justice. However, in no case after *Gosselin* has a court held that a state refusal to *fund* a benefit constituted a deprivation under section 7 in a manner that is contrary to fundamental justice.¹³⁸ Yet, the case law suggests that this may be a small step from points reached thus far. The differences between the facts in those cases and the present case are important for assessing why this case might meet the *Gosselin* test.

For three members of the Supreme Court in *Chaoulli v Quebec (Attorney General)*¹³⁹ (including McLachlin CJC), the prohibition in Quebec’s *Hospital Insurance Act*¹⁴⁰ on access to private insurance for treating life-threatening illnesses had engaged section 7. Evidence had clearly demonstrated that long wait-times in the public system for critical treatment had placed the applicant’s life or security of the person in jeopardy.¹⁴¹ Finally, the deprivation was contrary to the principles of fundamental justice for being arbitrary. On the evidence, the prohibition on private insurance was not necessary for advancing the legislation’s primary objective of maintaining the quality of the publically funded

138. One exception to this is the trial decision in *Toussaint*, *supra* note 18 (explored in more detail below), in which the exclusion of coverage from the IFHP of a non-status migrant (*i.e.* a refusal to fund her) amounted to a deprivation under section 7; but the deprivation was held to be not contrary to the principles of fundamental justice.

139. *Supra* note 123.

140. CQLR c A-28.

141. *Supra* note 123 at paras 119, 123.

healthcare system. Notably, however, *Chaoulli* involved a law that served as a *barrier* to accessing private care. The present case, by contrast, turns on the validity of a refusal to continue *providing* a benefit.¹⁴²

In some respects, the Supreme Court's decision in *PHS Community*, involving the government's decision to close a safe-injection site for heroine addicts in Vancouver, offers a closer analogy to the facts in the present case.¹⁴³ Among the issues in that case was the validity under section 7 of a ministerial exercise of discretion under the *Controlled Drugs and Substances Act*¹⁴⁴ to exempt healthcare workers and users of the site from the law's criminal prohibition on the possession of controlled substances. The Applicants had argued that the federal Minister of Health's refusal to renew an existing exemption amounted to a violation of section 7, given the likely impact of the refusal on the medical condition of the program's clientele. The evidence had established that the program clearly had much success in saving lives and avoiding further harm to a vulnerable population. The refusal had engaged clients' rights under section 7 given that without the exemption, the *CDSA*'s prohibition on possession hindered access to a form of assistance by healthcare professionals that reduced the risk of death or serious illness for those suffering from a drug addiction.¹⁴⁵ Writing for the Court, Chief Justice McLachlin invoked *Morgentaler*,¹⁴⁶ *Rodriguez*,¹⁴⁷ and *Chaoulli*¹⁴⁸ in affirming the proposition

142. The minority's approach to the constitutional protection of access to health care in primarily negative terms (a right not to be hindered from accessing care rather than a right to be provided a minimal level of care) has been the subject of extensive critical commentary. See e.g. Colleen M Flood, Kent Roach & Lorne Sossin, eds, *Access to Care: Access to Justice – The Legal Debate Over Private Health Insurance in Canada* (Toronto: University of Toronto Press, 2005); Jeff A King, "Constitutional Rights and Social Welfare: A Comment on the Canadian *Chaoulli* Health Care Decision" (2006) 69:4 Mod L Rev 631; Martha Jackman, "The Last Line of Defence for [Which?] Citizens': Accountability, Equality and the Right to Health in *Chaoulli*" (2006) 44:2 Osgoode Hall LJ 349.

143. *Supra* note 124.

144. SC 1996, c 19 [*CDSA*].

145. *Supra* note 124 at para 93.

146. *R v Morgentaler*, [1988] 1 SCR 30 [*Morgentaler*].

147. *Rodriguez v British Columbia (Attorney General)*, [1993] 3 SCR 519 [*Rodriguez*].

148. *Supra* note 123.

that “[w]here a law creates a risk to health by preventing access to health care, a deprivation of the right to security of the person is made out ... Where the law creates a risk not just to the health but also to the lives of the claimants, the deprivation is even clearer.”¹⁴⁹ The refusal to renew the exemption amounted to a deprivation, and one that was not in accordance with fundamental justice on the grounds that it was arbitrary, grossly disproportionate, and overbroad. It was arbitrary in part given the evidence that the site had saved lives and not increased crime, and the decision to refuse the exemption bore no relation to the CDSA’s objective of maintaining public health and safety.

As with the *Insite* case, the present challenge to the 2012 IFHP involves a decision to remove a benefit that results in adverse health consequences for those affected. A key difference is that in the *Insite* case, the Minister of Health decided to *exempt* the operation of a law (drug possession) rather than to *fund* a benefit (for example, the site itself). The question here is whether the refusal to fund refugee healthcare can be said to constitute a deprivation of life or security of the person on the basis that removing coverage is tantamount to depriving affected persons of access to care.

The Applicants argue that denying coverage amounts to “erecting a barrier to essential health services” since many if not most refugee claimants come to Canada in exigent circumstances, cannot afford to pay for care, and philanthropic funding may not be available consistently.¹⁵⁰ Denying coverage also entails a “deprivation” of security of the person comparable to the facts in *Chaoulli*, on the basis that at least one applicant is suffering from a potentially life-threatening illness (diabetes).¹⁵¹ On this reading, the first two stages in the *Gosselin* test would be made out.

The government, by contrast, argues that section 7 is not engaged because “it does not cause a deprivation of medical care, nor prevent or prohibit access to it.”¹⁵² Refugee claimants, failed claimants, and those ineligible for IFHP coverage can obtain care through other means

149. *PHS Community*, *supra* note 124 at para 93.

150. Applicants’ Memorandum, *supra* note 18 at para 75.

151. *Ibid.*

152. Respondents’ Memorandum, *supra* note 8 at para 101.

described above (community health centres, philanthropic programs, or emergency services at hospitals). On this view, migrants are deprived of healthcare only if clearly hindered by law or if removal of coverage has the effect of hindering access to *any* necessary care. The state has not deprived migrants of care because they still have *some* means of access. The Applicants' claim is, in the government's view, primarily economic. And, as the government contended, a wide range of authority holds that despite the possibility left open in *Gosselin*, courts have not recognized that section 7 imposes a positive obligation to provide a benefit necessary to protect life or security of the person – and have been especially reluctant to apply section 7 “when the benefit involves an economic component.”¹⁵³ Curiously, however, in *Canadian Doctors*, Mactavish J rejected the proposition that because migrants still had access to other avenues of care – community health centres, charity, emergency services – they were not *deprived* of care.¹⁵⁴ She also found that these other avenues are inadequate for a host of reasons, leaving at least some indigent migrants at risk of serious illness and in many cases “tremendous psychological strain.”¹⁵⁵ But she was reluctant to find that this deprivation of care endangering life and security of the person was therefore a possible deprivation of life and security of the person *under section 7*.

The Court in *Canadian Doctors* would have been justified in taking this further step on the basis that none of the authorities on which the government relies contemplate the guarantee of a *minimal* level of healthcare for a group analogous to refugees who come to Canada under exigent circumstances. The government's authorities for limiting section 7 to a negative duty can be distinguished into three categories of cases with each entailing a clearly different kind of claim from that in the present case. One consists of cases in which claimants have sought recognition of a social or economic right to social assistance or housing, with courts refusing to recognize a positive duty to provide a minimal level of social assistance.¹⁵⁶ A key factor here is that a minimal level of

153. *Ibid* at paras 102-03, citing *Masse, Flora, CCW, Sagarian, Wynberg, Grant*, and *Tanudjaja*, *supra* note 15; *Toussaint*, *supra* note 18.

154. *Canadian Doctors*, *supra* note 17 at paras 261-86.

155. *Ibid* at paras 285, 295-99.

156. See *e.g.* *Masse, Grant*, and *Tanudjaja*, *supra* note 15.

assistance is already available throughout Canada. In deciding not to recognize a section 7 claim in this context, courts are essentially resisting the invitation to set a *minimal* amount of assistance, given that a certain level of assistance is, for the foreseeable future, something close to a social and political certainty.

A second group contemplates coverage for prescriptions or treatment for autism and analogous conditions – matters impinging on security of the person but not life-threatening.¹⁵⁷ Finally, three cases that have the closest application (and are cited in *Canadian Doctors*) are ones in which applicants suffering life-threatening illnesses brought section 7 challenges to compel state funding.¹⁵⁸ However, the claimants in each of these cases are in distinctly different positions from those directly affected by changes to the IFHP. And the applicants in two of the cases were asking courts to recognize financial obligations on the part of the state of a different nature.

The first of these cases, *Toussaint v Attorney General of Canada*,¹⁵⁹ is significant because it involved a challenge under section 7 to the validity of the IFHP's exclusion from coverage (prior to 2012) of a foreign national who suffered a life-threatening illness. In contrast to the present case, Ms. Toussaint was a citizen of Grenada who visited Canada in 1999 and chose to outstay her visa, remaining illegally. From 1999 to 2006, she worked and could afford health care. At that point her health declined severely, preventing her from working and requiring greater care than she could afford. She received various treatments in hospital in 2007 and 2008, as her condition worsened, and she was unable to pay the bills she was incurring. In 2009, her condition, which included diabetes, a kidney disorder, and renal dysfunction, became life-threatening; yet she was able to obtain only emergency care and limited medication.¹⁶⁰ Justice Zinn

157. See *e.g. Auton* (a decision primarily concerning section 15, though a violation of section 7 was alleged and dismissed), *Wynberg*, and *Sagbarian*, *supra* note 15.

158. *Flora* and *CCW*, *supra* note 15; *Toussaint*, *supra* note 18.

159. *Ibid.*

160. *Ibid* at para 91. On the urgency of the Applicant's condition, Zinn J cited affidavit evidence of a doctor for the finding that "[i]f she were to not receive timely and appropriate health care and medications in the future, she would be at very high risk of immediate death (due to recurrent blood

found that in light of the applicant's condition, the IFHP's exclusion of coverage to non-status aliens deprived her of the right to security of the person under section 7. But his Lordship refused to accept that the deprivation was contrary to fundamental justice.

The Federal Court of Appeal affirmed the decision but upheld the holding that the Appellant's exclusion from coverage amounted to a deprivation under section 7.¹⁶¹ On the question of whether the deprivation was in accordance with fundamental justice, the Court went a step further than Zinn J by suggesting that the operative cause of the deprivation was not the IFHP's exclusion, but rather, the limitation in Ontario's health insurance plan to non-status aliens, together with the Appellant's voluntary choice to remain in Canada without legal status.¹⁶² As Stratas JA asserted, the "provision of public health coverage and the regulation of access to it is primarily the responsibility of the provinces and the territories, with the federal government playing a role in funding, the setting of standards under the *Canada Health Act* ... and, occasionally, regulation in specific areas under its criminal law power."¹⁶³ If a deprivation under section 7 occurred here, it was because the provincial plan did not extend "far enough to cover all of her medical needs."¹⁶⁴ The Court also affirmed the lower court's finding that the IFHP's exclusion was not arbitrary, citing Zinn J's dicta from the decision below that there is:

... nothing arbitrary in denying financial coverage for health care to persons who have chosen to enter and remain in Canada illegally. To grant such coverage to those persons would make Canada a health-care safe-haven for all who require health care and health care services. There is nothing fundamentally

clots and pulmonary embolism), severe medium-term complications (such as kidney failure and subsequent requirement for dialysis), and other long-term complications of poorly-controlled diabetes and hypertension (such as blindness, foot ulcers, leg amputation, heart attack, and stroke)."

161. *Toussaint* Appeal, *supra* note 56 at para 61.

162. *Ibid* at para 72. On the requirement that the claimant establish that an impugned law is the operative cause of a deprivation under section 7, the Court cited *TrueHope Nutritional Support Limited v Canada (AG)*, 2011 FCA 114 at para 11.

163. *Toussaint* Appeal, *supra* note 56 at para 72.

164. *Ibid* at para 70.

unjust in refusing to create such a situation.¹⁶⁵

In distinction to *Toussaint*, however, the present case does not involve applicants who came to Canada in a fully voluntary sense or chose to remain without status. A more complex question is whether limits in provincial and territorial coverage are also the operative cause of a deprivation on the part of refugees covered under the pre-2012 IFHP.

On one reading, they are. As in *Toussaint*, any deprivation under section 7 that claimants in this case suffer is due primarily to the failure of provincial and territorial plans to make up the shortfall in coverage – on the assumption that provinces and territories bear primary responsibility for regulating access to and coverage of health care *for refugees*. But Stratas JA may have oversimplified the question of federal jurisdiction over health care, and of jurisdiction over refugee health in particular. Under section 95 of the *Constitution Act, 1867*,¹⁶⁶ immigration is a matter of concurrent jurisdiction, with the federal government having paramount authority in the event of a conflict.¹⁶⁷ Section 91(25) provides the federal government exclusive jurisdiction over “naturalization and aliens.”¹⁶⁸ However, in *Schneider v The Queen*,¹⁶⁹ the Supreme Court held that:

‘[H]ealth’ is not a matter which is subject to specific constitutional assignment but instead is an amorphous topic which can be addressed by valid federal or provincial legislation, depending on the circumstances of each case on the nature or scope of the health problem in question.¹⁷⁰

Sections 91(11) and 92(7) of the *Constitution Act, 1867*¹⁷¹ address the operation of quarantine and hospitals, but the Constitution is otherwise silent on the subject of healthcare. Provincial responsibility for the

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165. *Ibid* at para 69; Stratas JA noted at para 71 that the “record reveals no attempt by the appellant to assert section 7 or 15 of the *Charter* against provincial legislation that limits her access to health care.”
166. (UK), 30 & 31 Vict, c 3, reprinted in RSC 1985, App II, No 5.
167. Nancy Miller Chenier, *Federal Responsibility for the Health Care of Specific Groups* (Ottawa: Parliamentary Information and Research Service, 2004) at 11.
168. *Ibid*.
169. [1982] 2 SCR 112.
170. *Ibid* at 142. See also Martha Jackman, “Constitutional Jurisdiction Over Health in Canada” (2000) 8 Health LJ 95 [Jackman, “Constitutional Jurisdiction Over Health”].
171. *Supra* note 166.

delivery of most health services is understood to derive from powers over property and civil rights in section 92(13) and matters of a merely local or private nature in section 92(16).¹⁷² The federal government's spending power over healthcare and criminal law power in matters impinging upon health are also well established.¹⁷³ A further potential source that may apply to refugee health is found at the outset of section 91, which provides Parliament the power to "make laws for the peace, order and good government of Canada, in relation to all matters not coming within the classes of subject by this Act assigned exclusively to the legislatures of the provinces."¹⁷⁴ The Supreme Court has held that the POGG power is available where a matter not addressed elsewhere in the division of powers is a matter of national concern, is "singular" or "indivisible" in nature, and is not amenable to being addressed in a more efficient manner by the provinces individually.¹⁷⁵ If refugee health care falls within the purview of the federal government, then by contrast to Stratas JA's holding in *Toussaint*, changes to the IFHP would serve as a more direct and thus operative cause of a deprivation of security of the person for the individual applicants in this case.

In the second case, *Flora v Ontario Health Insurance Plan*,¹⁷⁶ the appellant was diagnosed with liver cancer but found ineligible for a liver transplant in Ontario under a set of criteria commonly applied by doctors throughout the province, given the size and number of tumors in his liver. He then sought and obtained a transplant in England where the criteria for such a procedure were more generous. The transplant saved his life, but cost \$450,000. He applied under the Ontario Health Insurance Plan (OHIP) for reimbursement and was declined. The Health

172. Martha Butler & Marlisa Tiedemann, *The Federal Role in Health and Health Care* (Ottawa: Parliamentary Information and Research Service, 2011) at 1.

173. *Ibid* at 2-3. See also *Eldridge v British Columbia (Attorney General)*, [1997] 3 SCR 624 at para 15 [*Eldridge*]; *Reference Re Canada Assistance Plan (BC)*, [1991] 2 SCR 525 at 567; Jackman, "Constitutional Jurisdiction Over Health", *supra* note 170 at 97.

174. *Constitution Act, 1867*, *supra* note 166.

175. *R v Crown Zellerbach*, [1988] 1 SCR 401 at 431-32; Butler & Tiedemann, *supra* note 172 at 4.

176. *Supra* note 15.

Services Appeal and Review Board upheld the decision on the basis that the treatment did not meet the criteria for “insured service” under section 28.4(2) of Regulation 552 of the *Health Insurance Act*,¹⁷⁷ because the transplant was not “generally accepted in Ontario as appropriate for a person in the same medical circumstances.”¹⁷⁸ The Ontario Superior Court of Justice dismissed an appeal of this decision, and the dismissal was upheld by the Court of Appeal.¹⁷⁹

Before the latter Court, Flora had noted that an earlier version of the regulation had allowed funding for his treatment on the basis of “medical necessity” rather than what was “generally accepted” as “appropriate.” Flora argued that the amended law allowing for discretionary coverage violated section 7 because denying him coverage deprived him of access to life-saving treatment. He also argued more generally that “s. 7 imposes a positive obligation on the state to provide life-saving medical treatments, thus obviating the need for a finding of state action amounting to deprivation.”¹⁸⁰ Justice Cronk, on behalf of a unanimous Court of Appeal, held that Flora had “failed to demonstrate that the Regulation constituted a deprivation by the state of his rights to life or security of the person.”¹⁸¹

The Court arrived at this conclusion by distinguishing the facts from those in *Chaoulli*,¹⁸² *Morgentaler*,¹⁸³ and *Rodriguez*.¹⁸⁴ In each of those cases, the impugned provision placed the appellant in a situation in which his or her life or security of the person was affected or threatened: in *Morgentaler*, the mandatory therapeutic abortion committee system had this effect; in *Rodriguez*, the criminal prohibition on assisted suicide did so; and in *Chaoulli*, the prohibition on private healthcare forced people in critical condition onto waitlists.¹⁸⁵ By contrast, the regulation in *Flora* “does not prohibit or impede anyone from seeking

177. Regulation 552, *supra* note 58.

178. *Ibid*, s 28.4(2).

179. *Flora*, *supra* note 15.

180. *Ibid* at para 93.

181. *Ibid* at para 95.

182. *Supra* note 123.

183. *Supra* note 146.

184. *Supra* note 147.

185. *Flora*, *supra* note 15 at paras 98-100.

medical treatment” or limit the kind of treatment available.¹⁸⁶ It provides for coverage of some out-of-country treatments, but does not violate section 7 for its failure to cover *all* of them. On the question of a broader positive duty under section 7, Cronk JA cited McLachlin CJC’s dicta in *Gosselin*, and conceded that “s. 7 may one day be interpreted to include positive obligations in special circumstances where, at a minimum, the evidentiary record discloses actual hardship.”¹⁸⁷ But to this point, he noted, “the protection afforded by s. 7... has not been extended to cases – like this one – involving solely economic rights.”¹⁸⁸ Thus, in this case, absent evidence of “actual hardship,” or a loss of coverage that actually threatens a person’s life or security of the person, the claim was perceived to be “solely economic.” In distinction to this case, however, refugees or rejected claimants denied coverage under the IFHP do face actual hardship given the special circumstances that bring them to Canada (duress, endangerment, and persecution), their inability to pay, and a critical medical condition.

A third relevant case is *CCW v Ontario Health Insurance Plan*,¹⁸⁹ in which the three appellants had been denied coverage for out-of-country treatment due to a failure to obtain prior approval from the General Manager of the Ontario Hospital Insurance Plan. The appellants argued, *inter alia*, that the requirement of prior approval amounted to a deprivation of the right to life or security of the person under section 7. They also sought to draw an analogy between the requirement for prior approval and the prohibition on private health insurance in *Chaoulli*. Both required patients to wait for treatment in the public system, joining lengthy queues that created life-threatening conditions. At least one appellant in *CCW* risked serious injury or death if he did not leave Canada to seek treatment immediately, and could not obtain prior approval for coverage given his lack of timely access to his doctor.

Justice Swinton dispensed with the section 7 claim by citing *Flora* for the proposition that there is no deprivation under section 7 because of

186. *Ibid* at para 101.

187. *Ibid* at para 105.

188. *Ibid* at para 106.

189. *Supra* note 15.

the province's decision to limit funding in ways that do not hinder access or limit forms of treatment to which one has access. Nor does the law, at present, impose a positive obligation on the state to provide a "financial benefit that is not otherwise required by law"¹⁹⁰ – or, as Cronk JA held in *Flora*, not in the absence of evidence of "actual hardship."¹⁹¹ This case was also unlike *Morgentaler* or *Chaoulli* where the legislative regime at issue prevented a person from obtaining necessary treatment. Here, as Swinton J noted, there was "no evidence that the appellants suffered a delay in obtaining necessary medical services because of the legislation."¹⁹²

As with *Flora*, *CCW* can be distinguished from the present case by an absence of "actual hardship" that can be tied directly to the legislative provision. The denial of coverage in this case results in a financial hardship. But for the Applicants challenging the IFHP regime, the denial of coverage is a direct cause of the threat to life or security of the person. It serves as a direct cause in a way that has no direct analogy in these or any of the other cases on which the government seeks to rely. In distinction to the "minimal level of basic service" cases, the Applicants might have access to no alternate coverage – aside from emergency coverage at hospitals. This would mean that a person's right to life is not infringed under section 7, but the limitation of coverage to this level still leaves the question of whether a person is deprived of security of the person for suffering a serious or life-threatening illness and having to wait for a visit to the emergency ward to receive treatment. Moreover, unlike *Flora*, *CCW*, and other OHIP cases in which section 7 has been invoked, in the case of refugee claimants the issue is not strictly monetary. Their situation cannot be reduced to a strict inability to pay. It is an inability that flows from a position *as a refugee* or a person *in need of protection*. These may constitute the "special circumstances" contemplated in *Gosselin* by virtue of meeting the standard of "actual hardship" articulated in that case.

B. Principles of Fundamental Justice

If revisions to the IFHP result in a deprivation of life or security of the

190. *Ibid* at paras 98-100.

191. *Supra* note 15 at para 105.

192. *CCW*, *supra* note 15 at para 101.

person under section 7, the application must also meet the third part of the test in *Gosselin*: establishing that rights were deprived in a manner contrary to the principles of fundamental justice. Two principles on which the appellant seeks to rely are arbitrariness and gross disproportionality.

Writing for a minority in *Chaoulli*,¹⁹³ McLachlin CJC and Major J offered a definition of arbitrariness in the context of section 7 that has been cited approvingly by the Court in later decisions:

In order not to be arbitrary, the limit on life, liberty and security requires not only a theoretical connection between the limit and the legislative goal, but a real connection on the facts ... The question in every case is whether the measure is arbitrary in the sense of bearing no real relation to the goal and hence being manifestly unfair. The more serious the impingement on the person's liberty and security, the more clear must be the connection. Where the individual's very life may be at stake, the reasonable person would expect a clear connection, in theory and in fact, between the measure that puts life at risk and the legislative goals.¹⁹⁴

Chief Justice McLachlin defined gross-disproportionality in the *Insite* decision in terms of "state actions or legislative responses to a problem that are so extreme as to be disproportionate to any legitimate government interest."¹⁹⁵

The Applicants in the IFHP challenge contend that the 2012 changes were both arbitrary and grossly disproportionate in light of the objectives of the new plan set out in a press release issued at the time the changes were announced.¹⁹⁶ One objective was "fairness to Canadians," or to put in place a scheme that provided no greater benefits to refugee claimants than those available to most Canadians. It was assumed to be superior in the sense of providing limited dental and eye care benefits, which are not commonly included in provincial and territorial plans for citizens and residents. However, the same coverage is extended to those on social assistance in most provinces and to those eligible under Quebec's provincial plan – and this group is a more appropriate comparator to

193. *Supra* note 123.

194. *Ibid* at para 131, cited in *AC v Manitoba (Director of Child and Family Services)*, 2009 SCC 30, and *PHS Community*, *supra* note 124.

195. *Ibid* at para 133.

196. Applicants' Memorandum, *supra* note 18 at para 88.

refugees.¹⁹⁷ And thus, if it is not correct to assume that the earlier IFHP offered *superior* coverage to what is available to other Canadians, the Applicants argue that it is arbitrary to deprive persons of a right to life or security of the person on this ground. They also argue that denying coverage is arbitrary because the new plan does not equalize coverage in the name of fairness but removes it altogether (for certain classes of non-citizen).¹⁹⁸ These arguments are consistent with Mactavish J's analysis of the government's objectives under section 1 (explored further below), in which she dismissed the notion that the pre-2012 IFHP entailed an unfairness in coverage between migrants and working Canadians.¹⁹⁹

A second objective of the revised IFHP was to remove an incentive for foreigners who may come to Canada in bad faith or who intend to remain in Canada after a failed refugee claim. Yet, as the Applicants note, the government has offered no support for the proposition that withdrawing coverage from certain groups would deter fraudulent claims.²⁰⁰ In her section 1 analysis, Mactavish J agreed with this, asserting that the "deterrence argument is founded to a large extent on a subjective perception held by unidentified individuals."²⁰¹ It is also grossly disproportionate in the sense that by changing the plan and withholding health care coverage from one refugee claimant so as to deter another amounts to "a particularly egregious instance of treating a human being instrumentally as merely a means to an end."²⁰²

A further objective was cost savings, but the Applicants argue that the cost implications of the program render the changes to the IFHP both arbitrary and grossly disproportionate in relation to this stated goal. The Applicants tendered affidavit evidence from various stakeholders in support of the claim that "hospitals, clinics and even health practitioners have largely been forced to absorb the cost of treating refugees where the patients could not pay or fundraising came up short."²⁰³ The

197. *Ibid* at para 159.

198. *Ibid* at para 91.

199. *Canadian Doctors, supra* note 17 at paras 946-47.

200. Applicants' Memorandum, *supra* note 18 at para 92.

201. *Canadian Doctors, supra* note 17 at para 1019.

202. Applicants' Memorandum, *supra* note 18 at para 93.

203. *Ibid* at para 95.

changes affect cost transfers, but not cost savings. They are also grossly disproportionate in the sense that government estimates indicate that the per capita cost of the IFHP was \$552 or roughly 10 percent of the per capita cost for health care for Canadians, or 60 cents per taxpayer per year.²⁰⁴ As the Applicants contend, “the IFHP spent little on each recipient, but delivered crucial, life sustaining benefits.”²⁰⁵ Assessing this issue under the minimal impairment component of section 1, Mactavish J had found that there was “no reliable evidence” before the Court “of the extent to which the 2012 changes to the IFHP will, on their own, result in cost savings at the federal level.”²⁰⁶

A final objective was that the changes were meant to “safeguard public health and safety.”²⁰⁷ But given the reduced scope of health coverage for many groups that may carry a wide range of illnesses, including mental illnesses, this goal would seem to be undermined by the changes rather than supported. Moreover, operational changes to the administration of the IFHP may lead to delays in providing eligibility certificates to new arrivals who may have communicable diseases, thus reducing public safety.²⁰⁸ In her treatment of this issue under section 1, Mactavish J concurred: deterring DCO migrants from seeking or obtaining healthcare, she found, “potentially jeopardize[s] public health.”²⁰⁹

The Applicants also argue that the possibility of discretionary relief under the plan – a possibility preserved in the 2012 IFHP – does not rectify the deprivation of rights explored earlier. First, the discretion to raise a person's status from the third or fourth to the second tier would still leave him or her without coverage for essential medication for any condition that is non-communicable.²¹⁰ More to the point, discretion is practically moot given that in many cases, care is needed urgently and discretionary coverage is time consuming and involves a bureaucratic

204. *Ibid.*

205. *Ibid.*

206. *Canadian Doctors*, *supra* note 17 at para 1012.

207. Backgrounder to the *Order Respecting the Interim Federal Health Program, 2012*, *supra* note 106.

208. Applicants' Memorandum, *supra* note 18 at para 97.

209. *Canadian Doctors*, *supra* note 17 at para 954.

210. Applicants' Memorandum, *supra* note 18 at para 99.

process that is “opaque, unpublicized, [and] paper-driven.”²¹¹

In summary, we have argued in this part of the paper that the facts in the current challenge to the revised IFHP render this case better suited than any earlier jurisprudence to the *Gosselin* test for a positive state duty under the *Charter*. But we note that the *Gosselin* test runs counter to a considerable body of *Charter* case law – both before and since *Gosselin* – reflecting a deep resistance to a positive interpretation of rights. As Martha Jackman writes:

Since the inception of the *Charter*, judges in Canada have, with rare exceptions, adopted a deferential, negative rights based approach to socio-economic rights, including the right to health care. In clear contradiction of Canada’s obligations under the *International Covenant on Economic, Social and Cultural Rights* and other international human rights treaties, they have frequently held that governments have no affirmative duty to ensure that individuals, particularly those who are members of socially or economically disadvantaged groups, do in fact have the means to enjoy *Charter* rights to life, liberty, security of the person and equality.²¹²

This tendency may well extend to the final disposition in the present case. We anticipate that at the Federal Court of Appeal, there will be a strong impetus to apply the law on section 7 as presently configured, limiting its application to instances where access to health care is hindered (rather than where coverage is not provided). In one sense, this would be a simple function of *stare decisis*.²¹³ But it would also reflect a lack

211. *Ibid.* As the Applicants note, as of September 2013, no information had been published about how to apply for discretionary coverage, what criteria would be used to assess the application, and no reasons were required for a decision. The Applicants draw an apt comparison here between discretionary coverage under the IFHP and the hospital committee process for approving access to abortions under the *Criminal Code* regime challenged in *Morgentaler*, *supra* note 146. The Supreme Court in that case held, at 72, that the scheme was “manifestly unfair” in relation to the stated objective of the legislation (providing a “procedural structure for bringing into operation a particular defence to criminal liability”).

212. Martha Jackman, “Charter Review As a Health Care Accountability Mechanism in Canada” (2010) 18 Health LJ at 27.

213. In *Tanudjaja v Attorney General (Canada) (Application)*, *supra* note 15, the Ontario Superior Court summarily dismissed a claim under section 7 of a positive state duty for housing benefits primarily on the basis of the weight of authority against such an application of the *Charter*.

of clarity as to how lower courts should apply the test contemplated in *Gosselin*. In the absence of greater clarity as to when a case meets the test of “special circumstances” that merit a finding of a positive state duty under section 7, as McLachlin CJC had contemplated, the question may need to return to the Supreme Court of Canada for further clarification.

C. Section 12

Section 12 of the *Charter* states that “everyone has the right not to be subjected to any cruel and unusual treatment or punishment.”²¹⁴ The Applicants in *Canadian Doctors* argued that the changes to the IFHP resulted in a denial of “life sustaining health care” that constituted a form of “cruel and unusual treatment” under section 12. The government submitted that while the IFHP may provide for healthcare “treatment,” migrants were not “subjected” to the program and section 12 is concerned only with “mandatory matters imposed by the state.”²¹⁵ The government also argued that the IFHP “does not prevent anyone from obtaining medical care: rather it offers and funds some health services for eligible beneficiaries, who can access them if they choose, at state expense.”²¹⁶

Justice Mactavish began by noting that most section 12 jurisprudence concerned punishment rather than treatment, with limited authority as to the scope of “treatment” for the purposes of that section.²¹⁷ But as Mactavish J noted, the Supreme Court in *Rodriguez*²¹⁸ affirmed the possibility that “treatment” could include “that imposed by the state in contexts other than that of a penal or quasi-penal nature.”²¹⁹ In considering the meaning of “treatment” under section 12 in a challenge to section 241(b) of the *Criminal Code*, which prohibits “assisted suicide,”²²⁰ Sopinka J, for the majority in *Rodriguez*, held:

There must be some more active state process in operation, involving an exercise of state control over the individual, in order for the state action in

214. *Supra* note 14.

215. *Canadian Doctors*, *supra* note 17 at para 574.

216. *Ibid.*

217. *Ibid* at para 578.

218. *Supra* note 147.

219. *Ibid* at para 182.

220. *Ibid.*

question, whether it be positive action, inaction or prohibition, to constitute “treatment” under s. 12.²²¹

Drawing on this interpretation, Mactavish J held that while refugee claimants are in a distinct situation from that of Ms. Rodriguez, in seeking Canada’s protection, claimants are “effectively under the administrative control of the state.”²²² Their “rights and opportunities” can be “limited in a number of different ways” including their entitlement to benefits and their claims for protection.²²³ A further relevant distinction here was the fact that whereas Ms. Rodriguez had been subject to a law of general application, the decision to amend the IFHP “intentionally targeted an admittedly vulnerable, poor and disadvantaged group for adverse treatment ... for the express purpose of inflicting predictable and preventable physical and psychological suffering.”²²⁴ The government’s actions in both respects brought the IFHP changes within the scope of the word “treatment” for the purposes of section 12.

In *R v Smith*,²²⁵ the Supreme Court held that treatment or punishment will be found to be “cruel and unusual” under section 12 if it is “so excessive as to outrage [our] standards of decency.”²²⁶ Among the factors to be considered are whether treatment exceeds what is necessary to achieve a legitimate purpose, whether there are adequate alternatives, whether it accords with public standards, whether it shocks the general conscience, and whether it is “unusually severe and hence degrading to human dignity and worth.”²²⁷

When applying the factors to this case, Mactavish J found that the amendments to the IFHP have not “achieved a legitimate aim.”²²⁸

221. *Ibid.*

222. *Canadian Doctors*, *supra* note 17 at para 585.

223. *Ibid.* Justice Mactavish noted that recognizing “treatment” as the government decisions to withhold social benefits from migrants was consistent with foreign jurisprudence, including *R v Secretary of State for the Home Department, ex parte Adam*; *R v Secretary of State for the Home Department ex parte Limbuela*; *R v Secretary of State for the Home Department ex parte Tesema (Conjoined Appeals)* [2005] UKHL 66.

224. *Canadian Doctors*, *supra* note 17 at para 587.

225. [1987] 1 SCR 1045.

226. *Ibid* at para 83.

227. *Ibid* at para 44.

228. *Canadian Doctors*, *supra* note 17 at para 617.

There was not enough evidence to prove that the changes have deterred illegitimate claims or reduced the costs of the program.²²⁹ They are also “arbitrary,”²³⁰ “have limited social value,”²³¹ are highly criticized by key stakeholders including provincial governments, medical associations and non-governmental organizations,²³² and therefore do not “accord with public standards of decency and propriety.”²³³ Significantly, Mactavish J found that there was “substantial evidence ... not just of philosophical differences with a government policy choice, but of real outrage on the part of informed, affected individuals and groups at what has been done through the 2012 changes to the IFHP.”²³⁴ The effects were “especially evident insofar as they affect children.”²³⁵ Citing numerous examples given in evidence of cases in which children suffering from serious conditions including pneumonia, asthma, and suicidal depression were denied care, she held that the amendments to the IFHP “potentially jeopardize the health, and indeed the very lives, of these innocent and vulnerable children in a manner that shocks the conscience and outrages our standards of decency.”²³⁶

Finding a violation of section 12 on the basis of administrative control amounting to cruel treatment, Mactavish J offered a novel basis on which to capture the violation of dignity and humanity in this case. Notably, it did so in a manner that avoided the thornier debate about whether the *Charter* imposes a positive duty on the part of the state to provide a social benefit. And given the extensive factual findings supporting her application of the test in *Smith*, the holding on section 12 – at least with respect to the issue of cruelty – would appear to be on firm evidentiary ground.

229. *Ibid.*

230. *Ibid* at para 618.

231. *Ibid* at para 620.

232. *Ibid* at para 624.

233. *Ibid* at para 635.

234. *Ibid.*

235. *Ibid* at para 637.

236. *Ibid* at para 691.

D. Section 15

Section 15(1) of the *Charter* states that “[e]very individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age, mental or physical disability.”²³⁷ Section 15(2) qualifies this by stating: “[s]ubsection (1) does not preclude any law, program or activity that has as its object the amelioration of conditions of disadvantaged individuals or groups including those that are disadvantaged because of race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.”²³⁸

The Applicants in this case argued that the changes to the IFHP have created a “health care hierarchy.”²³⁹ Contrary to section 15, the 2012 IFHP discriminates on the basis of (a) national or ethnic origin and (b) immigration status.²⁴⁰ It does so on the basis of national or ethnic origin by providing a lower level of health care insurance to refugee claimants from DCO countries versus those from non-DCO countries.²⁴¹ And it does so on the basis of immigration status by offering certain migrants lesser coverage than those of immigrants or Canadians. For example, both individual Applicants, Ayubi and Rodriques, were denied similar coverage afforded to other migrants and Canadians, despite having obtained legal status.²⁴²

In response, the government argued that any discriminatory effect of the cuts was based not on the IFHP but on distinctions among categories of migrants in the *Immigration and Refugee Protection Act*, including those from Designated Countries of Origin.²⁴³ The government also pointed to earlier jurisprudence in which courts have rejected the argument that “immigration status” is an analogous ground under section 15 of the

237. *Supra* note 14.

238. *Ibid.*, s 15(2).

239. *Canadian Doctors*, *supra* note 17 at para 694; Applicants’ Memorandum, *supra* note 18 at para 64.

240. *Canadian Doctors*, *supra* note 17 at para 696.

241. *Ibid.*

242. *Ibid.*

243. *Ibid.* at para 699.

Charter.²⁴⁴ Moreover, the government submitted, the “right to state-funded health care”²⁴⁵ is not accessible to all Canadians equally.²⁴⁶

In *R v Kapp*²⁴⁷ the Supreme Court held that the purpose of subsection 15(1) of the *Charter* is:

[P]reventing governments from making distinctions based on the enumerated or analogous grounds that: have the effect of perpetuating group disadvantage and prejudice; or impose disadvantage on the basis of stereotyping.²⁴⁸

In *Quebec (AG) v A*,²⁴⁹ the Supreme Court set out a two-part test for establishing a section 15 violation. Challengers must show that

- i. the law creates a distinction based on an enumerated or analogous ground, and
- ii. the distinction creates a disadvantage by perpetuating prejudice or stereotyping.²⁵⁰

The analysis underlying the test considers whether the state action has a “discriminatory impact”²⁵¹ and whether “the state conduct widens the gap between the historically disadvantaged group and the rest of society, rather than narrowing it.”²⁵²

Justice Mactavish dismissed the claim that the revised IFHP discriminated on the basis of immigration status, but held that it did violate section 15(1) on the basis of national origin.²⁵³ The IFHP drew a distinction between refugee claimants from DCO countries and those from other countries, limiting the former to “Public Health or Public Safety (PHPS) benefits.”²⁵⁴ Her analysis relied in part on *Eldridge v British Columbia (Attorney General)*,²⁵⁵ in which the Supreme Court held that the state does not have to provide any particular social benefit; but if a

244. *Ibid* at para 702.

245. *Ibid* at para 703.

246. *Ibid*.

247. 2008 SCC 41 [emphasis removed].

248. *Ibid* at para 25.

249. 2013 SCC 5.

250. *Ibid* at para 162.

251. *Ibid* at para 332.

252. *Ibid*.

253. *Canadian Doctors*, *supra* note 17 at para 696.

254. *Ibid* at para 735.

255. *Supra* note 173.

government chooses to provide a benefit, “it is obliged to do so in a non-discriminatory manner.”²⁵⁶ The Court in *Eldridge* further reasoned that “in many circumstances, this will require governments to take positive action, for example by extending the scope of a benefit to a previously excluded class of persons.”²⁵⁷

Justice Mactavish also dismissed the government’s argument that the “IFHP is an ameliorative program directed at improving the situation of groups that are in need of assistance in order to enhance substantive equality.”²⁵⁸ The government had contended that the purpose of the distinctions drawn by the 2012 IFHP were in part to assist refugee claimants by allocating more funding to migrants whose claims have longer processing times and therefore stay in Canada for longer periods.²⁵⁹ The government relied on this approach to section 15(2) in *Alberta (Aboriginal Affairs and Northern Development) v Cunningham*,²⁶⁰ in which the Supreme Court held that “[a]meliorative programs, by their nature, confer benefits on one group that are not conferred on others.”²⁶¹ There will not be a violation of subsection 1(2) “if they serve or advance the object of the program, thus promoting substantive equality.”²⁶² But Mactavish J rejected the claim that increasing processing times for some migrants would advance the goal of substantive equality – since shorter processing times for refugee claimants from DCO countries will entail inequalities in health coverage and other discriminatory effects.²⁶³ As Mactavish J noted, “[i]t does not follow that a refugee claimant from Mexico (a DCO country) who arrives in Canada about to give birth necessarily requires less health care than does a pregnant refugee claimant who has to come to Canada from Sri Lanka (a non-DCO country).”²⁶⁴

By drawing a distinction between the level of health care insurance coverage provided to DCO countries versus non-DCO countries,

256. *Ibid* at para 73.

257. *Ibid*.

258. *Canadian Doctors*, *supra* note 17 at para 779.

259. *Ibid* at para 780.

260. 2011 SCC 37.

261. *Ibid* at para 53.

262. *Ibid*.

263. *Canadian Doctors*, *supra* note 17 at para 796.

264. *Ibid* at para 804.

the 2012 IFHP was also found to perpetuate a prejudice in the form of depriving coverage from seriously ill claimants,²⁶⁵ and it was found that the discrimination against DCO claimants “perpetuates negative attitudes about them.”²⁶⁶ The denial of health insurance coverage continues to enhance the marginalization faced by refugee claimants from DCO countries such as the Roma from Hungary and the LGBTQ communities in Mexico.²⁶⁷

E. Section 1

In light of the finding that changes to the IFHP violate sections 12 and 15 of the *Charter*, the Court in *Canadian Doctors* had to assess whether the violation constitutes a reasonable limit on the rights in accordance with section 1 of the *Charter*. To meet this test, the government had the onus of establishing, first, that the impugned measure has a pressing and substantial objective, and second, that it meets a general proportionality test.²⁶⁸ At this second stage, the court must assess whether the objective bears a rational connection to the chosen measure, whether the measure minimally impairs the violated rights, and whether the deleterious effects of the program are proportionate to its salutary objectives, thus justifying the limit on the rights in question.²⁶⁹ If appellate courts uphold the findings that *Charter* rights have been violated in this case, Mactavish J's factual findings supporting her analysis under section 1 will be relevant on appeal.

Justice Mactavish identified the objectives of the revised 2012 IFHP by citing a press release accompanying the announcement of the changes in April of 2012.²⁷⁰ These included “cost containment,” “fairness to Canadian taxpayers,” “the protection of public health and safety,” and the need to defend the “integrity of Canada's immigration system.”²⁷¹ Citing the Supreme Court's decision in *Newfoundland (Treasury Board)*

265. *Ibid* at para 813.

266. *Ibid* at para 830.

267. *Ibid* at para 837.

268. *R v Oakes*, [1986] 1 SCR 103 at 138-39.

269. *Ibid* at 139.

270. *Canadian Doctors*, *supra* note 17 at para 892.

271. *Ibid*.

v NAPE,²⁷² Mactavish J noted that while cost alone would not ordinarily constitute a pressing and substantive objective, it may when “wrapped up with other public policy considerations,”²⁷³ as was the case here. She found that “fairness to Canadians” might also have constituted a pressing and substantial objective, but found that a lack of fairness to Canadians with respect to the pre-2012 IFHP had not been established.²⁷⁴ It was implausible, in her view, to suggest that the earlier framework was unfair to working Canadians because migrants under that framework had received benefits such as eye and dental care that were only available to Canadians on social assistance. Given their indigent status and precarious position as refugees or migrants, and their willingness to abide by immigration and refugee laws, the provision of benefits to these individuals was not unfair.²⁷⁵ Protecting public health and safety was found to be a pressing and substantial objective, and in light of evidence of abuse of the refugee system, so too was the goal of protecting the integrity of Canada’s immigration system.²⁷⁶

Moving to the rational connection test, Mactavish J agreed there was a reasonable connection between the withdrawal of coverage to certain classes of migrants under the new framework and the goal of reducing costs to the program.²⁷⁷ But given her earlier finding of a lack of unfairness to Canadians in the earlier coverage under the program, she found no rational connection between the removal of coverage and the goal of addressing the alleged unfairness. As she put it, Canadians are “not treated any more fairly because refugee claimants from DCO countries, and failed refugee claimants who are still in compliance with Canadian immigration and refugee laws, are now denied any health insurance coverage whatsoever.”²⁷⁸ She also found that although aspects of the new scheme bore a rational connection to the goal of protecting public health and safety, removing all coverage from persons in the

272. 2004 SCC 66.

273. *Canadian Doctors*, *supra* note 17 at para 909, citing *ibid* at para 69.

274. *Ibid* at para 912.

275. *Ibid* at paras 913-21.

276. *Ibid* at paras 929-32.

277. *Ibid* at para 945.

278. *Ibid* at para 949.

fourth tier – including coverage for conditions that pose a risk to public health and safety – removed any rational connection to the stated goal with respect to this aspect of the plan.²⁷⁹ Finally, Mactavish J refused to recognize a rational connection between the new plan and the goal of protecting the integrity of the immigration system by virtue of the lack of evidence that changes to coverage remove a material incentive to illegitimate claimants or that the changes will encourage the quicker departure of failed claimants.²⁸⁰

Given her finding that the objectives of fairness to Canadians and protecting public health and safety were not substantial and not rationally connected to the IFHP in at least one case, Mactavish J found that the revised plan also failed the minimal impairment test in those respects.²⁸¹ However, she also found that it failed the minimal impairment test in seeking to advance the goals of cost containment and protecting the integrity of the immigration system. Although she accepted the government's evidence that changes to the plan would result in the "substantial" savings of \$70 million in the first three years of the new program and \$15 million each year after that, it was not clear that "the anticipated reduction in program spending is entirely, or even primarily, attributable to the 2012 changes to the IFHP."²⁸² In light of the fact that other recent legislation including the *Balanced Refugee Reform Act*,²⁸³ the *Protecting Canada's Immigration System Act*,²⁸⁴ and the *Faster Removal of Foreign Criminals Act*,²⁸⁵ have helped speed up the refugee determination process and deterred abuse of the system, the government had failed to prove what cost savings were due to the IFHP changes in particular. She concluded on this point that there was "no reliable evidence before this Court of the extent to which the 2012 changes to the IFHP will, on their own, result in cost savings at the federal level."²⁸⁶ But even if there were

279. *Ibid* at para 962.

280. *Ibid* at paras 964-70.

281. *Ibid* at para 994.

282. *Ibid* at para 999.

283. SC 2010, c 8.

284. SC 2012, c 17.

285. SC 2013, c 16.

286. *Canadian Doctors*, *supra* note 17 at para 1012.

such evidence, it would be necessary to establish that those savings could not have been obtained in a less infringing manner.²⁸⁷ The Applicants, however, were able to point to at least two less infringing measures that helped save costs in a “real and substantial manner” – the recent return to a full complement of adjudicators at the Immigration and Refugee Board, and carrying out speedier removals once claims are rejected, both resulting in shorter eligibility periods under the IFHP.²⁸⁸ Finally, given her finding that the government had failed to establish that the 2012 changes had removed an incentive for persons from Designated Countries of Origin to make illegitimate claims, and that this very assumption was based on subjective “perceptions” and “beliefs,” Mactavish J held that the government had not met the burden of proving that there were no less infringing ways of protecting the integrity of the immigration system.²⁸⁹

Justice Mactavish then considered whether the 2012 changes to the IFHP were proportionate in their deleterious effects to the program’s salutary goals, and whether attaining these goals outweighed the breach of the rights at issue.²⁹⁰ She made the significant findings that the revised IFHP was “causing significant suffering to an already vulnerable, poor and disadvantaged population,” and that the changes are “causing illness, disability, and death.”²⁹¹ The effects are both serious in terms of their quality and quantity, being felt “by a significant number of individuals, given the thousands of people who come to the country each year, seeking its protection.”²⁹² The salutary objectives of the IFHP do not outweigh its deleterious effects for various reasons.²⁹³ Removing coverage from those seeking a PRRA and who might pose a risk to public health or safety did nothing to advance the goal of protecting public health. Given that the earlier plan was not unfair to Canadians, the objective of being fairer to Canadians could not be said to outweigh the deleterious effects of the new plan. With no clear indication of how much money the program is

287. *Ibid* at para 1013.

288. *Ibid* at paras 1014-15.

289. *Ibid* at paras 1018-27.

290. *Ibid* at para 1044.

291. *Ibid* at paras 1048-49.

292. *Ibid* at para 1050.

293. *Ibid* at paras 1052-74.

saving the federal government – and the fact that there is still a “real cost to Canadian taxpayers to providing [various] alternative forms of health care” to which migrants are forced to turn, it is also not possible to say that cost of benefits outweigh the deleterious effects.²⁹⁴ Finally, lacking evidence that health coverage was a source of abuse of the system on the part of claimants from Designated Countries of Origin, it was not clear that the integrity objective outweighed the suffering of migrants deprived of benefits. The revised IFHP had failed to be justified under section 1 and was therefore not a reasonable limit on sections 12 and 15 in this case.²⁹⁵

F. International Humanitarian Law and Norms

The current challenge to the constitutional validity of the 2012 changes to the IFHP also involves a consideration of Canada's commitments under international human rights law. As Martha Jackman has noted, although Canada has ratified various treaties containing health-related protections, these have not been explicitly recognized in Canadian law and do not offer a basis for granting remedies for rights violations.²⁹⁶ Yet, as Jackman also notes, the Supreme Court has affirmed in *Baker*,²⁹⁷ *Canadian Foundation*,²⁹⁸ and *Hape*²⁹⁹ that international human rights law may serve as a guide for interpreting *Charter* rights as well as domestic law and policy, giving rise to a preference for applications of the law that are consistent with the values and principles in treaties and covenants at issue.³⁰⁰ The parties in this case debate the scope and proper

294. *Ibid* at para 1061.

295. *Ibid* at para 1087 (Justice Mactavish declared the 2012 IFHP orders in council invalid pursuant to s 52 of *The Constitution Act, 1982*, Schedule B to the *Canada Act 1982* (UK), 1982, c 11, but since those OICs had repealed the pre-2012 IFHP, she suspended the operation of the declaration for 4 months. The Attorney General has filed a Notice of Appeal).

296. Jackman, “The Implications of Section 7”, *supra* note 128 at 12.

297. *Baker v Canada (Minister of Immigration)*, [1999] 2 SCR 817 [*Baker*].

298. *Canadian Foundation for Children, Youth and the Law v Canada (Attorney General)*, [2004] 1 SCR 76 [*Canadian Foundation*].

299. *R v Hape*, 2007 SCC 26.

300. *Baker*, *supra* note 297 at para 70; *Canadian Foundation*, *supra* note 298 at para 31; *Hape*, *ibid* at paras 53, 56, 68.

application of treaty rights to refugee health coverage in Canada, a debate that was not resolved in Mactavish J’s treatment of international law in *Canadian Doctors*.³⁰¹ Justice Mactavish conceded that relevant portions of international law cited by the Applicants have not been incorporated into Canadian law and lacked the force of law, but she acknowledged the role of international law as an interpretative aid to *Charter* rights and drew on that law for this purpose.³⁰² What follows is a brief overview of provisions that Mactavish J considered and additional relevant provisions of international law.

The Applicants highlighted two sources of conflict between the new IFHP and the provisions of the 1951 Vienna Convention – a primary source for international refugee law.³⁰³ Article 3 of the Convention requires that contracting states “apply the provisions of this Convention to refugees without discrimination as to race, religion or country of origin.”³⁰⁴ This would appear to prohibit the IFHP’s differential coverage of claimants from DCO countries as a form of discrimination based on country of origin.³⁰⁵ Similarly, Article 7 states that “[e]xcept where this Convention contains more favourable provisions, a Contracting State shall accord refugees the same treatment as is accorded to aliens generally.”³⁰⁶ Prior to the changes in 2012, refugees received comparable coverage to that available to other immigrants, permanent resident holders, and temporary residents, including students or foreign workers. The changes to the IFHP now set apart certain refugees from other immigrants in terms of health coverage.³⁰⁷

The Applicants also invoked the 1990 *Convention on the Rights of the Child*,³⁰⁸ which Canada ratified in 1992. Article 6(2) calls upon signatory states to “ensure to the maximum extent possible the survival and

301. *Supra* note 17 at paras 441-75.

302. *Ibid* at para 474.

303. UN General Assembly, *Convention Relating to the Status of Refugees*, 28 July 1951, 189 UNTS 137.

304. *Ibid*.

305. Applicants’ Memorandum, *supra* note 18 at para 142.

306. *Supra* note 303.

307. Applicants’ Memorandum, *supra* note 18 at para 149.

308. 20 November 1989, 1577 UNTS 3, 28 ILM 1456, (entered into force 2 September 1990).

development of the child.”³⁰⁹ Article 2(1) calls upon parties to “respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child’s or his or her parent’s or legal guardian’s race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status.”³¹⁰ And finally, Article 3(1) of the Convention states that “[i]n all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.”³¹¹

Justice Mactavish also noted the European Union’s *Reception Directive* of 2013, which details standards in that jurisdiction for the “reception of applicants for international protection.”³¹² Article 19 of the Directive requires Member States to “ensure that applicants receive the necessary health care which shall include, at least, emergency care and essential treatment of illnesses and of serious mental disorders.”³¹³ Article 21, dealing with “vulnerable persons” more generally, mandates that states must

take into account the specific situation of vulnerable persons such as minors, unaccompanied minors, disabled people, elderly people, pregnant women, single parents with minor children, victims of human trafficking, persons with serious illnesses, persons with mental disorders and persons who have been subjected to torture, rape or other serious forms of psychological, physical or sexual violence ...³¹⁴

While this latter provision contemplates a softer form of protection, both articles set out standards that clearly prohibit the discriminatory treatment contemplated in the 2012 IFHP regime.

Martha Jackman has highlighted two further international human rights instruments that support a rights-based approach to improving

309. *Ibid.*

310. *Ibid.*

311. *Ibid.*

312. EC, *Directive 2013/33/EU of the European Parliament and of the Council of 26 June 2013 laying down standards for the reception of applicants for internal protection (recast)*, [2013] OJ, L180/96.

313. *Ibid.*

314. *Ibid.*

healthcare access.³¹⁵ Article 25(1) of the *Universal Declaration of Human Rights* of 1948 states that “everyone has the right to a standard of living adequate for the health and well-being of himself and his family, including ... medical care.”³¹⁶ Ratified by Canada in 1978, the 1966 *International Covenant on Economic, Social and Cultural Rights* relates implicitly to health care coverage in two of its articles.³¹⁷ Article 12(1) sets out “the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.”³¹⁸ Article 12(2)(d) calls upon signatories to the Covenant to take necessary measures to “assure to all medical service and medical attention in the event of sickness.”³¹⁹

V. Conclusion

Changes in 2012 to health care coverage for refugees and other migrants have marked a significant departure from earlier levels of coverage, with profound practical consequences for migrants dealing with a wide range of critical conditions. The changes to coverage have also, for the most part, set Canada apart from the approach taken in the United States, the United Kingdom, and Australia, and raise questions in relation to Canada’s obligations under international human rights law. In *Canadian Doctors*, the Federal Court held that the revised plan violates sections 12 and 15 of the *Charter* and the violations cannot be justified under section 1. However, the Court declined to find a violation of section 7 on the basis of a reluctance to recognize a positive duty on the part of the state to provide healthcare benefits under the *Charter*. An appeal of this decision is pending, giving rise to the possibility of revisiting the issue of a positive duty under section 7. This article has argued that while earlier courts have been consistently reluctant to recognize such a duty, the facts

315. Jackman, “The Implications of Section 7”, *supra* note 296 at 12-13; see also Jackman, “Constitutional Jurisdiction Over Health”, *supra* note 170 at 110.

316. GA Res 217 (iii), UNGAOR, 3rd Sess, Supp No 13, UN Doc A/810, (1948) 71.

317. 16 December 1966, 993 UNTS 3, 6ILM 368 (entered into force 3 January 1976).

318. *Ibid.*

319. *Ibid.*

in the present case offer a compelling and unique basis for doing so. Whatever the outcome of this case, however, the current challenge to the constitutionality of the IFHP represents a kind of limit case – combining some of the most vulnerable claimants in some of the most desperate situations – thus promising to lend greater clarity as to the possible scope of the *Charter* as a tool for protecting fundamental socio-economic and human rights.

Book Review

A Cruel Arithmetic: Inside the Case Against Polygamy, Craig Jones

Introduction

In August 2014, two of Canada's most notorious polygamists, Winston Blackmore and James Oler, were charged with practicing polygamy under the *Criminal Code*. Blackmore and Oler were two of the leaders of the Mormon Fundamentalist community in Bountiful, BC.

For many Canadians, the arrest of these two men raises the question: why now? The polygamy prohibition under section 293 of the *Code* was originally enacted in 1890, and complaints about the Bountiful sect go back to its founding in the 1940s. But, in the decades since, through the coming and going of governments and political parties, Canada's response to polygamy has been paralyzed by concerns over the constitutionality of the criminal prohibition in light of the *Charter* protection of religious liberty. This issue was finally addressed in the 2011 landmark BC Supreme Court decision of Chief Justice Robert J. Bauman in what is now commonly referred to as the Polygamy Reference. Arising out of this historic Reference is Craig Jones' *A Cruel Arithmetic: Inside the Case Against Polygamy*,¹ a work that creates its own genre and is as unique as the case it recounts.

The Polygamy Reference

Procedurally unprecedented and legally unusual, the Polygamy Reference proceeded pursuant to British Columbia's *Constitutional Questions Act*,

1. Craig Jones, *A Cruel Arithmetic: Inside the Case Against Polygamy* (Toronto: Irwin Law, 2012).

which allows for references to the BC Supreme Court. The idea of a reference had been initially rejected because such proceedings customarily take place before the Supreme Court of Canada or a provincial Court of Appeal, where arguments are heard in factual vacuums, precluding the opportunity to develop an evidentiary foundation. Both personal and expert evidence about polygamy and its harms was something that senior counsel, Leonard Doust QC and Richard Peck QC, had deemed crucial if the section 293 prohibition was to endure in the face of apparent interference with the *Charter* rights and freedoms of its participants.

The trial court reference would be the first of its kind, with Jones leading a dedicated and talented team of lawyers from the provincial Attorney General, working alongside lawyers from the federal Department of Justice. George McIntosh QC (now a Supreme Court Justice) was appointed as *amicus curiae* to litigate the opposing position.

A Book As Unique as the Case it Recounts

The book that emerged from the Polygamy Reference is both a historical and philosophical exposition, and a trial diary interwoven with a memoir of personal recollections and observations. From lighthearted exchanges between opposing counsel and impromptu meetings with the disarmingly personable former Attorney General Wally Oppal (whose finger found its way to Jones' chest on at least one occasion) the author depicts the human side of high-profile, public interest litigation.

The Comprehensive Theory

A Cruel Arithmetic challenges the default position of most who would seek to champion civil liberties by viewing polygamy as a practice between consenting adults with which others should not interfere. Jones explains that he understands this position because it was his own. He describes the way in which his perception of polygamy, which was characterized by a deep and profound ambivalence, changed dramatically. It was evidence of the harms of polygamy, both to its participants and to society at large, that challenged his laissez-faire instincts and caused him to conclude that it was not enough to target the visible abuses stemming from polygamy while ignoring the practice itself.

The author's shift in thinking happened over time, but there is one moment of realization that Jones cites as being just short of Damascene. The epiphany occurred when he came across the phrase "the cruel arithmetic of polygamy" in Daphne Bramham's book about Bountiful, *The Secret Lives of Saints*.² Bramham's phrase referred to the fact that polygamous communities create pools of unmarried men ('lost boys' in Bramham's parlance) who are vulnerable to exploitation and abuse. Insular religious communities then find ways to "dispose of" surplus males, who present a threat to those who wish to acquire more wives. Jones' realization was that, child brides, the other problem frequently associated with polygamy, was also an inevitable result of the "cruel arithmetic". In order to sustain the demand for more wives than the existing pool of women can satisfy, men in polygamous communities must recruit from the ranks of younger and younger girls. In this way, the culture of pedophilia, endemic in polygamist sects, cannot be separately addressed because it is a necessary feature of the culture. "Bountiful did not invent polygamy", Jones writes, "polygamy invented Bountiful."

This understanding formed the Attorney General of BC's comprehensive theory of polygamy upon which all of its resultant harms were demonstrated to be the inevitable explanation, rather than merely a sensible hypothesis. To organize the evidence in support of this theory, the government lawyers divided their tasks with Jones overseeing expert evidence while other members of his team searched for eyewitnesses, including a number of 'survivors' of polygamous communities. These compelling testimonies were presented, in large part, through the device of video affidavits, which were used to breathe life into witnesses' testimonies and allow the court an extra level of proximity to the personal, lived realities of those caught in polygamy's wake.

The Overwhelming Evidence

Some of the witnesses appeared in court to give live testimony, and the author provides brief vignettes detailing their examinations. One particularly moving example comes from the direct questioning of

2. Daphne Bramham, *The Secret Lives of Saints* (Toronto: Vintage Canada, 2008).

Truman Oler, the estranged brother of Bishop James Oler. Jones describes Oler speaking in a slow and halting fashion, pausing for half a minute at times before answering a question. His answers told the story of relational and emotional brokenness, rejection, and of a profound, enduring pain, the effects of which have rippled into his adult life. As Truman spoke, the gallery sat frozen in weighted silence. Jones recalls that a CBC report later referred to Oler's testimony as "unbelievably powerful."

In contrast, the expert evidence explained and rationalized the emotional eyewitness testimony in academic and sometimes empirical terms. According to Jones, the most compelling expert evidence, as reflected in the decision itself, came from Dr. Joe Henrich. This evidence showed *causation* of polygamy's harms rather than mere correlation.

On the stand, Dr. Henrich hypothesized that polygamy is the ready response of human psychology and if it were decriminalized, Canada might become a destination for polygamous families who wish to live without fear of the law. Further, because polygamous families have children at a dramatically higher rate, these communities would expand faster than their monogamous counterparts. And, given that within our society high-status men often divorce an older wife to marry someone younger, polygamy might create a more convenient alternative for men, especially those who wish to remain under the same roof as their children.

Finally, Dr. Henrich presented a lighthearted, but nevertheless startling anecdote. He explained that when he teaches evolutionary psychology at UBC, he issues "clickers" to all of his students. He then asks the female students to consider a scenario. "You're in love with two men", he states. "One is a billionaire, he already has one wife and he wants you to be his second wife."³ Dr. Henrich then asks female students to imagine they are equally in love with a regular, unmarried man, who is not a billionaire but identical in every other way. According to Dr. Henrich, about 70 percent of his female UBC undergraduate students choose the billionaire. In this way, Dr. Henrich explained that it is not ridiculous to think that polygamy could spread to non-trivial levels, even in a modern liberal democracy like Canada, if permitted.

3. *Reference re: Section 293 of the Criminal Code of Canada*, 2011 BCSC 1588, [2011] BCJ No 2211 (QL) at 555.

The personal and expert evidence of the Attorney General demonstrated an extraordinary level of convergence. This feature did not escape Chief Justice Bauman who stated in his decision that, “from high level predictions based on human evolutionary psychology, to the recurring harms identified in intra-cultural and cross-cultural studies, to the “on the ground” evidence of [polygamy] in contemporary North America... [the] convergence becomes increasingly striking.”⁴ In addition to direct evidence, Jones’ meticulous cross-examinations demonstrate that even the most competent expert witnesses may come undone on the stand where their footnotes reveal imprecise research.

The Decision

The Court released its decision on November 23, 2011 and arranged for a ‘lockup’, which is an uncommon procedure whereby the parties and the media are given permission to read a decision in specially designated rooms before it is made public. With much anticipation, the government lawyers waited in their assigned room in the basement of the courthouse. Finally, the voluminous 357-page decision was placed before them. Only having an hour and a half of reading time, they quickly flipped to the back to learn they had won, and, as the pages flipped forward, they soon realized they had won convincingly. Their evidence was referred to as “overwhelming” and their singular theory of polygamy and its harms was broadly adopted with almost wholesale endorsement. When Jones left the room, he called Victoria to relay the news; his report was met with an uproar of cheers as well as the effusive personal congratulations of the Attorney General, Shirley Bond.

Commentary

A Cruel Arithmetic has a literary quality, which, when combined with the simplicity and clarity of the writing style, almost camouflages the sophistication of its content. Judiciously-placed literary flourishes illustrate the Reference courtroom as an ocean of black wool and silk, humming with muted excitement, silenced only by the entrance of a

4. *Ibid* at 492.

clerk and a call to order. While containing the educational value of a textbook in constitutional law, advocacy, and civil procedure, literary techniques contribute to a reading experience where the vast amount of information learned by the reader seems incidental, a byproduct of an enjoyable read.

A Cruel Arithmetic is also deeply philosophical, grappling with the essence of what it means to be human, the nature of causation itself, and the way we organize the most intimate, and perhaps even sacred, aspects of our lives. Jones challenges those with a tendency to perceive their natural discomfort with polygamy as a manifestation of cultural imperialism, prejudice, or intolerance. He convincingly argues that this thinking has clouded our ability to form a sincere concern for the boys who have been discarded by their communities and the young girls who have been indoctrinated to believe that their purpose is to fulfill the desires of old, powerful men who trade them like collectibles.

Implications

On August 27, 2014 a federal judge in Utah issued a final ruling striking down a part of the state's polygamy ban as unconstitutional. In response to the decision, Marci Hamilton, a professor at the Cardozo School of Law made the surprising statement that, "Partly, Utah is to blame because they did a lousy job of presenting the evidence of the effects of polygamy and the way that the system operates."⁵ This observation does more than cast that case in sharp relief to the work done by the Attorney General of BC in the Polygamy Reference, it also highlights the far-reaching implications of the team's combined efforts. Our Canadian legal landscape might look quite different but for the 2011 case.

As for Blackmore and Oler and the future of polygamy in BC, Craig Jones concludes *A Cruel Arithmetic* by stating, perhaps presciently:

Of what consequence are Blackmore and Oler to the progressive development of rights in Canada? They can exploit individuals, but, as

5. Amanda Holpuch, "Utah Judge Strikes Down Part of State's Polygamy Ban in Sister Wives Ruling", Editorial, *The Guardian* (28 August 2014) online: The Guardian <<http://www.theguardian.com/world/2014/aug/28/utah-strikes-down-polygamy-ban-sister-wives>>.

the reference decision showed, society will not tolerate them forever, and they will eventually be swept aside.

ANNE COCHRANE

Book Note

Law, Policy, and Reproductive Autonomy, Erin Nelson

Many of today's social environments in which women find themselves appear to uphold an ideal of individual liberty and unprecedented access to education. In the case of reproductive choice, women often have options to help facilitate their rights, but policies across jurisdictions are inconsistent. Many women face barriers to the meaningful exercise of choice. In *Law, Policy, and Reproductive Autonomy*,¹ Erin Nelson examines differences in reproductive law and practice in Canada, the United States, the United Kingdom, and Australia in ways that highlight these differences. Her study encourages us to question whether advances in reproductive policy and technology are, for many, merely theoretical.

Nelson's analysis of the level of reproductive autonomy permitted across these jurisdictions is extensive and details the history of regulation on reproduction, including benchmark case law and recent legislation. She argues in favour of greater recognition of the capacity for choice, improved access to health care, and a broader understanding of the context in which reproductive decisions are made. She is particularly engaging on the interests of the fetus, including a possible duty of care owed during pregnancy. Nelson concludes by considering the implications of various new reproductive technologies and the regulatory challenges to which they give rise. The book offers a valuable overview of the current field of reproductive case law and policy that will likely be of interest to lawyers, scholars, and practitioners in the many areas in which reproductive rights are implicated.

LEAH SENEVIRATNE

1. Erin Nelson, *Law, Policy, and Reproductive Autonomy* (Oxford: Hart Publishing, 2013).

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