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# Studies in Disability

Edited by  
Moira Ferguson and Alain Beaulieu

The conference “Disability: Definitions, Representations, Classifications” that took place at Laurentian University (February 6-7, 2012) provided a forum within which individual work was shared and wider conversations began. We are glad to present here a selection of papers delivered at this conference. The authors are focusing thematically on a series of concerns animating cutting-edge scholarly work in this emerging and growing interdisciplinary field. The book is divided into three sections where key issues in disability are explored: Theoretical Perspectives, Child Development, and Cultural Representations. Among the questions raised and discussed are the following ones: How do we define “disability” as an object of study and as a lived experience? What is the relationship between the category of disability and state classificatory policies, such as those governing classrooms, medical decisions, and support for families? How is disability represented in both popular culture and academic settings? We hope that this collective work will make a positive contribution in the way disabilities are usually seen, experienced and understood.

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Moira Ferguson and Alain Beaulieu

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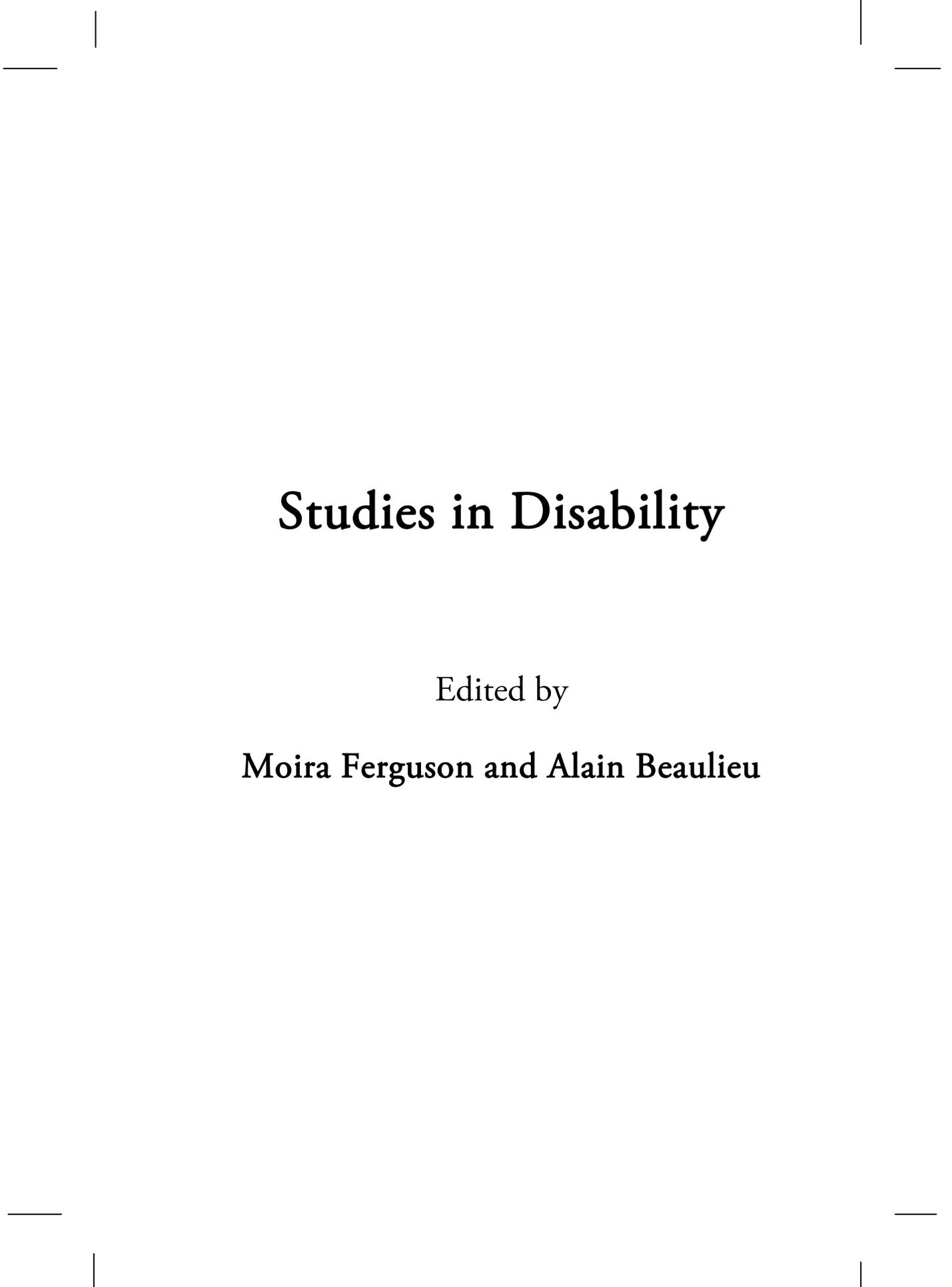
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## Forward

*Alain Beaulieu*

*Director of the International Centre for Interdisciplinary Research in  
the Human Sciences - Laurentian University (Canada)*

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I am delighted to present this selection of papers originally delivered at a conference on disability organized by the International Centre for Interdisciplinary Research in the Human Sciences (ICIRHS) during Laurentian University's research week on February 6-7, 2012. The aim of this collective work is to bring together authors from various horizons in order to provide an interdisciplinary forum to study and research issues surrounding visible and invisible forms of disabilities. Its purpose is also to raise social awareness regarding concrete problems faced by the people with disabilities in the hope of shaping a different world for the future. The disability conference and this publication fit perfectly with ICIRHS' aim which is to facilitate and nurture interdisciplinary research in social sciences and humanities.

Disability studies is a relatively new field considering that it finds its origins about forty years ago in the civil rights movements and in the neo-Marxist critics of society. The chapters that follow explore various practices, interpretations and subfields that fall under this young area of scholarship. Authors discuss disability in connection with mental health, cultural representations, families, school and education, theories and policies. This short list already shows the interdisciplinary character of disability studies which indeed stands at the crossroad of the humanities

and the social sciences. One of its starting points consists in considering that disability excludes people with impairments, and thus acts as a form of social oppression. This social model of disability was at the core of the conference, and remains here a fundamental concern by challenging the medical model which tends to conceive disability in terms of a limitation that has to be cured or in terms of an in-capacity that has to be managed by health professionals. Many chapters discuss the obstacles and pathways to the social model by arguing in favor of a collective responsibility for inclusion of people who are facing disability issues. Other chapters take into account the inseparability of the social perspective and the concrete physical impairment or the lived experience of mental health conditions.

On a more biographical note, I would like to share briefly a personal story that put into question what could be called the “ableist myth of perfection”. As I was studying philosophy in Paris more than a decade ago, I had a strong interest in all the readings that dealt with “depsychiatrisation” and “demedicalisation” (Deleuze and Guattari's schizo-analysis, Foucault's history of madness, antipsychiatric movements, etc.). I was fascinated by these topics, but at the same time I deeply felt that gaining this type of knowledge from books alone might be insufficient and even inadequate. So I decided to pay a visit to the psychiatric ward of *Hôpital de la Salpêtrière* close to the *Gare d'Austerlitz* with the firm, yet naive, intention of volunteering in order to encounter people classified as mentally ill. At that time, I didn't know the meaning of the word “professionalization”. When I opened the heavy door of the psychiatric department, I saw about 10 nurses in white uniforms. Without any specific background in health care, I asked foolishly: “Can I volunteer in your institution? I would like to take walks in the park with the patients at lunch time.” The nurses stared at each other in a peculiar way without knowing what to say. After a few

seconds of desperation, one of them answered me in deadly earnest: “Come back tomorrow. The psychiatrist is not here today.” I understood that they thought I was crazy. After all, only a mad person can offer to spend time with other mad people without getting paid! I never made an appointment with their psychiatrist. Instead, I went to Unafam (*Union nationale des amis et familles de malades psychiques*) which is an association that brings support to friends and families of people classified as mentally ill. They showed a much greater openness and immediately understood my desire to meet with so-called mad people, gain a more concrete experience of madness, and potentially make a small contribution to their well-being. Unafam referred me to IRIS-Paris which is a non-profit organization located close to *Gare de l'est* that offers accompaniment services to social life to people who are facing psychiatric difficulties. Not only were they pleased to allow me to volunteer, but the director proposed to have regular meetings with the IRIS members who, she said, have strong philosophical needs and capacities. So I found myself organizing monthly philosophical debates for two years with people classified as mentally ill! These fantastic encounters gave me the opportunity to get to know more about the complex relationships between the social life and the medical life, broaden my philosophical horizons and also to build strong friendships with outstanding people. It became clear that disability, far from being a form of inability or inability, can express a full capacity in itself. Realizing this in return can increase one's own capacities for humility, modesty and wisdom. What it also shows is that, contrary to the sovereign power of exclusion which is often simplistic and one sided, the capacities of adaptations are infinite. To paraphrase Spinoza, the *potestas* is the lowest degree of *potentia*...

The public event on disability at Laurentian offered a unique opportunity to investigate further some of these interests shared by a wide range

of scholars, and to explore new territories. I was thrilled to feel a real enthusiasm generated by the organisation of this conference which rapidly and joyfully became bigger than what was initially planned. All the sessions were well attended and very stimulating, including the presentation of the historical documentary *A Life Worth Living: The Great Fight for Disability Rights* (dir.: Eric Neudel, 2011). I am especially proud of the participation by the graduate students (a total of ten for the conference) who were involved in every aspect of the conference, either as presenters, session chairs or by bringing technical assistance. It is always exciting to have these kinds of intergenerational exchanges.

I would like to thank our sponsors and funding agencies without whom this project would not have been possible. From Laurentian University: Accessibility Services and its Coordinator Earl Black; Ph.D. Program in Human Studies and its Directors Simon Laflamme and Cynthia Whissell; Dean Elizabeth Dawes of the Faculties of Social Sciences and Humanities; Research, Development and Creativity Office and its Director Yves Alarie; Centre for Humanities Research and Creativity and its Director Alexis Shotwell; Work-Study and Employment Program Coordinator Todd Gagnon; Department of Philosophy's Chair Michael Yeo and Secretary Claire Raymond; and Social Sciences and Humanities Research Council of Canada.

I am also very appreciative of Independent Living Sudbury Manitoulin and its Executive Director Rob DiMeglio, the University of Sudbury's Department of Philosophy and its Chair Carole Collier, as well as the Social Sciences and Humanities Research Council of Canada for their precious support or financial contribution.

Acknowledgements also go to all those who actively participated in the realization of this event, more specifically to Moira Ferguson who had the original idea and worked with me in the planning stages, Fiona Ferguson who kindly offered to volunteer and brought priceless help to the organization, our technician, infographist and closed captioner Carolyn Leblanc, as well as Melissa Pafford, Scott Neigh, Tanya Pothier and Stéphane Richard. A special thank you goes to Dana Cudney for helpful guidance and support during the conference and in the preparation of this publication. I would like to express gratitude to the presenters at the conference who unfortunately were not able to contribute to this publication: Brenda Brueggemann (Ohio State University), Kathryn Church and Esther Ignagni (Ryerson University), Geoffrey Reaume (York University), Shelley Tremain (independent scholar), Alexis Shotwell (Carleton University), as well as Nicole Yantzi, Nancy Young, Shelley L. Watson, Karen McCauley, Kelly D. Coons and Scott Neigh (all from Laurentian University). I am also grateful to Hoi Cheu for the sound check! Special thanks to Ali Reguigui who kindly welcomed this book in the Monograph Series in Human Sciences.

Finally, I would like to acknowledge and thank community members from Sudbury and North Bay who expressed their interest in this conference through their attendance and correspondence with us. It is my hope that this publication will continue the important discussions that began at the conference.



# Introduction

*Earl Black & Moira Ferguson*

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Accessibility Services (formerly the Special Needs Office) has been providing services to students with disabilities at Laurentian since 1989. The department has grown substantially since then. Accessibility Services now has approximately 450 students registered each year with disabilities ranging from mobility disabilities, vision and hearing impairments, medical conditions, learning disabilities and psychological/emotional issues. The role of Accessibility Services to provide supports and to remove barriers to access is mandated by the Ontario Human Rights Code as it relates to people with disabilities. This is the statement which you will find on Laurentian University's website.<sup>1</sup> The website also defines disability and describes the legal duty to accommodate that Laurentian University is bound to uphold.

These are, of course, the fundamental issues and concerns of disability. They speak to a legally bound duty to accommodate and point to legally defined descriptions of disability. When we began to discuss disability as a larger and more elusive concept, it became apparent that at Laurentian University at least, we had, as many universities had, included disability in some of our disciplines, particularly in the Humanities and Arts. Disability as a collective issue had been taken up as a site of oppression, injustice and unfair labour practices. Disability as an individual experience had been explored from many

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<sup>1</sup>Laurentian University Accessibility Services <[www.laurentian.ca/content/accessibility](http://www.laurentian.ca/content/accessibility)>

different and sometimes opposing perspectives and through the lens of various models of disability. The small group of us who first began to discuss a conference on disability issues saw it as an opportunity to provide a forum to open up the growing dialogue on disability issues. Although not all of the people who presented at the conference are represented in this collection, we think that the journal represents fairly many of the intriguing and emerging theories and perspectives on disability that were discussed at the conference. Another issue that often comes up for us is that of inclusion. Each of us looks at the broad category of Disability Issues from a particular standpoint. Barriers to social inclusion, some of which are tangible and some of which are attitudinal affect people quite differently, and these issues, about wheelchair ramps, about sexuality, about social roles and functioning, about autonomy and reliance on services, and about the intricate dance around and within various systems, can be spoken about also from various standpoints. In short, as we see it, there are no experts on disability issues but often one gains a unique perspective from one's personal lived experience.

We provide here a brief history of what has come to be known as Accessibility Services and start with the rich history that surrounds the hard fought battle to have the basic human rights of people living with disabilities legally recognized and enforced, within an academic institution and in the larger community. When we began discussing disability issues at Laurentian University, one of us was the Manager of Accessibility Services at Laurentian University and one of us was a Ph.D. student working occasionally for Accessibility Services. Our first ideas, as we began to discuss what could happen to make things better for students and staff with disabilities, as well as those interested in theoretical perspectives on disability issues, were grand and expansive. We envisioned an entire Disability Studies Centre with a focus on the inclusion of community organizations such as Independent Living

Sudbury Manitoulin and the wider Northern Ontario remote and rural communities, where access to services for people with disabilities is known to be difficult and hampered by many barriers. In some ways, it seemed, the Disability Rights movement had come so far in twenty years and in other ways the groups that Disability Rights had started with during the rights movements of the nineteen seventies and eighties “had passed us with flying colours”.

These groups, LGBTQ groups, black people and women had organized, mobilized and had been recognized at least to some extent. Despite the progress that has been made, many students, and indeed staff and faculty, face humiliation, embarrassment, curiosity, and sometimes hostility when they ‘come out’ particularly when they disclose that they have a mental, emotional or cognitive disability. Somewhere in the historical trajectory from there to here, from being institutionalized to being at least allowed and sometimes accommodated, the fault still seemed to be found in the individual, not in the environment.

It was not that Disability Rights were not legally accounted for; they were. The problem was that the legislation outlined in the *Ontario Human Rights Code*<sup>2</sup> ‘had no teeth.’ By the time we realized that our original dream of an entire Disability Studies Centre was a bit ambitious,

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<sup>2</sup>The Ontario *Human Rights Code* (the *Code*) provides for equal rights and opportunities, and freedom from discrimination. The *Code* recognizes the dignity and worth of every person in Ontario. It applies to the areas of employment, housing, facilities and services, contracts, and membership in unions, trade or professional associations. At work, employees with disabilities are entitled to the same opportunities and benefits as people without disabilities. In some cases, they may need special arrangements or “accommodations” so they can do their job duties. Customers, clients and tenants with disabilities also have the right to equal treatment and equal access to facilities and services. Examples of facilities and services are restaurants, shops, hotels and movie theatres, as well as apartment buildings, transit and other public places. Public and private education providers must also make sure their facilities and services are accessible, and that students with disabilities are accommodated.

the word was out. We were not the first to speak openly of disability, of course, but by now everyone did want to talk about it and the idea of a conference was brought to one of our colleagues, who passionately took up the idea and got the ball rolling. One of the practical issues we wanted to talk about was disability and the law. We now take a step back to explain the history involved in getting basic rights for people with disabilities implemented at Ontario institutions, including Laurentian University.

Officially, all institutions in the public sector have a duty to be accessible to the public. Historically, ‘the public’ has not included people with disabilities. Institutions had been built to house, and by house we of course mean store people with mental, physical, and cognitive disabilities. With deinstitutionalization, people with disabilities were moved from institutions to communities. Some of the group homes and special homes had been built to accommodate people with disabilities, but now that people with disabilities were out in the public, malls, banks and movie theatres soon proved to be beyond the access of some people. With the implementation of the Ontarians with Disabilities Act every publicly funded institution had a responsibility to identify and remove barriers.

What was needed was real legislation to ensure and enforce compliance and this wasn’t clear so groups lobbied the government to get the Ontarians with Disabilities Act (O.D.A.) turned into the Accessibility for Ontarians with Disabilities Act (A.O.D.A.). This is the big task of Laurentian University in the present moment of Disability Rights. Laurentian University’s First International Conference on Disability Issues brought together many issues from many perspectives. Our colleagues from Ryerson spoke of Disability Rights history, and disabled people as people *in* their bodies, as sexual and social beings. Our colleagues from Laurentian spoke of educational and cognitive

issues and of society as a confining barrier, obsessed often with classifying human behaviour around a problem-solution or normal-deviant model. Our appearance in the Great Hall this February was hard won. The issues we are working with began to gain attention and some recognition 20 years ago, but people with disabilities have been cultivating this voice for a couple of centuries.

What we are working with now, the A.O.D.A. which was the O.D.A. came about after disability rights activists began lobbying the government at every event beginning about 16 years ago. They could no longer ignore the legal obligation to change the structure and the mindset of the environment; not an easy task. At the end of the day, people want to belong, and we don't mean in some simplistic or metaphorical sense, we mean they have to get there. There was lots of talk about the built environment but it was taking too long. The Human Rights Code, a precursor to both the O.D.A. and the A.O.D.A. was what activists and lobbyists fell back on. The Human Rights Code specified our rights but time and again, they were ignored. The conference provided at least a forum to begin to discuss these very real issues. We can't just keep talking about inclusion and then stalling on actual implications. The participants in the Disability Conference made it clear that it is time for Disability Issues to be taken seriously in our environment, in our attitudes and in our curriculum.

#### Summary of Chapters

In "The Normalizing Society and Disabilities," Martin Boucher studies the work of Ann Waldschmidt in relation to Foucault's normalizing society. He places the normalizing society within its historical context, describes what norms are and how they function in the normalizing society, and reflects on Waldschmidt's work regarding biopolitics, genetic counselling, and disabilities.

Moira Ferguson, in the second chapter entitled “Managed Detours: The Strategic Organization of Social Problems,” adopts a phenomenological perspective to present the experiences of people with mental disorders. This brings her to discuss the survivor movement as well as the way chemical substance abusers and mental health consumers have come to be related in contemporary societies.

In “Classification Systems in Special Education: Social Justice or Just Social?,” Sean Cousins explores the history of special education discourses situated within the concern of classification, and he critically examines those normative practices that are employed in the service of implementing such classification systems.

Jana Duncan's paper, “The Models of Disability and the Effect of a Child with Autism on the Family,” presents a review of literature on autism and families. The author discusses the medical and social models of disability as well as recent arguments for combining or moving beyond these models in order to provide a better understanding of autism.

In the final chapter, “Raising a question mark: Disability and Textual Recalibration in Contemporary Canadian Writing,” Angelo Muredda surveys a series of cultural representations of disability in Canadian literature. He uses these texts as points of departure into a discussion on how disability intersects with both aesthetic matters of form and more thematic explorations of filial responsibility in Canadian literature.

# I - Theoretical Perspectives



# The Normalizing Society and Disabilities

*Martin Boucher*

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As part of the theory section of the First International Conference on Disability Studies, I thought it would be a good idea to explore a few of Foucault's ideas that seem to underlie a great deal of research in what I would call, the 'politically-oriented' research disciplines in our universities today such as race studies, gender and sexuality studies, native studies, and of course disability studies among countless others. Specifically, this paper will explore the work of Dr. Ann Waldschmidt, a German disability theorist and activist, in relation to Foucault's "normalizing society". In doing so, this chapter will aim to do three things: (1) to place the normalizing society within its historical context, (2) describe what norms are and how they function in the normalizing society, and (3) reflect on Dr. Waldschmidt's work regarding biopolitics, genetic counselling, and disabilities.

The decision to focus on Dr. Waldschmidt's work is twofold. Firstly, she has developed some interesting theoretical concepts in relation to the switch-point between the disciplinary and normalizing society. Secondly, she offers us a reflection on her earlier work, which I think is both interesting and formative in relation to understanding the aforementioned historical event. Although Dr. Waldschmidt's work takes German disability discourse as its object, and thus resists different legislation and political discourse than we would (here in Canada), I believe that her analysis is relevant in many ways. I would encourage those of you who are interested in these ideas to make connections with your work here in North America.

### **The Disciplinary Society, the Normalizing Society, and Norms**

The concept of a “normalizing society” was first explored in Foucault’s “*Society Must be Defended*” and subsequently in the first volume of *The History of Sexuality*, though the concept of norms can be said to permeate the entirety of Foucault’s *opus*. Already in Foucault’s first important work (and graduate thesis) the *History of Madness*, Canguilhem notices that he was able to “tear open the envelope within which a technique of normalization presented itself as a knowledge/*déchirer l’enveloppe sous laquelle une technique de normalisation se présentait comme un savoir*”.<sup>1</sup> What he meant here is that certain knowledges, such as medicine and psychiatry, though they may present themselves as neutral, they do in fact contribute to political or social normalization processes. We can see this happen in his works on several institutions such as the asylum, the hospital, the prison, the school and the military (and their accompanying knowledges). These institutions were primarily objects of reflection for Foucault in his early career, and were analyzed as disciplinary institutions; though he never lost sight of the knowledge that made them possible. While these institutions still exist today (in the normalizing society), their functions depend on a different type of power, and thus make use of norms in different ways.

In short, the disciplinary society is “a regulated, anatomical, hierarchical society whose time is carefully distributed, its spaces partitioned, characterized by obedience and surveillance”; whereas “[a] normalizing society is the historical outcome of a technology of power centered on life”, and the regulation of its processes.<sup>2</sup> The crux of the difference between the two is that in the former power is exercised through a

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<sup>1</sup>Georges Canguilhem, “Sur l’*Histoire de la folie* en tant qu’événement”, quoted in Jean-François Braunstein (ed.), *Canguilhem. Histoire des sciences et politique du vivant* (Paris: PUF, 2007), p. 14.

<sup>2</sup>Michel Foucault, *The History of Sexuality. Volume 1* (Vintage: NY, 1990), p. 144.

‘micro-physics’ of the body, while in the latter power is exercised primarily through norms (statistical) of populations’ life markers (as their target). In the former discipline is applied to the body to “mould” it to a determined end (a type of student, a type of worker, a type of prisoner), while in the latter the objective is the regulation of populations (life processes) towards an increase in the health of a population as a whole. The important thing to note is that the term “the normalizing society” is a rough historical periodization based on the dominant mode of power present in today’s political discourse. It is not the case that these represent universal or exhaustive descriptions of power at any given historical period or even the present. To say that one dominates is not to say that the other disappears; the transition between these dominant modes of power develops in interesting ways. The periodization is based on which mode of power ‘permeates’ the discourse; however, other modes of power do not entirely disappear.

As Foucault reminds us, “there is one element that will circulate between the disciplinary and the regulatory, which will also be applied to body and population alike [...] The element that circulates between the two is the norm” which “can be applied to both the body one wishes to discipline and a population one wishes to regularize.”<sup>3</sup> In fact, when Foucault says that “[t]he normalizing society is a society in which the norm of discipline and the norm of regulation intersect along an orthogonal articulation”<sup>4</sup>, he seems to suggest that the normalizing society is not a transition, but a historical emergence from and beyond disciplinary technologies of power. In other words, discipline and regulation are mutual but not exclusive. In fact they coexist; we can imagine them as ‘backwards compatible’.

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<sup>3</sup>Michel Foucault, *Society Must be Defended* (Picador: NY, 2003), p. 253.

<sup>4</sup>*Idem*

The question remains: ‘What kind of norms are we talking about here?’ Dr. Waldschmidt makes the claim “that there are now two types of norms that guide human action: *normative norms* and *normalistic norms*”.<sup>5</sup> Firstly, there are norms that correspond to normativity: “Normative norms orient people to external rules that they must follow or to which they must conform.”<sup>6</sup> Most importantly these are explicit, and fixed. They are expressed through control mechanisms which “ensure conformity with social norms; deviation and disobedience are subject to penalties and sanctions.”<sup>7</sup> The clearest examples of these, of course, are laws (which dominate the disciplinary society). Using an apt metaphor, Foucault tells us that “[t]he law always refers to the sword”, in other words discipline; “[b]ut a power whose task is to take charge of life needs continuous regulatory and corrective mechanisms.”<sup>8</sup> It is precisely this need that is filled by the normalistic norm. “Normalistic norms, in contrast to normativity, are less static and less oriented to stability; they are based on change and dynamics.”<sup>9</sup> Examples of these would be percentiles in psychological testing, economic growth statistics in regional development studies, risk assessments in finance, insurance, or health. Evidenced in these examples, “[s]ince normalistic norms are supported by statistics, these norms exist only in highly data-oriented societies.”<sup>10</sup> This is a bold statement, but I think it is supported by critico-historical investigations into the emergence of the social/human sciences. Regardless, these co-existent types of norms help us understand

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<sup>5</sup>Ann Waldschmidt, “Who is Normal? Who is Deviant? ‘Normality’ and ‘Risk’ in Genetic Diagnostics and Counseling” in Shelley Tremain (Ed.) *Foucault and the Government of Disability* (Ann Arbor: Michigan UP, 2008) p. 193.

<sup>6</sup>*Idem*

<sup>7</sup>*Idem*

<sup>8</sup>Foucault, *History of Sexuality*, p. 144.

<sup>9</sup>Waldschmidt, “Who is Normal? Who is Deviant?”, p. 194.

<sup>10</sup>*Idem*

the complex interplay between anatomico-disciplinary norms and regulatory norms within the normalizing society. We must look more closely at this emergence, or more precisely, at what it is exactly that changed.

### **Human Development, Statistics, and Risk**

The technology of population statistics and the concepts of risk are centrally important to both the normalizing society in the 21<sup>st</sup> century, and to Waldschmidt's analysis of human genetic counselling. Before we get to this, we have to be pretty clear about what we mean when we talk about life entering the field of politics. Certainly, as Foucault reminds us, before the nineteenth century we did think about population in certain rudimentary ways. Military generals certainly were concerned about troop numbers and sustenance, or the sovereign worried about his standing army. In general this could be considered thinking about population, and the population as object of political control. However, there are three dynamics, or three aspects that emerge from the entry of life into the "realm of explicit calculations" in the nineteenth century that are not present in these examples. These aspects arise precisely as result of the emergence of biopower, which comes to permeate the logic of governance in the west.

The three aspects of this entry of life into the 'realm of explicit calculation' are: Firstly, we see the emergence of certain concerns, such as public health [*hygiène publique*], the condition of habitats, or epidemics; secondly, we see the emergence of specific knowledge that deal with these issues, such as demography or epidemiology; and lastly, the emergence of apparatuses [*dispositifs*] of power like social medicine

and childcare.<sup>11</sup> We can already see a major problem here, one that Foucault recognized quite early in his career; that on this second point, the emergence of specific knowledges, though they may appear neutral, are part of this general technology of governance. It will be essential in the normalizing society to rely on specialized knowledge in order to regulate ‘naturalized’ social issues (like epidemics/ illness/disability for example). I think it’s useful to quote Foucault at length here:

“The discourse of disciplines is about a rule: not a judicial rule derived from sovereignty, but a discourse about a natural rule, or in other words a norm. Disciplines will define not a code of law, but a code of normalization, and they will necessarily refer to a theoretical horizon that is not the edifice of law, but the field of the human sciences. And the jurisprudence of these disciplines will be that of a clinical knowledge.”<sup>12</sup>

As McWhorter puts it, “Newton and Leibniz invented calculus in the late seventeenth century. Before the beginning of the nineteenth, that invention had been put to use to create the science of statistics, which made it possible to study various developmental trajectories and ‘norm’ them.”<sup>13</sup> From the 19<sup>th</sup> century a great many human or social sciences come to make use of statistics to establish norms within their disciplines; the most notable by far are medicine/psychiatry, sociology and criminology. As Hacking reminds us, “Durkheim’s innovation was to found his argument on the sheer regularity and stability of quantitative social facts about statistics and crime.”<sup>14</sup> It is certainly interesting that “one name for statistics, especially in France, has been

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<sup>11</sup>Michel Foucault, “The Confession of the Flesh” in Colin Gordon (ed.) *Power/Knowledge: Selected Interviews and Other Writings, 1972-1977* (New York: Pantheon, 1980), p. 226.

<sup>12</sup>Foucault, “*Society Must be Defended*”, p. 38.

<sup>13</sup>Ladelle McWhorter, “Sex, Race, Biopower: A Foucauldian Genealogy,” *Hypathia* 19, No. 3 (2004), p. 38.

<sup>14</sup>Ian Hacking. “How Should we do the History of Statistics?”, in Graham Burchell, Colin Gordon, and Peter Miller (eds.), *The Foucault Effect; Studies in Governmentality* (Chicago: Chicago UP, 1991), p. 182.

‘moral science’: the science of deviancy, of criminals, court convictions, suicides, prostitution, divorce”, and the like.<sup>15</sup> In other words, the human sciences were quick to make use of statistical concepts to formulate analyses that problematize certain behavioural trends within a population. While the development of statistical methods related to epidemics in medicine was taking hold, the social sciences were carving out their own turf: a science of deviancy and of the ‘social ills’ of the time. This gives rise to a dangerous political problem; namely, that with the entry of life into the realm of explicit calculation, the human sciences were brought squarely within the apparatuses of governance — *the* essential tool for its exercise in fact. Legal scholarship ceases to be the dominant discourse for the production of norms. Again from Hacking:

“It is no accident that Durkheim conceived that he was providing a general theory to distinguish normal from pathological states of society. In the same final decade of the nineteenth century, Karl Pearson, a founding father of biometrics, eugenics and Anglo-American statistical theory, called the Gaussian distribution the normal curve.”<sup>16</sup>

The normal curve becomes the major tool for a scientific definition of normality in the social and human sciences. It comes to redefine the norms of social life and the governance of marginal populations. Essentially, we can say of statistics that “it may think of itself as providing only information, but it is itself part of the technology of power in a modern state”.<sup>17</sup> Clinical knowledge armed with statistics, becomes the producer of norms *par excellence*; as we see in Foucault’s quote above — (“not a judicial rule derived from sovereignty, but a discourse about a natural rule”).

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<sup>15</sup>*Idem*

<sup>16</sup>*Ibid.*, p. 183.

<sup>17</sup>*Ibid.*, p. 181.

The proliferation of biopower within the social/human sciences takes many forms, some examples are: medicine's role in public health [*hygiène publique*] in the 18<sup>th</sup> century and social medicine in the 19<sup>th</sup> century (Foucault), the development of a science of sexuality in the 19<sup>th</sup> century (*scientia sexualis* vs. *ars erotica*), psychiatry's discourse on delinquency which underpinned the science of criminology (turn of the 20<sup>th</sup>), or in 21<sup>st</sup> century bio-psychology, to be more specific, the development of a mapping of abnormality directly onto the brain, and the emerging 'screen and intervene' rubric (this in Rose).<sup>18</sup> The later example, from psychology, is quite similar to Waldschmidt's account of medicine in genetic counseling, though I will not do a comparative reading here, given the lack of space. It remains that the concept of normality, as it emerged in 19<sup>th</sup> century social science, is central to the experience of disability in the west.

As Waldschmidt understands, one of Canguilhem's greatest theoretical insights was to discover that "[w]hen we define ourselves as normal, we also simultaneously define who should be considered as abnormal in comparison to us. In other words, both freedom and normality have their drawbacks, their social 'costs,' and their victims."<sup>19</sup> The definition of normality, based on clinical knowledge, has a truth function in today's technologically advanced information society; it legitimates the rules of exclusion on which we base our values about life. Norms of health become social norms of life. What this means is that clinical visions of 'able bodies and minds' become normative, and alternatives are not alternatives at all, but clear deviances or abnormalities. What is not the norm must be corrected towards the norm. This is essentially the logic of the medical model, i.e. disability

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<sup>18</sup>Nikolas Rose, "'Screen and Intervene': Governing Risky Brains", *History of the Human Sciences*, Vol. 23, No.1 (2010), 79-105.

<sup>19</sup>Waldschmidt, "Who is Normal? Who is Deviant?", p. 192.

as an abnormality in need of fixing; at the very least, it is seen as *a problem* well within medical expertise and practice. One of the challenges for disability theory is to look critically at the practices and discourses of those social/human sciences which establish the norms of life. It is no longer a matter of mere inclusion or community integration, but of letting marginalized voices equal weight in the definition of societal norms. This does not entail a rejection of science — an anti-medicine or anti-psychiatry — but the acceptance that living *is* a normative activity. Health, ability, and the worthiness of life are not established by clinical observations, but emerge in the confrontation with difficulties in living. As Canguilhem would have it, “[h]ealth is creative — call it normative — in that it is capable of surviving catastrophe and establishing a new order.”<sup>20</sup>

Historico-critical investigations undertaken by Canguilhem, Foucault, Hacking, McWhorter and Rose show us that the concept of normality is intricately linked to the development of the social/human sciences. These investigations enhance the “contestability” of clinical norms, “thus helping make possible other presents and other futures.”<sup>21</sup> It is on this point that we can see how Waldschmidt’s case fits into the more general problems of disability theory (something she is well aware of). As we shall see, Waldschmidt believes the case of pre-natal genetic screening in Germany shows how the concept of normality has come to dominate the apparatuses of normalization in the west. As a specific case in a much larger problem, it may help us understand how “the apparatuses of normalization that are applied in human genetics diagnostics and counseling highlight in a special way the impact

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<sup>20</sup>Georges Canguilhem, *A Vital Rationalist; Selected Writings*, François Delaporte (ed.) (NY: Zone Books, 2000) p. 355.

<sup>21</sup>Nikolas Rose, “Life, Reason and History: Reading Canguilhem Today”, *Economy and Society*, Vol. 27, No. 2&3 (1998), p. 165.

that normality has already gained on our daily lives.”<sup>22</sup> Thus, if we agree, its insights can be applied to other phenomena that occupy our social and academic projects. I will now discuss Waldschmidt’s analysis, followed by a general conclusion about Disability Theory in the normalizing society.

### **Risk, Normality, and Genetic Counseling**

As Waldschmidt recognizes, “[t]here is an important difference between normality and risk: whereas normality is based on quantitative data and the calculation of the average, risk implies a further operation, namely, probabilistic measurements.”<sup>23</sup> Risk is a probabilistic projection of a future event. It involves the prediction of a future ‘evil’ that can or should be controlled. In this way risk, in the human sciences, problematizes and moralizes decision patterns. For example, one problem that Waldschmidt raises — *vis-à-vis* the traditional feminist movement — is that the issue of selective genetics has not yet entered the abortion debates; though this issue had been recognized in the ’80s by some feminist disability thinkers. Namely, “[t]hey claim that selective abortion is in fact directed against an unborn child which was actually wanted in the first place.”<sup>24</sup> The genetic quality assessment of the fetus turns a heartily welcomed pregnancy into an undesirable one.”<sup>25</sup> That is to say, where the traditional pro-choice debate concentrated on the right to abort unwanted pregnancy, it didn’t address the issue of clinical knowledge problematizing (and terminating) wanted pregnancies.

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<sup>22</sup>Waldschmidt, “Who is Normal? Who is Deviant?”, p. 192.

<sup>23</sup>*Ibid.*, p. 197.

<sup>24</sup>She takes this from Theresia Degener’ and Swantje Köbsell’s research.

<sup>25</sup>Anne Waldschmidt, “Normalcy, Bio-Politics and Disability: Some Remarks on the German Disability Discourse”, *Disability Studies Quarterly*, Vol. 26, No. 2 (2006), No pagination. Open Source: <http://dsq-sds.org/article/view/694/871>

The reversal is interesting, because it emphasizes that the “clinical risk” projects a future evil that makes use of the expectation or want for a “normal” pregnancy and child.

Expectation here is produced both at the individual and social levels. “At the clinical level, as well as at the actuarial level, risk socializes events”; that is, “one can see clearly that the given misery afflicts not one individual alone; it afflicts a mass of people at the same time”.<sup>26</sup> That is to say, thinking at the level of the life of populations or the health of mankind as a species produces norms that proliferate in social discourse. On the other hand, it individualizes because the ‘data’ and the choice comes down to the mother’s body. It individualizes in terms of the actual medical practices and physical tests/procedures, but also in terms of her expectations of life, of child rearing, aspirations and the like. It is this complex interplay that animates the decision making process: the interplay between normalistic norms (of pregnancy, health, what makes life worthwhile) and perceptions of risk (i.e. the presence of undesirable deviation).

Given that these norms are produced by clinical knowledge, it has a certain authority in today’s society. The belief that these knowledges are objective and neutral, that their practitioners are objective and neutral, and that the information they produced is personalized, objective and neutral leaves little room for ambiguity. “They receive standards against which they can determine and objectivize their own personal risk”<sup>27</sup>; this in terms of “where one stands in relation to others: in the middle, in a transitional zone, at the negative or positive pole. Of course, one is also expected to draw a (proper) conclusion

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<sup>26</sup>Waldschmidt, “Who is Normal? Who is Deviant?”, p. 197.

<sup>27</sup>*Ibid.*, p. 204.

from this piece of information.”<sup>28</sup> Surely the nature, type, and content of this information are important factors. Waldschmidt proposes that “on the basis of clinical and statistical data, clients of genetic diagnostics are offered a number of different ‘landscapes’ with which to choose a normalistic location.” She points to three such “landscapes”; namely, the “family tree”, the “age curve”, and the “triplet test”.<sup>29</sup>

This first landscape “applies universal laws of heredity to individual cases” and past events “are extrapolated into the future”.<sup>30</sup> This landscape is well known to all of us, because it is ubiquitous to medicine in general — thinking here of the question ‘do you have a family history of —’. Though, in the case of genetic counseling the data is used for a probabilistic calculation. This comes in the form of a percentage statement such as “your son has a 25 percent chance of contracting the disorder”.<sup>31</sup> This is important for genetic counseling since this type of information sometimes “leads to the use of prenatal diagnostics”<sup>32</sup> — a foot in the door so to speak.

The second landscape, the age curve, “is used to statistically interpret a given pregnant woman’s relationship to her fetus.”<sup>33</sup> This landscape is based on the assumption that there is a link between a woman’s age and the presence of disorders at birth (this is not a contestation of this correlation). In Germany, since 1985, there has been a threshold of 35 that justifies genetic tests and counseling. At this threshold the genetic risk for Down syndrome is 1:370, which is roughly .3%. Basically, as age goes up and genetic risk factors are identified by

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<sup>28</sup> *Ibid.*, p. 198.

<sup>29</sup> *Ibid.*, p. 204.

<sup>30</sup> *Ibid.*, p. 199.

<sup>31</sup> *Idem*

<sup>32</sup> *Idem*

<sup>33</sup> *Idem*

the family tree and age curve, the client must weigh the risks of a disorder against the risk of an amniocentesis causing a miscarriage.<sup>34</sup>

The third landscape is the triplet test. This test is interesting because, as Waldschmidt points out, it was probably developed to escape the “35 years old” threshold and generalize risk assessments to younger women.<sup>35</sup> Specifically this is a hormone test that measures the level of a certain fetal metabolic product and two hormones. This data is then correlated with age and pregnancy duration and, with the help of a computer program, a risk statistic is calculated.<sup>36</sup> It is important to note that this test does not actually confirm the presence of a genetic “defect”; however, a “positive” result can lead to other, more invasive, examinations (such as amniocentesis).<sup>37</sup>

All three of these landscapes taken together make up the space within which expectant mothers find their normalistic location. Risk assessments come into play, in the first two cases, before impregnation and all three can be used in conjunction to assess risk during pregnancy. In the first case, it may lead to the decision not to conceive, and in the latter, if an elevated risk is identified, it will most likely lead to further examinations to determine with certainty if a “defect” is present. If one is found, the client must then make the decision of continuing or terminating the pregnancy. As she reminds us “[u]ltimately, orientation to probability calculations does not eliminate the basic problems linked with selective human genetics.”<sup>38</sup> This represents a significant challenge for disability theory *vis-à-vis* ever increasing genetic screening and manipulation technologies.

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<sup>34</sup>*Ibid.*, p. 201.

<sup>35</sup>*Idem*

<sup>36</sup>*Idem*

<sup>37</sup>*Ibid.*, p. 202.

<sup>38</sup>*Ibid.*, p. 205.

Given the socio-historical dimensions of eugenics in the 20<sup>th</sup> century, post-1945 medical practice does “not *officially* employ the concept of normality”<sup>39</sup>: “In the past, experts could give direct advice; in the days of neoliberal government, however, they may only help clients to identify their own position in the broad terrain of normality and deviation.”<sup>40</sup> This makes a lot of sense, but only if we understand that her claim is not that genetic counselors today are ‘closet Nazis’; it is not about the practitioners’ intentions.<sup>41</sup> It is a eugenics that derives from this change from legal to clinical norm producing discourse, and in the participation of the population itself in the production of norms. In other words, any *human genetic practice* that bases itself on statistical data to identify norms will *always already* apply or lead to a selective eugenics in practice. The argument is this: it would be wrong to have genetic counseling that identifies risk and applies a static rule (e.g. abort or not). This would be the eugenics of pre-1945. Additionally, it is unacceptable for a genetic counselor to use explicit normative statements, such as ‘based on the tests you ought to abort’, as this would be a case of using their ‘authority’ to carry out a selective eugenics project (it remains much too explicit). However, if the woman is made to choose herself, based on objective clinical data, the situation becomes much more complex (what Waldschmidt tries to show). This situation suggests that in today’s neoliberal way of thinking “the concept of self-determination [...] is increasingly being instrumentalized as a social weapon.”<sup>42</sup> By employing both individual and social normalization strategies, in conjunction with the problematic use of risk and

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<sup>39</sup> *Ibid.*, p. 196 (*my emphasis*).

<sup>40</sup> *Ibid.*, p. 198.

<sup>41</sup> Waldschmidt, “Normalcy, Bio-Politics and Disability”, no pagination.

<sup>42</sup> Degener, T., & Köbsell, S. (1992). “Hauptsache, es ist gesund!”, quoted in Anne Waldschmidt, “Normalcy, Bio-Politics and Disability: Some Remarks on the German Disability Discourse”, *Disability Studies Quarterly*, Vol. 26, No. 2 (2006).

probability, there is little question as to what 'choice' is expected of the mother. The concept of choice gives rise to what we could call eugenics without a head, with a much more flexible and dispersed method of 'selection'. The situation encountered by the mother is not one dominated by disciplinary power; the clinical relationship depends on self-regulating mechanisms that operate through discourses of personal choice and normality. What this case shows is that at the switch point between a predominantly disciplinary society and a normalizing society new problems for disability theory emerge.

### **Conclusions**

In 1996, Waldschmidt makes this statement:

"It is conceivable that disabled people may soon be considered as 'waste products' or 'accidents' in a genetically screened, technically engineered reproductive process that is designed to prevent sickness and suffering (...). Genetic therapy would be the only assistance offered to them. They would no longer receive any financial or social support. There would be cuts in social security and rehabilitation systems. The living conditions of the disabled would deteriorate (...). Before long, disabled people themselves could be held accountable for their fate and left to cope with life on their own. After all, they would only be people who should never have been allowed to be born anyway. In the long term, they would have no essential right to existence any more in an age of applied human genetic engineering (...). They would all face the dilemma of being alive but irrelevant factors according to the technocratic logic of the year 2000. The disabled would become the human 'garbage' of a future society."<sup>43</sup>

This is quite the gloomy prediction. Thankfully, this has never materialized. As we can see in her later works, though the human reproductive cycle has been thoroughly medicalized, it has not led to a complete

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<sup>43</sup>Waldschmidt, "Normalcy, Bio-Politics and Disability", no pagination.

deterioration of the experience of disability. In many ways, and as result of engaged and sustained effort by disability activists, the situation has improved. Waldschmidt writes, “[a]t present, one can witness a so-called “paradigm shift” in disability policies. Great efforts are being undertaken to increase general acceptance of disabled people, to make participation and self-determination possible for them and to build up an inclusive society.”<sup>44</sup> However, as we can see in the case of human genetic counseling, the problem of eugenics does not entirely disappear. Much to the contrary the questions of life in the 21<sup>st</sup> century — dominated by complex biotechnologies, bio-economy/bio-capital (insurance, organs/tissues, cost analysis of continuing life), and the socio-political instrumentalization of scientific knowledge (as in the example of genetic counselling) — presents an important problem for disability theory in the normalizing society. This is evident in other types of interventions which are also emerging elsewhere in the form of psychiatric or psychological screening in schools (for ADHD for example), or assessments of criminal risk (re-offense or violence) etc... In more general terms, she recognizes that “German disability rights activists [...] have not yet fully recognized that we live in a normalization society and not under authoritarian rule.”<sup>45</sup> This is a recommendation we could all benefit from. I think this is an important statement because it reminds us that there is neither universal truth to our condition, nor an immutable liberation “movement”, but *a constant battle or conflict whose battlefield shifts through time*. Yesterday’s battle is not today’s; we have to remain vigilant.

The war metaphor is not an appeal to ‘militant’ activism, but points to a fundamental dynamic of power. We can no longer understand our condition by “the old theory [...] of the seventeenth century [which]

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<sup>44</sup> *Idem*

<sup>45</sup> *Idem*

is articulated around power as a primal right that is surrendered” under a judicial/contractual framework, where an overstep results in “oppression” (i.e. an abuse of power); that is, of power as object/right derived from human nature or naturalized social structures.<sup>46</sup> Rather, we need to adopt what Foucault calls the “Nietzschean hypothesis”, where “the basis of the power-relationship lies in a warlike clash between forces”; in other words, “that what is rumbling away and what is at work beneath political power is essentially and above all a warlike relation.”<sup>47</sup> What follows is a need for constant engagement, vigilance, and active political resistance. Our political power today, i.e. our ability to effect change in our social condition, is contingent on our ability to understand the dominant modes of power against which we resist. In this sense, to understand the modes of power that emerge and proliferate through the course of history is reminiscent of the old maxim ‘know your enemy’. I think this is the political essence of Waldschmidt’s above statement that we should recognize that “we live in a normalization society and not under authoritarian rule.”

This is certainly very complex, and possibly discouraging; however, we need to be careful not to be too pessimistic. This movement is not treading water. It has led to positive developments for many people internationally; but there is work left to be done. I, like Waldschmidt, see much potential in disability theory. I see in this movement the possibility of escaping the positivist frameworks of mental illness and disability, which only give the appearance of neutrality, towards a more politically relevant/responsible framework that incorporates insights from social models and critical theory perspectives. However,

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<sup>46</sup>Foucault, “*Society Must be Defended*”, p. 16-17.

<sup>47</sup>*Ibid.*, Note: This is a simplified version of his reading of Nietzsche; even as it appears in the cited work it is meant to be a gloss. I believe it functions here as an introduction to the dynamic without much problem.

we must remember that there is no utopia or perfect system, no one answer that will *conclude* those various social movements that emerge from the indignation of those who are not privileged by the current “order of things”. This political situation is artfully described by Deleuze in his “Postscript on the Societies of Control” where he says: “[t]here is no need to ask which is the toughest regime, for it's within each of them that liberating and enslaving forces confront one another. [...] There is no need to fear or hope, but only to look for new weapons.”<sup>48</sup>

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<sup>48</sup>Gilles Deleuze, “Postscript on the Societies of Control”, *October*, Vol. 59 (1992), p. 4.

# Managed Detours: The Strategic Organization and Management of Social Problems

*Moira Ferguson*

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The impetus for this piece came about as I was completing social historical research on mental illness in Northern Ontario for my doctoral thesis. I had undertaken research in the archives of Ontario and had included in my thesis a critical ethnographic study wherein I interviewed fifteen people who had been diagnosed with or experienced a period of mental illness. I also interviewed fifteen people who had worked with, cared for, or delivered services to those considered to experience various mental health conditions. One of the most interesting ruptures I found was in the understandings of what mental illness is from each of these perspectives. The phenomenology of mental illness or madness, when considered from the experiences of people who identify or who have been identified with mental disorders, or as having mental illness, continues to raise interesting questions about human experience and meaning production. As well, what has been called mental illness, when considered within social historical contexts, calls for a thoughtful and critical analysis of the ways in which people have historically been separated, quarantined and ostracized from their societies, both geographically and socially. Indeed, in the contemporary moment, a diagnosis of what is called schizophrenia often comes with a prognosis of social isolation

and frequent hospitalizations, even for those so diagnosed who have good family and social support. I include in this piece excerpts from a person so diagnosed. Many of the people I interviewed spoke of the place of drugs or alcohol in either ameliorating or exacerbating the experience of mental illness, some to the extent that addiction to alcohol or drugs had become a secondary or concurrent diagnosable illness. I use the terms madness and mental illness and other descriptors as people, in my experience, generally self describe using a variety of terms.

The main point I want to focus on in this paper is that to live with what is called mental illness in post-modern society is to live also within the echo of a historically misunderstood phenomenon, a phenomenon that has also been the focus of science, charity and most recently, an industry of mental health. To this end I will discuss some attempts and successes of social reformers in 19<sup>th</sup> century to scientifically categorize and classify prisoners, habitual drunkards and those considered deviant. I will open up also an exploration of the latest classification system which considers consumers, survivors and addict/alcoholics under the same system of delivery of services.<sup>1</sup> The 19<sup>th</sup> century social reformist strategy and the current provincial integration of services strategies have relied on ideas of normal, moral and functional behavior which can be explored through a post-structuralist lens of power / knowledge relations. I have done this to some extent in other works.<sup>2</sup> In this paper, I will limit the discussion to the parallels of social reform in 19<sup>th</sup> century Ontario and the evolution of the consumer

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<sup>1</sup>Ontario's Local Health Integration Networks, *Highlights of the Local Health System Integration Act*, (2006), Retrieved 11 March 2012 from <<http://www.lhins.on.ca/legislation.aspx>>.

<sup>2</sup>Moira Ferguson, "*Tracing Paths: A Critical Ethnographic Study of Mental Illness in Northern Ontario*," Comprehensive Examination paper (Sudbury, Ontario: 2009).

model of health service delivery at the end of the 20<sup>th</sup> century in Ontario, with a focus on disrupting the discourse of mental illness.

### **The Search for Madness**

Michel Foucault writes in *History of Madness* that, “In the midst of the serene world of mental illness, modern man no longer communicates with the madman: on the one hand is the man of reason, who delegates madness to the doctor, thereby authorizing no relation other than through the abstract universality of illness; and on the other is the man of madness, who only communicates with the other through the intermediary of a reason that is no less abstract, which is order, physical and moral constraint, the anonymous pressure of the group, the demand for conformity.”<sup>3</sup> Foucault points to a parting of the way, in terms of conversation, between the madman and the man of reason; a space wherein the voice of psychiatry may step in and clarify what is madness and what isn’t. “The language of psychiatry,” he suggests “...is a monologue by reason *about* madness.”<sup>4</sup>

The rupture in conversation between the madman and the man of reason, to which Foucault directs us, began in Ontario with the physical separation of one from the other and the creation of spaces specifically built to house those people called old, feeble-minded, imbecilic, and lunatics. Certainly the treatment of many of these people within their communities cannot be said to have been kind or humane, but their removal from society, often far from their communities, began the silence, curiosity and myth making that surrounded many institutions.

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<sup>3</sup>Michel Foucault, *History of Madness* (Routledge: NY, 2009), p. xxviii.

<sup>4</sup>*Idem*

Indeed, as Foucault suggests, psychiatry claimed its voice in these times and madness began to be talked about with authority rather than ‘common sense’. One’s neighbor was no longer described as ‘not right in the head’ or as ‘having fits’. There was language for these conditions and a place for treatment. Ontario’s first of many hospitals for the reception of the insane opened in 1841 at a temporary location in Toronto’s York jail; in 1850, it was moved to 999 Queen street and was known from then until 1871 as the Provincial Lunatic Asylum.<sup>5</sup> This asylum became known as 999 Queen Street and is known infamously by this name by many, despite its having been renamed as 1001 Queen Street. In 1846, and until 1905, all such institutions were known as lunatic asylums. These institutions were under the management of a superintendent and were regularly inspected by the Inspector of Hospitals for the Insane.

In Ontario, from the 19<sup>th</sup> century institution building phase to the present, mental illness has been dealt with as a social problem at worst and as a curiosity at best. Insanity and lunacy had long been the subjects of morbid fascination. An 1848 *Globe and Mail* column reports on the Annual Lunatic Asylum Ball. Attendees, in letters to the editor describe the events of the social evening. On February, 23<sup>rd</sup>, 1848, ‘Spectator’ writes of receiving his much anticipated invitation to the Ball and his subsequent visit to the Insane Asylum. “About 9 o’clock”, he writes, “the lunatics withdrew to partake of some refreshments, and the visitors having got over the feeling of sadness, which naturally pervades the mind in contemplating such a number of shattered intellects, enjoyed themselves in a set of quadrilles. Wishing to see

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<sup>5</sup>Archives of Ontario, retrieved in 2009 from <[www.archives.gov.on.ca/english/collections/index.aspx](http://www.archives.gov.on.ca/english/collections/index.aspx)>.

as much as possible of the insane, we accompanied them down stairs, and watched their movements with tolerable closeness.”<sup>6</sup>

The tone of pity in ‘spectator’s’ letter, however condescending, is reflective of many of the public and political speeches that bolstered the agendas of social reformists. The insane lunatic and the imbecile were, for spectators and others, pitiable creatures. Whether motivated by compassion, the appearance of compassion, or concern for the soul, the lunatic presented a body upon which one could find repentance, political opportunities and the demonstration of reasonable and rational process as well as charity.<sup>7</sup> Lunacy appeared as a subject to be discussed through the establishment of laws and through constructions of what constituted good and rational behavior, often read as moral and functional behaviour.

One of the more vocal and successful reformists of the nineteenth century was John Langmuir. Langmuir was a gifted rhetorician who wrote successful proposals year after year. Richard Splane, professor emeritus in the School of Social Work at the University of British Columbia, Vancouver, credits Langmuir with widespread social reform. “Year after year” writes Splane, “during his fourteen years as inspector, Langmuir presented superbly prepared proposals that won governmental acceptance for new or enhanced programs in corrections and mental health, new facilities for the deaf and blind, and support and direction for a wide range of voluntary social welfare and health services under the Charity Aid Act.”<sup>8</sup>

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<sup>6</sup>*Globe and Mail* Feb. 23<sup>rd</sup>, 1848 Canada’s Heritage from 1844, retrieved from Laurentian University, (2009).

<sup>7</sup>For more on the theory of redemption through care, see Guenter Risse, “*Mending Bodies: Saving Souls*” (New York: Oxford University Press, 1999).

<sup>8</sup> Francis J. Turner, *Encyclopedia of Canadian Social Work* (Waterloo: Wilfred Laurier University Press, 2005), p. 210.

Langmuir began his long career with the intention of building a facility to house habitual drunkards. *The Fifth Annual Report of the Inspector of Asylums, Prisons & Charities* discusses the establishment of 'Inebriate Asylums'. Langmuir was most successful in both helping to establish a classification system by which to sort out society's institutionalized population and in maintaining institutional systems for the whole time of his tenure and beyond. One of the goals of reformists such as Langmuir was to determine a more humane and rational approach to the treatment and management of people, whether the fault was determined to lay in their genes or in their habits. Page 35 of the 5<sup>th</sup> Annual Report begins "...the statements and opinions which have been cited here are sufficient to prove that the plan of treating drunkenness as a *disease*, and of establishing hospitals for its cure or amelioration is not chimerical or impracticable..." The author continues in his case for such an institution:

"And last of all the establishment and maintenance of an Asylum of this character falls within the true sphere and work of the Government. It would be pre-eminently an institution of *public utility*, as the evil against which it would contend is pre-eminently a public burden and calamity. The degree of disease, idiocy, insanity and crime directly and indirectly caused by drunkenness, and the extent of the pecuniary expenditure out of the public funds together with the decrease and limitation of the general wealth thus occasioned are simply incalculable."<sup>9</sup>

Consequently, a committee, named the Select Committee appointed to enquire into the development of a Plan for the Control and Management of Habitual Drunkards, considered and agreed to a lengthy study at this time. Among these agreed to items was that 'the great evil of drunkenness' could be attributed to 'higher wages and shortened

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<sup>9</sup>Fifth annual report of Asylums, Prisons &c., for the province of Ontario, 1871-1872 printed by order of the legislative assembly. Toronto: Hunter, Rose & CO., 1873, p. 35.

hours of labour’ (pg35 *ibid.*). It is also noted and agreed to in this Report that the problem of habitual drunkenness does not seem to be as prevalent in agricultural districts.”<sup>10</sup>

One of Ontario’s first inspectors, Langmuir made it his life’s work to scientifically and rigorously study the nature of vice to better understand how to manage and classify the ever growing asylum population. Early eugenicists as well as mental health reformers sought the solution to what were considered emerging social and moral problems in classification and rehabilitation. Langmuir was at the tide of this wave, and can be read as standing on the moral/pragmatic side of reform. The underlying ethic was one of early to bed, early to rise philosophy which saw idleness as a breeding ground for ‘vicious’ behavior. In his attempts to classify the many types of people held in the provinces asylums, prisons and charitable institutions, and to suggest various effective methods of rehabilitation for each, Langmuir set up a committee to inquire into the nature of vice.<sup>11</sup> Much attention was given in this study to the types and reasons for crime; the idleness associated with shorter work weeks and the move from agricultural to industrial communities were cited as contributing to the general depravity of those with a propensity for vicious behavior. Among the contributors to Langmuir’s and his Commissioners’ study was Havelock Ellis author of *The Criminal* (1891) who suggested that there were classes of criminals, those being political criminals, (the victim of a despotic government), criminals by passion, insane criminals, instinctive criminals, and occasional criminals.<sup>12</sup> Of these, the instinctive criminal and the insane criminal

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<sup>10</sup>*Idem*

<sup>11</sup>Report of the Commissioners Appointed to Enquire into the Prison and Reformatory System of the Province of Ontario, Toronto 8<sup>th</sup> April 1891, Ontario Sessional Papers Vol. 23, Vic. 54, (no. 18) - 1891 Warwick and Sons, Toronto, 1891) p. 35..

<sup>12</sup>*Idem*

received the most colourful and speculative analysis. The instinctive criminals, for Ellis, “in their fully developed form are moral monsters in whom the absence of guiding or inhibiting social instincts is accompanied by unusual development of the sensual and self-seeking impulses....”<sup>13</sup> The insane criminals, suggests Ellis, “being in a condition of recognizable mental alienation perform some flagrantly anti-social acts....”<sup>14</sup>

Langmuir was not without the ability to think critically and must be read within both the political and social contexts of that time. However he can also be read as a particularly pragmatic and strategic liberalist in his distribution of funds and his plan to sort out first the classes of people, in relation to the greater society, and then the treatment of people, according to available institutions. His plans for the specific use of institutions were not always immediately successful. His report of 1877 indicates that a building constructed to house inebriates was actually used to take in the overflow of “chronic cases of insanity of a mild type, to be drawn from the Asylums at Toronto, London and Kingston.”<sup>15</sup> Langmuir’s social reform and his excellent ability to write persuasive proposals, although not always successful went some way in fortifying the use of the institutional spaces in such a way as to demonstrate their usefulness. Why let people (bad people) idle away when they could be put to practical use in institutions and could provide a profit for the province (good, hardworking people)?

The Report of the Commissioners also complemented the prevailing ideology of punishment as discipline. Prison wardens report almost

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<sup>13</sup> *Idem*

<sup>14</sup> *Idem*

<sup>15</sup> Langmuir, J.W. 10<sup>th</sup> Annual Report of the Inspector of Asylums, Prisons and Public Charities for the Province of Ontario, 1877, Toronto: Hunter, Rose & Co., 1878), p. 6.

gleefully on the availability of rock piles to be hammered down by inmates. Once the institutions were built they now had to be kept. Finally, Langmuir situates the causes of insanity, and of criminality in the person, not an unusual philosophy for his time. He wanted to ensure that the institutions were being used for their intended and specific purposes, having gone to great lengths to ensure that people were sent to the institution which would provide them with a scientifically calculated treatment; rest and discipline for the habitual drunkard and toil and discipline for the pauper and the criminal. He cautions against the practice by some people of handing family members over to the care of the province when it was not warranted. Langmuir described a process wherein the cause of insanity was ascertained by information given by witnesses such as family, a process which is hindered, as Langmuir saw it, by the commitment of lunatic's under the warrant of the Lieutenant Governor.<sup>16</sup> A person guilty of nothing more than outrageous behavior such as spending or promiscuity, as well as those who had become a financial burden could be sent to institutions with enough pressure from family members or, as was often the case, dissatisfied husbands.<sup>17</sup> Langmuir believed that it was too easy to obtain the Lieutenant Governor's Warrant and for the sake of humanity and prudence, the process should be changed to avoid the abuse of the institutions. This was, in part, why Langmuir wanted more control of the classification system. The method he proposed, a rigorous and rational inquiry calling on known experts in the treatment

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<sup>16</sup>Report of the Commissioners Appointed to Enquire into the Prison and Reformatory System of the Province of Ontario, Toronto 8<sup>th</sup> April 1891, Ontario Sessional Papers Vol. 23, Vic. 54, (no.18)- 1891 Warwick and Sons, Toronto, 1891) p. 35.

<sup>17</sup>For more on this explanation, see Thierry Nootens, "*To be quiet, orderly, obedient and industrious: La normalité dans le district judiciaire de Saint-François entre 1880 et 1920 d'après l'interdiction des "malades mentaux"*" (Québec : 1997).

of criminals and insane persons, would go some way toward establishing a system of classification, management and control.

In discussing the nature and genesis of crime, the Commissioners suggest that “these vices however, are in many cases the roots or germs of the greater offences called crime.”<sup>18</sup> It is here that Ellis submits his thoughts on the causes of crime, and brings the focus back to the weakness of character present, in varying degree, in each of the classes of criminals. Ellis is quoted extensively in this document, the Commissioners explain because he “...expresses the views of a large and important section of those who make the causes of crime a special study.”<sup>19</sup> One of the witnesses, in addressing the question as to the causes of crime, the Report explains, suggested that “...the tendency to cause crime is hereditary as are the formation of the body...”<sup>20</sup> This witness, a ‘specialist of considerable observation and experience’, theorized that “...mankind as a whole is steadily progressing, that each generation adds to the stock of general knowledge and thus contributes to the improvement of the race, but that some do not keep pace with the march of civilization.”<sup>21</sup> As to the prevalence of children of criminals who lead ‘honest, virtuous lives’ this witness suggested that it was only a matter of time until these committed some crime. This unnamed witness states that “...the only effectual mode of repressing or reducing crime was to shut up all the criminals, so that they could do no further mischief and could not propagate

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<sup>18</sup>Report of the Commissioners Appointed to Enquire into the Prison and Reformatory System of the Province of Ontario, Toronto 8<sup>th</sup> April 1891, Ontario Sessional Papers Vol. 23, Vic. 54, (no. 18)- 1891 Warwick and Sons, Toronto, 1891) p. 35.

<sup>19</sup>*Idem*

<sup>20</sup>*Ibid.*, p. 37.

<sup>21</sup>*Ibid.*, p. 37.

their kind.”<sup>22</sup> Clearly, a eugenic philosophy was at the heart of the inquiry in much the same way that prevailing philosophies, about work, about functional roles, about quality of life, about class, lie at the heart of even the most pragmatic of policy decisions in the present time.

By the time of the 1891 Report of the Commissioners, Langmuir already had a well-developed career in social reform. He continued his efforts to establish a social science of the classification of types of people ending up in institutions. In the case of the causes of insanity, which was also discussed in the 1877 10<sup>th</sup> Annual Report of the Inspector, a ‘scientific’ approach, again based on eugenics was used. A number of studies are used in these reports which point to the presence of insanity in the families of criminals. The family of Margaret Jukes is offered as an example of the worst case of hereditary criminality and insanity. The Jukes-Edward case was cited often in the early days of the eugenics movement. Margaret Jukes is said in the Report to have been responsible for ‘200 descendants who were criminals, besides great numbers of idiots, drunkards, lunatics, paupers and prostitutes.’<sup>23</sup>

The method used was to trace the family history for evidence of insanity, drunkenness, prostitution, idiocy or lunacy. ‘‘The Jukes: A Study in Crime, Pauperism, Disease and Heredity’’, written by Richard Dugdale and published in 1877, was written for the Prison Association of New York, and was the result of inquiries into county jails and state prisons. The study was used to strengthen the case for degeneration theory and to stress the necessity of classification, institutions and moral

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<sup>22</sup>*Ibid.*, p. 37.

<sup>23</sup>Langmuir, J.W. 10<sup>th</sup> Annual Report of the Inspector of Asylums, Prisons and Public Charities for the Province of Ontario, 1877, Toronto: Hunter, Rose & Co., 1878), p. 6.

reform. Mr. Vaux, another 'well-known student of criminal science' is quoted from the report of the inspectors of the State Penitentiary of Pennsylvania, 1887. Vaux is quoted as saying, ``... inherited crime cause and a crime class, the result of hereditary taint, are already demonstrated. The statement given (a statistical table), proves that many persons are criminals by reason of transmitted moral defects of character peculiar to families and traceable to transmitted conditions."<sup>24</sup> Eugenic theory was used extensively in sorting out the likelihood of both criminality and insanity. Of course, there was no Margaret Jukes. She and her offspring were born in eugenic imagination. We can picture her though, as an apt description has been provided of her behavior. She is slovenly, toothless, and either too fat or too thin. She is surrounded by wailing children, clinging to her stained dress while she clutches a bottle of liquor with one hand and grasps the belt buckle of a rough looking male companion with the other. This person cannot be allowed to breed. This person must be locked up and her brood must soon follow.

Langmuir reflects darkness in his writing of this period. He writes, with provincial pride, of the new asylums that have been erected. Asylums continued to be built or added to during this period largely due to the belief, commonly held and substantiated, at least in sheer numbers, that there had long been a need for institutions to which families could send their blind, deaf, dumb, elderly or insane relatives. The buildings were always full to capacity so it is hard to argue that families were at the mercy of a great plan of institutionalization carried out by an oppressive and overly zealous provincial leadership. As soon as they were built, they were rapidly filled. The physical structures erected during this time were ominous and foreboding. Beyond this, they

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<sup>24</sup>*Idem*

soon generated webs of myth and stories of the sheer terror of madness. This part of the discourse of madness, perhaps unreason taking its voice, is very much part of our cultural and social present.

### **The Mental Health Consumer and the Psychiatric Survivor**

Despite the stigma attached to mental illness, the consumer/survivor movement continues to flourish. Consumer/survivor initiatives or CSIs struggle to define themselves and their *raison d'être*. CSIs are usually run by and for people with lived experience of mental illness. These organizations offer a place for people with lived experience of mental illness to volunteer, work or in other ways participate with others who have similar lived experiences within the mental health system. They stress the need for consumer/survivors to have their own places and their own voices. They offer an alternative to the medical system. Like complementary medicine, which stands somewhere between allopathic medical practice and naturopathy, CSIs strike a philosophical bargain between a strictly medical model of mental illness and a social construction model of mental illness. In essence, CSIs make an argument for social inclusion for those with mental illness and for the reduction of barriers to society for people with lived experience of disability.

Still, it is hard to join up. It is hard to 'come out' as mentally ill or as alcoholic or addicted, even though these categories are medically sanctioned. The paradigm that joins 'consumer' and 'survivor' suggests an easy and natural relationship but it actually erases the separate trajectories of each movement. To some, perhaps to Don Weitz and others who identify strongly as psychiatric survivors of the system, consumer/survivor might roll off the tongue about as smoothly as

sandpaper.<sup>25</sup> In other cases, the consumer model as a movement has learned to make peace with the psychiatric system, adopting some of its language, some of its ideologies, some of its policy decisions and accepting some re-channeled funding.

Historically, psychiatric survivors vehemently refused funding. Somewhere, the survivor movement acquiesced and became part of the new health delivery service model. It is an interesting history of social outrage, social justice and compromise. The survivor and the consumer and the alcoholic are three separate entities. Once upon a time, all deviants, the compliant and the non-compliant, the lunatic and the drunkard were housed together, the idea being that society must be defended in the same way against all public nuisances and immoral influences. At present, mental health and addictions agencies are funded under the same governing and policy making body. In this relatively new political framework, people who use mental health services take up and either resist or internalize the ideology of the dominant discourse. In Ontario, the reforming of categories in the newest model began approximately 30 years ago, with the restructuring of health care delivery services focused on indentifying gaps in the delivery of health services.<sup>26</sup> A provincial policy analysis paper outlines the challenge for the government between the late nineteen fifties and the late nineteen seventies:

“Between 1959 and 1979, the province of Ontario closed 7,000 of its 11,000 provincial psychiatric hospital beds. Since that time the mental health policy debate has revolved around what to do with the remaining provincial hospital beds and the hospitals themselves, general hospital psychiatric programs and community mental health programs. Often

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<sup>25</sup>For more on Don Weitz, see “Call me Antipsychiatry Activist- not 'Consumer'”, *Radical Psychology*, Spring, 2002 (online: <http://www.radicalpsychology.org/vol3-1/don.html>)

<sup>26</sup>Robert Graham, “Building Community: A Plan for Mental Health Reform in Ontario” Ontario: 1988.

referred to as the three solitudes, these components of what should be a mental health system have historically not been well connected.”<sup>27</sup>

Public service announcements claim that we are all affected by mental illness in some way, that there is nothing to hide. However, in more subtle ways, through the media, through dominant ideologies which reward competition, the message is implanted; if you are not achieving success, in relationships, at work, in your cycles of sleep and rest, the error, weakness or misfiring neuron is in you. This individualization subtly points the lens of surveillance toward the self and away from the socially constructed environment. We would perhaps do well to take seriously the fear and bewilderment that defines the present. Psychiatry, still cloaked in mystery and esoteric language and often experienced as coerced obedience, offers solutions for sleeplessness, impotence, sadness, and existential musing gone a step too far. The new discourse of mental illness rewards consumption especially as the consumption of mental health services maintains a flourishing industry.

When one enters the mental health system, one becomes part of a system that thrives on maintenance rather than cure. At the top of this hierarchical system, at least if understood in terms of power, money and access to knowledge are psychiatrists, administrators, social scientists, policy makers, pharmacists and funding bodies. Somewhere in the middle layers are social workers, counsellors, occupational therapists, rehabilitation specialists, and most recently methadone counsellors or addiction specialists. Nearer the bottom of this hierarchy are the ‘troubled people’ of what Joseph Gusfield has called the troubled person’s industry.<sup>28</sup>

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<sup>27</sup>Steve Lurie, “Comparative Mental Health Policy: Are there Lessons to be Learned”, [http://www.toronto.cmha.ca/ct\\_PDFs/articles/sl\\_comparative\\_mental\\_health\\_policy.pdf](http://www.toronto.cmha.ca/ct_PDFs/articles/sl_comparative_mental_health_policy.pdf) retrieved 2010.

<sup>28</sup>Joseph Gusfield, “Deviance in the welfare state: the alcoholism profession and the entitlements

As the brief history of the search for madness and consequent treatment of those deemed to be mad shows, ideas about mental illness are tethered to historical frameworks which create binary relationships between moral traits and vicious traits, between good genes and bad genes. What has come to be called mental illness came into the social world as a problem to be solved and quickly became conflated with deviance and viciousness. What was built up or conceptualized to promote or at least to work in tandem with the eugenicist goals of a new world served also to differentiate normal from pathological, and to 'rigorously' classify one from the other. In Canada, this dichotomous relationship thrives in the contemporary moment on an ideology in which to be healthy means to contribute to the process of producing and consuming. Historically, social reform as a project in Ontario conceptualized mental illness through a discourse of deviance, wickedness and immorality. The contemporary corollary of this discourse serves to maintain and create a binary system of mental health consumer and expert advocate in a multi-layered system of surveillance and self surveillance. *Non-compliant* has replaced *wicked* and terms such as schizophrenia continue to suggest deviance and unreason. I include here an excerpt from a recent ethnographic interview, wherein a person describes the experience of living with a diagnosis of schizophrenia:

Morag: And then the next diagnosis... treatment was ten years later, '94 I had a span of no treatment for anything but the doctor at the uhh... it was another psychiatric referral and she gave me a diagnosis of schizo-affective disorder and once again a treatment of anti-psychotic and antidepressant both... yeah that was in '94

M: Did you have any ideas about that term, schizo affective, did it mean anything to you?

- Morag: Well it was a disconcerting diagnosis because as she explained it to me I had a delusion of reference... I was incorporating events around me into a central play that was psychotic..... so I didn't like it... I tried the medication for a while and I don't know it made me stupid dumbing me down which I guess is the idea of the anti-psychotic to get rid of those higher end thoughts
- M: Okay and so do you have any idea about what that word meant to other people... how did your family react?
- Morag: No. They didn't know. I was single at the time and I didn't really tell anybody... I didn't like the word schizo ..... sounds like psycho
- M: Tell me a bit more about that..... those words.... guess that's what I'm trying to get at... where these words come from and what they mean to us
- Morag: Well for a person with a mental illness diagnosis anything with the SKZ in it... sound ....is offensive like schizophrenic or schizoaffective
- M: How is that... what is that experience of having that diagnosis?
- Morag: It's because they're hard it's like an axe an ... an axe has been blunted into your personality that says you got an skz .....it's not a happy diagnosis ..... but the bi-polar as opposed to the manic- depressive that's a nice soft diagnosis... it's not offensive
- M: Oh geez.....okay
- Morag: But anyway the bipolar diagnosis came two years after the schizo-affective diagnosis... the company doctor at \*\*\*\* sent me to the psychiatric consultant they had at \*\*\*\* ... Dr. \*\*\*\* ....and together they came up with the diagnosis..... bi-polar based on the pressure of speech presentation I was giving... rapid talking ... many high end manic events associated with the bi-polar high.
- M: Okay..... And how was that..... I don't know if I've ever heard such a good description.....like the one was like an axe it's a good description...how is the bi-polar diagnosis softer

- Morag: Well that BP is just a nice sound it's like British Petroleum .... a trusted gas station.....hmm? .....a trusted gas station.... It's a trusted....it's a trusted diagnosis
- M: Trusted? The diagnosis is trusted or the person with the diagnosis?
- Morag: Well the person who receives that diagnosis *can* be trusted but if you have an SKZ you *can't* be trusted....bi-polar is more of an intellectual fragmentation.....instead of like....an SKZ always implies a dangerous personality ....the.... so intellectual fragmentation is easier with the bp... um...yeah so I like that
- M: Okay...how about the MD?
- Morag: The MD? The Manic Depressive?
- M: Is it the same as bi-polar or different ... a different sound? Different meaning?
- Morag: No as long as it's got that ...like AK or SK ....
- M: AK?
- Morag: Formulation manAK ... Depressive.... it's just umm.....it sounds dangerous again like a manic depressive sounds..... and people perceive that as... mania..... manic ..... Maniac.....maniac and psycho...if you get those two connotations out of the lingo it's easier on the person with the diagnosis to make it all soft....it's easier to wear that badge...
- M: Okay...okay
- W: Although if you have a bi-polar illness and you have a long period of unmedicated activity it can be dangerous in that you come up with very complicated schemes to fit your hypo-mania ... so a soft um a softer diagnosis but it's one that's easier to hide into if you're up to something
- M: Okay....it makes sense
- Morag: Not really ...it's psychotic but..... in the thinking of the mental illness so

M: So with these diagnoses....um you have your own perception about what they meant....yes....does it matter ...you said it's easier to wear that badge but why is it easier if no one knows you have it

Morag: Well word gets out your family and friends who do find out they tell other people and what happens is you do become socially isolated because people think 'geez buddy's got a mental illness there and he could snap.... there could be a bad scene or we might have to share the burden of something untoward or illogical even devious in our social milieu' so you do become socially isolated because people are afraid..... with any one of those the.... a soft one or a hard one people are afraid

M: Do you think it's just a physical thing or what else do you think people are afraid of?

Morag: Every so often you read in a newspaper that a SKZ or BP does kill someone out of either an unmedicated rage scenario or a mental deviation ....that's what people are afraid of is that there's something there that is unexpected and unpredictable and cannot be trusted ..... do not associate with openly because it is dangerous....in the percentile..... like people..... as soon as you get a diagnosis there is a danger for other people on a percentage basis...like you just can't be trusted<sup>29</sup>

## **The Survivor Movement**

The psychiatric survivor movement had a radically different origin than that of the consumer movement. In some ways, the consumer movement came out of the need to share funding and to close identified gaps in services during the nineteen eighties.

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<sup>29</sup> Personal Interview, 2009.

Among funding issues that came about during the Harris government's social spending cuts of the nineteen seventies in Ontario were the duplication of services and gaps in services.<sup>30</sup> It was thought that the community mental health model could address these issues by collecting the identified needs of mental health consumers (even if they preferred to be called survivors) and those with addictions. In Northern Ontario this model now sees mental health and addictions services under the auspices of 14 Local Integrated Health Networks or LHINs. In terms of funding, LHINs provide the same kinds of services to the same kinds of consumers. One may enter this system by way of a health or a mental health crisis, and may then be channeled through a series of community service programs which ensure long term involvement and dependence on the health care system. The main point of analysis of this paper is the subsuming of the very different and radical goals of psychiatric survivors, self support groups and other truly independent movements under the rubric of "consumer" and all that term implies. Consuming in the community mental health model can be indicative of compliance. The consumption of medicine, of definitions, of ideologies, of therapy, of services is often perceived as "getting better" or actively participating in one's recovery.

The term "consumer" as it has been applied to consumers of mental health services or users of mental health services came out of the collective activism of the nineteen sixties and nineteen seventies, consumer advocacy as a social movement and the "needs assessment" projects of the nineteen eighties. Human rights activism in the nineteen sixties and nineteen seventies in Canada saw black people and people of

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<sup>30</sup>Steve Lurie, "Comparative Mental Health Policy: Are there Lessons to be Learned," [www.toronto.cmha.ca/ct\\_PDFs/articles/sl\\_comparative\\_mental\\_health\\_policy.pdf](http://www.toronto.cmha.ca/ct_PDFs/articles/sl_comparative_mental_health_policy.pdf) retrieved 2010.

colour, lesbian, gay, transgender and bisexual people, and queer people, women and “disabled” people collectively demanding Human Rights.<sup>31</sup> Around this time, ex- patients or self described ex-inmates of psychiatric prisons<sup>32</sup> began to tell their stories and to self describe as psychiatric survivors. This was not the first time in Canadian history that people confined against their will had told their stories. Clifford Beers in *A Mind That Found Itself*<sup>33</sup> described the cruel treatment he underwent at the hands of attendants of a New Haven mental hospital. Beers established in America the National Committee on Mental Hygiene which later partnered with the Canadian Mental Health Agency.

Sally Clay, one of the first consumer advocates, writes of her first experiences doing consumer advocacy work with the Alliance for the Mentally Ill (a group of family members of consumers) and the Consumer Coalition. Clay writes of being invited to speak at the public hearing of the Office of Mental Health. Given a copy of the rights and regulations included in a document said to spell out the rights of patients confined to state hospitals, Clay was outraged to find in the document rules of behaviour for staff when faced with clients who would not comply with what was asked of them. There was, writes Clay, no mention of rights for patients.<sup>34</sup>

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<sup>31</sup>Bonnie Burstow open interview on AIDS/Gays/Lesbians on CKLN ( audiotape 75) Psychiatric survivor archives <[www.psychiatricsurvivorarchives.com/](http://www.psychiatricsurvivorarchives.com/) 1989>.

<sup>32</sup>Don Weitz, “Notes of a Schizophrenic Shitdisturber” (audiotape 92) Psychiatric survivor archives <[www.psychiatricsurvivorarchives.com/](http://www.psychiatricsurvivorarchives.com/)>

<sup>33</sup>Clifford Beers, *A Mind That Found Itself: An Autobiography* (Pittsburgh: University of Pittsburgh Press, 1980).

<sup>34</sup>Sally Clay, “A Personal History of the Consumer Movement” (no pagination).

There are critical distinctions to be made in the motivations and trajectories of the first organized groups of ex-patients. They did not call themselves consumers but survivors and they refused any government funding. In the United States, these activists called themselves, among other group names, the Insane Liberation Front, Mental Patients Liberation Front, Network Against Psychiatric Assault, Project Acceptance, and Mental Patients Alliance.<sup>35</sup> After years of protesting, these early activists, at least in the United States, writes Clay, eventually began to organize around offering services, rather than protesting treatment of psychiatric patients. Certainly, anti-psychiatry movements and conferences continue to critique and challenge the discourse of psychiatry, often now with a focus on pharmaceutical interventions. Historically, acts of nonviolent civil disobedience were acts of resistance against specific intrusive psychiatric treatments such as bed-strapping, confinement and electroshock treatment. A conference in Syracuse, New York saw psychiatric survivors block the doors of Benjamin Rush Psychiatric Center as an act of resistance against shock treatment.<sup>36</sup> This was, in America at least, the day the music died. From here on in, and by no means taking a straight path to complacency, those protesting the treatment of people said to be mentally ill continued to organize and to hold conferences and protests, but as the movement became more service oriented, consumer/ survivor initiatives and drop in centers became the focus for many people who had 'lived experience' with the mental health system. Even Clifford Beers had recognized the wisdom in recognizing that he who pays the piper calls the tune. Still radical psychiatric survivors such as Don Weitz continue to speak out. Indeed, anti-psychiatry is the focus of the Psychiatric Survivors Archives

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<sup>35</sup> *Idem*

<sup>36</sup> May 23-24 Tribunal -11th Annual International Conference for Human Rights and Against Psychiatric Oppression (Syracuse NY, 1983).

of Toronto, a grassroots organization which collects and maintains artifacts, interviews and all information pertaining to the period of psychiatrization in Canada from the institutional period to the present.

Time and again, movements, and attempts by ex-psychiatric survivors to band together to provide non-professional support and help in transitioning from hospital to community have been co-opted or taken over by professionals. In essence, when the troubled and disturbed mentally ill attempted to make sense of their lived and shared personal experiences and their lived and shared mad and psychiatric history (some caring more or less about the latter) they often found only funded organizations (of diverse mandates). These often relied, among therapies, on psycho-social rehabilitation, a technique born out of the recognized need to reintroduce institutionalized people back into the communities from which they had been removed. Psycho-social rehabilitation, and rehabilitative therapy more broadly understood often highlight the psychological (or physical) as problematic and erase the social as problematic, contending that the person in need of service needs to learn how to get along.

The consumer as a political entity began to take shape in the late nineteen eighties when “the three solitudes” of psychiatric services, beds and community services were attempting to better utilize resources.<sup>37</sup> After decades of protesting treatment at the hands of psychiatry, ex patients in Canada and in the United States were now demanding to be heard. The demand of ex-patients to participate in their own treatment decisions and the identified needs of the government to use most

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<sup>37</sup>Steve Lurie, “Comparative Mental Health Policy: Are there Lessons to be Learned,” [www.toronto.cmha.ca/ct\\_PDFs/articles/sl\\_comparative\\_mental\\_health\\_policy.pdf](http://www.toronto.cmha.ca/ct_PDFs/articles/sl_comparative_mental_health_policy.pdf) (retrieved 2010).

prudently and efficiently the resources they had could be said to represent a happy coincidence. A more critical analysis recognizes the turn from psychiatry as an industry to mental health as an industry. Psychiatry had acquired a long list of indictments by the end of the nineteenth century and well into the present, with charges of wide scale institutionalization, physical and mental experimentation, torture and abuse. One therapeutic intervention of psychiatry in particular, psychoanalysis, was taken up by mainstream pop psychology. Talk therapy is widely known as the therapeutic tool of the hippie generation which embraced transactional analysis and free for all psycho-social encounters. This move from the psychiatrist's couch to the encounter with self and existence, could have represented a pivotal moment in the history of mental illness, had it not been for the professionalization of even one's encounter with one's self; social work, social service and psychology took over where psychiatry left off, asserting that human beings, especially disturbed human beings, were not to be left to themselves.

One could perhaps liken the late nineteen seventies and eighties to a trade show for the mental health industry, with professional bodies of various strata claiming expertise and ownership of mental illness. Mental illness as a product was proving to be lucrative indeed. Psychiatric survivors went as far as to claim that their own experiences with mental illness or madness had been manipulated and exploited. How could this moment fail to have been realized; a moment when mentally ill human beings would claim their own experience, without professional rephrasing and analysis and from there decide what treatment they would have? The moment is not yet over, but it is a question that will not be answered here. In some ways, the radical notions of patients, survivors or ex-psychiatric inmates, along with those who identified as mental health consumers were linked to the recovery movement.

Consumers and some survivors saw the commonality of their experiences and some of the sting was then naturally taken out of the angry activism of the survivor. Tethered to the consumer, who saw a need for the mental health services and quite compliantly consumed medicine, services and ideas, the survivor was tamed to a great extent.

The term consumer starts to be readily found in mental health policy papers around the time that community programs are being funded. In fact, outside of policy papers, the term just starts to appear. One would assume that the term has come out of the social activism of the nineteen seventies mentioned earlier.

The consumer, the survivor and the chemical substance abuser share a common social and historical past. Once seen as one and the same, the lunatic and the habitual drunkard were the subject of many public and private discussions. This is the institutional and ideological history from which the consumer, the survivor and the chemical substance abuser or addict/alcoholic emerge. Certainly, the move toward community involvement can be said to have benefits and perhaps even to promote and enhance mental health. The challenge is in recognizing that the concept of mental health is a moving target, historically defined from a concept of normality which has an equally tainted history in eugenics. The happy move to community mental health should not be had at the cost of the erasure of the historical trajectory which saw anything outside of normal as deviant and in need of repair of rehabilitation.

As recently as 1988, the human mind or the brain provoked imagery of esotericism, secrecy and even Mad Scientists. David Reville and Kathryn Church, writing of user involvement in mental health services, re-capture for us the image on the cover of Maclean's magazine in

1988, *The Scientists Who Are Unlocking the Brain's Mysteries*. Reville and Church suggest that this might be “reflective of a general trend in medicine toward specialized, high-cost, technological solutions...” wherein mental disorder was “... a scientific problem to be solved primarily by engineers and equipment.”<sup>38</sup>

Church’s and Reville’s analysis of user involvement in mental health services situates the first of ex-inmate writings around the end of the nineteen seventies. *Phoenix Rising*, a distinctly antipsychiatry publication was among the first of the antipsychiatry publications. The quarterly was founded and published by a Toronto self help group called On Our Own.<sup>39</sup>

At about the same time that self-described ex-psychiatric patients began to form groups and to write about their experiences in the psychiatric system, there was a backlash in the media and a return to the practice of vilifying those involved in crimes whenever it was known that they had a history of using the services of the psychiatric system. Church and Reville, writing in 1988, describe the image of the psychiatric patient or user of mental health services.<sup>40</sup> The psychiatric patient is frightening and unreasonable and should not be legally allowed to make decisions concerning his or her treatment. The user of mental health services, while not quite conjuring up images of a mad man frothing at the mouth, shot gun in hand should, it is subtly suggested in nineteen eightie’s news stories, be treated with caution and should certainly not be given any position of authority or leadership.

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<sup>38</sup>Kathryn Church & David Reville “User Involvement in Mental Health Services in Canada: A Work in Progress,” University of Sussex, International Conference on User Involvement in Mental Health Services, 1988.

<sup>39</sup>*Idem*

<sup>40</sup>*Idem*

Historically, the discourse of mental illness included the use of words and images meant to conjure up fear when more institutions were wanted. This discourse was powerful and persuasive enough to be grounds for many, who were diagnosed as mentally ill, to be denied the right to determine their own course of treatment, and for many to be sent to spend the remainder of their lives in over-crowded institutions. The insurgence against psychiatric power in the nineteen eighties sought to dislocate the dominant discourse, which having taken on a distinctly medicalized lexicon, effectively shut out the voices of all but those taking pleasure in authority. Critical investigations of both the discourse of mental illness and the social relations involved in the mental health industry disrupt these images created by words and ask what, and for whom, they are being created.<sup>41</sup>

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<sup>41</sup> Some of the ideas and themes from this piece appear in my upcoming thesis, titled "Tracing Paths: A Social Historical Ethnography of 'Mental Illness' in Ontario".



## II – Child Development



# Classification Systems in Special Education: Social Justice or Just Social?

*Sean Cousins*

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**A**s an elementary teacher who has had direct experience with special education in public schools, I often ask myself questions about how the concept of disability has been imported into the office of public education. Terms such as “exceptional pupil<sup>1</sup>,” “inclusion<sup>2</sup>,” and “special needs<sup>3</sup>,” for example, litter the discourse of special education and serve as technologies of classification. In this paper I demonstrate an analysis of the classification system in special education and argue that the practice of labelling students with exceptionalities, by definition, should furl eyebrows and raise questions about whether the classificatory schema works to meet a model of social justice.

Special education in Ontario is a recent intervention of public policy. It was not long ago that the provision to provide educational services for children living with disability was a responsibility solely exercised at the discretion of parents and caregivers. In 1980, however, the

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<sup>1</sup>*Education Act of Ontario* R.S.O. 1990 c E.2, last revised 2002, s 1(1). Retrieved 4 January 2012 from <[www.e-laws.gov.on.ca](http://www.e-laws.gov.on.ca)>.

<sup>2</sup>Ontario Ministry of Education, *Education For All: The Report of the Expert Panel on Literacy and Numeracy Instruction for Students with Special Education Needs, Kindergarten to Grade 6* (2005), p. 2. Retrieved 10 January 2012 from <[www.edu.gov.on.ca](http://www.edu.gov.on.ca)>.

<sup>3</sup>Ontario Ministry of Education, *Special Education: A Guide for Educators* (2001), p. vi. Retrieved 8 January 2012 from <[www.edu.gov.on.ca](http://www.edu.gov.on.ca)>.

provincial government changed this scenario with the adoption of the Education Amendment Act. Commonly known as Bill 82, the Education Amendment Act requires Boards of Education to provide special education services to a specific class of students known as “exceptional pupils,”— that is, those who have been officially identified to stand in need of modifications and/or accommodations to their schooling. For little over 32 years, the provision of services for students with exceptionalities has been a mandatory practice amongst all of Ontario’s Boards of Education.

The significance of special education reflects the consciousness of a broader social movement that advocated for the public dissolution of segregation and, in its place, lobbied for the advancement of inclusion in everyday life, including in the context of public education. The historicity of disability is a subject too grand to explore in detail in this paper, but one aspect I do wish to touch upon is that those who have been classified as disabled, broadly speaking, have often experienced social oppression and exclusion from the public sphere. Even worse, individuals with disabilities have historically occupied positions as outcasts. Disability theorist Rosemarie Garland-Thomson, for example, has recently examined how persons with disability experience what it is like to be a “misfit<sup>4</sup>.” Thomson’s conceptualization of persons with disability as occupying the status of a misfit contributes to a social justice analysis of disability, since it attributes disability to the social and material processes of disablement. Thomson’s argument that disability emerges in contexts where there are social and material barriers is relevant to the system of classification of exceptionality in the context of special education in Ontario schools.

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<sup>4</sup>Rosemarie Garland-Thomson, “Misfits: A Feminist Materialist Disability Concept,” in *Hypatia*, vol. 26, No. 3 (2011), p. 591-609.

The relevance of a social justice model of disability is not lost on an analysis of exceptionality in context of special education. In fact, one of the fundamental premises of the social justice model of disability is that equal access is about changing the shape of the world, not changing the shape of the human figure. Changing the shape of the world costs money and it is an expenditure that the Ministry of Education subsumes as part of a commitment to the social justice. The system of funding elementary and secondary education in Ontario — Grants for Student Needs (GSN) — provides annual operating and capital funding to the 72 Boards of Education, allocated on the basis of several grants, one of which being the Special Education Grant. The size of the Special Education Grant depends on the total number of students identified in a particular Board of Education. Access to intensive, individualized support can be interpreted as a competitive process, given that monies to Boards of Education are allocated on the basis of identification of special needs students via formal assessment. Specific Boards of Education committees called “Identification, Placement and Review Committees” (IPRCs) function in each Board to decide whether individual students meet the criteria for various categories of exceptionality and to decide upon placement. Parents and guardians as well as children “sixteen and older” have input into the deliberations of these committees but do not possess final decision-making authority.

In Ontario, then, students’ learning, behavioural/emotional, developmental or other atypical characteristics are classified based on formal assessments done through the deliberations of the IPRC. Questions can be raised about the system of labelling that takes place within the IPRC and whether the practice of labelling constitutes an infringement of social justice. This paper contributes to the conversation about socio-material processes of disablement that Garland-Thomson initiated in her work on examining the experience of “misfitting”. More specifically, I

argue that the experience of misfitting can arise in the education system through the practice of labelling students with exceptionalities.

The coincidence of labelling a student with exceptionality and the situation of misfitting that I offer here is examined in relation to the fact that (a) identifications of exceptionality overlap with the medical model of disability; and (b) Boards of Education practice a system of labelling students with exceptionality that does not lay outside the encounter between flesh and world. One such case in the history of special education makes it clear that labelling students with exceptionalities can be synonymous with socio-material processes of disablement. Emily Eaton, a student with a disability, was initially placed in an integrated classroom. However, after three years, her teachers and assistants concluded that this placement was not in her best interests and she was subsequently moved to a specialized classroom. Her parents disputed the change of placement and appealed the decision up to the Supreme Court of Canada. The Court stated that the failure to place Emily Eaton in an integrated setting did not create burden or disadvantage to her, because such a placement was not in her best interests. According to the Court,

While integration should be recognized as the norm of general application because of the benefits it generally provides, a presumption in favour of integrated schooling would work to the disadvantage of pupils who require special education in order to achieve equality...Integration can be either a benefit or burden depending on whether the individual can profit from the advantages that integration provides<sup>5</sup>.

Previous to the legal case involving *Eaton v. Brant County Board of Education*, the Supreme Court of Canada had ruled that the search

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<sup>5</sup>Supreme Court of Canada, *Eaton v. Brant County Board of Education*, [1997] 1 S.C.R. 241, Retrieved 15 December 2011 from [www.scc.lexum.org/en/1997/1997scr1-241/1997scr1-241.html](http://www.scc.lexum.org/en/1997/1997scr1-241/1997scr1-241.html).

for accommodation is a multi-party inquiry<sup>6</sup>. In education, this ruling meant that the practice of labelling students must always be done in a spirit of collaborative effort insofar as each decision is determined according to the identification of exceptionality and the corresponding placement of accommodation. However, there is no one to one correlation necessarily between any particular category of exceptionality and placement of accommodation. All decisions that are made are done so on a case by case basis. This particular pattern of world-making involved in socio-material becoming for children with special needs is governed by the principle of individualization rather than by generalizations about specific disabilities. To comply with international human rights law and specific educational policy of Ontario, all children designated as special needs must be given an individualized learning plan within thirty days of identification<sup>7</sup>.

Thus a child identified as having a severe behavioural disorder, for instance, might be placed in a regular classroom with additional support if the IPRC so decides. Placement thus can be (a) in an integrated setting in a regular classroom with support, (b) in a partially integrated setting where the child is withdrawn for a certain period of time to receive special education service in another setting for one or more classes, (c) a segregated setting in a special education classroom with other exceptional students only for most of the time or (d) finally the most exclusionary setting involving a special education catering only to students that have been identified as belonging to some category or categories of exceptionality and who are deemed to require some more specialized service such as provided in provincial demonstration

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<sup>6</sup>Supreme Court of Canada, *Central Okanagan School District No. 23 v. Renaud*, [1992] 2 S.C.R. 970, para. 43. Retrieved 16 December 2011 from <[www.scc.lexum.org/en/1992/1992scr2-970/1992scr2-970.html](http://www.scc.lexum.org/en/1992/1992scr2-970/1992scr2-970.html)>.

<sup>7</sup>*Education Act of Ontario* R.S.O. 1990, c E.2, last revised 2011.

schools for the deaf and hard of hearing, for the blind, or cases involving pupils living with severe conditions of Attention Deficit Disorder/ Attention Deficit Hyperactivity Disorder. Let us turn then to an examination of the practice of labelling students with exceptionality in the Ontario special education system.

### **Classifications of exceptionality in Ontario's special education system**

The *Education Act of Ontario* specifies among the duties of the Minister of Education the following:

to define exceptionalities of students and *to prescribe classes, groups or categories* of exceptional pupils and *to require the use of these definitions* by school boards or such prescriptions as established under this clause.<sup>8</sup>

The categories of exceptionality to which a child can be assigned in Ontario are set out in section 1(1) of the *Education Act of Ontario* as follows:

An exceptional pupil is defined as:

A pupil whose *behavioural, communicational, intellectual, physical or multiple exceptionalities* are such that he or she is considered to need placement in a special education program by a committee...of the board...(a) of which the pupil is a resident pupil, (b) that admits or enrolls the pupil other than pursuant to an agreement with another board for the provision of education or (c) to which the cost of education in respect of the pupil is payable by the Minister.<sup>9</sup>

These broad categories of exceptionality are designed to address the wide range of conditions that may affect a student's ability to learn,

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<sup>8</sup>*Education Act of Ontario* R.S.O. 1990 c E.2, last revised 2011, s 8(3), emphasis added.

<sup>9</sup>*Education Act of Ontario* R.S.O. 1990 c E.2, last revised 2011, s 1(1), emphasis added.

and do not exclude any medical condition, whether diagnosed or not, that can lead to particular types of learning difficulties. Ministerial publications, such as the *Special Education: Guide for Educators*, further elaborate upon the inclusion of some medical conditions in the Education Act's definitions of the five categories of exceptionalities, thus basing the definitions on overt essentialist norms consonant to a medical model and referring to the specific exceptionality as a disorder and cause of the inadequate level of school function. Although decisions to place exceptional students in special education programs are made on grounds of "need" such decisions run the risk of appealing to the medical model of disability to interpret why needs arise in the first place at all.

The Ministry's Special Education Policy and Programs Branch recently sent a memorandum to Board of Education administrators on the subject of exceptionalities. In this memo the Ministry urged all Boards of Education to "interpret broadly"<sup>10</sup> the categories of exceptionality. The Ministry of Education claims that the IPRC process is safe from charges of misrepresentation because the force of any interpretation of exceptionality does not reach the effect of a clinical diagnosis. This kind of work is something reserved for health professionals under the *Ontario Regulated Health Professions Act*, since identifying a child with "dyslexia," "dyscalculia," or "attention deficit hyperactivity disorder," for example, is considered to be diagnostic health information.

Interpreting exceptionality as a form of "demonstrable learning based needs"<sup>11</sup> is meant to distance thinking about disability away from some

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<sup>10</sup>Barry Finlay, "Memorandum to Directors of Education, Supervisory Officers and Secretary-Treasurers of School Authorities, Director of Provincial Schools Branch, Superintendent of Centre Jules-Léger," in *Ministry of Education Letter 19 December 2011*, p. 1. Retrieved 7 January 2012 from <www.edu.gov.on.ca>.

<sup>11</sup>*Idem.*

general abnormality arising from a deficit in the body or mind. The significance of this interpretation is twofold: first, it maintains that exceptionalities exist on a continuum rather than comprising a discrete category of handicap; second, it identifies that special educational needs are, in part at least, the consequence of inappropriate educational facilities. The Ministry of Education attempts to situate its special education policy within a social model of disability; the “exceptional pupil” is viewed as one who cannot perform expected learning behaviour due to social and architectural barriers that factor into behavioural expressions of disablement. Yet the practice of labelling students as an exceptional pupil on any grounds complicates the business of interpreting exceptionality exclusively within a social model. The determining factor for the provision of special education programs or services is the needs of individual students based on the individual assessment of strengths and needs. The decision of accommodation at the discretion of the IPRC is thought to be a sufficient condition in removing the social and architectural barriers that hinder academic performance and which had led to socio-material processes of disablement.

But does the classification of exceptionality do away with a medical model? The significance of formulating the question in this way is that it seeks to discern whether the meaning of exceptionality denotes something intrinsic to the person even if the Ministry of Education claims otherwise. The terms of reference used by members of the IPRC to classify students with exceptionalities are also used by the broader public in ways that point to something residing within the individual. For example, the term “exceptionality” is defined in the current edition of Merriam-Webster’s online dictionary as “deviating from the norm” as in “having an above average intelligence” or “being

physically disabled”.<sup>12</sup> The term emphasizes essence over context, origination over mediation, isolation over relation. Exceptionality says something about the person in terms of some mental or bodily state, and what the person has is judged according to some “norm.” If some person is “physically disabled,” for example, that person has “exceptionality” because he or she demonstrates “deviance” from the “norm.” The label of exceptionality carries with it connotations that fix meanings intrinsic to the person which can lead to deeply embedded experiences of stigmatization.

The meaning of misfit, as I shall demonstrate, is not far removed from what is meant, at least in a colloquial register, by the term exceptionality. The utility of the concept of misfit is that it lodges social injustice and discrimination firmly in the materiality of the world. The term misfit carries with it a richly complex dimension of meaning. According to the same online dictionary, misfit denotes “an improper fit; someone who is badly adjusted to his or her environment.”<sup>13</sup> As a term that can be used either as a verb or noun, misfit refers to both the subject who does not fit and the act of not fitting. Used as a verb, to misfit denotes an encounter in which two things come together in disjunction. The shape and substance of these two things are instrumental in determining whether (or not) a match or “fit” is realized. Although a “perfect” fit may be construed as a fanciful ideal, the consequence of a lack of correspondence between two things often results in some-thing concretely felt as a socio-material problem. Taking hold of the situation that occurs when a square peg meets with a round hole approximates what it is like to observe a misfit. The situation revolving around a person is

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<sup>12</sup>*Merriam-Webster Online Dictionary*, (Merriam-Webster Inc., 2012). Retrieved 8 January 2012 from <www.merriam-webster.com>.

<sup>13</sup>*Idem*

altogether a different matter. A student, for example, may be said to “misfit” with his or her classroom. For instance, a student regularly demonstrates a lag between oral speech and its translation into print. This event may be interpreted as a misfitting experience, because the student’s ability to translate oral speech to print “misfits” with the expectation of being able to quickly translate oral speech to print. To misfit implies that there is something about the situation that makes for the student’s misfitting experience. What is an “improper fit” lies in the action that takes place when the student carries out the expectation to translate oral speech to print which results in a misfitting experience.

A student, however, is not an object (like a peg is). The problem with a misfit is more complicated than something that takes place in the space between two things, in their situated spatial and temporal relationship. When the spatial and temporal context shifts, so does the relationship between one thing and another; and with this shift comes consequences and meanings. A student with dyslexia, for example, is going to find conventional prose difficult, if not impossible, to decipher. But change the spatial and temporal conditions to reduce or minimize the experience of disablement and there can be promise of a more perfect union or fit in the classroom. The student can parse what is written on the whiteboard when the terms appear decipherable for the student.

The status of disability is literal when the shape and function of bodies comes in conflict with the shape and substance of the constructed world. The Ministry of Education claims that what is in store about the meaning of exceptionality has everything to do with “demonstrable learning needs<sup>14</sup>” and nothing at all to do with some underlying biological abnormality.

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<sup>14</sup>Barry Finlay, “Memorandum to Directors of Education, Supervisory Officers and Secretary-Treasurers of School Authorities, Director of Provincial Schools Branch, Superintendent of Centre Jules-Léger,” in *Ministry of Education Letter 19 December 2011*, p. 1. Retrieved 7 January 2012 from <[www.edu.gov.on.ca](http://www.edu.gov.on.ca)>.

But this claim is hard to accept when the whole IPRC process turns on the question of whether a student *should* be classified as an exceptional pupil. The student is judged according to some presumed characteristics that are assumed to be true of the personage of the student and not about his or her situation. The meaning of exceptionality closely resembles the meaning of being a misfit because the label of exceptionality says something about person in terms of the kind of student that person is within the context of public education. The student is not any student but an “exceptional pupil.” Someone is a misfit because he or she is “badly adjusted to his or her environment.” Someone is an exceptional pupil because he or she has “a learning disorder” that requires special programs and services.

The Ontario Human Rights Commission has received many reports from individuals and organizations that express concerns about the practice of labelling students with exceptionality or exceptionalities. Community advocacy groups within several Special Education Advisory Committees have alleged that the practice of labelling students with disabilities in the education system does harm apart from granting access to special education services and programs. The Cornwall Parent Support Group, for example, has stated that students “are judged against presumed group characteristics rather than being assessed by their own abilities.”<sup>15</sup> The practice of labelling students does not occur in isolation but rather takes place at various stages during the IPRC process. Consider the specific categories of exceptionality authored by the provincial legislature and used by members of the IPRC. According to the *Education Act of Ontario*, there are categories of exceptionality, including:

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<sup>15</sup>Ontario Human Rights Commission, *Guidelines on Accessible Education*, (OHRC: 2004), p. 30. Retrieved 9 January 2012 from <www.ohrc.on.ca>.

1. *Behaviour*: A learning disorder characterized by specific behaviour problems...that may be accompanied by one or more of the following:
  - an inability to build or to maintain interpersonal relationships;
  - excessive fears or anxieties;
  - a tendency to compulsive reaction;
  - an inability to learn that cannot be traced to intellectual, sensory, or other health factors, or any combination thereof.
2. *Communication*: (a) Autism: A severe learning disorder that is characterized by disturbances in rate of educational development, ability to relate to the environment, mobility, perception, speech, and language, and lack of the representational symbolic behaviour that precedes language; (b) Deaf and Hard of Hearing: An impairment characterized by deficits in language and speech development because of a diminished or non-existent auditory response to sound; (c) Language Impairment: A learning disorder characterized by impairment in comprehension and/or the use of verbal communication or the written or other system of communication...which may involve one or more of the form, content, and function of language in communication and include one or more of language delay, dysfluency, voice and articulation development...; (d) Speech Impairment: A disorder in language formation that may be associated with neurological, psychological, physical, or sensory factors...; (e) Learning Disability: A learning disorder evident in both academic and social situations that involves one or more of the processes necessary for the proper use of spoken language or the symbols of communication....
3. *Intellectual*: (a) Giftedness: An unusually advanced degree of general intellectual ability that requires differentiated learning experiences of a depth and breadth beyond those normally provided in the regular school program to satisfy the level of educational potential indicated. (b) Mild Intellectual Disability: A learning disorder characterized by ability to profit educationally within the regular class with the aid of considerable curriculum modification and supportive service... (c) Developmental Disability: A severe learning disorder characterized by... a limited potential for academic learning, independent social adjustment and economic self-support.
4. *Physical*: (a) Physical Disability: A condition of such severe physical limitation or deficiency as to require special assistance in learning

situations... (b) Blind and Low Vision: A condition of partial or total impairment of sight or vision that even with correction affects educational performance adversely.

5. *Multiple*: Multiple exceptionalities: A combination of learning or other disorders, impairments, or physical disabilities....<sup>16</sup>

With the exception of “physical disabilities” (including blind and low vision), “deaf and hard-of-hearing,” and “giftedness” all exceptionalities from the Ontario categorical scheme include definitions in terms of a *learning disorder*. It is important to note that when the *Education Amendment Act* made special education in Ontario mandatory, the Ministry of Education issued a set of definitions of exceptionality that were meant to refer to only deficits in functional level of performance. “Exceptionality” is meant to be interpreted without connotation to a medicalized model of disability and the presumed “learning disorder” is held not to originate and reside within the individual body. In recent years, the Ministry of Education has come under increasing criticism for its perceived noncompliance with principles of equity and social justice, given that the decades old list of exceptionalities has not evolved to reflect the maturation of special education and changes in philosophies, scientific knowledge, and social practices<sup>17</sup>.

It may be worth noting at this time that the distinction between disorder as an underlying cause and disability as a consequence of that disorder at the behavioural level is highly relevant to considerations of social justice, and particularly a consideration of the section 15 Charter equality issues involved in classification systems of special needs. At this section the Charter states that:

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<sup>16</sup>*Education Act of Ontario* R.S.O. 1990 c E.2, last revised 2011.

<sup>17</sup>Ontario Human Rights Commission, *The Opportunity to Succeed: Achieving Barrier-Free Education for Students with Disabilities*, Consultation Report (OHRC: 2004). Retrieved 9 January 2012 from <www.ohrc.on.ca>.

Every individual is equal before and under the law and had the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on...mental or physical disability...”<sup>18</sup>

The claim here is that Boards of Education in requiring assessments and classifications of the child based on special needs categories of exceptionalities overlap with mental health diagnoses are strikingly parallel, if not actually engaged in, adverse impact discrimination respecting exceptional students and their families. The fact that parents or caregivers in Ontario must provide written consent for any psychological, psychiatric, or other health assessment ordered at the discretion of the Board of Education that the student is a resident of as per the Ontario Health Consent Act (1996) does not eliminate, or detract from, the implicit coercive element in the situation. Another aspect of social justice that appears to be infringed is that section 15 of the Charter also guarantees that every person be accorded equal respect for their human dignity. As previously mentioned, the Ontario Human Rights Commission has detailed how the practice of labelling students through the IPRC process may fail to consider individual learning needs on a case by case basis.

I think the discourse of special education in Ontario’s public education system should provoke a vibrant public debate about how a more just and inclusive form of public education can be practiced. The allocation of taxpayer money to support the diversity of students in classrooms should not require the use of a classificatory system that in effect points fingers and draws attention to bodies in ways that creates a “misfitting” experience.

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<sup>18</sup>Government of Canada, *Canadian Charter of Rights and Freedoms*, 1982.

# The Models of Disability and the Effect of a Child with Autism on the Family

*Jana Duncan*

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In this paper, I begin by discussing the medical and social models of disability, and recent arguments to combine or move beyond these models, and define autism. I use the literature on the effects of a child with autism on the family to demonstrate that neither the medical nor the social model of disability could encompass the effects of autism on the family. Although parents discuss social constructions that are disabling to people with autism, such as society's lack of understanding, they also talk about impairments, such as aggressive behaviours.

## **Models of Disability**

The model of disability has changed, grown, and branched out over the past 30 years. It began with the medical or individual model of disability, which was overtaken by the social model of disability. The social model is based on the concept that the medical model looked at impairment, while the social model looks at how society disables people with impairments. As the social model of disability also began to be critiqued, theorists tried to combine or move beyond the medical and the social models of disability. There is currently no dominant model of disability that combines or moves beyond the medical or social models of disability.

Before the 1980s, the medical model was the dominant model of disability.<sup>1</sup> As Siebers points out, “disability has been a medical matter for as long as human beings have sought to escape the stigma of death, disease, and injury”.<sup>2</sup> Siebers defines the medical model of disability as “an individual defect lodged in the person, a defect that must be cured or eliminated if the person is to achieve full capacity as a human being”.<sup>3</sup> Wendell gives the United Nations definition of impairment as “any loss or abnormality of psychological, physiological, or anatomical structure or function”.<sup>4</sup> In summary, the medical model only looks at the effect of an impairment on a person, not the social effects leading to disability. It treats the impairment as the cause of the problems the impaired person faces, and it looks for solutions that cure the impaired person’s impairment.

Siebers defines the social model, as opposed to the medical model, by defining disability relative to the social and built environment, arguing that “disabling environments produce disability in bodies and require interventions at the level of social justice”.<sup>5</sup> The social model of disability “does not treat disease or disability, hoping to cure or avoid them; it studies the social meaning, symbols, and stigmas attached to disability identity and asks how they relate to enforced systems of exclusion and oppression”.<sup>6</sup> Thomas claims that now that disability is defined by social barriers, “the term ‘disability’ now refers to a type of social oppression, and disablism enters the vocabulary alongside sexism, racism,

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<sup>1</sup>Colin Barnes, Mike Oliver, and Len Barton, “Introduction,” in *Disability Studies Today* (Malden: Polity Press, 2002), p. 3.

<sup>2</sup>Tobin Siebers, *Disability Theory* (Michigan: University of Michigan Press, 2008), p. 3.

<sup>3</sup>*Idem*

<sup>4</sup>Susan Wendell, *The Rejected Body: Feminist Philosophical Reflections on Disability*, (New York: Routledge, 1996), p. 13.

<sup>5</sup>Tobin Siebers, *Disability Theory* (Michigan: University of Michigan Press, 2008), p. 25.

<sup>6</sup>*Ibid.*, p. 3

and other discriminatory practices”.<sup>7</sup> In summary, the social model looks at the social world as the only cause of disability, and it looks for solutions in changing the social world.

### Combined Models of Disability

Neither the medical nor the social model of disability adequately represents the lived experiences of people with disabilities when taken separately. Barnes, Oliver, and Barton claim that “concerns have been expressed regarding the social model's apparent neglect of the experience of impairment, the body, and questions of difference”.<sup>8</sup> The social model has been questioned by various theorists, including Allan.<sup>9</sup> Other theorists have attempted to combine the social/medical models, or impairment/disability, to create a blended model based on this dualism. There is not one generally accepted model of disability that goes beyond the social/medical models.

Wendell (1996) argues that we need a balance between thinking about impairment as uncontrollable, and thinking of disability as so socially constructed that it is controllable by human action and thought. She acknowledges that social justice can eliminate some disability, but that there is some impairment that cultural change cannot solve.<sup>10</sup> She gives a concrete example of the need to look beyond socially created aspects of disability when she talked about her own experiences getting sick:

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<sup>7</sup>Carol Thomas, “Disability Theory: Key Ideas, Issues and Thinkers,” in *Disability Studies Today*, ed. C. Barnes, M. Oliver and L. Barton (Malden: Polity Press, 2002), p. 38.

<sup>8</sup>Colin Barnes, Mike Oliver, and Len Barton, “Introduction,” in *Disability Studies Today* (Malden: Polity Press, 2002), p. 9.

<sup>9</sup>Julie Allan, “The Sociology of Disability and the Struggle for Inclusive Education,” in *British Journal of Sociology of Education*, vol. 31, no. 5 (2010), p. 603-619.

<sup>10</sup>Susan Wendell, *The Rejected Body: Feminist Philosophical Reflections on Disability* (New York: Routledge, 1996), p. 45.

“I felt taken over and betrayed by a profound bodily vulnerability.... This experience was not the result of any change of cultural “reading” of the body or of technological incursions into the body. I was infected by a virus, with debilitating physical and psychological consequences. Of course, my illness occurred in a social and cultural context, which profoundly affected my experience of it, but a major aspect of my experience was precisely that of being forced to acknowledge and learn to live with *bodily*, not cultural, limitations”.<sup>11</sup>

She had to come to terms with both her disability and her impairment, and finds the experiences of the body relevant.

McClimens criticizes the social model of disability in light of people with intellectual disabilities. He points out that many people with intellectual disabilities feel excluded from a model of disability designed around people with physical disabilities. He claims that the social model could be oppressive to certain sections of people with disabilities. He starts a discussion on thinking of disability on a continuum. He asks “is there some middle position that allows for the experience of intellectual disability to be understood as an amalgam of both?”.<sup>12</sup> He believes that impairment belongs in the definition of disability. He claims that impairment forces us to consider how some conditions cannot be changed through changes in the environment or society's view of people with impairments.<sup>13</sup>

Anastasiou and Kauffman also criticize the social model of disability. They claim that social constructionists only replace the biological determinism of the medical model of disability with cultural determinism, and that the social model is unable to encompass each and every

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<sup>11</sup>*Ibid.*, p. 169

<sup>12</sup>Alex McClimens, “The Organization of Difference: People with Intellectual Disabilities and the Social Model of Disability,” in *Mental Retardation*, vol. 41, no. 1 (2003), p. 43.

<sup>13</sup>*Ibid.*, p. 37

one of many disabilities.<sup>14</sup> Like McClimmins, they criticize social constructionists for applying a disability model and movement of people with physical disabilities to other disabilities such as intellectual disabilities, autism, sensory disabilities, and emotional and behavioural disorders. They argue that there is more to be gained from recognizing an impairment than by denying it as a social construction. They claim that “it is difficult to see what social barriers should be removed to accommodate the needs of people with autism”.<sup>15</sup>

When Clare discusses not being able to make it to the top of Mount Adams, he claims that he “decided that turning around before reaching the summit was more about impairment than disability. But even as [he] formed the thought, [he] could feel [his] resistance to it. To neatly divide disability from impairment doesn't feel right”.<sup>16</sup> He goes on to point out that his “frustration knows no neat theoretical divide between disability and impairment. Neither does disappointment or embarrassment”.<sup>17</sup> Clare wants to talk about disability and impairment, but he realizes that there is something else besides a social disability and a medical impairment. The duality no longer works in his story.

Paterson and Hughes agree that “the social model has to be reworked to incorporate all the complexities of being disabled”.<sup>18</sup> The complexities of being disabled include more than just the social constructions of disability and the biological or medical problems of impairment.

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<sup>14</sup>Dimitris Anastasiou and James Kauffman, “A Social Constructionist Approach to Disability: Implications for Special Education,” in *Exceptional Children*, vol. 77, no. 3 (2011), p. 376.

<sup>15</sup>*Ibid.*, p. 378

<sup>16</sup>Eli Clare, *Exile and Pride: Disability, Queerness, and Liberation* (Cambridge: South End Press, 2009), p. 7.

<sup>17</sup>*Ibid.*, p. 8

<sup>18</sup>Kevin Paterson and Bill Hughes, “Disability Studies and Phenomenology: the Carnal Politics of Everyday Life,” in *Disability and Society*, vol. 14, no. 5 (1999), p. 602.

They claim that “the problem with this dualistic position is that it requires the social model to embrace a disembodied view of disability and an asocial view of impairment”.<sup>19</sup> They also define active social disability as disabling barriers, and passive social disability as “attitudes and emotions that came from experiences of discrimination”.<sup>20</sup>

Hughes continues to talk about embodiment when he tries to bring the sociology of impairment into disability theory. Unlike the social model of disability, the sociology of impairment looks at the body without separating it from society, as the site of human experience. He looks at disability as embodied, and this can bring up issues that are not addressed by either the social or the medical model of disability, such as emotions that result from pain.<sup>21</sup>

Siebers' complex embodiment includes conditions such as chronic pain, secondary health effects, and ageing. He does not consider these defects, but calls them 'resistant to change', and claims that they must be considered along with the social forces.<sup>22</sup> Siebers claims that some disabilities can be approached with changes to perception or the environment, or some can be treated through medical care. Other disabilities cannot be approached by either.

Thomas' social-relational model acknowledges “pain, discomfort, fatigue, limited functioning, and other impairment effects”<sup>23</sup> by including

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<sup>19</sup>*Ibid.*, p. 599

<sup>20</sup>*Ibid.*, p. 600.

<sup>21</sup>Bill Hughes, “Disability and the Body,” in *Disability Studies Today*, ed. C. Barnes, M. Oliver, and L. Barton (Malden: Polity Press, 2002), p. 58-76.

<sup>22</sup>Tobin Siebers, *Disability Theory* (Michigan: University of Michigan Press, 2008), p. 25.

<sup>23</sup>Lorella Terzi, “The Social Model of Disability: A Philosophical Critique,” in *Journal of Applied Philosophy*, vol. 21, no. 2 (2004), p. 150.

'impairment effects' in her model of impairment and disability, along with 'barriers to doing' and 'barriers to being'.<sup>24</sup>

Shakespeare and Watson agree that the priority of a model of disability should be social change and barrier removal, not medical research, but they support appropriate action and prevention on impairment. They argue that people are disabled both by social barriers and by their bodies.<sup>25</sup> They also point out that “removing environmental obstacles for someone with one impairment may well generate obstacles for someone with another impairment”.<sup>26</sup>

Silverman, in his review of social science research on autism, addresses disability theory when he claims that

“specialists in disability studies distinguish between the social model and the medical model of disabilities. The most successful studies are those that refuse to situate their claims firmly within one model or the other, but instead pay attention to the strategic uses of different models by various interest group”.<sup>27</sup>

Although no one model of disability that combines or moves beyond the medical or social models has been clearly established, there are many arguments to move in this direction.

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<sup>24</sup>Bill Hughes, “Being Disabled: Towards a Critical Social Ontology for Disabled Studies,” *Disability and Society*, vol. 22, no. 7 (2007), p. 675.

<sup>25</sup>Tom Shakespeare and Nicholas Watson, “The Social Model of Disability: An Outdated Ideology?” in *Researching in Social Science and Disability*, vol. 2 (2001), p. 17.

<sup>26</sup>*Ibid.*, p. 18

<sup>27</sup>Chloe Silverman, “Critical Review: Fieldwork on Another Planet: Social Science Perspectives on the Autism Spectrum,” in *BioSocieties*, vol. 3 (2008), p. 336.

## Autism

Autism is defined in the DSM-IV as impairments in social interaction, communication, and stereotypic behaviour.<sup>28</sup> Children with autism also commonly experience hyper- and hypo- sensitivities to multiple senses<sup>29</sup>, seizures, behaviour difficulties, motor difficulties, self-care difficulties<sup>30</sup>, educational development delays<sup>31</sup>, and atypical physical, psychological, and perceptual difficulties.<sup>32</sup> Autism Spectrum Disorder is a spectrum of disorders, with a spectrum of severity.<sup>33</sup> Jensen and Spannagel used a two dimensional graph to create a chart with levels of autism symptoms (autism severity) on the x axis and level of cognitive impairment (deficit) on the y axis to attempt to encompass the full range of the autism spectrum.<sup>34</sup>

## Effect of a Child with Autism on the Family

The Educational Resources Information Center (ERIC), Sociological Abstracts, and Psyc INFO databases were searched for articles with “autism,” “family,” and effects such as “stress” in the titles since Pisula's

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<sup>28</sup>American Psychiatric Association, *Diagnostic and Statistical Manual for Mental Disorders*, 4<sup>th</sup> Ed. (Washington: APA, 1994), p. 75.

<sup>29</sup>Joyce Davidson, “It Cuts Both Ways’: A Relational Approach to Access and Accommodation for Autism,” in *Social Science and Medicine*, vol. 70 (2010), p. 307.

<sup>30</sup>National Research Council, *Educating Children with Autism* (Washington: National Academy Press, 2001). Pamela Norton and Clifford Drew, “Autism and Potential Family Stressors,” in *American Journal of Family Therapy*, vol. 22, no. 1 (1994), p. 67-76.

<sup>31</sup>Ministry of Education, *Special Education: A Guide for Educators* (Ontario, 2001), p. A18.

<sup>32</sup>Kristin Bumiller, “Quirky Citizens: Autism, Gender, and Reimagining Disability,” in *Signs: Journal of Women in Culture and Society*, vol. 33, no. 4 (2008), p. 973.

<sup>33</sup>American Psychiatric Association, *DSM-5 Development Website* (2011), <[www.dsm5.org/Pages/Default.aspx](http://www.dsm5.org/Pages/Default.aspx)>.

<sup>34</sup>Vanessa Jensen and Sarah Cain Spannagel, “The Spectrum of Autism Spectrum Disorder: A Spectrum of Needs, Services, and Challenges,” in *Journal of Contemporary Psychology*, vol. 41 (2011), p. 3.

2003 review of the literature on parents of children with autism. Bibliographies of significant articles were searched. Articles that were about dealing with the initial diagnosis of autism, adult children with autism, coping strategies, or the effects of external factors on parent stress such as parent traits were not included. Articles on the variety of Pervasive Developmental Disorders were included, as Mugno, Ruta, D'Arrigo and Mazzone found no statistically significant difference between parents of children across the range.<sup>35</sup>

The literature on the effect of a child with autism on the family included positive aspects of having a child with autism, such as enrichment<sup>36</sup>, a positive learning experience, finding true friendships, strengthened marriages and families, increased spirituality, becoming more patient, compassionate, humble, and accepting (Altiere & Von Kluge, 2009)<sup>37</sup>, greater selflessness, more compassion, a feeling of peace during uncertain times<sup>38</sup>, a new understanding of disability, being glad for child's uniqueness, enriched lives, positive emotions, appreciation of little things, marriage enrichment, positive family adjustment, positive effect on siblings, and spiritual enrichment (Myers, Mackintosh, &

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<sup>35</sup>Diego Mugno, Liliana Ruta, Valentina Genitori D'Arrigo, and Luigi Mazzone, "Impairment of Quality of Life in Parents of Children and Adolescents with Pervasive Developmental Disorder," in *Health and Quality of Life Outcomes*, vol. 5 (2007), p. 22.

<sup>36</sup>Kenneth Phelps, Susan McCammon, Karl Wuensch, and Jeannie Golden, "Enrichment, Stress, and Growth from Parenting an Individual with an Autism Spectrum Disorder," in *Journal of Intellectual and Developmental Disability*, vol. 34, no. 2 (2009), p. 133-141.

<sup>37</sup>Matthew Altieri and Silvia von Kluge, "Searching for Acceptance: Challenges Encountered while Raising a Child with Autism," in *Journal of Intellectual and Developmental Disability*, vol 34, no. 2 (2009), 142-152.

<sup>38</sup>Kenneth Phelps, Jennifer Hodgson, Susan McCammon, and Angela Lamson, "Caring for an Individual with Autism Disorder: A Qualitative Analysis," in *Journal of Intellectual and Developmental Disability*, vol. 34, no. 1 (2009), p. 27-35.

Goin-Kochel, 2009)<sup>39</sup>, but this analysis of the literature will focus on the negative aspects because it attempts to apply models of disability to the literature, and positive aspects are not considered impairments or disabilities.

Parents of children on the autism spectrum had more depression<sup>40</sup>, anxiety<sup>41</sup>, daily hassles<sup>42</sup>, and hopelessness<sup>43</sup> and less family adaptability and cohesion<sup>44</sup>, relationship satisfaction<sup>45</sup>, sleep quality and quantity<sup>46</sup>, quality of life<sup>47</sup>, physical activity and health, social

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<sup>39</sup>Barbara Myers, Virginia Mackintosh, and Robin Goin-Kochel, "My Greatest Joy and my Greatest Heartache: Parents' own Words on how Having a Child in the Autism Spectrum has Affected their Lives and their Families' Lives," in *Research in Autism Spectrum Disorders*, vol. 3, no. 3 (2009), p. 670-684.

<sup>40</sup>Paul Benson, "The Impact of Child Symptom Severity on Depressed Mood among Parents of Children with ASD: The Mediating Role of Stress Proliferation," in *Journal of Autism and Developmental Disorders*, vol. 36 (2006), p. 685-695.

<sup>41</sup>Gloria Lee, "Parents of Children with High Functioning Autism: How Well do they Cope and Adjust?" in *Journal of Developmental and Physical Disabilities*, vol. 21 (2009), p. 93-114.

<sup>42</sup>Nicole Quintero and Laura Lee McIntyre, "Sibling Adjustment and Maternal Well-Being: An Examination of Families with and without a Child with an Autism Spectrum Disorder," in *Focus on Autism and Other Developmental Disabilities*, vol. 25, no. 1 (2010), p. 37-46.

<sup>43</sup>Ewa Pisula, "Parents of Children with Autism - Review of Current Research," in *Archives of Psychiatry and Psychotherapy*, vol. 5, no. 4 (2003), p. 51-63.

<sup>44</sup>Daryl Higgins, Susan Bailey, and Julian Pearce, "Factors Associated with Functioning Style and Coping Strategies of Families with a Child with Autism Spectrum Disorder," in *Autism*, vol. 9, no. 2 (2005), p. 125-137.

<sup>45</sup>Jennifer Brobst, James Clopton, and Susan Hendrick, "Parenting Children with Autism Spectrum Disorders: The Couple's Relationship," in *Focus on Autism and Other Developmental Disabilities*, vol. 24, no. 1 (2009), p. 38-49.

<sup>46</sup>Lisa Meltzer, "Brief Report: Sleep in Parents of Children with Autism Spectrum Disorders," in *Journal of Pediatric Psychology Special Issue: Sleep in Pediatric Medical Populations*, vol. 33, no. 4 (2008), p. 380-386.

<sup>47</sup>Gloria Lee, Christopher Lopata, Martin Volker, Marcus Thomeer, Robert Nida, Jennifer Toomey, Sabrina Chow, and Audrey Smerbeck, "Health-related Quality of Life of Parents of Children with High-Functioning Autism Spectrum Disorders," in *Focus on Autism and Other Developmental Disabilities*, vol. 24, no. 4 (2009), p. 227-239.

relationships<sup>48</sup>, and sense of coherence, or confidence that a situation is manageable and engagement is meaningful<sup>49</sup> than parents of children without disabilities.

Mothers of children on the autism spectrum had more depression<sup>50</sup>, more emotional disorder<sup>51</sup>, more fatigue, more negative emotions<sup>52</sup>, and lower sense of self-efficacy<sup>53</sup> than mothers with typically developing children and less positive perceptions of their child than mothers of children with other disabilities.<sup>54</sup>

Stress is the most common and most commonly researched effect of having a child with autism on the family. The National Research Council

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<sup>48</sup>Diego Mugno, Liliana Ruta, Valentina Genitori D'Arrigo, and Luigi Mazzone, "Impairment of Quality of Life in Parents of Children and Adolescents with Pervasive Developmental Disorder," in *Health and Quality of Life Outcomes*, vol. 5 (2007), p. 22-31.

<sup>49</sup>Ewa Pisula and Zuzanna Kossakowska, "Sense of Coherence and Coping with Stress among Mothers and Fathers of Children with Autism," in *Journal of Autism and Developmental Disorders*, vol. 40, no. 12 (2010), p. 1485-1494.

<sup>50</sup>Leonard Abbeduto, Marsha Mailick Seltzer, Paul Shattuck, Marty Wyngaarden Krauss, Gael Orsmond, and Melissa Murphy, "Psychological Well-Being and Coping in Mothers of Youths with Autism, Down Syndrome, or Fragile X Syndrome," in *American Journal on Mental Retardation*, vol. 109, no. 3 (2004), p. 237-254.

<sup>51</sup>Vasiliki Totsika, Richard Hastings, Eric Emerson, Gillian Lancaster, and Damon Berridge, "A Population-Based Investigation of Behavioural and Emotional Problems and Maternal Mental Health: Associations with Autism Spectrum Disorder and Intellectual Disability," in *Journal of Child Psychology and Psychiatry*, vol. 52, no. 1 (2011), p. 91-99.

<sup>52</sup>Leann Smith, Jinkuk Hong, Marsha Mailick Seltzer, Jan Greenberg, David Almeida, and Somer Bishop, "Daily Experiences among Mothers of Adolescents and Adults with Autism Spectrum Disorder," in *Journal of Autism and Developmental Disorders*, vol. 40, no. 2 (2010), p. 167-178.

<sup>53</sup>Mieke Meirsschaut, Herbert Roeyers, and Petra Warreyn, "Parenting in Families with a Child with Autism Spectrum Disorder and a Typically Developing Child: Mothers' Experiences and Cognitions," in *Research in Autism Spectrum Disorders*, vol. 4, no. 4 (2010), p. 661-669.

<sup>54</sup>Gemma Griffith, Richard Hastings, Susie Nash, and Christopher Hill, "Using Matched Groups to Explore Child Behaviour Problems and Maternal Well-being in Children with Down Syndrome and Autism," in *Journal of Autism and Developmental Disorders*, vol. 40, no. 5 (2010), p. 610-619.

stated that the parents of children with autism may experience sadness, anger, or disappointment about their child's disability and how it affects their lives, and that although many families cope well, some experience “very substantial stress”.<sup>55</sup> Thirty eight percent of parents of high functioning children with autism showed a clinically significant total stress score on the Parenting Stress Index – short form and, emotional difficulty, including stress, was a theme in their attached qualitative content analysis.<sup>56</sup> In Myers, MacKintosh, and Goin-Kochel's qualitative questionnaire, they found that “stress was the most frequent theme that arose in parents' accounts of how their child in the spectrum affected them and their families”.<sup>57</sup> It also arose as a theme in the content analysis of other qualitative papers on parents of children with autism, such as Papageorgiou & Kalyva.<sup>58</sup> Similarly, Hutton and Caron found that “the overwhelming majority of parents used the word 'stressful' to describe their experience of having a child with autism”.<sup>59</sup>

Parents of children on the autism spectrum had more stress than parents of children without disabilities<sup>60</sup> and children with other disorders,

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<sup>55</sup>National Research Council, *Educating Children with Autism*, (Washington: National Academy Press, 2001), p. 32.

<sup>56</sup>Myra Beth Bundy and Linda Kunce, “Parenting Stress and High Functioning Children with Autism,” in *International Journal on Disability and Human Development*, vol. 8, no. 4 (2009), p. 404.

<sup>57</sup>Barbara Myers, Virginia Mackintosh, and Robin Goin-Kochel, “My Greatest Joy and my Greatest Heartache: Parents' own Words on how Having a Child in the Autism Spectrum has Affected their Lives and their Families' Lives,” in *Research in Autism Spectrum Disorders*, vol. 3, no. 3 (2009), p. 674.

<sup>58</sup>Vaya Papageorgiou and Efrosini Kalyva, “Self-Reported Needs and Expectations of Parents of Children with Autism Spectrum Disorders who Participate in Support Groups,” in *Research in Autism Spectrum Disorders*, vol. 4 (2010), p. 653-660.

<sup>59</sup>Adam Hutton and Sandra Caron, “Experiences of Families with Children with Autism in Rural New England,” in *Focus on Autism and Other Developmental Disabilities*, vol. 20, no. 3 (2005), p. 186.

<sup>60</sup>Brooke Ingersoll and David Hambrick, “The Relationship between the Broader Autism Phenotype, Child Severity, and Stress and Depression in Parents of Children with Autism Spectrum Disorders,” in *Research in Autism Spectrum Disorders*, vol. 5, no. 1 (2011), p. 337-344.

such as Down Syndrome.<sup>61</sup> Mothers of children on the autism spectrum have more stress than mothers with typically developing children<sup>62</sup> and with other developmental disabilities without autism<sup>63</sup> and chronic physical illness.<sup>64</sup> Smith et al. found that mothers of children with autism had more stressful daily events than mothers with typically developing children.<sup>65</sup>

The question must be raised, why is raising a child with autism stressful? The quantitative data gives us an idea of the impact of both social and child variables on stress (but not how parents of children with autism view these variables).

### Social and Child Variables

When toddler aged children with autism received childcare interventions, mothers showed significant reductions in child-related

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<sup>61</sup>A. Dabrowska and E. Pisula, "Parenting Stress and Coping Styles in Mothers and Fathers of Pre-School Children with Autism and Down Syndrome," in *Journal of Intellectual Disability Research*, vol. 54 (2010), p. 266-280.

<sup>62</sup>Charles Hoffman, Dwight Sweeney, Danelle Hodge, Muriel Lopez-Wagner, and Lisa Looney, "Parenting Stress and Closeness: Mothers of Typically Developing Children and Mothers of Children with Autism," in *Focus on Autism and Other Developmental Disabilities*, vol. 24, no. 3 (2009), p. 178-187.

<sup>63</sup>Annette Estes, Jeffery Munson, Geraldine Dawson, Elizabeth Koehler, Xiao-Hua Zhou, and Robert Abbott, "Parenting Stress and Psychological Functioning among Mothers of Preschool Children with Autism and Developmental Delay," in *Autism*, vol. 13, no. 4 (2009), p. 375-387.

<sup>64</sup>Ewa Pisula, "Parents of Children with Autism - Review of Current Research," in *Archives of Psychiatry and Psychotherapy*, vol. 5, no. 4 (2003), p. 51-63.

<sup>65</sup>Leann Smith, Jinkuk Hong, Marsha Mailick Seltzer, Jan Greenberg, David Almeida, and Somer Bishop, "Daily Experiences among Mothers of Adolescents and Adults with Autism Spectrum Disorder," in *Journal of Autism and Developmental Disorders*, vol. 40, no. 2 (2010), p. 167-178.

stress.<sup>66</sup> Also, when a grown child with autism moved out of the family home, maternal anxiety was reduced.<sup>67</sup> These two results demonstrate that when there is support in the form of care for the person with autism, stress and anxiety is reduced. An increase in family, social, emotional, and informal support was found to lead to decreased maternal stress<sup>68</sup>, while a decrease in support has been found to lead to more maternal stress.<sup>69</sup> Hutton and Caron found that most parents said services greatly reduced their stress, although some found them more stressful due to the work involved.<sup>70</sup> Norton and Drew believe that respite care is crucial for the well being of parents with autism.<sup>71</sup> Meadan, Halle, and Ebata claimed that although there is limited research on the effect of respite care on families of children with autism, they believe that respite would reduce stress based on stress being caused by things such as time demands.<sup>72</sup>

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<sup>66</sup>Mary Baker-Ericzén, Lauren Brookman-Fraze, and Aubyn Stahmer, "Stress Levels and Adaptability in Parents of Toddlers with and without Autism Spectrum Disorders," in *Research and Practice for Persons with Severe Disabilities*, vol. 30, no. 4 (2005), p. 194-204.

<sup>67</sup>Erin Barker, Sigan Hartley, Marsha Mailick Seltzer, Frank Floyd, Jan Greenberg, and Gael Orsmond, "Trajectories of Emotional Well-being in Mothers of Adolescents and Adults with Autism," in *Developmental Psychology*, vol. 47, no. 2 (2011), p. 551-561.

<sup>68</sup>Naomi Ekas, Diane Lickenbrock, and Thomas Whitman, "Optimism, Social Support, and Well-Being in Mothers of Children with Autism Spectrum Disorder," in *Journal of Autism and Developmental Disorders*, vol. 40, no. 10 (2010), p. 1274-1284.

<sup>69</sup>Jo Bromley, Dougal Julian Hare, Kerry Davison, and Eric Emerson, "Mothers Supporting Children with Autistic Spectrum Disorders: Social support, mental health status, and satisfaction with services," in *Autism*, vol. 8, no. 4, (2004), p. 409-423.

<sup>70</sup>Adam Hutton and Sandra Caron, "Experiences of Families with Children with Autism in Rural New England," in *Focus on Autism and Other Developmental Disabilities*, vol. 20, no. 3 (2005), p. 185-186.

<sup>71</sup>Pamela Norton and Clifford Drew, "Autism and Potential Family Stressors," in *American Journal of Family Therapy*, vol. 22, no. 1 (1994), p. 71.

<sup>72</sup>Hedda Meadan, James Halle, and Aaron Ebata, "Families with Children who have Autism Spectrum Disorders: Stress and Support," in *Exceptional Children*, vol. 77, no. 1 (2010), p. 27.

A child's behaviour or emotional problems have an effect on maternal stress<sup>73</sup> and stress.<sup>74</sup> Lecavalier, Leone, and Wiltz found that behaviour problems were more associated with stress than child adaptive behaviour or parent familiarity with applied behaviour analysis (a method of teaching children with autism) and autism spectrum disorders.<sup>75</sup> Herring et al. found that child emotional and behaviour problems contributed more to maternal stress than diagnosis or delay.<sup>76</sup> A qualitative study found that “the parents [of children with autism] who were the most distressed were those whose children were aggressive and/or severely obsessive.<sup>77</sup> Ninety percent of parents reported that they were sometimes unable to deal effectively with their child's behaviour, and felt stretched beyond their limits.<sup>78</sup>

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<sup>73</sup>Richard Hastings, Hanna Kovshoff, Nicholas Ward, Francesca degli Espinosa, Tony Brown, and Bob Remington, “Systems Analysis of Stress and Positive Perceptions in Mothers and Fathers of Pre-School Children with Autism,” in *Journal of Autism and Developmental Disorders*, vol. 35, no. 5 (2005), p. 635-644.

<sup>74</sup>Supapak Phetrasuwan and Margaret Shandor Miles, “Parenting Stress in Mothers of Children with Autism Spectrum Disorders,” in *Journal for Specialists in Pediatric Nursing*, vol. 14, no. 3 (2009), p. 157-165.

<sup>75</sup>L. Lecavalier, S. Leone, and J. Wiltz, “The Impact of Behaviour Problems on Caregiver Stress in Young People with Autism Spectrum Disorders,” in *Journal of Intellectual Disability Research*, vol. 50, no. 3 (2006), p. 172-183.

<sup>76</sup>S. Herring, K. Gray, J. Taffe, B. Tonge, D. Sweeney, and S. Einfeld, “Behaviour and Emotional Problems in Toddlers with Pervasive Developmental Disorders and Developmental Delay: Associations with Parental Mental Health and Family Functioning,” in *Journal of Intellectual Disability Research*, vol. 50 (2006), p. 874-882.

<sup>77</sup>David Gray, “Ten Years On: A Longitudinal Study of Families of Children with Autism,” in *Journal of Intellectual and Developmental Disability*, vol. 27, no. 3 (2002), p. 218.

<sup>78</sup>Vicki Bitsika and Christopher Sharpley, “Stress, Anxiety and Depression among Parents of Children with Autism Spectrum Disorder,” in *Australian Journal of Guidance & Counselling*, vol. 14, no. 2 (2005), p. 155.

### **A Model of Disability for Parents of Children with Autism**

The question now is how families with children with autism view these variables, whether they are based on social or medical / individual views of disability. Baker researched how the public, through newspaper articles, defined autism. She found that discussions about autism focused on health care policy, not rights<sup>79</sup>, so public opinion, represented by the news, used the medical model of disability. My interest is the model of disability used by families of children with autism, through a literature review on the effect of a child with autism on the family. The model of disability used by parents of children with autism is primarily and overwhelmingly social, so much so that the literature review could nearly be called “the effect of society on families of children with autism”.

Looking at the qualitative research on parents of children with autism, the most common theme content coded was society's lack of understanding and acceptance.<sup>80</sup> The theme of a lack of understanding in Myers, MacKintosh, & Goin-Kochel was actually called “bad treatment by strangers”.<sup>81</sup> Woodgate, Ateah, & Seccon claimed that parents felt that society valued their children with autism less than other children.<sup>82</sup>

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<sup>79</sup>Dana Lee Baker, “Defining Autism in Canada: Unfolding the Public Aspects of Neurological Disability,” in *The Social Science Journal* vol. 44 (2007), p. 687-697.

<sup>80</sup>Mieke Meirsschaut, Herbert Roeyers, and Petra Warreyn, “Parenting in Families with a Child with Autism Spectrum Disorder and a Typically Developing Child: Mothers’ Experiences and Cognitions,” in *Research in Autism Spectrum Disorders*, vol. 4, no. 4 (2010), p. 661-669.

<sup>81</sup>Barbara Myers, Virginia Mackintosh, and Robin Goin-Kochel, “‘My Greatest Joy and my Greatest Heartache:’ Parents’ own Words on how Having a Child in the Autism Spectrum has Affected their Lives and their Families’ Lives,” in *Research in Autism Spectrum Disorders*, vol. 3, no. 3 (2009), p. 681.

<sup>82</sup>Roberta Woodgate, Christine Ateah, and Loretta Secco, “Living in a World of our Own: The Experience of Parents who have a Child with Autism,” in *Qualitative Health Research*, vol. 18, no. 8 (2008), p. 1078.

This lack of understanding went well beyond society as a whole, and included strained family relationships<sup>83</sup>, difficulty with the church community<sup>84</sup>, and lost friendships.<sup>85</sup> Altieri & Von Kluge point out that, “as they experience difficult incidents with the public, friends, and extended family members, parents learn that most people are ignorant of the issues associated with raising children with autism”.<sup>86</sup> For example, it is common for parents to talk of this lack of acceptance, such as saying “People do not welcome us into their homes,” and “I get angry and depressed about the way that strangers stare at her some-times in public”.<sup>87</sup> One can understand why although parents want to improve services, their main goal is “to gain acceptance and recognition from others”.<sup>88</sup> Acceptance by schools and other services was also specifically addressed by parents of children with autism.<sup>89</sup>

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<sup>83</sup>Heather Hall and Carolyn Graff, “Parenting Challenges in Families of Children with Autism: A Pilot Study,” in *Issues in Comprehensive Pediatric Nursing*, vol. 33, no. 4 (2010), p. 195.

<sup>84</sup>Kenneth Phelps, Jennifer Hodgson, Susan McCammon, and Angela Lamson, “Caring for an Individual with Autism Disorder: A Qualitative Analysis,” in *Journal of Intellectual and Developmental Disability*, vol. 34, no. 1 (2009), p. 30-31.

<sup>85</sup>Vaya Papagergiou and Efrosini Kalyva, “Self-Reported Needs and Expectations of Parents of Children with Autism Spectrum Disorders who Participate in Support Groups,” in *Research in Autism Spectrum Disorders*, vol. 4 (2010), p. 655.

<sup>86</sup>Matthew Altieri and Silvia von Kluge, “Searching for Acceptance: Challenges Encountered while Raising a Child with Autism,” in *Journal of Intellectual and Developmental Disability*, vol 34, no. 2 (2009), p. 150.

<sup>87</sup>Barbara Myers, Virginia Mackintosh, and Robin Goin-Kochel, “‘My Greatest Joy and my Greatest Heartache:’ Parents’ own Words on how Having a Child in the Autism Spectrum has Affected their Lives and their Families’ Lives,” in *Research in Autism Spectrum Disorders*, vol. 3, no. 3 (2009), p. 681.

<sup>88</sup>Matthew Altieri and Silvia von Kluge, “Searching for Acceptance: Challenges Encountered while Raising a Child with Autism,” in *Journal of Intellectual and Developmental Disability*, vol 34, no. 2 (2009), p. 151.

<sup>89</sup>Myra Beth Bundy and Linda Kunce, “Parenting Stress and High Functioning Children with Autism,” in *International Journal on Disability and Human Development*, vol. 8, no. 4 (2009), p. 406.

Phelps, Hodgson, Mc Cammon, & Lamson claim that “a clearer understanding of autism by informal and formal supports would alleviate strain for caregivers”.<sup>90</sup>

I have witnessed this lack of understanding in my professional practice when bringing students into the community. When students engage in harmless self-stimulatory behaviours (e.g., Hand flapping or rocking), they have experienced stares or even comments under people's breaths. This is not to say that this is the norm, but even once could be painful to a child with autism or a family member who loves the child.

The next most common theme content coded in the qualitative literature on parents of children with autism was the need for support and services. The system was considered unsupportive and “inaccessible”<sup>91</sup>, services such as education and medicine were found to be lacking in knowledge, and parents suggested that educators and medical professionals were educated.<sup>92</sup> Woodgate, Ateah, & Seccon agree that “professionals, family, friends, and others in the system who lack an understanding of the impact that autism has on children and parents need to be educated”.<sup>93</sup> The financial cost of having a child with autism, including employment

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<sup>90</sup>Kenneth Phelps, Jennifer Hodgson, Susan McCammon, and Angela Lamson, “Caring for an Individual with Autism Disorder: A Qualitative Analysis,” in *Journal of Intellectual and Developmental Disability*, vol. 34, no. 1 (2009), p. 27-35.

<sup>91</sup>Mieke Meirsschaut, Herbert Roeyers, and Petra Warreyn, “Parenting in Families with a Child with Autism Spectrum Disorder and a Typically Developing Child: Mothers’ Experiences and Cognitions,” in *Research in Autism Spectrum Disorders*, vol. 4, no. 4 (2010), p. 665.

<sup>92</sup>Heather Hall and Carolyn Graff, “Parenting Challenges in Families of Children with Autism: A Pilot Study,” in *Issues in Comprehensive Pediatric Nursing*, vol. 33, no. 4 (2010), p. 194.

<sup>93</sup>Roberta Woodgate, Christine Ateah, and Loretta Secco, “Living in a World of our Own: The Experience of Parents who have a Child with Autism,” in *Qualitative Health Research*, vol. 18, no. 8 (2008), p. 1075-1083.

effects<sup>94</sup>, shows a clear need for support for parents.<sup>95</sup> Even themes such as time demands, pervasiveness of autism in life, sleep problems and exhaustion, missed activities, neglected siblings, and marital strain<sup>96</sup> can be seen as a need for support in the form of relief. Although there was some individual model language, the need for support in the form of relief was primary. One parent, when discussing marital strain, said she needed respite care.<sup>97</sup> Another parents, talking about living in a world her own, felt like she had to “go it alone”.<sup>98</sup> Parents advocated for other parents so that the system would not “rip them off<sup>99</sup>,” and felt like they needed to fight to get services.<sup>100</sup>

Again, I have witnessed this lack of support in my own professional practice, attempting to advocate for respite services for parents. The paperwork and meetings involved would be far too overwhelming for

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<sup>94</sup>Matthew Altieri and Silvia von Kluge, “Searching for Acceptance: Challenges Encountered while Raising a Child with Autism,” in *Journal of Intellectual and Developmental Disability*, vol 34, no. 2 (2009), p. 142-152.

<sup>95</sup>Vaya Papageorgiou and Efrosini Kalyva, “Self-Reported Needs and Expectations of Parents of Children with Autism Spectrum Disorders who Participate in Support Groups,” in *Research in Autism Spectrum Disorders*, vol. 4 (2010), p. 655; Kenneth Phelps, Jennifer Hodgson, Susan McCammon, and Angela Lamson, “Caring for an Individual with Autism Disorder: A Qualitative Analysis,” in *Journal of Intellectual and Developmental Disability*, vol. 34, no. 1 (2009), p. 32.

<sup>96</sup>Barbara Myers, Virginia Mackintosh, and Robin Goin-Kochel, “‘My Greatest Joy and my Greatest Heartache:’ Parents’ own Words on how Having a Child in the Autism Spectrum has Affected their Lives and their Families’ Lives,” in *Research in Autism Spectrum Disorders*, vol. 3, no. 3 (2009), p. 670-684.

<sup>97</sup>*Idem*

<sup>98</sup>Roberta Woodgate, Christine Ateah, and Loretta Secco, “Living in a World of our Own: The Experience of Parents who have a Child with Autism,” in *Qualitative Health Research*, vol. 18, no. 8 (2008), p. 1075-1083.

<sup>99</sup>*Idem*

<sup>100</sup>Matthew Altieri and Silvia von Kluge, “Searching for Acceptance: Challenges Encountered while Raising a Child with Autism,” in *Journal of Intellectual and Developmental Disability*, vol 34, no. 2 (2009), p. 142-152.

many people to follow through on an application. I could understand why parents feel like they jump through hoops for very little gain.

When parents specifically addressed a lack of understanding and acceptance or a need for support and services as above, they are clearly working from a social model of disability. There are other issues, such as child variables, that are not so clear until the language of the parents is considered. For example, maladaptive behaviour is the most common child variable theme content coded (also called disruptive and inappropriate behaviour). Parents see this as both an impairment and a socially constructed disability. Parents list behaviours including aggression, fecal smearing, extended screaming<sup>101</sup>, “tormenting” siblings, violence with police involvement, physically assaulting a child under five years old several times, aggression requiring hospitalization, living in fear of child taking own life or losing it to poor judgment<sup>102</sup>, obsessive and perseverative behaviours, and tantrums.<sup>103</sup> From the language used to describe the behaviours above, it is clear that these behaviours are impairments for parents, and are a medical issue. On the other hand, parents claim that “it hurts when people are looking at your child like he is an alien” when he acts up in public<sup>104</sup> and “when we go out, strangers

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<sup>101</sup>Heather Hall and Carolyn Graff, “Parenting Challenges in Families of Children with Autism: A Pilot Study,” in *Issues in Comprehensive Pediatric Nursing*, vol. 33, no. 4 (2010), p. 187-204.

<sup>102</sup>Barbara Myers, Virginia Mackintosh, and Robin Goin-Kochel, “My Greatest Joy and my Greatest Heartache: Parents’ own Words on how Having a Child in the Autism Spectrum has Affected their Lives and their Families’ Lives,” in *Research in Autism Spectrum Disorders*, vol. 3, no. 3 (2009), p. 670-684.

<sup>103</sup>Myra Beth Bundy and Linda Kunce, “Parenting Stress and High Functioning Children with Autism,” in *International Journal on Disability and Human Development*, vol. 8, no. 4 (2009), p. 401-410.

<sup>104</sup>Heather Hall and Carolyn Graff, “Parenting Challenges in Families of Children with Autism: A Pilot Study,” in *Issues in Comprehensive Pediatric Nursing*, vol. 33, no. 4 (2010), p. 194.

blame us for the temper tantrums that our child throws”.<sup>105</sup> Hall & Graft points out that child maladaptive behaviours contribute to the social isolation of parents, but that this is related to limited respite and support.<sup>106</sup> Therefore, it is not only the behaviour as an impairment that creates isolation, but the society that disables the child by not understanding and accepting their behaviours in public. This is reinforced by Gray when he claims that “parents of aggressive children were more likely to experience stigma than the parents of passive children”.<sup>107</sup> Boyd also reinforces this when he claims that “behavioural issues may present more of a challenge than cognitive one because of the potential public scrutiny parents face from society, and perhaps from family and friends as well”.<sup>108</sup>

As a teacher, I experience many of these same conflicting opinions and emotions about problem behaviours. It is difficult as a teacher to choose which behaviours to make educational goals for in the Individual Education Plan, and which ones should be acceptable. Sometimes this decision is simple. For example, self-abusive or aggressive behaviour is usually treated as medical and programs are written to reduce these behaviours, but for most of my students, I do not write programs to reduce self-stimulation such as hand flapping. (I say most, because there are students who want to stop this behaviour in public.) This is

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<sup>105</sup>Vaya Papageorgiou and Efrosini Kalyva, “Self-Reported Needs and Expectations of Parents of Children with Autism Spectrum Disorders who Participate in Support Groups,” in *Research in Autism Spectrum Disorders*, vol. 4 (2010), p. 655.

<sup>106</sup>Heather Hall and Carolyn Graff, “Parenting Challenges in Families of Children with Autism: A Pilot Study,” in *Issues in Comprehensive Pediatric Nursing*, vol. 33, no. 4 (2010), p. 198.

<sup>107</sup>David Gray, “Ten Years On: A Longitudinal Study of Families of Children with Autism,” in *Journal of Intellectual and Developmental Disability*, vol. 27, no. 3 (2002), p. 218.

<sup>108</sup>Brian Boyd, “Examining the Relationship between Stress and Lack of Social Support in Mothers of Children with Autism,” in *Focus on Autism and Other Developmental Disabilities*, vol. 17, no. 4, (2002), p. 213.

difficult as a teacher because even if I believe that a certain behaviour is not a medical issue and should be accepted by society, it is not, and therefore a decision has to be made based on what is best for the student. Not all behaviours are so easily categorized.

Many of the other student variables are neutral to parents, without hinting as to whether it is the impairment or society's lack of understanding and support that causes the stress around them, such as difficulties with self help, motor difficulties, difficulties with social skills, and worry about the child's future.<sup>109</sup> Educational concerns that were based on the child's ability to learn at school used some individual language such as "parents had various concerns about the child's ability to understand the rigours of education"<sup>110</sup>, but this was not brought up frequently, accommodation to assist with learning was brought up, and all of these issues were also not shown to cause as much stress in the qualitative literature as a lack of support and behaviour.

Finally, there were two themes in the qualitative literature on families of children with autism that were talked about from the perspective of a medical or individual model, and they were emotional well being and communication.<sup>111</sup> The emotional difficulties were fear, anxiety, uncontrollable rage, emotional well being<sup>112</sup>, and panic

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<sup>109</sup>Myra Beth Bundy and Linda Kunce, "Parenting Stress and High Functioning Children with Autism," in *International Journal on Disability and Human Development*, vol. 8, no. 4 (2009), p. 401-410.

<sup>110</sup>*Ibid.*, p. 406

<sup>111</sup>Vaya Papagergiou and Efrosini Kalyva, "Self-Reported Needs and Expectations of Parents of Children with Autism Spectrum Disorders who Participate in Support Groups," in *Research in Autism Spectrum Disorders*, vol. 4 (2010), p. 653-660.

<sup>112</sup>Myra Beth Bundy and Linda Kunce, "Parenting Stress and High Functioning Children with Autism," in *International Journal on Disability and Human Development*, vol. 8, no. 4 (2009), p. 406.

attacks.<sup>113</sup> It is understandable that parents would talk about these emotional difficulty as medical, because it would be difficult to consider how society could prevent these difficulties through understanding and support. Bundy & Kunce point out that emotional ups and downs could be the underlying cause of disruptive behaviour.<sup>114</sup> It is more surprising that communication is seen as a medical/individual issue, because there are many supports that can be put into place to assist children with autism with communication such as picture communication, sign language, or gestures. Although there are times when communication is a medical issue because no amount of effort could break the communication barrier, there are many communication strategies that can be attempted first. Myers, MacKintosh, & Goin-Kochel included the fact that a child didn't speak in with behaviours<sup>115</sup>, and Hall & Graff quote a parent as saying that her child looks at her like he wants to tell her something, but he doesn't have the words.<sup>116</sup>

When asked what I found surprising about what parents found stressful and what model they used to interpret these stressors, I was surprised that sensory issues were not discussed by parents as being more stressful, because they can be a cause of great pain to children with autism, and have been a source of stress for myself in my professional

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<sup>113</sup>Heather Hall and Carolyn Graff, "Parenting Challenges in Families of Children with Autism: A Pilot Study," in *Issues in Comprehensive Pediatric Nursing*, vol. 33, no. 4 (2010), p. 194.

<sup>114</sup>Myra Beth Bundy and Linda Kunce, "Parenting Stress and High Functioning Children with Autism," in *International Journal on Disability and Human Development*, vol. 8, no. 4 (2009), p. 406.

<sup>115</sup>Barbara Myers, Virginia Mackintosh, and Robin Goin-Kochel, "My Greatest Joy and my Greatest Heartache: Parents' own Words on how Having a Child in the Autism Spectrum has Affected their Lives and their Families' Lives," in *Research in Autism Spectrum Disorders*, vol. 3, no. 3 (2009), p. 675.

<sup>116</sup>Heather Hall and Carolyn Graff, "Parenting Challenges in Families of Children with Autism: A Pilot Study," in *Issues in Comprehensive Pediatric Nursing*, vol. 33, no. 4 (2010), p. 194.

practice as a teacher of students with severe autism. I had expected parents to discuss sensory issues from a social point of view because many sensory issues can be compensated for in the environment, even though it could be seen as a medical issue when the environment can't be changed, or two children with opposite sensory issues (e.g., A hypersensitivity and a hypsensitivity to sound) share the same space.

Although the literature used some medical language while talking about the effect of a child with autism on the family, such as wishing for or missing a “normal” child or life<sup>117</sup>, wanting a “cure”<sup>118</sup>, wanting to “fix” the child's problems<sup>119</sup>, claiming there is something “wrong” with the child<sup>120</sup>, and asking about etiology<sup>121</sup>, and although there were some aspects of autism that were seen as medical, such as some behaviours, emotional difficulties, and communication, this was outweighed by the desire for understanding, acceptance, support, and services by parents of children with autism.

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<sup>117</sup>Roberta Woodgate, Christine Ateah, and Loretta Secco, “Living in a World of our Own: The Experience of Parents who have a Child with Autism,” in *Qualitative Health Research*, vol. 18, no. 8 (2008), p. 1078.

<sup>118</sup>Myra Beth Bundy and Linda Kunce, “Parenting Stress and High Functioning Children with Autism,” in *International Journal on Disability and Human Development*, vol. 8, no. 4 (2009), p. 405.

<sup>119</sup>Barbara Myers, Virginia Mackintosh, and Robin Goin-Kochel, “My Greatest Joy and my Greatest Heartache: Parents’ own Words on how Having a Child in the Autism Spectrum has Affected their Lives and their Families’ Lives,” in *Research in Autism Spectrum Disorders*, vol. 3, no. 3 (2009), p. 681.

<sup>120</sup>Matthew Altieri and Silvia von Kluge, “Searching for Acceptance: Challenges Encountered while Raising a Child with Autism,” in *Journal of Intellectual and Developmental Disability*, vol. 34, no. 2 (2009), 145.

<sup>121</sup>Heather Hall and Carolyn Graff, “Parenting Challenges in Families of Children with Autism: A Pilot Study,” in *Issues in Comprehensive Pediatric Nursing*, vol. 33, no. 4 (2010), p. 194.

## Conclusion

Autism is a complex disability that includes both impairments and social constructions. Taking autism into account would require a model of disability to include the experience of impairment as well as the social construction of disability. There are two distinct forms of social construction recognized by parents, called here lack of understanding and acceptance and lack of support and services, and also aspects of autism that are recognized as based on impairment. A model for parents that puts more weight on the social construction of autism would be most accurate. Thomas calls the lack of understanding and acceptance a “barrier to being” and a lack of support and services a “barrier to doing”.<sup>122</sup> Patterson and Hughes talk about passive social disability, which would come from the lack of understand and acceptance, and active social disability, which would come from a lack of support and services.<sup>123</sup> Both Thomas and Patterson and Hughes include what Thomas calls “impairment effects” in their models.<sup>124</sup> These models would be most reflective of the way parents view autism, but this does not speak for the people with autism themselves.

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<sup>122</sup>Bill Hughes, “Being Disabled: Towards a Critical Social Ontology for Disabled Studies,” *Disability and Society*, vol. 22, no. 7 (2007), p. 675.

<sup>123</sup>Kevin Paterson and Bill Hughes, “Disability Studies and Phenomenology: the Carnal Politics of Everyday Life,” in *Disability and Society*, vol. 14, no. 5 (1999), p. 597-610.

<sup>124</sup>Lorella Terzi, “The Social Model of Disability: A Philosophical Critique,” in *Journal of Applied Philosophy*, vol. 21, no. 2 (2004), p. 150.



### III – Cultural Representations



# 'Raising a Question Mark': Disability and Textual Recalibration in Contemporary Canadian Writing

*Angelo Muredda*

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## Warped Family Relations and Blighted Harvests

In *Survival*, her thematic guide to Canadian literature up to the book's publication in 1972, Margaret Atwood famously characterized Canada as a nation of victims, struggling to survive against the imposing elements of their environment.<sup>1</sup> Far less remarked upon in the critical appraisal of this seminal text, though, is the corporeal language of her claim that one of the key victimizers in mid-twentieth century Canadian writing is the family. Atwood proposes that while in representative American literature of the same period, male subjects tend to leave their families to light out for the frontier, finding their own private America and transcending their fathers in the process, these narratives portray the family largely as a trap on which one gets snagged. Canadian intergenerational family portraits, she goes on, generate a "lurid gothic light"<sup>2</sup> insofar as they focus on the decaying heritage bound up with domineering grandfathers who beget families that "rot away," resulting in "warped family relations and blighted harvests."<sup>3</sup> Their children try to escape and are "somehow crippled"<sup>4</sup> as a result.

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<sup>1</sup>Margaret Atwood, *Survival: A Thematic Guide to Canadian Literature* (Toronto: Anansi, 1972), p. 3.

<sup>2</sup>*Ibid.*, p. 158.

<sup>3</sup>*Ibid.*, p. 161.

<sup>4</sup>*Ibid.*, p. 163.

The implication is that all those who survive their rotten inheritances are disabled, in both a corporeal and a figurative sense. Yet Atwood qualifies this bleak portrait, and proposes that Canadian writers often provide an escape clause, albeit one that cannot be fully depicted within the confines of the narrative. Gesturing to Adele Wiseman's 1956 novel *The Sacrifice*, which depicts a Jewish immigrant named Abraham's settlement in Winnipeg and thwarted hopes for his son, Atwood identifies the third generation child (his grandson Moses) as a redemptive figure, whose prospective life might belatedly give meaning to the struggles of his predecessors – transmitting cultural values without reproducing the disfigurements that once attended them. "Wiseman can only project authentic success into the future, not depict it<sup>5</sup>," Atwood writes, gesturing to Moses's brief surfacing at the novel's close, and suggesting that literary formulations of Canadian identity are inherently directed outward toward an uncertain future that has yet to take shape.

Atwood's focus on this ambiguous moment of baton-passing between generations of male immigrants and their descendants now seems anachronistically Eurocentric and patriarchal at best – the product of a specific moment of nationalist Canadian literary studies born out of the thematic criticism of scholars like Northrop Frye, which became prominent in the mid- nineteen sixties.<sup>6</sup> What interests me about this reading, however, and what strikes me as a necessary site of intervention in the present, is the language of disability that Atwood attaches to this intermediary generation. I am similarly drawn to the language of bodily integrity that in this example is bound up with the child

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<sup>5</sup>*Ibid.*, p. 187.

<sup>6</sup>See Northrop Frye, *The Bush Garden: Essays on the Canadian Imagination* (Toronto: Anansi, 1971) for a collection of such suppositions on the quintessential features of a national Canadian literature.

who supposedly offers a way out of the parents' and grandparents' morass, a tentative step forward into contemporary Canadian identity.

The child's future cannot be depicted in full, Atwood suggests, because a more exhaustive representation might reveal the kind of bodily contingencies that would muddy its signification of a triumph over the past, and, to extend the nationalist analogy, would render uncertain Canada's present condition as a child out in the world, away from its European antecedents. But what if the future that the child ostensibly represents is complicated by a physical blemish, as is often the case in contemporary Canadian depictions of disability, and how does this disfigured form signify something other than a transparent success story? In other words, if the transparently average child, a variant on the figure that Rosemary Garland-Thomson terms the normate, "outlined by the array of deviant others"<sup>7</sup> who shore up its boundaries, spells out a promising future and signals a satisfying conclusion to the generational narrative that defines so much canonical Canadian writing, what ambiguities does a disabled child portend? What narratives does it facilitate or modulate?

Atwood's reading does not explore the ethical implications of such literary instrumentalizations of disabled children, and there is much work to be done in considering how the disabled child's body serves in this example as an aesthetic impetus for raising questions about the form that the future will take. My research revisits Atwood's contentions about Canadian literature by focusing on this apparent oscillation between the heightened corporeality of disability and the vague, often apocalyptic anxieties to which it gives a form. My approach in the larger project from which this paper is excerpted is generally

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<sup>7</sup>Rosemarie Garland-Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (New York: Columbia UP, 1997), p. 8.

historical in orientation, considering the recurrence of disability imagery within modernist Canadian fiction and later turning to how treatments of deformity figure into centennial representations of the form of Canadian identity in the late nineteenth sixties, for example. In keeping with the broadly conceptual nature of this collective work, however, I want to forego this historicist framework and instead use this space to consider a selection of formally and historically disparate texts by Timothy Findley, Barbara Gowdy, and Ian Brown. Rather than presenting a definitive explication of the role disability plays in particular moments of Canadian literary identity formation, then, my aim here is to explore in a largely speculative manner how disability complicates literary imaginations of the future, especially those bound up with a larger national narrative. I do not intend to present these texts as ultimate examples, consequently, but as points of entry into a discussion about how disability intersects with both aesthetic matters of form and more thematic explorations of filial responsibility in a national literature that, as Atwood's comments demonstrate, is preoccupied with both.

### **Most Anything, Other Than Themselves**

Although as I have noted, my approach here is intended to be one of non-mastery, it is necessary to give a brief account of my theoretical grounding in reading this body of texts on intergenerational crises. Given their focus on the labour of preparing for the future, and on transitional moments between generations who represent different phases of Canadian identity, it is unsurprising that the texts I consider tend to frame disability with respect to questions of reproduction, responsibility, and care. My work consequently grapples not only with disability studies but also with theoretical modellings of the child, particularly in queer theory, where much of what I consider

the most exciting recent work on the subject has been done. In part I take my influence from Kathryn Bond Stockton, whose 2009 book *The Queer Child, or Growing Sideways in the Twentieth Century* is a remarkable study of the inherent strangeness and queerness of the figure of the child, which explores the many wayward paths children take in literary and cinematic narratives about the formation of subjects.<sup>8</sup> Reviewing Stockton's earlier essays in 2005, and surveying the proliferation of work on children and futurity in recent queer theory, Michael Cobb ventures the fascinating possibility that children are fertile ground for such aesthetic and theoretical abstractions precisely because they are unsettled, and "can be most anything, other than themselves."<sup>9</sup> Cobb's notion that the figure of the child is both placeholder and ambiguous future projection informs my own thinking about Atwood's argument about Canadian literature as a literature of victimhood – helping me to situate her gesture toward the next generation's curious steps forward into a kind of post-victimhood.

If Stockton's study of children who buck the linear trajectory weighs heavily on this project, which similarly considers children who grow in unorthodox directions, my research takes its cue more from the oppositional voice of Lee Edelman's rigorously contrarian polemic about the child. In 2004's *No Future*, Edelman proposes that political discourse insidiously champions an ideology of *reproductive futurism*.<sup>10</sup> Under the mandate of reproductive futurism, he contends, all must be oriented toward the propagation and protection of successive generations, rendering those who practice non-procreative sex treasonous, and

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<sup>8</sup>Kathryn Bond Stockton, *The Queer Child, or Growing Sideways in the Twentieth Century* (Durham: Duke UP, 2009).

<sup>9</sup>Michael Cobb, "Childlike: Queer Theory and Its Children," in *Criticism*, vol. 47, no. 1 (Winter 2005), p. 119-130.

<sup>10</sup>Lee Edelman, *No Future: Queer Theory and the Death Drive* (Durham: Duke UP, 2004), p. 2.

intrinsically, even radically, self-involved. Such holdouts are deemed insufficient believers in the cult of the child as well as political dissents because we are no more able to conceive of “a politics without a fantasy of the future,” Edelman summarizes, “than we are able to conceive of a future without the figure of the Child.”<sup>11</sup> To this impossible situation, Edelman proposes a sharp turn: the “compulsory investment in every adorable Annie<sup>12</sup>,” he insists, can only be decisively refused by embracing an alternative ethic he terms *sinthomosexuality* – a call to “Fuck the social order and the Child in whose name we’re collectively terrorized.”<sup>13</sup>

The mandate of reproductive futurism, Edelman observes, extends to literary discourse, so that in Charles Dickens’s *A Christmas Carol*, for instance, miserly and in his reading queer Scrooge must be made a second father to Tiny Tim before the novella is through. In this seemingly obvious example of the quintessential child we might begin to see how disability is often imbricated with futurity in the literary imagination. Nonetheless, I want to propose that Tiny Tim is a curious example given Edelman’s assertion earlier in his book that the Child is typically made “to image...an Imaginary fullness that’s considered to want, and therefore to want for, nothing.”<sup>14</sup> The limping young Cratchit in fact wants quite a lot *because* of his disability: if he is to want for nothing, it is not simply because he is a child but because he is the most vulnerable of children, and visibly so – his limp a totem of his poverty and its manifestation as illness. The narrative’s impulse to restore him to that imaginary fullness, to make and to keep him well lest The Ghost of Christmas Yet to Come’s bad tidings of his premature

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<sup>11</sup>*Ibid.*, p. 11.

<sup>12</sup>*Ibid.*, p. 18.

<sup>13</sup>*Ibid.*, p. 29.

<sup>14</sup>*Ibid.*, p. 21.

end should come true, is to be sure bound up with its reformation of Scrooge, a bachelor for whom singleness marks an obstinate refusal of the social order. Edelman emphasizes Scrooge's procreative stinginess, the way in which his "nuttness" is aligned with his refusal to "drop acorns from the family tree."<sup>15</sup> Impressive as this reading is in terms of its breathless excavation of a hallowed text, Edelman curiously makes little of the bodily particularity of Scrooge's young foil, an unhealthy acorn whose disability, in conjunction with his youth, compels ethical interventions from his community.

This reading leaves me dissatisfied, but in some ways that dissatisfaction is a productive point of departure, an opportunity to raise some of the same questions Edelman raises with theoretical sophistication from a different angle. My project is similarly drawn to texts involving children who make ethical demands of those around them, as I have said; it takes its cue from the same animating spirit of Edelman's inquiry into the political project of securing the future. But it focuses on the particular requirements of problem cases like Tiny Tim. What happens, I want to ask, when the acorn that falls from the parents' tree is not depicted as being abstractly perfect? How does disability intensify or otherwise modulate these anxieties about what is coming? Finally, what future does the disabled child signal, and what narrative mechanics are triggered as a result of the necessity of representing the child's deformity?

### Cut Off at Birth

I have dwelled on Edelman's ironic call for queer subjects to embrace conservative political culture's caricature of queerness as a radically

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<sup>15</sup>*Ibid.*, p. 44.

non-procreative force, oriented against the future, because it is also a call to reject an ethic of communitarian intervention that the texts I consider explore in their depictions of disabled children. Edelman's interest in what has to happen to Scrooge figures in narrative terms is, I would argue, an instructive tangent in thinking about how disability operates in these texts. I want to begin to focus this discussion by turning to Timothy Findley's 1977 novel *The Wars*, which is often treated as the capstone of Canadian postmodernism and historiographic metafiction<sup>16</sup> but only tangentially discussed in terms of the extent to which that project relies on representations of disability. The novel concerns the fate of Robert Ross, a Southern Ontarian soldier in the First World War, whose wartime experience is recreated piecemeal through the archival interventions of a researcher figure who becomes a surrogate for the reader, finding fragments of Robert's life in photographs and interviews with friends. Disability haunts the novel from the outset, where this reporter figure describes a rare photograph of Robert with his generally under-photographed older sister Rowena, a wheelchair-user with hydrocephalus for whom Robert was a guardian figure despite his age.<sup>17</sup> We learn early on that Rowena's death in an accident that took place while she was under his watch is the inciting incident of Robert's conscription. Later we are given an account of the moments after the funeral, where Robert's bereaved mother interrupts him in the bathtub to try to disabuse him of his notion that Rowena, whose image haunts him throughout the war, was his charge. "No one belongs to anyone," she tells him: "We're all cut off at birth with a knife and left at the mercy of strangers. You hear that? Strangers."<sup>18</sup> She also washes her hands of his plan to become a soldier, an endeavour

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<sup>16</sup>Linda Hutcheon, *The Canadian Postmodern* (Toronto: Oxford UP, 1988), p. 16.

<sup>17</sup>Timothy Findley, *The Wars* (Toronto: Clarke Irwin, 1977), p. 3.

<sup>18</sup>*Ibid.*, p. 23.

that by the end of the novel leaves him burned beyond recognition: “You can go to hell. I’m not responsible. I’m just another stranger. Birth I can give you – but life I cannot. Not anymore. I can’t keep anyone alive.”<sup>19</sup>

Now, I do not want to suggest that Mrs. Ross’s apparent disavowal of her filial bond and resultant obligation toward both her deceased daughter and her easily bruised son is necessarily an instance of the kind of disavowal Edelman has in mind. Her situation is quite specific, given that she is responding in part to the sanctimoniousness of the mourners around her, who are scanning her face for signs of grief. What I would note though is how, like Tiny Tim, Rowena makes particular ethical demands on those around her because she requires near-constant care; her status as a problem child ushers in a debate about filial responsibility. So strong is this call that Rowena retroactively forces her mother either to account for or to disavow personal responsibility for her death. Outside of this charged discussion and Robert’s haunted dreams, it bears mentioning, Rowena hardly exists in the text as a character in her own right. The very notion of Rowena as subject seems antithetical to her status as a token of Robert’s past, interchangeable with the single extant photo of her. She is largely an instigating device, starting this critical discussion about what can be done for children after childbirth, as well as the novel’s metafictional exploration of the responsibility a nation-state bears toward its soldiers. Her haunting presence forces these competing models of parenting – that of the dutiful brother, racked with guilt over his momentary inattentiveness, and that of the mother who has removed herself from care and drawn the line of her responsibility at accidents – into a crisis of self-definition.

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<sup>19</sup>*Idem*

Moreover, as I have already suggested, Rowena's death before Robert goes away and is laid waste by the titular wars instigates the narrative's recuperation of his wartime experience. It is also the inaugural moment of the novel's criticism of the war effort that processes young bodies in the name of national identity consolidation, without accounting for the meaningless sacrifices of human life that such consolidations require. If, as Edelman notes, Dickens's novella must resolve itself via even the most miserly citizen's embrace of Tiny Tim, Findley's far less redemptive portrayal of a nation that has sent its youth to die in the wars must proceed with a critical difference. The child, in this case Robert, must indeed be cut off at birth (if not by his mother than certainly by his nation) and left at the mercy of strangers abroad. His mother's caution, and the analogy she makes between her two children, is therefore a preemptive strike against the wars, a Cassandra-like prophesy concerning the vulnerability of all children, spurred by the example of the disabled child, for whom a mundane fall proved fatal. The fate of the disabled child thus gives rise to a contemplative moment that prepares us for the ethical project in which the novel is invested – a curious moment insofar as there is no authenticating source for this discussion, no documentary text to explain how the researcher might have come upon it. It is there, and depicted almost as a one act play, complete with stage directions<sup>20</sup>, because it must be in order to prime us for Robert's own multiple bruises to follow, and in more figurative terms, for his own status as a kind of national cast-off for archivists to reconstruct after the fact, or, to extend the filial metaphor, a historical orphan.

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<sup>20</sup>*Idem*

### ...For There to be Such Perfection

Disability also serves as an impetus for anxious ruminations on the future in the short fiction of Barbara Gowdy, whose 1992 collection *We So Seldom Look on Love* is full of depictions of disabled children on various temporal thresholds. In the opening story “Body and Soul,” for instance, we are introduced to a woman named Aunt Bea, who serves as a waystation for a range of physically and mentally disabled foster children, socializing and keeping them until they are deemed fit for adoption by the world at large. I want to focus on the second and longest story in the collection, “Sylvie,” about the titular character, a young woman with a Siamese twin named Sue, who presents as a second set of legs that Sylvie attempts to hide under her dresses, and who is described as an arrested child that the more developed Sylvie must carry with her.

As the story begins, Sylvie is on the verge of two seemingly quite different appraisals of her deformity, that of the circus community on the outskirts of her town, which cheerfully welcomes her into their company, and that of a series of medical men who diagnose her as an “autosite parasite”<sup>21</sup> and identify Sue as a vestigial limb. While the former community gives her work because of her physical variation, the latter speaks instantly of amputation and the removal of her so-called “excess plumbing.”<sup>22</sup> After a short-lived career as a vaudeville performer, Sylvie subjects herself to the rehabilitative gaze of medicine. She falls in love with a doctor who eagerly takes her to a specialist in congenital deformities; her would-be spouse proposes to her almost from the first, and looks on her body with vampiric lust, chanting “New territory...new data”<sup>23</sup> as if he finds himself before a welcoming spreadsheet.

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<sup>21</sup>Barbara Gowdy, *We So Seldom Look On Love* (Toronto: HarperCollins, 1992), p. 51.

<sup>22</sup>*Idem*

<sup>23</sup>*Ibid.*, p. 55.

Obviously we are far from the territory of Findley's effort to redress the historical record, and to sew cast offs like Robert back into the nation that shuttled them off to a stranger's mercy. Gowdy is of a piece with Southern Ontario Gothic in this use of both magical realism and the grotesque. Yet here too we find disability posing a series of questions about the future, and resulting in a kind of narrative parenthesis – a moment of reflective pause before what is to come. Sylvie's anxieties about going through with the amputation are twofold. First, she obsesses on the possible link between this undeveloped, soon-to-be excised sister Sue, who she has decided is only a set of legs, and the dead child of Mary, one of her co-performers, who is also named Sue. Sylvie is unsettled by the abrupt death of this infant, which launches her into a reverie about the value of deformity:

She couldn't understand why she and Mary and the other freaks were alive, and a perfectly formed baby was dead. The minute she'd laid eyes on Sue it had struck her that it was all right being deformed if deformity had to exist for there to be such perfection.<sup>24</sup>

Second, she worries that the surgery will occasion the loss of her almost supernatural capacity for memory – one of the many quasi-divine gifts with which Gowdy's disabled characters are endowed. While her yearning to be normal turns her to the doctor following her early flirtation with the freak show, before long she worries that if her second set of legs are removed, she will not only forget this perfect child but also lose her own idiosyncrasy:

Will she forget baby Sue's face? What if her freak memory is connected with her freak legs? What if she becomes somebody else for whom nothing that happened to the person she was will be worth preserving?<sup>25</sup>

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<sup>24</sup>*Ibid.*, p. 57.

<sup>25</sup>*Idem*

What most interests me about this doubling of the Sues, as well as this fear that the amputation might erase Sylvie by restoring her to a form she has never possessed, is how the incessant presence of disability, even in the threat of its cure, seems to arrest the narrative progression of the short story. Disability throws a wrench into both Sylvie's aborted performing career and her prospective romance with the doctor. The haunting possibility of a "tiny, normal, perfect"<sup>26</sup> Sue makes it impossible for her to continue exploiting her own attached Sue for the act. The parasitic twin becomes for her a haunted text, always gesturing toward her perfectly formed namesake.

Similarly, Sylvie's procession into a reproductively typical future – "we'll have four children"<sup>27</sup>, her paramour assures her – is cast into doubt once the threat of amputation introduces anxieties about cutting off the idiosyncrasies she suddenly deems must be preserved if she is to be herself, the bearer of Sue. Indeed, faced with the prospect of having children, Sylvie curiously begins to think of herself as a guardian to the Sues: both her sister's and her surrogate daughter's keeper. What we have in this moment of reflective pause and anxiety before Sylvie goes through with the surgery, as she does in the final moments of the story, is an instance of what Ato Quayson calls "aesthetic nervousness."<sup>28</sup> Disability, to borrow Quayson's terms, "short circuits"<sup>29</sup> the tenets of representation, in this case deforming the genres that the story is on the verge of becoming at various points – the bildungsroman, the grotesquerie, and the domestic melodrama, to name a few. And as in Findley's novel or even the failed intergenerational narratives

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<sup>26</sup>*Ibid.*, p. 46.

<sup>27</sup>*Ibid.*, p. 57.

<sup>28</sup>Ato Quayson, *Aesthetic Nervousness: Disability and the Crisis of Representation* (New York: Columbia UP, 2007), p. 15.

<sup>29</sup>*Ibid.*, p. 17.

Atwood describes, the figure behind that short circuiting is once again a child.

### **A Frame on Which to Hang the Human World**

The last text I want to look at, Ian Brown's 2009 memoir *The Boy in the Moon*, shares Findley's and Gowdy's texts' preoccupations with disability and filial duty. But it is also something of an outlier, not least as nonfiction, and largely because it explicitly confronts this capacity of the disabled child to raise questions about the future, as well as to prompt a discussion of guardianship. The book chronicles Brown's life with his son Walker, who has CFC (cardiofaciocutaneous syndrome), a genetic disorder so rare that he likens its diagnosis to being blasted into an unknown galaxy.<sup>30</sup> At present, Walker, who does not speak and who is significantly developmentally delayed, is in an assisted living home, whose precarious funding structure is part of the rhetorical exigency that gives rise to the book, which is concerned with the necessary costs of such forms of assistance. "Raising Walker," Brown writes at the end of the first chapter, "was like raising a question mark"<sup>31</sup> "What is the value of a life like his," he asks, turning from the aesthetic to the economic – "What is the cost of his life to those around him?"<sup>32</sup>

This series of framing questions as well as this depiction of Walker as himself a "question mark" cues us early on to think of the book not just as a memoir but also a polemic, with political stakes engendered by this enigmatic subject. This is not merely "a father's search for his

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<sup>30</sup>Ian Brown, *The Boy in the Moon: A Father's Search for His Disabled Son* (Toronto: Random House, 2009), p. 8.

<sup>31</sup>*Ibid.*, p. 10.

<sup>32</sup>*Idem*

disabled son,” as the subtitle promises, but a provocation to allegorize Walker in thinking of more systematic questions of disability and value, cost and care. What I want to call particular attention to here, though, is the complexity of Brown’s notion of ‘raising a question mark’ – the way *raising* a child who is a genetic unknown inherently *raises*, that is, poses questions. Furthermore, I want to think about the question mark largely as an aesthetic principal – an impetus to textuality and particularly to narrative, and a call that anticipates a range of responses. As Brown notes when he describes Walker’s inscrutable expression while handling a bag full of pop-can tabs, his ambiguity becomes a site of readerly intervention for him and by extension for the reader.<sup>33</sup> His most banal actions are freighted with meaning, inviting a range of readings that span the concrete – he plays with the bag because he likes it – as well as the abstract – whereby the bag might represent Walker’s version of negative capability. “Maybe I’m reaching,” he admits, but “he gives me no choice but to reach this way...Everything about him compels me.”<sup>34</sup>

It might be fruitful to think of Brown’s depiction of Walker as a compelling interpretive object, the titular boy in the moon, in terms of David T. Mitchell and Sharon L. Snyder’s concept of narrative prosthesis. To summarize, Mitchell and Snyder claim that in cultural texts, disability is often the inaugural site of narrative.<sup>35</sup> Its irreducibly corporeal, problem status, they argue, forces certain “cultural accommodations<sup>36</sup>,” narrative resolutions that range from charitable donations to euthanasia. Narratives are thus forced to account for disabled characters,

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<sup>33</sup>*Ibid.*, p. 13.

<sup>34</sup>*Ibid.*, p. 16.

<sup>35</sup>David T. Mitchell and Sharon L. Snyder, *Narrative Prosthesis: Disability and the Dependencies of Discourse* (Ann Arbor: University of Michigan Press, 2000), p. 57.

<sup>36</sup>*Ibid.*, p. 47.

whether by rehabilitating them, casting them aside, or, to borrow Quayson's terms, coming apart in a spell of aesthetic nervousness. Brown at once relies on Walker as a narrative prosthetic of his own, I want to argue, while reflexively commenting on this textual reckoning that Walker's disability requires, acknowledging that the "constant questioning" that rules his life as Walker's caregiver is both troubling and strangely comforting – "a frame on which to hang the human world, a way of living"<sup>37</sup>

Walker's question mark status is largely depicted in such generative terms. In a particularly stressful early meeting with the family doctor occasioned by Walker's refusal to eat, Brown tells us, the doctor off-handedly muttered what became a fundamental question: "We do want this child to live, don't we?"<sup>38</sup> Brown is alert, I think, to the possible narratives that such questions evoke – the way expressions of uncertainty about the value of Walker's life or the value of being his caregiver interpellate both parent and child into a number of pre-formed narrative structures. The ambiguity of the question seems to invite the stability of readymade literary genres as a way of processing the unknown, even if none of those genres are sufficient to account for the complexities that his singularity entails. Describing his response to this question, for example, Brown's register slides from biblical evocations of suffering saints, to devotional literature, to tragedy. He speaks of a "medieval urge"<sup>39</sup> spurred by the sight of his crying child in the doctor's office: he is motivated, he admits, by "fear of retribution if I ignored the dull call of his flesh and his body and his need."<sup>40</sup> He goes on:

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<sup>37</sup>Ian Brown, *The Boy in the Moon: A Father's Search for His Disabled Son* (Toronto: Random House, 2009), p. 39.

<sup>38</sup>*Ibid.*, p. 26.

<sup>39</sup>*Idem*

<sup>40</sup>*Idem*

In any event I felt like an ox slipping into its yoke. I could feel the heavy tragic years coming on ahead of me, as certain as bad weather; there were nights when I even welcomed them. At last a fate I didn't have to choose, a destiny I couldn't avoid.<sup>41</sup>

At other points Walker is likened to a shaman, and Brown to one of his followers: “The boy recalibrates the world<sup>42</sup>,” Brown says, gesturing to how raising Walker transforms his notions of value. Much of that recalibration, it seems, is textual. That is to say, Walker’s unknown form and the strangeness it results in for his caretakers gives rise to a shifting mass of explanatory narratives. Walker raises question marks that Brown responds to with his own interpretive “reaches.”

### **The Last Frontier**

These texts, it must be admitted, are quite different in tone and scope, as are the various ends to which they put disability. By placing them beside one another I do not want to suggest that they are doing the same things, or that they can simply be reduced to “doing” any one thing with disability. Gowdy’s recuperation of a host of eccentrics at most bears a family resemblance with Findley’s belated restoration of Robert to the national consciousness that discarded him, or Brown’s inquiry into the cost of ensuring Walker’s survival. Putting aside questions of form and genre, their rhetorical situations are also quite different, complicated by the extent to which each claims to possess an ethical valence in the world; in this regard, Brown’s book is clearly the most directly engaged in the political arena, or at least the most focused on ensuring a particular future. Yet putting them beside one another nevertheless reveals a governing preoccupation with how

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<sup>41</sup>*Ibid.*, p. 27.

<sup>42</sup>*Ibid.*, p. 36.

disability, and especially the disabled subject's ostensible dependence on the nondisabled, serves as an aesthetic embodiment of anxieties about the future. Moreover, it shows how varied that embodiment can be – scanning variously as an instrumental use of disability to denote "warped family relations" and as an unwieldy trope that troubles the coherence of narratives.

In each case, as in Atwood's broad survey, disability serves a Janus-like function –facilitating narratives that at once glance back on a preceding generation and nervously look forward to a future that does not appear to be self-sustaining. Further, the questions disability raises are coterminous with the unfinished form of children, particularly those who are unable to articulate a position of their own, who must be advocated for by others. I do not say this to glorify self-expression, which might seem to privilege certain disabilities over others, but to observe that in each of these cases, it is largely the absence of the child's expression of a statement of self, a point of view, that invites such textual recalibrations on the part of non-disabled observers and narrators – suppositions on what is to be done for him or her. If disability is, as Mitchell and Snyder have put it, "the last frontier where the conflictual nature of our beliefs about 'viable' lives gets acted out"<sup>43</sup>, then what these texts demonstrate is that the disabled child is often situated on the edge of that frontier.

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<sup>43</sup>David T. Mitchell and Sharon L. Snyder, *Narrative Prosthesis: Disability and the Dependencies of Discourse* (Ann Arbor: University of Michigan Press, 2000), p. 178.

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