

**A Literature Review of Theoretical Disability  
Literature as it Relates to Advocacy**  
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**Introduction:**

Disability advocacy has had a long history in Canada; it has been a crucial part of Canadian disability culture for years. Despite this history, advocacy continues to be an area of tremendous challenge and struggle. There is a noticeable absence of literature surrounding disability advocacy, but the literature that does exist paints a picture of isolation, intimidation, and conflict. Furthermore, the results of disability advocacy appear to be woefully slow and are often met with overwhelming resistance. This paper aims to look at current advocacy and provide a theoretical analysis of recurring themes. Above all, this paper aims to contribute towards disability advocacy literature and emphasize that advocacy is a fight that does not end with legislative victories.

Part one of this paper will examine concrete examples of disability advocacy outside the courtroom in the current Canadian context. It will then trace the presence of advocacy and the context that constructs how disability is treated before the law. Part two will pull out themes from part one; the issue of isolation and separation that people with disabilities experience, the prevalence and necessity of the “fight like hell” mentality, and the employment endemic that disproportionately affects the disability community. This paper will articulate these themes with examples from literature, and will explore how these issues prevent progress for society at large. Part three intends to synthesize and

analyze the information from parts one and two, and proposes a coherent review on what space disability advocacy occupies in the current climate.

### **Part One: Overview of Concrete Examples of Disability Advocacy**

Real world advocacy is both emotionally and politically charged. Most advocates can agree that there are certain pressure points that influence the fight, and certain improvements that need to be made. The following interviews with disability advocates illustrate the barriers that plague the community, and speak to the larger treatment of disability in the public sphere. These interviews lay the foundation for what modern day advocacy is and provide insight as to the barriers that exist.

#### Interview With A<sup>1</sup>

An interview with an individual this paper will refer to as “J” made note of three major themes regarding advocacy. The first theme is the “fight like hell” message; A emphasizes that the improvements that the disability community has received, particularly in the area of legislation, have not been handed to them. A argues that coverage under the *Ontario Human Rights Code*<sup>2</sup> and the *Canadian Charter of Rights and Freedoms (Charter)*<sup>3</sup> have been a result of extensive organization and fighting “like hell.” J’s second theme regards technology; A argues that decades ago, technology was built up to be the answer to all the problems people with disabilities face. Technology was supposed to “set us free and make us equal” but it has not. In fact many would argue

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<sup>1</sup> “Interview with J” Transcript, on file with author.

<sup>2</sup> Human Rights Code, R.S.O. 1990, c. H.19

<sup>3</sup> Part I of the *Constitution Act*, 1982, being Schedule B to the *Canada Act 1982 (UK)*, 1982, c 11. [Charter]

that technology has made a few things easier, but has also created many new obstacles and in many cases has not been effectively implemented in any way that would provide significant support outside of mechanical doors and chairs. Finally, the third theme is representation at the decision-making level; A argues that this is the most depressing theme. The idea that people with disabilities are often not consulted in the changes that will affect them, or in the making of devices and institutions that are made for them, is appalling. Even fewer people with disabilities are placed in consistent positions of oversight in decision-making bodies. These three themes provide the context for J's consultation and advocacy work, and are very concerning.

J argues that the concept of the disabled body has gone through a series of perceptual changes over time. People with disabilities used to be hidden away, sent to institutions out in the country, "out of sight out of mind." Following this came medicalization, where people with disabilities were analyzed and attempts were made to "fix" them. A describes how people with disabilities were "expected to passively acquiesce with how others felt we should live our lives and what we ought to do." At this phase, professionals, social workers, researchers, psychiatrists etc. researched and studied people with disability but never included them in decisions that directly affected them. The next period was the 1950's era of advocacy when people with disability lobbied for "human rights and protection." They eventually secured this equality under the law through the *Ontario Human Rights Code* and the *Charter* yet people with disabilities continue to be "chronically unemployed, chronically in poverty, and chronically excluded and marginalized." Equality before the law clearly doesn't translate to equality in practice. The "nothing about us without us" call for involvement has emerged as a result

of this. A argues that the success of this latest perceptual change relies on integration of people with disabilities in decision-making positions so that the lived experience may influence how disability is approached at the higher levels.

The question becomes, why is the legislation not enough? A argues that this is simply because of a lack of follow through by the government and the disability community. The government is weary of the time and money that disability needs require, they have no easy solutions and every cost-based analysis demonstrates that the venture is far too expensive. Disability needs require more regulation and more legislation than most groups as a result of the vulnerable position people with disabilities occupy in society. The disability community themselves do not have the resources to push for and demand solutions; they are perpetually underfunded and advocates are rarely hired into positions where they can initiate change. The government has not expanded outside the legislation and there has been very limited implementation of systems to streamline complaints. The systems that are required call – yet again – for time, resources, and money. It is difficult to maintain a level of public interest for project like this since there is no clear-cut solution and, unlike the fight for legislative change, there is no major rallying point. Advocates need to find ways to keep disability issues on the public and legislative radars and to move disability issues “up on their list of priorities.” Because of how unrefined the system is, often times the law gets in its own way and legal technicalities frequently decide a case instead of facts. There needs to be more support from administrative bodies in order for any real progress to be made, and we need to recognize that this is not an issue that can be fixed with half hearted attempts.

Given the historical background, A argues that the “nothing about us without us” paradigm is the new “go to” form of advocacy. This type of advocacy calls for a ramp up in public education; the public needs to be aware that people with disability are capable of filling jobs and being in control of their own futures. The public perception needs to consciously recognize that people with disability are not just passive bodies. In order for this to happen A argues that there also needs to be direct education. People with disabilities need to be made aware of their rights and need to know how to access them. The process of advocacy A argues for requires the following elements; the advocate must go to the media to drum up interest and support, they should assert their rights by citing the *Human Rights Code* and the *Charter*, they should demand and fight for change in public platforms by communicating with people in positions of authority, and they should engage in education via presentation and dialogue.

While this is a well-stated objective, the reality of the situation is much more complicated. There are many barriers in advocacy. For starters, to be informed about opportunities to get involved and voice your opinion you have to be connected and you have to know the right people. This is made very difficult when people with disabilities are routinely excluded from the political sphere. The inaccessible language that lawmakers and politicians tend to favor is another barrier to people with disabilities who are often unable to understand the legislation that directly affects and is meant to protect them. The entire process of filing complaints or advocating for change is an intimidating one. It involves a generally underprepared and underfunded individual going up against much larger powers in a system that is not designed for people with disability. Attitudinal barriers play a huge role here. A notes that people with disabilities are generally taught to

be passive and are trying to be “ordinary individuals” who can lead a full life in the current social structure. Combine this with the fear of being harassed or having your aid revoked, a very real and commonly perceived fear for people who often cannot attain regular jobs to support themselves, and you have a real roadblock to progress. Finally, there is a general advocacy fatigue that plagues people in the disability community. Given the past treatment and lack of action on disability issues, many people just don’t believe in the process and see no reason to bother. A argues that the only solution to such barriers is to stay involved even when legislators try to resolve issues internally or attempt to give subpar settlements – to insist on involved negotiation in order to forge a process that includes voices of the disabled community in the future.

#### Interview With B<sup>4</sup>

An interview with an individual who will be referred to as “B” echoes the concerns expressed by A. B argues that the root of issues that plague the disability community currently stem from a lack of enforcement when it comes to minimum accessibility standards being enforced. There exists no obligation to conform to a cross-Canadian standard and, without any push for action, there will be no response. Effective advocacy then, according to B, consists of knowing the right people and making the right connections. The example that B provides is to contact your local Member of Provincial Parliament or “somebody in the Ministry [for the *Accessibility for Ontarians with Disabilities Act*],” people who are in a position to “do something.” Additionally, going to the media and engaging the public generally is part of B’s strategy. Finally, B discusses the grassroots approach of building a base of support. B emphasizes being involved with

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<sup>4</sup> “Interview with E” Transcript, on file with author.

groups and talking to people, writing articles and sending them to media and politicians alike. In this way advocacy emerges as a sort of shared network that gradually acquired new people and organizations who share the ideas further. Somewhere along the way the right people may get involved and creative, achievable salutations will emerge. There is a fair amount of overlap between A and B's strategies, but this grassroots idea adds a certain dimension to what advocacy can be.

The first issue with advocacy that B points out is how hard it is to maintain public interest when it comes to disability issues. Disability is not a "hot button issue" to the general public, and as such they move on from it very quickly. This is why immediately acting on any small momentum by turning to your contact in a position of power is important. Even knowing that person, there is little that can be done to expedite the process when it comes to disability advocacy. B has a fair number of contacts and still observes how slow the process is, and how discouraging that can be. Just to get an appointment with a government official is "very difficult and tedious," let alone forging a relationship with one. B points out that because of this, you have to take a lot of the changes you want to see upon yourself on a one to one basis. You have to reach out to businesses where you personally encounter a problem and make them aware of alternatives and incentivize them. They can either choose to make the change if they value your business and the incentive of continued business that you have made, or they are free to ignore it. This is why, as B states, we need government support. We need government support when it comes to public education; making businesses aware that this is something they should be doing and setting mandatory minimum requirements. We need government support to offer better incentives than just one person can offer. We

need government support above all because advocacy is currently a voluntary process that has virtually no funding. People like B cannot afford to take on all these issues as if they are a full time job without some compensation. If the government were to support the initiative, even just by hiring advocates, it would make a tremendous difference.

Unfortunately the issues do not end with lack of support. The support that is provided by the government is problematic in itself. Formal consultation projects that B has been involved with have had issues with sincerity and action as well as maintaining contact. They have asked halfhearted questions, made halfhearted attempts to fix the issues that were expressed (if they made any attempt at all), and did not bother updating the participants at the conclusion. Ongoing consultation would have been ideal here, but this is not how formal consultations tend to go. Additionally, there is a severe lack of communication between departments that serves to further disadvantage people with disabilities. For example, recently updated building code legislation really should have considered *Accessibility for Ontarians with Disabilities Act*<sup>5</sup> stipulations as to building code minimums for accessibility. This did not occur, so we will not have standardized accessibility architecture in any new buildings built between now and the next building code update – which could be many years away and which may also chose not to observe accessibility standards. All it would take to change this is some form of continued consultation or one person with a disability in a position to say something, and we could have more effective solutions that would save a lot of money in the long term. Accessible buildings are only good for business and contribute to a better functioning society, yet this kind of oversight is what is preventing progress. B notes that all of this leads advocates into a “why should I bother?” slump, an advocacy fatigue if you will.

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<sup>5</sup> 2001, S.O. 2001, c. 32

B also thinks the legislation is not sufficient; although the *Accessibility for Ontarians with Disabilities Act* exists, it is not being enforced. The legislation has holes; it mandates a great number of legally significant and important things, but doesn't provide avenues to achieve the mandate. For example, certain architectural requirements are legislatively provided for but as in the earlier example, the follow through does not exist. B argues these holes should be filled by consultation with people with disabilities, as they are in the best position to recognize where the gaps are. A prime example of oversight that B notes is that up until recently there was no body to contact about getting the legislation enforced. The new 1-800 number is now in place, but there is still no enforcement officer to impose timelines, fines, or consequences generally. B argues that although the legislation is there in theory, in practice it is so shrouded in secrets that it becomes inaccessible. The legislation doesn't provide for someone who brings up accessibility when new architectural projects are constructed, and it has no means of enforcing timelines.

Given what we know about the current system, how must advocacy adapt? Advocacy calls for persistence, diplomacy, and follow through by advocates as well as the creation of contacts. B tells us that advocacy is useful when it offers solutions and economically aware compromises – basically innovation such as working with technology, appealing to demographics like veterans, aging populations etc. The idea that B puts forward is to make something so commonplace via advocacy, make it so appealing that it becomes conceivable and desirable. For example, kneeling busses can be convenient to people in wheelchairs, people with walkers, people with strollers, and even individuals with suitcases. B argues that progress relies on circumstance and opportunity

above all else, and advocates must capitalize on this. Much of what the disabled community needs for accessibility already exists and is not too far out of reach, it just needs to be implemented and sold in a way that appeals to the implementers.

## **Part Two: Review of the Literature Surrounding the Themes**

A and B's interviews deal with many overlapping themes, which can be broken down into; isolation and separation, fighting like hell, and chronic unemployment. The isolation and separation theme refers to the alienation of disability as a whole from the public eye and thus from public consideration. It is a deeply historical issue rooted in years of turmoil. The fight like hell theme is more of mentality brought on by the struggle, it explores the persistence of struggle that is required of disability advocacy. Finally, the unemployment theme explores how the achievements of disability advocates have worked out in practice over time. In these broad themes lie the answers to why advocacy continues to be an area of tremendous challenge and struggle for people with disabilities. Using what we have learned from the interviews above, we can pull out the nuances of the disability advocacy struggle to come up with some alternative lenses through which to view the subject.

### Isolation/Separation

The theme of isolation and separation refers to the segregation of people with disabilities within society; this segregation has led to many attitudinal barriers that prevent effective advocacy. These attitudes are not without cause; a historically medical approach to disability led to the mass institutionalization of people with disabilities in

asylums and institutions where they were treated inhumanely and often abused. This is well documented and undeniable, and the ripples of mass institutionalization are still felt throughout Canadian society today. In a January 2006 hearing before the Ontario Human Rights Tribunal,<sup>6</sup> the lawyer for the provincial government argued that accounts of the abuse of 19<sup>th</sup> and 20<sup>th</sup> century insane asylum inmates was “ancient history” and should not be used to argue for inquest into patient deaths of people with disabilities at medical institutions today.<sup>7</sup> The presumption here was that abuses that happened so long ago could no longer be relevant to modern medical practices regarding people with disabilities. This presumption is flawed in that it assumes events that took place in only the last two generations are “ancient,” and also in that it assumes there is no place for historical context in evaluating age-old prejudices and abusive attitudes perpetrated by the Ontario government towards people with disabilities (an identifiable group).<sup>8</sup>

In this particular case, the family of two deceased people with disabilities wanted to change section 10 (2) of the *Coroners Act*.<sup>9</sup> This section gives the Coroner the discretion to decide whether or not to order an inquest into the death of involuntary patients in a psychiatric facility. The families wanted to change it to provide automatic inquest as is done for the families of prisoners who die according to section 10 (4) and (5).<sup>10</sup> This was initially granted, but was overturned in 2007 in large part because it was found that there was no differential treatment of people with disabilities as compared to

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<sup>6</sup> Braithwaite and Illingworth v Attorney General for Ontario and Chief Coroner of Ontario, [2006] 56 CHRR 171, (HRTO).

<sup>7</sup> Geoffrey Reaume, “‘Ancient History’? The Relevance of the Past to the Present in Ontario’s Psychiatric History” *Honouring the Past, Shaping the Future: 25 Years of Progress in Mental Health Advocacy and Rights Protection* (2008) Toronto: Psychiatric Patient Advocate Office.

<sup>8</sup> Ibid.

<sup>9</sup> Coroners Act, R.S.O. 1990, c. C.37

<sup>10</sup> Braithwaite v. Ontario (Attorney General) 2005 HRTO 31, 2005 CarswellOnt 10350, 2005 HRTO 31, at para 11.

prisoners, because there was “no distinction drawn on the basis of disability.”<sup>11</sup> What the courts meant here was essentially that, given the context, there was no proof of discrimination. Given the context of the times however, it seems almost negligent to operate without a presumption of historical discrimination against people with disabilities. The courts recognize that “The mentally ill have historically been the subjects of abuse, neglect, and discrimination in our society.”<sup>12</sup> They also recognize that “For centuries, persons with a mental disability have been systematically isolated, segregated from the mainstream of society, devalued, ridiculed and excluded from participation in ordinary social and political processes.”<sup>13</sup> The courts have acknowledged the historical isolation of people with disabilities but this hasn’t really amounted to anything substantive.

We cannot ignore the past if we hope to understand attitudes towards people with disabilities by health care providers and the government. People with disabilities are plagued by the negative stereotypes of history, ideas that they are violent, unreliable, unintelligible, and lazy.<sup>14</sup> The histories of people with disabilities are few, they were often dismissed and were rarely preserved. They represent the stories of an extremely diverse group of people, the only thing they truly all had in common is that they have been erased, silenced, and put out of sight and out of mind.<sup>15</sup> Studies surrounding the public perception of disability demonstrate how the harmful effects of history inform the current understanding. Even within our legal system, the influence of older times persists.

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<sup>11</sup> *Braithwaite v. Ontario (Attorney General)* 2007 CarswellOnt 8249, [2007] O.J. No. 4978, 288 D.L.R. (4th) 138, at para 63.

<sup>12</sup> *R. v. Swain* 1991 CarswellOnt 93, 1991 CarswellOnt 1016, [1991] 1 S.C.R. 933, at para 39.

<sup>13</sup> *Ibid.*

<sup>14</sup> Geoffrey Reaume, “Portraits of People with Mental Disorders in English Canadian History” (2000) *CBMH/BCHM*, Volume 17, p. 95. [Portraits]

<sup>15</sup> *Ibid.*, at 100.

The creation of laws aimed at keeping people with disabilities in cycles of poverty and the desire to maintain an “out of sight out of mind” mentality with regard to disability was the only solution in the early days.<sup>16</sup> It resulted in a culture of poverty and street begging with people with disabilities trying to differentiate themselves from “undeserving” beggars.<sup>17</sup> The repercussions of such laws and mentalities was a separation of spheres; disability was not to enter the public sphere, it was to be put away and regulated.<sup>18</sup> The so called “ugly laws” relegated the “unsightly beggar” permanently to the sidelines of society.<sup>19</sup> In this period, the concept of the worthy poor developed, some people with disabilities was designated worthy of charity with the rest being lazy or frauds<sup>20</sup>. The disabled were to fix themselves. They were to earn the charity of the generous beneficiaries who were creating almshouses and running psychiatric institutions.

The idea of people with disabilities being prone to violence has been reinforced with assumptions about the actions of people with disorders that many scholars have jumped on and embellished leading to phrases like being “nuts” or a “raving maniac.”<sup>21</sup> This sort of a clinical approach has damaged the reputation of mental disability and translates to immediate gut reactions to physically noticeable disabilities. This attitude was rampant in Canada. Between 1928 and 1972 Canada was especially involved in eugenics, bodies were medicalized and subject to the whims of doctors who aimed to

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<sup>16</sup> Susan M. Schweik, “All about Ugly Laws (For Ten Cents)” *The Ugly Laws: Disability in Public*. (2009) New York: New York University.

<sup>17</sup> *Ibid* at 156.

<sup>18</sup> Susan M. Schweik, “Producing the Unsightly” *The Ugly Laws: Disability in Public* (2009) New York: New York University. Pg 26.

<sup>19</sup> *Ibid*, at pg 23.

<sup>20</sup> *Ibid*, at pg 29.

<sup>21</sup> *Portraits*, *supra* at 107.

protect humanity from the threat of disability.<sup>22</sup> Doctor's were given unchecked power that sometimes resulted in horrific experiments and abuses of their position of power.<sup>23</sup> Canada had 16 institutions, many of which have ongoing legal cases out against them. One such case<sup>24</sup> gives accounts of how people with disabilities were "beaten, sexually abused, held upside down in ice-cold water and medicated against their will at the Huronia Regional Centre (originally known as the Orillia Asylum for Idiots)."<sup>25</sup> Only recently have class action lawsuits against the Canadian government acknowledged how wrong this was.<sup>26</sup> In Ontario, a court approved a "\$36-million compensation deal for people mistreated at 12 now-closed institutions for adults with mental disabilities."<sup>27</sup> Although it is good that recognition and compensation are being paid to affected parties, we must focus on what can be done to create a future society that will not repeat these mistakes due to a fundamental misunderstanding of what disability is. Short of an aggressive public rebranding, there is little that can be done to quickly change public perception of disability.

### Fight Like Hell

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<sup>22</sup> Colette Leung, "The *Living Archives* Project: Canadian Disability and Eugenics" *Canadian Journal of Disability Studies* (2012) Canadian Disability Studies Association, University of Alberta, Vol 1 No 1.

<sup>23</sup> Ann Collins, "In the Sleep Room: The Story of the CLI Brainwashing Experiments in Canada" (1988) Toronto: Lester and Orpen Dennys Ltd.

<sup>24</sup> *Slark (Litigation guardian of) v Ontario*, 2013 Carswell Ont 16973, 2013 ONSC 6686, [2013] OJ No 5530.

<sup>25</sup> Carol Goar, "Ugly Secret of Ontario Psychiatric Hospitals Won't Stay Hidden" *The Star* (2013) Friday, June 7.

<sup>26</sup> "Court approves \$36M for ex-residents in class action against Ontario institutions" *CBC News Toronto* (Apr 27, 2016)

<sup>27</sup> *Ibid.*

The “fight like hell” theme is a reality for advocacy, and has been for quite some time. Disability rights, although they seem like an obvious necessity now, were not easily attained. Early advocacy in Canada took the form of various disability groups<sup>28</sup> who sought to capitalize on the civil rights movements and fights that were taking place in the pre-Charter era.<sup>29</sup> These groups had national forums, they united to lobby the government on the concerns raised at their meetings, and they released literature and recommendations for improvement.<sup>30</sup> From 1977 to 1983 these groups fought hard to obtain protection for people with disabilities through inclusion in the Canadian Human Rights Act and for “the inclusion of a guarantee of equality for people with disabilities in the *Charter*.”<sup>31</sup> In 1980, when Parliament read the new section 15 list of protected classes, disability was intentionally excluded and the disability community mobilized in public media debates, protests to the “Parliamentary Handicapped Committee,” and educational presentations to any and every official parliamentary body they could reach.<sup>32</sup> They countered high cost arguments with the argument that protection was needed and necessary to a better functioning society. In the end, pre-Charter advocates used every tool advocates like B and A suggested but it all boiled down to circumstances; this entire debate took place during the “United Nations International Year of Disabled

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<sup>28</sup> Groups Armstrong focused on: the Ontarians with Disabilities Act Committee, the Council of Canadians with Disabilities, The Canadian Hearing Society, the Queen Street Patients Council, the Canadian Association for Community Living, the Disabled Women’s Network—Ontario, the Canadian Hard of Hearing Association, the Canadian Mental Health Association, and ARCH.

<sup>29</sup> Sarah Armstrong, “Disability Advocacy in the Charter Era” *Journal of Law & Equality Spring* (2003) Vol. 2, No. 1. Pg. 51. [Disability Advocacy in the Charter Era]

<sup>30</sup> *Ibid*, at pg 52.

<sup>31</sup> *Ibid*.

<sup>32</sup> *Ibid*, at pg 53.

Persons.”<sup>33</sup> Canada could not be seen to support the initiative while denying protection to people with disabilities, and so they were forced to include disability in the Charter.

The *Charter* era in particular was largely a human rights struggle that gained exposure for the disabled community in an unprecedented manner. This was an example of physical protest, of “fighting like hell” really meaning a fight in the mainstream of society. Success in the *Eldridge v. British Columbia (Attorney General)* case made private institutions like hospitals liable to the *Charter* when acting for government policy, giving people with disabilities a cause of action when their rights to understand their own health are breached.<sup>34</sup> However, actions of this sort are very often and very effectively barred by a lack of implementation and cost inquiries. The cost to remedy disability issues often is enough to prevent any real implementation, and renders any litigation claims on the premise a waste of time. This echoes a lot of the issues that B and A complained about in their interviews, people with disabilities have fought hard for legislative equality but in the end it doesn’t amount to real and genuine protection. The rights granted provide only theoretical equality, but the *Charter* itself has become too litigious to provide any real help. The *Charter* is extremely important in that creates a legal recognition of formal equality, this cannot be denied, but a lack of implementation stymies further progress and the extreme cost that litigation places on people with disabilities is far too onerous to be practical.<sup>35</sup>

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<sup>33</sup> *Ibid*, at pg 54.

<sup>34</sup> [1997] 3 S.C.R. 624 para 42.

<sup>35</sup> Laverne Jacobs, “‘Humanizing’ Disability Law: Citizen Participation in the Development of Accessibility Regulations in Canada (May 31, 2016)” *Citizen Participation and Collaboration in Promoting Open Government*, Irène Bouhadana, William Gilles, and Russell Weaver (eds.), (2017 Forthcoming) Carolina Academic Press. Pg. 5 [Humanizing Disability Law]

Although litigation is usually an onerous and lengthy process for people with disability, there are a number of cases that were both contentious and fundamental in establishing that individuals with mental health issues and disabilities had rights.<sup>36</sup> These are areas where the legislation has been used successfully. For example, the case of *Fleming v Reid* it is established that “mentally competent patients in psychiatric facilities... like competent adults generally, are entitled to control the course of their medical treatment. Their right of self-determination is not forfeited when they enter a psychiatric facility. They may, if they wish, reject their doctor's psychiatric advice and refuse to take psychotropic drugs.”<sup>37</sup> In 1991 this case finally linked bodily autonomy with liberty interests expressed in section 7 of the *Charter*, and established the presumption of mental competency with regard to people with disabilities. In the case of *Starson v Swayze*, we see an example of capitalization on success in the media after the success of the movie “A Beautiful Mind” captured public interest.<sup>38</sup> It established that “a person cannot be found to lack capacity on the basis of lack of information about his or her illness or the fact that he or she holds contrary views to a prescribed diagnosis.”<sup>39</sup> This decision sparked a lot of friction between people with disability who were attempting to fight for their right to reject bodily interference, and medical professionals and family members who wanted a “right to [enforce] treatment.”<sup>40</sup> In a way, the assertion of individual rights was a fight against the medical perception of disabled bodies. In *R v Winko* Canadian courts attempted to balance the rights of those who

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<sup>36</sup> Anita Szigeti, “The Big Cases that Changed the Landscape” *Honouring the Past, Shaping the Future: 25 Years of Progress in Mental Health Advocacy and Rights Protection* (2008) Toronto: Psychiatric Patient Advocate Office, pg 202. [Big Cases]

<sup>37</sup> *Fleming v. Reid*, 1991 CarswellOnt 1501, [1991] O.J. No 1083, 82 D.L.R. (4th) 298, para 35.

<sup>38</sup> Big Cases, supra at 203.

<sup>39</sup> *Starson v. Swayze* 2003 S.C.C. 32, 2003 CarswellOnt 2079, [2003] 1 S.C.R. 722, para 14.

<sup>40</sup> Big Cases, supra at 203.

committed criminal acts because of mental illness, with public interests.<sup>41</sup> They defined what constitutes a “significant threat” to public safety, until 1999 the fear of the violent person with disability gave Review Boards the discretion to continue jurisdiction over the individual.<sup>42</sup> This effectively created a regimen for general discharge for psychiatric institutions, the right to reenter the world that had to be fought very hard for. The recognition of rights in practice has been a huge struggle for the disability community, and it has not been a struggle of the past. Many of these cases are extremely recent and have taken place within this lifetime, demonstrating how ongoing the “fight like hell” matter really is.

The modern advocacy fight is evolving into something much more involved and refined, the legislation exists but many barriers still remain to be fought. For example, the *Ontarians with Disabilities Act* (ODA)<sup>43</sup> came into force in 2001, and the *Accessibility for Ontarians with Disabilities Act* saw a push for enforcement potential in 2005.<sup>44</sup> The fact that a new Act with stronger enforcement powers came into play a mere four years later already suggests issues with implementation of the ODA. These administrative bodies aim to remedy instances of discrimination by providing solutions to the issues facing the disability community in a reactive way.<sup>45</sup> The benefit offered by the ODA and AODA are that they aim to consult people with disabilities directly in order to provide opportunities for them to identify and remove barriers.<sup>46</sup> This, in theory, is where the “fight like hell” mentality overlaps with the “nothing about us without us” movement.

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<sup>41</sup> *Winko v Forensic Psychiatric Institute*, 1999 CarswellBC 1266, [1999] 2 S.C.R. 625, [1999] S.C.J. No 31,

<sup>42</sup> *Big Cases*, supra at 203.

<sup>43</sup> S.O. 2001, CHAPTER 32.

<sup>44</sup> *Humanizing Disability Law*, supra at pg 3.

<sup>45</sup> *Ibid*, at pg 4.

<sup>46</sup> ODA s 1 and AODA s 1.

Tracing the advocacy struggle shows the modern evolution to a demand for inclusion at decision-making levels.<sup>47</sup> So, even with all this progress, all the legislation aimed at protecting people with disabilities, and the new consultative processes – the fight continues.

### Employment Issues

With all these rights and legislative promises, we should in theory have broken the cycle of poverty and be living in an equal world. This is very clearly not the case. Given the amount of people with disabilities that exist and interact in Canadian society, there should be more progress on ensuring fair hiring practices for people with disabilities. 15 to 17 per cent of the population can be described as having a disability, yet they represent a “substantial and substantially disadvantaged minority” in Canada.<sup>48</sup> There is a severe issue of over-representation of people with disabilities in the impoverished and unemployed in Canada. They are overwhelmingly reliant on social welfare and assistance out of necessity<sup>49</sup>. On the other hand, they are alarmingly underrepresented in politics and in places of authority – a major issue noted by both B and J.<sup>50</sup> Unfortunately, society tends to overlook this issue for a number of reasons. If we were to compare this to other enumerated groups, the numbers would be considered shocking; the denial of employment, positions in educational systems, or even onto public transit is unacceptable in Canadian society with any other group of people<sup>51</sup>. Yet if

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<sup>47</sup> Richard K. Scotch, "Nothing about Us without Us": Disability Rights in America" *OAH Magazine of History* (2009) 23, no. 3, 17-22.

<sup>48</sup> Disability Advocacy in the Charter Era, *supra* at pg 34.

<sup>49</sup> *Ibid.*

<sup>50</sup> *Ibid.*

<sup>51</sup> *Ibid.*

a person who “uses a wheelchair is denied access to public transportation because of steps or if a person who is blind is denied the benefits of a particular academic program because the materials for that program are not provided in Braille” there is no shock or outrage, there is almost an understanding.<sup>52</sup> There is a certain underlying presumption that accommodating for disabilities is just far too onerous or expensive.

The earlier discussed historical biases are also so woven into the public perception of disability that it is difficult for wider society to step back and see the issue in hiring numbers for people with disabilities. When it comes to hiring for people with disabilities, the “best man for the job” ethos is a myth, and discriminated parties continue to be passed over for jobs they are suited to. The idea of productivity above all else is frequently trumpeted as a reason for discriminatory hiring, but there is never much explanation given beyond that.<sup>53</sup> There is an emphasis on physical output that seems to correlate with proper job performance in the minds of employers that cannot be explained. Perhaps it is the influence on the old days, perhaps physical ability continues to be seen as capable while disability continues to be seen as weak, pitiful, and burdensome. A common trend in discriminatory hiring against a particular group of workers is to attach a cost to some characteristic of said group that doesn’t actually account for their work abilities.<sup>54</sup> In the case of people with disability, they are seen as too costly, needing too many accommodations and creating too many issues that employers simply cannot afford. This is usually enough to deter, and rarely do people look beyond the imagined cost to see what the real cost may be. The cost is often

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<sup>52</sup> Ibid.

<sup>53</sup> Dennis J. Aigner, and Glen G. Cain, "Statistical Theories of Discrimination in Labor Markets" *Industrial and Labor Relations Review* (1977) 30, no. 2, 175-87. Pg 177.

<sup>54</sup> Ibid.

negligible and in many cases there is no cost at all, but the idea of a person with a disability presenting an obstacle and burden on company resources continues to inform hiring. Employers will frequently dismiss applicants on the presumption that they will not be as productive as the next applicant, without any real evidence to support this.<sup>55</sup> Even the difference in pay is astounding, often when people with disabilities are hired into positions they can expect a lower pay and this usually is accounted for by a presumption of inexperience by employers.<sup>56</sup> In many situations the worker with a disability does lack experience because they are unable to find employment in a society that thinks this way. In this way, discriminatory hiring practices create a cycle of poverty.

So what reasons do employers give for not hiring people with disabilities? The top three reasons appear to be the cost of accommodation, lack of awareness on how to accommodate, and fear of being stuck with a worker they cannot fire or who will pull them into a lawsuit.<sup>57</sup> Other concerns include concerns over applicant's ability to perform tasks and concerns regarding extra supervision time.<sup>58</sup> These concerns make sense in a world where little is known about disability, and where the entire structure of society is built without people with disabilities in mind. A survey of employers who have hired people with disabilities boast very favorable results. "Employers report that accommodations provided to workers with disabilities typically cost little or nothing, but are generally effective and "worth the investment" in terms of retaining experienced workers and increasing productivity, as well as improving organizational culture and

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<sup>55</sup> Ibid at pg 181.

<sup>56</sup> Ibid at pg 185.

<sup>57</sup> H. Stephen Kaye, Lita H. Jans, and Erica C. Jones. "Why Don't Employers Hire and Retain Workers with Disabilities?" *Journal of Occupational Rehabilitation* (2011) 21, no. 4, 526-36.

<sup>58</sup> Ibid.

climate.”<sup>59</sup> Accommodation resources are not very difficult to figure out if employers and employees are willing to work together, but the employment barrier remains firmly in place for many people with disabilities.

Something needs to be done to address the fears of employers and to bring the rates of discrimination down. The solutions for such misconceptions are education campaigns that inform employers of the reality, and mediations that allow for open communication between employers and employees.<sup>60</sup> This seems in theory to be the best solution available, but the issue becomes where we place the burden. Who has to initiate this conversation and will people with disabilities really want to speak up and tell their employers that they need a little bit of accommodation in a job market where being a burden on the time and resources of a company is so strongly frowned upon? Additionally, education campaigns exist and are in place, but the numbers continue to be what they are. Society should be alarmed and concerned about the high rate of unemployment among people with disabilities in spite of anti-discriminatory legislation and in light of the willingness to the work and the existence of appropriate accommodations.<sup>61</sup> If we recall the interviews with B and J, low employment of people with disabilities in positions of power regarding decision-making was a huge hindrance. How likely does it seem, given the adversity faced by the disabled community and the barriers in place against them, that a person with disabilities will be able to climb to such a position?

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<sup>59</sup> Ibid.

<sup>60</sup> John C. Bricout, and Kia J. Bentley, "Disability Status and Perceptions of Employability by Employers." *Social Work Research* (2000) 24, no. 2, 87-95. Pg 93.

<sup>61</sup> Ibid, at pg 94.

### **Part Three: Synthesis and Analysis**

Advocacy is important, but it is also exhausting, resources are scarce and it relies on voluntary actors. Perhaps the biggest barrier to disability advocacy today, is advocacy fatigue. Advocacy fatigue is “the increased strain on emotional, physical, material, social, and wellness resources that comes from continued exposure to system inequities and inequalities.”<sup>62</sup> Many people with disabilities and advocates experience the effects of this strain in life, litigation, and in their health. Advocacy tends to become overwhelming for disability advocates because of the tensions between their individual visions and what the institutions in power are pushing for.<sup>63</sup> It should be noted how much of a barrier exhaustion from fighting poses, and how much of a burden gets placed on people with disabilities. So what can be done about this? Perhaps one of the largest steps would be in hiring, B and A both mentioned how putting people with disabilities in decision-making positions would be beneficial. Arguably, this would allow for advocacy to take place within a safe space with programs and provisions in place for open communications, co-operations between advocates and the community, and professional counseling.

Advocacy is clearly important; it is the only thing so far that has allowed for advances in the treatment of people with disabilities. The themes are fairly straightforward: a history of medicalization of disabled bodies has left some prejudice, the fight for anything has been long and hard, and the results have so far been less than great. So what do we do from here? Advocacy needs to be encouraged and people with disabilities need to be hired into positions where they can make the appropriate changes. Additionally, there needs to be some sort of middle ground between employers or

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<sup>62</sup> Carrie Griffin Basas, “Advocacy Fatigue: Self-Care, Protest, and Educational Equity” *Windsor YB Access Just* 37 (2015) 32. Pg 39.

<sup>63</sup> *Ibid* at pg 54.

government officials and people with disabilities. This may be accomplished by some form of mediation and consultation program, which brings both parties together in mutually beneficial pursuits. We have pre-existing organizations that are advocates for people with disabilities, this kind of legal mobilization should be encouraged and supported by the government as it can help alleviate responsibility from the individual and thus eliminates certain attitudinal barriers.<sup>64</sup> All of this calls for a shift in thinking towards a more inclusive and integrated approach, this does not mean that the social or medical models should be scrapped but rather that they should be sampled in appropriate situations. The social approach may hold some keys to integration, and the medical model may allow for progress in fields like technology and procedures that could offer tremendous help.<sup>65</sup>

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<sup>64</sup> Lisa Vanhala, "Disability Rights Activists in the Supreme Court of Canada: Legal Mobilization Theory and Accommodating Social Movements." *Canadian Journal of Political Science / Revue Canadienne De Science Politique* (2009) 42, no. 4, 981-1002.

<sup>65</sup> Lorella Terzi, "The Social Model of Disability: A Philosophical Critique." *Journal of Applied Philosophy* (2004) 21, no. 2, 141-57.