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RDS EDITORIAL

Weak and Lame: Parenting in the 21st Century

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It's not often that a statistical report robs me of my sleep for a week, but that's exactly what happened when the National Council on Disability (NCD) released its September 2012 report, *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and their Children* (http://www.ncd.gov/publications/2012/Sep272012/). The long-overdue report includes findings such as:

> "The child welfare system is ill-equipped to support parents with disabilities and their families, resulting in disproportionately high rates of involvement with child welfare services and devastatingly high rates of parents with disabilities losing their parental rights," and

> "Parents with disabilities who are engaged in custody or visitation disputes in the family law system regularly encounter discriminatory practices."

In my 2 AM weariness and bleariness, I could hear the FBI pounding on my door, demanding the relinquishment of my seven-year-old daughter. "But officers," I would cry, "I carried her for nine months in my womb just like any other woman!"

"That is no matter, you are not woman enough."

"I nursed her and bathed her and held her when she cried!"

"That is no matter, you are not woman enough."

"I fed her, I clothed her, I protected her and loved her!"

"That is no matter, you are not woman enough."

"But I *agonized* over sending her to public school versus private school…and the local public school is really rather good…"

"You sent your child to public school? Officers, take this child away!"

Fortunately this is the point where my imagination realizes it is ridiculous, waking me from my trance. But realities are so much more sobering.

From the NCD report:

> "Parents with disabilities and their children are overly, and often inappropriately, referred to child welfare services and, once involved, are permanently separated at

disproportionately high rates. The children of parents with disabilities are removed at disproportionately high rates owing to a number of factors, including…state statutes that include disability as grounds for termination of parental rights…" and

"…[There are] inconsistent state laws, many that overtly discriminate against parents with disabilities, others that fail to protect them from unsupported allegations that they are unfit or create a detrimental impact on their children solely on the basis of presumption or speculation regarding the parental disability…"

What if my husband's habit of leaving his socks scattered all over the house and my habit of rearranging his belongings finally get to be too much and we should decide to part ways? Would I lose custody of my daughter because my husband can drive and I cannot? What if someone observes my daughter taking my arm as we approach the sidewalk curb, saying, "Curb, Mommy," and decides my daughter has too much responsibility for a seven-year-old? What if my tolerance of my daughter's current liking for polka-dot pants paired with striped shirts is interpreted as negligence rather than parental indulgence?

Observing interactions between parents and their children has always amused me. Since my daughter's birth, I have had ample opportunity to indulge myself in this interest. The struggles of the 21st-century parent never cease to amaze me. My daughter has a friend, "Amy," who we invited to dinner. I asked Amy's mother the obligatory, "Does Amy have any dietary restrictions?" I received the following instructions:

> "Amy will not eat tomatoes of any kind, cooked mushroom (raw is fine), pasta (except the bow shaped ones), brown rice, peanut butter and jelly sandwiches (unless the peanut butter and jelly are served on separate pieces of bread that are not stuck together), cheese (she does like string cheese), meat that is not shaped like a bunny rabbit, nor mashed, baked or boiled potatoes (french fries :-)."

Another friend, "Blaire," has a flair for the dramatic. One evening as we sat enjoying a glass of wine with Blaire's parents, Blaire led my daughter into the living room, both stark naked and giggling, "We are the forest fairies." Blaire's mother jumped to her feet and said, "Oh how cute! Let me get my camera…"

There is a darling little boy in my daughter's class who insists on Kung-Fu-ing every individual who crosses his path. His father explains with a smile to the individual who is grimacing and holding their shins, "Oh, he doesn't mean it really. We're trying to get him to be a bit more assertive, so he won't turn out to be a homosexual, ha, ha."

Then there is "Frank," who just last week, with the unfortunate perception of all bullies, told my daughter within earshot of her friends, "Your Mommy is weak and lame!" My daughter came home from school indignant, telling me what Frank had said. After I had given the maternal pep talk about how "you and I are stronger than Frank any day of the week," and also checked the web for martial arts studios in our neighborhood, I reflected, "How on earth does a seven-year-old already know how to objectify and demean a person with a disability?" And a scary thought, "What if little Frank becomes Judge Frank one day?"

"Mommy," said my daughter later, "When Frank says mean things about me it hurts my feelings. But when he says mean things about you, it hurts me even more."

My daughter has compassion, the capacity to love and a sense of responsibility. Where did I go wrong?

Comparative Canadian and United States Autism: A Narrative Analysis

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Abstract: This article examines autism policy narratives in Canada and the United States. In both nations, meta-narratives emerged, establishing federal autism policy. Whereas the stories associated with these meta-narratives shared starting points, the stories unfolded in nationally distinct ways.

Key Words: Autism, Policy, Narrative Analysis

Introduction

Policy narratives surrounding autism became more prevalent in Canada and United States during the past two decades (Baker & Stokes, 2007). This article explores stories, non-stories, counter-stories, and meta-narratives in autism policymaking using the narrative policy analysis approach presented by Roe (1994) with a specific focus on the 2006 Federal Autism Initiatives in Canada and the U.S. Combating Autism Act of 2006 (Lynch, 2006). The article begins with a brief overview of autism and then presents relevant aspects of narrative analysis. The introduction is followed by the Canadian case study and that, in turn, is followed by the United States case study. The article concludes with a comparative examination of the cases of Canada and the United States.

Autism

The U.S. Centers for Disease Control and Prevention (CDC) defines autism as a "collection of neurologically-based developmental disorders in which individuals have impairments in social interaction and communication skills, along with a tendency to have repetitive behaviors or interests" (Centers for Disease Control 2008). There is no scientific consensus as to the cause of autism spectrum disorders (hereinafter referred to as autism). However, most research to date focuses on genetic or environmental explanations (see, for example, Morrow et al., 2008).

As a spectrum difference, autism presents differently in each individual identified as having autism (Miller 2009). Although symptoms may emerge in early infancy, autism may not be considered as a diagnosis until much later in a person's life (Twyman et al., 2009). A young child who has major speech delays and sensory issues and avoids eye contact, for example, may be diagnosed with classical autism before his or her third birthday. However, a teenager with typical speech development but difficulties in social situations may not be diagnosed with high functioning autism (HFA) until the age of 16 or even later (Twyman et al., 2009). Diagnosis of

autism depends on observed behavior rather than a medical test. To further complicate the situation, over a person's lifespan, behaviors associated with autism may change (Miller 2009).

The inherent diversity and (perceived) mystery around autism complicate the creation of effective autism related public policy. For example, these factors complicate data collection on the prevalence and incidence of autism, both over time and across different contexts. They also complicate the work of incorporating input from multiple stakeholders, such as school systems, health care providers, and the families of people with autism. Finally, success of interventions is not consistent across the population of individuals with autism. What helps one person with autism cope with anxiety, for example, may do nothing for a person with the same diagnosis.

Narrative Policy Analysis

Narrative policy analysis is particularly well suited to the case of autism policy. Autism-related policy is characterized by high degrees of uncertainty, ambiguity, complexity, and, in Roe's words, is an area "where most everyone is playing it by ear" (Roe, 1994, p. 13). In such instances, those involved in the policy process rarely agree on the criteria for success. Success can be constructed from movements within the narratives (Kaplan, 1986). Given this, an understanding of policy narratives is critical to an understanding of autism policymaking because these narratives provide the most cohesive framework around which policy can be developed.

Narrative policy analysis assumes language constructs the world. The approach focuses on the importance of language in constructing policy (Bridgman & Barry, 2002, p. 141). In this method, discourse surrounding an issue is the focal point rather than empirical data. Discourse can, in effect, "respond" to empirical data by shifting meanings without exiting the policy arena. Narrative policy analysis, as developed by Roe, employs a case study approach and focuses on "the scenarios and arguments on which policies are based" (Roe, 1994, p. 2). It examines the policy narratives or "stories" developing around a complex policy issue. Focus is placed on the stories or narratives that "dominate the issue in question" (Roe, p. 3).

Roe also stresses the need to identify stories not fitting the traditional definition of a story. These "nonstories" do not have beginnings, middles, and ends. Furthermore, if the narrative "run(s) counter to the controversy's dominant policy narratives," it is called a "counterstory" (Roe, p. 3). The narrative generated from a comparison of stories and nonstories or counterstories is the "metanarrative" (Roe, p. 4). The metanarrative may then "recast(s) the issue in such a way as to make it more amenable to decision making and policymaking" (Roe, p. 4). In polarized policy disputes, the metanarrative can make the issues more tractable by foregoing a search for compromise and consensus in favor of a story that all can accept and can be the basis for moving forward in the policy process. A metanarrative, as Roe reminds us, is a "small-a answer" providing "room to maneuver on an issue that has hitherto been treated as so uncertain, so complex, and so polarized that is affords little or no movement whatsoever" (Roe, p. 17). Power and politics are involved in shaping how the issue is perceived and communicated and how the narratives are created and communicated (Roe, p. 14).

Canada and the 2006 Federal Autism Initiatives

On November 24, 2006, the Ministry of Health announced Federal Autism Initiatives. These initiatives included:

- sponsor an ASD stakeholder symposium in 2007 to further the development of ASD knowledge and dissemination among health care professionals, researchers, community groups, teachers, individuals, and family members;
- begin exploring the establishment of a research chair focusing on effective treatment and intervention for ASD;
- launch a consultation process on the feasibility of developing an ASD surveillance program through the Public Health Agency of Canada (PHAC) to help shape appropriate ASD programming and research;
- create a dedicated page on the *Health Canada Web site* to guide the public to ASD information available through the Canadian Health Network and other resources;
- designate the Health Policy Branch of Health Canada as the ASD lead for actions related to ASD at the Federal Health Portfolio level (Health Canada, 2006).

These initiatives were novel both because of the stated goals and the fact that they came from the national government as opposed to the provinces. Autism related groups welcomed the initiatives, even if they were not fully satisfied with their content, scope, or budget (approximately $800,000). Autism Society Canada explained in a press release:

> "We applaud the government for initiating some of the elements that ASC believes will help develop a comprehensive national autism strategy. These are modest first steps, and we will work to ensure that many more steps are taken by government to meet the multifaceted needs of our other partners across Canada." (Anderson, 2006)

This creation of a national strategy broke from previous, provincially focused, autism policy trajectories. Primarily because autism issues were located in the health policy subsystem, defining autism as a federal concern had been no easy task. After all, Canadian provinces of the Canadian federation had been almost exclusively responsible for the design of health care systems under the Charter of Rights and Freedoms. Establishing a federal autism initiative necessitated careful balancing of federal leadership on the part of a newly elected government with respect for traditional provincial autonomies with regard to publicly provided health care. In the process of creating such a balance, different stories about autism were employed within Canadian public and government discourse.

Medically Necessary

The Canadian medicare system receives funding from the federal and provincial governments. To receive federal funding, provincial and territorial health care insurance programs must meet the guidelines of the Canadian Health Act (adopted in 1984) (Canada Health Care Act Annual Report, 2008-2009). A fundamental component of the Act is the universally available provision of medically necessary health care delivered in hospitals and by physicians (Canada Health Care Act Annual Report, 2008-2009). Although strictly speaking,

provincial participation under the Canadian Health Act is voluntary, the value placed on the federal fiscal support on the part of provinces is high enough to generally ensure compliance on the part of provinces. No definition of "medically necessary" appears in the Canadian Health Act (Commission on the Future of Health Care in Canada, 2002). As a result, both the professional's judgment and lists created by the provincial governments serve to discern which illnesses, differences, procedures, and treatments are covered.

One story expressed in the Canadian public discussion of autism revolved around the theme of medical necessity. Basically, the premise of this story was that autism is a treatable disease affecting a growing number of Canadian children. In keeping with this story, the incidence and/or prevalence growth of autism observed in Canada in recent years was described as an epidemic (Senate Standing Committee on Social Affairs, 2007).

In the version of the story most often told in Canadian discourse, autism can be effectively treated only by intensive behavior intervention, preferably applied behavior analysis. According to this story, for reasons ranging from miserly provincial governments to sheer lunacy on the part of other autism policy stakeholders, this medically necessary treatment had been withheld from children with autism. The FEAT BC website described an organization committed to achieving universal public provision of applied behavior analysis for all children with autism living in Canada:

> "F.E.A.T. of B.C was established for another important reason – to publicize discrimination in B.C. against children with autism. Specifically, it is wrong that children with physical disabilities have access to government health insurance coverage, yet children with the mental, neurological disability of autism do not receive treatment." (FEAT, 2010)

The penultimate expression of this story was the Supreme Court case *Auton (Guardian ad litem of) v. British Columbia (Attorney General)*, [2004] 3 S.C.R. 657, 2004 SCC 78. This case revolved around the question of whether or not the equality rights of children with autism under the Charter of Rights and Freedoms (the Canadian constitution) was violated if the children were not provided medically necessary treatment, particularly in the form of applied behavior analysis. The decision of the provincial Supreme Court supported the parents who brought the case (The Learning Disabilities Association of Canada, 2008).

However, the Supreme Court of Canada reversed the decision, finding that the provinces were not required to provide all medically necessary treatment except for the core medical services (Baker 2008). This finding created what Roe would call a "nonstory," not providing a discernible beginning, middle, or end, or a redefinition of obligatory health care in Canada. The remaining controversy surrounding the treatment, particularly as connected to the story of autism as a different way of being human as opposed to an illness or disability, also cast influential doubt on the story presenting ABA as a virtual cure for autism. As is stated above, a key component of the 2006 Federal Autism Initiatives was the establishment of a research chair focusing on effective treatment and intervention for autism. This component of the initiatives connected back to the debates within the narratives on medical necessity left unsettled by the Supreme Court decision.

Scientifically Proven

Another influential narrative surrounding autism was rooted in the concept of scientific proof. The "scientifically proven" presented intensive behavioral intervention (in particular ABA) as the only scientifically proven intervention for autism. As such, the story created extreme urgency for providing treatment, since ABA is generally expected to be most (if not only) beneficial to young individuals with autism.

Drawing primarily from the work of Dr. Ivar Lovaas, the story typically told in the Canadian public discourse was that little scientific evidence supporting the existence of other effective treatments for autism. In fact, expressions of this narrative typically did not address scientific studies of other options, such as dietary intervention. For example, an online dialogue called "Riding Talk" employed this narrative as follows:

> "…since the 1980s the medical community has known that the application of Intensive Behavior Intervention (IBI) based on the principles of Applied Behavior Analysis (ABA) can help as many as 47% of children with autism develop to the extent that they are able to function as average children, indistinguishable from their peers. Such medically necessary autism treatment is the core healthcare need of children struggling to overcome the ravages of autism. Yet, even though the provision of this treatment is far less costly than a lifetime of social support and institutionalization for untreated children, there is not even one province in Canada that offers autism treatment under provincial public health insurance programs (Medicare)." (Canada Votes, 2006)

According to this narrative, the public policy challenges associated with autism were relatively easy to locate within the health care policy arena, and the blame for the problem was placed firmly on the shoulders of provincial governments failing to recognize a scientifically proven fact well established within the health care community.

The Canadian press frequently cited the only scientifically proven treatment narrative. Almost always, the narrative was expressed first with a statement of the cost of the treatment (in the range of tens of thousands of Canadian dollars per year), followed by the description of either intensive behavioral intervention or ABA as the only scientifically proven treatment, and concluding with a description of the government's failure to provide the treatment.

After the Auton verdict, however, the scientific proof narrative slightly decreased its focus on identifying a unique treatment for autism. For example, the website for the Geneva Center for Autism in Toronto stated:

> "While there is no one treatment which is entirely accepted by all professionals and parents as the 'only' approach to use, treatment based on the principles of Applied Behaviour Analysis (ABA) have been scientifically proven to facilitate the best outcomes for children with autism." (Toronto Partnership for Autism Services, 2008)

Although the meaning of the quotes around "only" was open to interpretation, it appeared to reference Canadian public and government discourse surrounding the scientifically proven narrative.

The only scientifically proven narrative was controversial. Perhaps surprisingly, the counter-stories on scientific evidence usually did not come from or are motivated by providers or supporters of other types of therapies or interventions. Evidence regarding alternative treatments and interventions tended to appear in less well publicized nonstories in Canada and did not address the science backing to the intensive behavioral interventions (Baker, 2008). The leading counterstories to the scientifically proven narrative engaged the concepts of human individuality and human rights.

Autistic Rights

The most common version of the autistic rights narrative was a counterstory to both the medically necessary, and, less frequently, the scientifically proven story. Whereas parents of children with autism and professionals in the behavioral intervention programs were the most fervent in expressing the scientifically proven and medically necessary stories, adults with autism who managed to integrate into the Canadian economy—if not society at large—were the most ardent in expressing the counterstory of autism rights.

The basic elements of the autistic rights counterstory were: 1) autism is not a disease or—in an inclusive society—even a disability; 2) behavioral intervention therapy is at best unnecessary and at worst an oppressive exercise robbing children with autism of their childhoods; and 3) other autism policy stakeholders, including the Canadian government, deliberately ignore and exclude the voices of adults with autism from related policy debates because they fear the truths revealed by the autistic-rights counterstory. As a result, these narratives were often expressed outside the formal policy debate (although individuals such as Michelle Dawson were not allowed to present evidence in settings including the Supreme Court debate of the *Auton* case).

Often autistic rights narratives were expressed in letters to members of government, and then the original letters and responses are posted on the World Wide Web. For example, Ralph Smith of The Autism Project, Ontario, wrote to his government representative liberal Minister of Parliament Karen Redman on October 4, 2004 to request she consider materials discussing the rights of autistic Canadians. She (or her office) responded in less than two weeks, citing her support for efforts to better identify and prevent autism. Michelle Dawson, a staunch advocate of neurodiversity,[1] wrote back to her, explaining their concern about rights of adults with autism. Karen Redman's response expressed her support to the Minister of Health for the designation of one treatment (presumably ABA) as a medically necessary treatment for autism. Ralph Smith's response read:

"Regarding your reply of November 18, 2004, I have not received a copy of your expected response from the Minister of Health. Also I do not support the request

which apparently you have made on my behalf. I do not support your request for an amendment to the Canada Health Act." (Smith, 2004)

In another letter, Mr. Smith said the following:

"I believe you have mistaken me for the parent of an autistic child, rather than the independent autistic adult which I am. While mistaking current issues regarding autistic people is far more serious an error, I believe your oversight would equate to your assuming I am heterosexual when I am in fact a gay male, or in anyone assuming that you are heterosexual or lesbian." (Smith, 2004)

Ironically, as seen in Smith's letter, Redman's formulaic response began with the story of autistic rights—individuals with autism who considered autism to be a formative element of their selves within society (the "autistics") found themselves facing passive and active discrimination in society. Failing to recognize (or denying outright) the autistic identity was understood as an expression of bigotry similar to those experienced by all non-elite populations.

Such narratives have been a common element of modern disability studies. Much conversation on disability rights in both Canada and the United States began with the statement "nothing about us without us" (Shapiro, 2011). These narratives portray efforts *for* individuals with disabilities as oppressive and in line with understandings of disability that, for the most part, blame the individual with the disability for any associated disadvantage. Often these narratives have called for a replacement of organizations *for* individuals with disabilities (or with a particular disability) with organizations *of* individuals with disabilities (Shakespeare, 2005). In the Canadian public and government discourse surrounding autism, the autistic rights narrative tended to not be so separatist. This narrative has been heard, if not fully accepted or understood, in Canadian government discourse. For example, regarding government funding of autism treatment, the report of the Senate's Standing Committee on Social Affairs stated the following:

"The second definition presented to the Committee was provided by other autistic individuals and researchers in the field. In their view, autism (or ASD) is not a mental disorder; it is rather a neurological difference classified as a developmental disability that begins in early childhood and persists throughout adulthood…In their view, autistic individuals have strengths and traits not seen in the general population, just like "non-autistics" have strengths and weaknesses of their own. Like non-autistic people, individuals with autism may suffer from mental health problems and illnesses, including for example depression, self-hate and suicidal ideation. Those mental health problems may be exacerbated by the lack of knowledge about and appreciation of autism among non-autistic individuals." (Senate Standing Committee on Social Affairs, 2007)

The Canadian Government discourse tended to present a version of the autistic rights characterizing the story as an interesting (and arguably relevant) side note. After all, the 2006 initiatives listed individuals with autism alongside several other stakeholders (albeit towards end of the list) to be included in the anticipated national autism symposium. References to this narrative tended to be followed either by a return without comment to another narrative or a

discussion of the responsive viewpoint that autistic rights narratives were presented only by extremely high functioning individuals with autism who failed to understand the plight and needs of individuals who are more deeply affected by autism.

Provincial Rights—Metanarrative

The three categories of policy stories discussed above encompass classic premises of public activity targeting disability—those of care, cure, cause and celebration. Juxtaposition of any pair of these premises created tensions capable of thwarting or stalling efforts to develop and implement new programs or policies. The presence of these premises in the culturally dominant autism policy stories underscores a necessity for the employment of a metanarrative for decisions to be made and for action to be taken. The 2006 Federal Autism Initiative demonstrated the federal autism policy, and the metanarrative emphasized the perfection and protection of Canadian federalism.

The Canadian federalism metanarrative began on a note of good intentions. Well-meaning citizens, groups, and even government officials wanting to improve conditions turned to the federal government to solve a problem. This problem in question, however, shaped daily lives and called for public policy sacrosanct to the provincial level of government. The challenge for the federal government, therefore, was to discern how to guide and support development of provincial programs and policies without becoming domineering or repressive. The conclusion of the metanarrative was to carefully protect the Canadian federalist system by maintaining a high degree of provincial autonomy in health care, despite perceived costs to individuals (particularly children) with autism. As Pat Lynch, a ministerial candidate, puts it:

> "I am very reluctant to infringe on Provincial jurisdiction. I know the Liberals have done it repeatedly... but they are creating a real mess of things with all the side deals they are making…however, I do wonder why Medicare does not cover treatment of autism related disorders." (Lynch, 2006)

The primary role of the federal government was, as a result, understood as to provide support for research, including $15 from the Canadian Institutes of Health Research between 2000 and 2006, and to reach out to other countries to create joint research agendas (Scott, 2006).

United States and the Combating Autism Act of 2006

In the case of the United States autism policy, a metanarrative emerged and lead to the policy's success. The metanarrative of an autism epidemic formed the basis for Congressional action on autism and the passage and eventual funding of the Combating Autism Act of 2006 (Lynch, 2006). Moreover, the metanarrative of an autism epidemic was broad and encompassing and did not, as a "grand" or "master" narrative can do, marginalize other narratives or substitute a form of autism canon.[2] Equally importantly, the epidemic metanarrative supported powerful advocacy groups and members of Congress and was policy relevant.

Information on autism in the United States was important for establishing the context in which the metanarrative appears. There was no consensus in the United States as to the

prevalence or incidence of autism. The CDC, for example, reported prevalence rates between 2 and 6 per 1,000, or between 1 in 500 and 1 in 166. This placed the prevalence rate for autism lower than the rate for mental retardation but higher than the rates for cerebral palsy, Down syndrome, or childhood cancer (Volkmar et al., 2004). The National Institute of Neurological Disorders and Stroke (NINDS) placed the rate at 3 to 6 per 1,000 (www.ninds.nih.gov). The CDC used figures demonstrating a 600 percent increase, from 22,644 to 141,022, of children classified as autistic between 1994 and 2003 (www.cdc.gov). More recently, the Autism Developmental Disabilities Monitoring Network (ADDM) suggested the prevalence may be as high as 1 in 110 (http://www.cdc.gov/ncbddd/autism/index.html).

Mercury Story, Counter-Story, and Non-Story

As noted earlier, there was no scientific consensus as to the factors involved in the etiology of autism. In the United States, a vocal group, including national organizations such as Safeminds and celebrities such as Jenny McCarthy, supported the belief that autism was caused by thimerosol, a mercury-based preservative in vaccines (Baker & Stokes, 2007). This lack of consensus as to the cause of autism, coupled with the lack of consensus as to the prevalence or incidence, encouraged the epidemic metanarrative.

The status of organized autism advocacy and its efforts to gain federal passage of autism legislation also played a major role in developing the context of the epidemic metanarrative. The organized autism advocacy began in 1965, when Dr. Bernard Rimland founded the first nationwide group devoted to autism, the Autism Society of America (ASA). Rimland, a father of a child with autism, began ASA as a parent advocacy organization. It expanded to over 100,000 members and supporters and some 200 local chapters. The ASA, however, had no major federal legislative success until the emergence of other advocacy groups, arguably because of the low profile of autism as a low incidence difference. Indeed, significant policy impact at the federal level did not occur until 2000 with the passage of the Children's Health Act (Lynch, 2006). ASA supported the legislation, but the advocacy group Cure Autism Now (CAN) was largely responsible for the inclusion of autism in this omnibus bill.

Jonathan Shestack and Portia Iverson, parents of a son with autism, founded CAN in 1995. As Shestack and Iverson were members of the entertainment community, CAN used their connections to gain congressional attention for autism. Their efforts eventually resulted in the inclusion of autism in the Children's Health Act (Lynch, 2006). The Children's Health Act mandated the establishment of the Interagency Autism Coordinating Committee (IACC) to coordinate autism research, programs, and activities (Lynch). The IACC supported the federal policy response to autism and can enhance the government's response to autism.

As CAN was successfully advocating the inclusion of autism in the Children's Health Act, Rep. Burton (R-IN) was holding hearings on the mercury and vaccine connection to autism (Lynch). Altogether, Rep. Burton conducted over 20 hearings on topics related to mercury, vaccines, and autism, none of them led directly to major autism legislation. Nonetheless, his efforts were a major factor in placing autism on the congressional agenda.

The next major legislative initiative was the Combating Autism Act (CAA) of 2006. First introduced in 2005, the CAA became the focus of national controversy. From the perspective of its supporters, it was "held captive" by Rep. Joe Barton (R-TX), then Chair of the House Energy and Commerce Committee (Lynch, 2006). Barton argued he was interested in his bill to reform the NIH and was not willing to support single-issue legislation, such as the CAA, until the reform was enacted. Consequently, he became the object of intense pressure from autism advocacy groups. Also, radio host Don Imus relentlessly campaigned against Barton, in large part because of his friendship with Bob and Suzanne Wright and their new organization, Autism Speaks. Autism Speaks characterized Barton's actions in particularly negative terms:

> "(I)n his unwillingness to act on a bill meticulously crafted over 18 months and unanimously passed by the United States Senate, Congressman Barton has decided to put politics before the welfare of our children." (Autism Speaks, 2006)

The statement, consistent with the Autism Speaks message, referred to autism as "an epidemic now affecting one in every 166 of our children, yet federal funding for autism remains woefully insufficient" (Barton, 2006). Barton's speech about CAA to the floor before the House included the possible connection between autism and vaccines and did not refer to an epidemic, but did present figures on incidence.

Autism Speaks (now Autism Speaks, Inc.) was founded by Bob and Suzanne Wright, the grandparents of a child with autism, and friends of Don Imus and his wife Deirdre. Bob Wright was the chair and CEO of NBC Universal and vice chair and executive officer of General Electric Company. Autism Speaks quickly became a major player in autism advocacy and, along with CAN, lobbied for the passage of the CAA. The Wrights were thanked on the floor of the Senate when the CAA passed. Congress approved the bill, and President Bush signed it into law on December 19, 2006.

The CAA authorized spending for the early detection and treatment of autism as well as research and education and reauthorized and restructured the IACC. Bob Wright and Jon Shestack noted when the Senate and House of Representatives approved the final version of the CAA, "(T)he passage of this landmark single-disease legislation signals the federal government's declaration of war on the epidemic of autism" (Cure Autism Now and Autism Speaks, 2006).

However, the discourse around legislative victory reflected controversy. Although Rep. Barton finally released the bill from the committee, the discussion from some in the autism community included objection to the version that became law, primarily because it removed earmark funding for research into the environmental causes of autism, including mercury in vaccines. Deirdre Imus, in a letter to *Newsweek*, advanced the epidemic metanarrative while not dismissing a possible mercury connection by writing:

> "What has caused autism rates to grow so much in less than 20 years? The idea that it's just better diagnosis is, to parents and supporters of the autistic community, like fingernails on the chalkboard. This epidemic is real and recent and cannot be explained by saying the diagnostic skills of doctors suddenly improved in the late 1990s. Perhaps the number of mercury-containing vaccines

given to children tripled in the '90s and resulted in a toxic tipping point, causing these children to regress into a disorder we call autism." (Imus, 2006)

A-CHAMP withdrew its support for the CAA. Other organizations, such as Sensible Action for Ending Mercury-Induced Neurological Disorders (SAFE MINDS), supported the legislation, but expressed reservations. Even before the bill became law, there was dissension within the Wright family. Katie, the Wright's daughter, and mother of their grandson with autism, said on the Oprah Winfrey show in April 2007 that she believes mercury in his vaccinations was responsible for her son's autism. Autism Speaks responded with a disclaimer on its website, distancing themselves from Katie's views.

Nonetheless, the "mercury story" advanced by Rep. Burton and supported by a number of advocacy organizations accomplished what Roe predicted: when confronted with uncertainty concerning the etiology of autism, the mercury story simplified that reality (Roe, 1994, p. 35). For some, the mercury connection was discredited, and alternatives, including environmental and or genetic factors, were suggested. Some who refused to abandon the mercury story modified it. Still, others, mainly small parent organizations, continued to question the validity of the scientific research, basically constructing a story of deception and cover up.

The pressure from these groups was so great that the Senate Committee on Health, Education, Labor, and Pensions released the executive summary of a report on the allegations (Enzi, 2007).[3] The report made no conclusions concerning the safety of thimerosol and focused on whether or not there had been improprieties by government agencies or private entities, particularly the pharmaceutical companies. These allegations of improprieties included conflicts of interest, instances of compromised research, and cover-up of the dangers posed by thimerosol. The mercury story and the counterstory that autism was not caused by mercury in vaccines was joined by a nonstory, one that, following Roe, had no beginning, middle, or end and had no answer to what caused autism.

Epidemic—Metanarrative

In this context, CAN and Autism Speaks turned to the metanarrative of the autism epidemic. In support of the 2005 version of the Combating Autism Act, Shestack, the founder of CAN, noted, "(w)e are determined to make the nation treat the autism epidemic as the crisis that it is" (Autism Speaks, 2008). The most dramatic and effective use of the epidemic metanarrative, however, was the Autism Speaks 1 in 166 message. This story was heavily publicized in public service announcements and print media.[4] As Fischer notes, "counting is also used as a tool of political mobilization" (Fischer, 2003, p. 171). Autism Speaks chose to use the metanarrative, including the 1 in 166 number. In an interview with *Autism Spectrum Quarterly*, Suzanne Wright, when speaking of lobbying on behalf of the CAA, noted,

"…This is an epidemic and they know how serious it is. The autism community is so committed to this and we really came together. As you know, since you've been involved with autism for so many hears, the autism community can be a very disjointed

group. You might have your agenda and it might be worthwhile, but if you don't have one voice, nobody's going to pay attention to you." (Twachtman-Cullen, 2006, p. 2)

Wright went on to say:

"There are so many issues–research, genetics, the environment. We can't let the Senate and the full Congress point at us and say we are not together, because then we will not have a voice to their attention." (Twachtman-Cullen, p. 2)

As would be expected by narrative policy analysis, there was no consensus per se as to whether or not an autism epidemic exists. The Department of Health and Human Services (HHS) website, for example, notes:

"The question of whether there is an autism epidemic requires an understanding of trends in autism. Understanding autism trends is particularly difficult due to the lack of historical population-based tracking of autism rates and the fact that many early studies used different methods and a narrower definition of autism." (Department of Health and Human Services, 2005)

The Enzi report (2007) stated:

"Autism has been called a national epidemic by the media, medical science and many active in the autism community but stops short itself of endorsing the existence of an epidemic per se. The report accompanying the CAA presented data on the incidence and prevalence of autism but makes no mention of an epidemic." (Senate Committee on Health, Education, Labor and Pensions, 2006, pp. 2-3)

The report did state, however, "the committee encourages the CDC to examine specific trends of autism spectrum disorder over time" (Senate Committee on Health, Education, Labor and Pensions, p. 14). In addition, President Bush's signing statement did not mention an epidemic (White House, 2006, p. 1).

The epidemic metanarrative was successful because it managed to transcend the mercury narrative, and there were no competing narratives compelling enough to counter it. ASA's official stance rejected the finding that there of no connection between vaccines and autism (ASA, 2004). Both CAN and Autism Speaks carefully sidestepped the most radical form of the mercury narrative. CAN, for example, sponsored a number of research initiatives, including one focusing on the neurotoxicity of mercury. Autism Speaks' position was circumspect but not dismissive of a possible connection between mercury and autism. The official Autism Speaks position was as follows:

"Autism Speaks plans to strongly support a multidisciplinary research agenda on environmental exposures and autism. We believe that projects acknowledging the role of gene-environment interaction and incorporating markers of exposure susceptibility and etiologic heterogeneity will be the most productive in the long-term. Given present knowledge, there is a fairly broad array of neurotoxic

environmental exposures worthy of further study but, moving forward, the type and timing of exposures under investigation should continue to comport with emerging developments in autism neurobiology." (Autism Speaks, 2010)

Autism Speaks and CAN were able to secure passage of federal legislation while acknowledging the need for research on more controversial issues, such as a mercury/vaccine connection to autism. Representative Burton supported the compromise legislation, referring to it as a "down payment" on what must be done to combat autism (Burton, 2008). In the same statement, he remained committed to the mercury story, but fully embraced the epidemic metanarrative.

The policy process could have responded to a known epidemic in ways not amenable to situations involving more uncertainty and ambiguity. Even the suggestion of an epidemic was important since policymakers seek to avoid appearing unresponsive or callous in the face of such concerns. The autism epidemic, in Roe's terminology, became a "metanarrative that recasts a difficult policy problem in a more tractable way" (1994, p. 108).

Discussion and Conclusion

Autism creates fascinating modern policy challenges in both Canada and the United States. Because of a relative lack of scientific understanding, there was significant room for the creation of stories to establish the consensus necessary for developing public policy. In both Canada and the United States, metanarratives emerged and helped to establish federal autism policy. Whereas the stories associated with these metanarratives shared starting points, they unfolded in distinct ways.

In both Canada and the United States, uncertainty surrounding current scientific evidence for autism-related theories created a starting point for policy stories. However, the dominant stories had different endings. This implied policy trajectories. In the United States, the narratives surrounding the source of an autism epidemic frequently drew on contested scientific evidence. In Canada, the more influential stories surrounded scientific proof in support of particular interventions for autism. In other words, whereas the predominant narrative on the theme of scientific proof surrounds causality in the United States, in Canada narratives tended to center on the concept and goal of a cure.

Autism is not a disease in the traditional sense of the word. In fact, many adults with autism (and quite a few other autism policy stakeholders) in both Canada and the United States take significant offense at this characterization (see, for example, the Autistic Self Advocacy Network at www.autisticadvocacy.org). After all, the concept of a disease suggests wholly undesirable condition. It also implies an anticipated downward trajectory of functionality. Finally, a disease is often something a person catches, not a fundamental element of his or her personhood.

In both Canada and the United States, the elements of a disease narrative were invoked. They were not, however, fully embraced. As discussed above, in the United States, thimerosal was sometimes identified as the villain in the metanarrative of the autism epidemic by groups

such as Safeminds. Since childhood vaccines have been considered by policymakers, medical professionals and much of the general public to have be one of the greatest public health achievements of the twentieth century, this plot point of the story relatively quickly became divisive and politically counter-productive (Kirby, 2006). To become successful, proponents of the narrative became focused on the concept of epidemic growth itself. The epidemic narrative was also employed in Canada, though not as a metanarrative. In Canada, the question of contagion was largely sidestepped and the epidemic concept was present in legislative discourse as part of stories about treatment, including what (if any) treatments are necessary and the attempt to establish a treatment favored by some policy entrepreneurs as the most scientifically proven. Whereas the stories of both Canada and the United States depend on a starting point that characterizes autism as a disease, the stories diverge with regard to the middles and ends found most compelling.

This comparative study reinforces the importance of understanding the context in which narratives emerge and unfold. In Canada, the emphasis was on federal funding for intervention. In the United States, the narratives focused on what the federal government could do in the absence of national healthcare, such as regulate vaccines and fund research. These so-called medically necessary and scientifically proven stories, so crucial to the efforts in Canada to provide treatment for individuals with autism, were not the focus in the United States. The Canadian federalism metanarrative and the United States epidemic metanarrative were influenced as much if not more by the specific structures of government of the two countries as they were by the challenges presented by autism. As such, this history presents a useful reminder of the role of social construction in the creation of disability. It also demonstrates how the unfolding of the same scientific process can motivate markedly different policy outcomes in even quite similar democratic contexts.

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Trudy Steuernagel was a political science professor at Kent State University. Dr. Steuernagel passed away in February 2009. She is deeply missed and fondly remembered.

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Notes

[1] Examples can be seen online at www.neurodiversity.com and
http://www.sentex.net/~nexus23/naa_02.html.

[2] For more information on grand or master narratives see, for example, John Harley Warner,
"Grand Narrative and Its Discontents: Medical History and the Social Transformation of
American Medicine," *Journal of Health Politics, Policy and Law,* 29(4), 757-780.

[3] Only the executive summary was released. The full report was not made available to the
public.

[4] A series of television commercials incorporating the 1 in 166 aired during this time.
Interestingly, incidence figures at the time to 1 in 150, a figure Autism Speaks utilizes on its
website and in public service announcements.

Jeremy Bentham on Physical Disability: A Problem for Whom?

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Abstract: This paper examines Bentham's provision for indigent people with disabilities, to reveal the discourse within which he constructs the problem of disability. Bentham's analysis reifies and institutionalizes such people, but also demonstrates insight into the social nature of "disability," in a way that anticipates both the strengths and weaknesses of the social model of disability.

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Introduction

This paper discusses Bentham's proposal for creating "appropriate establishments" for the indigent poor with disabilities to investigate the discourse within which he constructs the problem of disability. In the first section, the presumptions underlying Bentham's poor plan will be examined in the light of two modern discussions of disability, both of which connect the concept with the development of market societies, in which the primary distributive system is governed by the sale of labour. Bentham's employment of a deficit model of disability, derived from a "scientific," physiological basis in impairment, was typical of the individualized model of disability developed in the Enlightenment by the emerging science of medicine. In the next section, Bentham's plans for appropriate establishments will be examined, and a tension within his view of disability identified. On the one hand, the recognition that all human beings began life in a condition of abject dependency on others allowed Bentham to anticipate the central insight of the social model of disability, in seeing that the life prospects of people with impairments could be enhanced or diminished by the way in which society reacted to their impairment. On the other, Bentham's commitment to a deficit understanding of impairment was allied to his conviction of the central role of individual responsibility for individual subsistence in the creation of wealth. This conviction prevented him from recognizing the full implications of his "social model" insight for the individualized and medical model to which he, for the most part, subscribed. In the final section, it is argued that Bentham's treatment of sex in his appropriate establishments is free from the infantilization that has blighted institutional provision. However, his discussion is anchored in an implicit ranking of disabilities according their economic productivity that is shared with some presentations of the social model.

Capitalism, Individualism, and Disability as Competitive Disadvantage

Mike Oliver draws a causal connection between the rise of capitalism, with its individualistic construction of the world, and the development of both the "individual and tragic view of disability," and the medicalization of disability, upon which depends the view that "the social dimensions of disability and handicap arise as a direct consequence of individual impairments" (1990, pp. 3, 7). The construction of the individualized notion of disability

buttresses capitalism economically by constructing "disabled people" as part of the reserve pool of labour, and ideologically by imposing inferior status on them (Oliver, 1990). The asylums or workhouses in which people with disabilities were incarcerated after the Poor Law Amendment Act of 1834 stood "as visible monuments to the fate of others who might no longer choose to subjugate themselves to the disciplinary requirements of the new work system" (Oliver, 1990, p. 86).

The causal connection asserted by Oliver between the historical development of capitalist political economy and the emergence of the concept of disability has been contested, on the basis that disability presents other economic systems, characterized by different distributive rules, with similar challenges (Kohrman, 2005). However, as Deborah Stone argues, the twin features of compulsory able-bodiedness in a work-based system of distribution and officially-validated incapacity as the criterion of entry to a needs-based system are found in all modern societies, whether nominally capitalist or socialist. Together these twin features constitute the solution of the distributive dilemma that arises from capital accumulation, whether public or private (Stone, 1985). Stone discusses the way in which the medicalization of disability promised to reinforce the work-based system by providing "objective" criteria that acted as a passport to the needs-based system. Says Stone: "Clinical medicine, then, offered a model of illness that gave legitimacy to claims for social aid, and it offered a method of validation that would render administration of the category [of disability] feasible" (1985, p. 91).

Bentham's Poor Plan and Disability

These analyses seem strikingly applicable to the poor law writings of Jeremy Bentham, the English philosopher, jurist, and celebrated proponent of utilitarianism, who, between 1796 and 1798, analyzed the crisis in English poor-relief and proposed a detailed scheme for its reform. Fundamental to Bentham's analysis was the distinction between poverty (defined as "the state of everyone who, in order to obtain subsistence, is forced to have recourse to labour") and indigence ("the state of him who, being destitute of property … is at the same time either unable to labour, or unable even for labour, to procure the supply of which he happens thus to be in want"; 2001, p. 3). For Bentham, the production of both the matter of subsistence and—by the accumulation of surplus productivity—the matter of abundance, or wealth, depended on the "natural" connection between the investment of labour by individuals and the acquisition of individual subsistence. As labour was the source of wealth, so was poverty of labour. A central role of security of property was to encourage industry, while unconditional relief for any but those entirely lacking ability to labour threatened to destroy industry. Bentham asserted the importance of the connection between enjoyment of the fruits of labour and readiness to invest labour (2010, p. 195). Conversely, he repeatedly argued that the supply of subsistence without labour constituted a bounty upon idleness (2001, pp. 51, 56, 149, 171). In short, Bentham was an unapologetic advocate of economic competition between individuals as the motor of increasing wealth, while the energy driving the motor was derived from individual responsibility for individual subsistence. For those without property, the sale of labour power was the only option: "Property, bounty or labour—there are no other sources of existence" (Bentham, 2010, p. 67). In Stone's terminology, the creation of all resources, both those consumed in the way of subsistence and those that constituted the social surplus, depended on the efficient functioning of the work-based system.

Bentham remained committed throughout his career to public provision for the relief of indigence on two grounds. Even where indigence was the result of an agent's irresponsibility, the pain of death outweighed the pain of taxation to fund its prevention. Further, abolishing relief would undermine the security of all, by encouraging those abandoned to their fate to resort to violence (Bentham, 2001, p. 10). However, the state was justified in imposing conditions upon the relief it supplied. First, since the aim of relief was to prevent avoidable starvation, its extent should be limited to the "necessaries of life." Any other arrangement invited the instrumentally rational who preferred comfortable idleness to labour, to down tools and be maintained at the expense of others, "till at last there would be nobody left to labour at all, for any body" (Bentham, 2001, p. 38–9). Second, only where the ability to labour was utterly non-existent could there be such a thing as a free lunch. Since the independent poor were obliged to work in order to subsist, the indigent could have no objection to the condition of working to the extent of their ability in return for relief. Third, since home relief was incompatible with the efficient extraction of labour and was frankly too comfortable an option, the indigent were to be obliged to enter large-scale houses of industry and to remain there until the expense of their relief had been recovered. Clearly, if the marketable ability of the indigent was insufficient to make such a return, they could be confined for the remainder of their lives, while the long-term presence of the aged and infirm in workhouses deterred the rest of the population from seeking to join them, "in repelling from the establishment unfounded claims" (Bentham, 2010, p. 27).

In relation to disability, Oliver argues that the ideology of individualism constructs the disabled individual as a necessary antithesis of the able-bodied individual. The idea of disability as individual pathology is parasitic on the idea of able-bodiedness, which itself is indebted for existence to the rise of capitalism and wage labour (1990). Stone notes the manner in which medically-certified admission to an officially recognized category of disability legitimizes exemption from the work based system (1985). Precisely because aversion to labour was a natural human characteristic, policy-makers feared that such exemptions were likely to prove irresistible to many, hence the insistence on official investigation and certification of disability on empirically demonstrable grounds.

Bentham too believed that instrumental rationality was likely to produce attempts to simulate or fabricate physical impairments and thereby secure subsistence without labour. His general response was to extend the boundary of the work-based system. In his plan, receipt of relief provided no exemption from the obligation to labour, except with reference to the tiny minority utterly incapable of work. He proposed a fourfold division of human agents with regard to ability to generate subsistence through labour, ranging from "utter inability" to "extra ability," that is, capacity to generate a surplus in excess of the amount required to keep body and soul together. He argued that the fact that massive surpluses had been generated over the course of history implied strongly that "*extra-ability* is the *natural* and *general* state of man: and that even *simply adequate* ability, much more *inadequate* ability and *utter* inability, form but so many exceptions to the general rule" (2001, pp. 5–6). Utter inability was in fact almost never encountered:

"Not one in a hundred is absolutely incapable of all employment. Not the motion of a finger—not a step—not a wink—not a whisper—but might be turned to account, in the way of profit, in a system of such magnitude. A bed-ridden person, if he can see and converse,

may be fit for inspection; or though blind, if he can sit up in the bed, may knit, spin, &c. &c."
(Bentham, 2010, p. 518)

Further, since he eschewed the attempt to demarcate between the deserving and the undeserving poor, Bentham was not obliged to distinguish those who would not work from those who could not work, and thus continually to redefine capacity to work, to prevent the burdening of services with the incurable or the lazy (Lawrence, 1996; De Renzi, 2004; Stone, 1985). In his discourse, almost everybody could work, and almost everybody would be obliged to work.

Bentham undertook an exhaustive analysis of the causes of indigence; the fruit of which was the "Table of Cases Calling for Relief" (2010, between pp. 476 and 477). He made an initial distinction between causes external to the individual (unemployment, loss of property) and causes internal to the individual (insanity, physical disability, illness, childbirth, infancy, old age). Bentham's view of disability was explicitly that of a deficit with regard to the ability to secure subsistence through labour, and this deficit approach is encapsulated in his label "Imperfect hands" for the category consisting of the deaf and mute, the deaf, the blind, and "cripples." Individuals suffering from disease, the habitually drunk, and the elderly also faced a decline in ability and were grouped in the category "Feeble hands." The chronically ill, whose ability varied with the severity of their condition, or who, like those suffering from epilepsy, were faced with unpredictable episodes of acute vulnerability, were categorised as "Sick and Well hands." Finally, those suffering particular impairments, such as hernias, that rendered them unfit for a limited range of work though leaving ability intact across an extensive range were allocated to the category "Tender hands." The division of the indigent into categories of "hands" reveals a mercantilist focus with maximizing national wealth through expanding the number of productive labourers (Andrews, 1991). As Bentham himself explained: "The word *Hands* is chosen, as bearing reference to *Employment*, serving thereby to point the attention to the consideration of the *Employments*, to which the persons thus characterized may respectively be competent or incompetent" (2010, between pp. 476 and 477).

The deficit approach is also evident in the book *An Introduction to the Principles of Morals and Legislation*: "By bodily imperfection may be understood that condition which a person is in, who either stands distinguished by any remarkable deformity, or wants any of those parts or faculties, which the ordinary run of persons of the same sex or age is furnished with" (Bentham, 1996, p. 55). Expressing a view that remains prevalent (Hunt, 1966), Bentham viewed all such people as victims of misfortune, in that they lacked capacities possessed by "normal" human beings. Indigence resulting from disability was thus an individual rather than a social problem, its cause being impairment of normal function. Individuals with impairments typically faced competitive disadvantages in securing employment and subsistence. Loss of strength or stamina, periods of complete inability, and sensory impairments could each reduce an individual's earning potential and render them dependent on others, and ultimately the state, for their survival.

This deficit approach is reflected in the World Health Organization definitions of impairment: "any loss or abnormality of psychological, physiological, or anatomical structure and function," and disability: "any restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered normal for a human being" (World Health Organization, 1980). These definitions likewise identify impairment with deficit

and locate the cause of the disability in that deficit, without regard to the social aspect of disability, constituted by the physical, cultural, and political environment that confronts persons with impairment in their efforts to live a life (Oliver, 1990; Abberley, 1998). In this regard, it is significant that Bentham's fourfold division of degrees of ability with regard to labour entails, as its obverse, a fourfold hierarchy of degrees of disability, based upon differences in the productivity of marketable labour, themselves derived in part from differences in functional impairment. As will be argued in the next section, Bentham's recognition that differences in functionality issue from the interaction between the internal fact of bodily impairment and the range of external circumstances constituting the physical and cultural context within which those impairments manifest makes him all too conscious of the socially mediated nature of disability.

For the present, however, the central point is that for Bentham the claim to relief and the obligation to enter the industry house arose not from disability, but from indigence. People with impairments fortunate enough to possess either marketable abilities or families possessed of extra-ability or existing property would never apply for relief and thus never become dependent: "Domestic connections and a permanent source of employment may place a man, though labouring under this affliction [i.e. epilepsy], above the need of public charity: the want of either requisite may expose him to it" (Bentham, 2010, p. 28). Bentham did believe that impairment implied lack or loss of capacity (and that such lack or loss might issue in indigence), whilst provision for indigence, in a context where the sale of labour power provided the main source of income, required a deterrent character. However, he had no desire to confine, segregate, and institutionalize people with disabilities simply because they were people with disabilities.

Oliver notes that capitalism, by its incompatibility with home-working, swept away mechanisms of informal care and undermined "many previously acceptable social roles, such as begging or 'village idiot'" (1990, p. 86). Bentham would have rejected the notion that either begging or village idiocy were acceptable social roles. He knew that people with physical impairments often became beggars: "the idle part find in their respective infirmities, a qualification for exercising ... the profession of a beggar; a profession, which in such a country … may be set down as much superior in point of profit to the vulgar herd of labouring occupations" (2010, p. 26). Under Bentham's scheme, all beggars, whether they have a physical impairment or not, would be obliged to enter the industry house and to work. His defence of coercion was uncompromising. First, begging destroyed the connection between investment of labour and acquisition of subsistence and thereby undermined the motivation to labour. Introducing Bentham's conditions of relief without coercive measures to eradicate begging would multiply the population of mendicants exponentially. Second, Bentham believed that extended idleness was itself immoral and contrary to the long term interests of the idle: "The habit of industry is a source of plenty and happiness. The habit of idleness in one who has property is a cause of uneasiness, and, in one who has no property, of indigence and wretchedness" (2001, p. 45). In this he echoes a connection between disciplined industry and good morals found in the writings of several theorists of punishment, and which has been traced back to Thomas More's *Utopia* (1965): "Utility was the guiding principle in their ideal societies. Every author considered idleness as the supreme vice, and begging was to be combated through employment plans and repressive measures" (Spierenburg, 1996, p. 21). The habit of idleness was at the root of both indigence and criminality, while the message from the materialist and associationist psychology of Hartley and Helvetius was that habits could be reformed: "The

overwhelming corrupting influence in the lives of the poor that tempted them into crime was idleness; and the cure for idleness was work" (Semple, 1993, p. 155).

Bentham was a typical enlightenment thinker. He believed that the amelioration of human affairs depended upon the replacement of prejudice with reason. He also believed that whole swathes of human activity, previously considered to be outside the sphere of governmental action, would benefit from subjection to public policy founded on rational, empirical knowledge, the result of inductive inferences from quantifiable data, accumulated through repeatable observation and experiment (Rose, 1994; Jenner, 2004).

In his poor law writings, Bentham lamented the lack of statistical data upon which to base firm conclusions (2010) and promised that the National Charity Company would generate invaluable quantitative data on a host of subjects, from meteorology to epidemiology, from the healthiest diet to the healthiest age to commence sexual activity. The industry houses were to be centres both for the collation of data and for experiment, laboratories offering unexampled opportunities for the expansion of useful knowledge: "Observation and experiment compose the basis of all knowledge. ...The institution of the proposed Company would afford the first opportunity ever presented to mankind, of enriching the treasury of useful knowledge by contributions furnished on a national scale" (2010, p. 624). The paupers upon whom such experimentation was to be performed were indeed objectified, but Bentham did envisage imposing ethical restraints to protect the health and safety of the subjects (2001; see also Bentham, n.d., UC cliii. 337).

From a contemporary perspective, the notion that the human sciences could give rise to unproblematically objective knowledge may seem somewhat naive. Foucault demonstrated that medical knowledge was not simply lying about, waiting to be "discovered," but was constructed, in a Faustian exchange between the medical profession and the state. In defining health, medicine functioned as an extraordinarily powerful normalizing discourse:

> "Medicine must no longer be confined to a body of techniques for curing ills and of the knowledge that they require; it will also embrace a knowledge of *healthy man*, that is, a study of *non-sick man* and a definition of the *model man*. In the ordering of human existence it assumes a normative posture, which authorizes it not only to distribute advice as to healthy life, but also to dictate the standards for physical and moral relations of the individual and of the society in which he lives." (1973, p. 34)

It is as part of this normalizing discourse that disability becomes medicalized and located as a problem with the physical functioning of people with disabilities. Deviance is departure from the normal, and people with disability who do so depart, whether they wish to or no, while such departure is typically characterized as unfortunate, useless, and sick (Hunt, 1966, p. 146). Stone details the manner in which the political role of medicine in the definition of disability has been contested within the medical profession itself, thereby providing an illustration of the impact on the content of particular bodies of knowledge, of the political and cultural context within which they develop (1985). However, with the hindsight lent by two hundred years of medical hegemony and the critique thereof, it seems that the strategic importance of medical knowledge and its promise of effective definition and treatment of problems proved simply irresistible to policy-makers (Rose, 1994; Jones, 1996; Risse, 1996).

"Appropriate Establishments": Elements of the Social Model?

Bentham proposed that provision for indigent persons who were insane (including persons who would currently be described as having learning disabilities), deaf and dumb, or blind should be made in specific industry houses called "appropriate establishments." With regard to persons with other physical impairments, he concluded that they "may require something of particularity in respect of employment and attendance, but not any separation in point of place." (2010, p. 166) The reason concerned the division of labour and the manner in which manufacturing processes could be broken down into separate operations, some of which could be adapted to their remaining faculties: "The convenience of the business would therefore require a mixture of workmen, the partly disabled with the undisabled." (2010, p. 166) One final category of hands might require an appropriate establishment, not because of any benefit to them, but because of their fellows' reaction to the impairment, namely "persons labouring under a degree of bodily deformity too striking to admit of their [being] left to mix with society at large." (2010, p. 153) Here, Bentham's concern is utterly unrelated to any hierarchy of impairment based on productivity, since there is no necessary correlation between unsightliness and ability to labour. If there is a hierarchy at work, it is rather the binary opposition between those with unsightly impairments and the "ordinary run of persons," and it is the sensitivities of the latter that Bentham is concerned to protect. He also suggested that persons with unsightly impairments be accommodated in establishments for the blind, who would suffer no inconvenience from exposure to "deformity or disease particularly loathsome or offensive to the sight" (2010, p. 26).

Bentham listed the reasons for appropriate establishments as follows:

1. Appropriate Education.
2. Appropriate [medical] Attendance.
3. Appropriate instruction in regard to Employment.
4. Exercise of appropriate employment, when instructed in it.
5. Religious instruction and exercise. (2010, p. 154)

One reason for gathering indigent people with disabilities in appropriate establishments was that everybody benefited: the patients, from expert medical attention, the doctors, from opportunities for learning in "a school for philosophical and medical science" (2010, p. 161), and the public, from the dissemination of such learning. Bentham did have faith in the objectivity of medicine and in the motives of medical men. In his industry houses, medicine trumped economics when the two collided.

Central to the justification of appropriate establishments was the assertion that "Rare and particular cases excepted, the remnants of ability possessed by persons labouring under … modifications of bodily imperfections are capable of being as profitably employ'd as the entire stock of ability possessed by individuals at large" (2010, p. 26). People with sensory impairments required assistance in developing their capacities, in addition to that required by the able-bodied. In small parish workhouses, the provision of such assistance would be ruinously expensive, and few parishes could purchase the necessary equipment and expertise in medicine, education, or employment-training, for the benefit of the handful of recipients that the parish would supply. In a national system of large-scale regional centres, the necessary assistance could

be given to two thousand people with impairments in each appropriate establishment by a small (and therefore relatively cheap) staff of specialist doctors and teachers.

Bentham recognized that all human beings were born into a state of helpless dependence, and that all would perish without external assistance. People with physical impairments were likely to require additional assistance to enable them to function, so that the level of their disability would depend on the reaction of others to the impairment. That reaction could be enabling or disabling, as Bentham noted with reference to the deaf and dumb:

> "These are either ideots or of sound mind, destitute of or endowed with intelligence, according to the species and degree of care that has been bestowed upon them at an early part of life. A deaf and dumb person left a prey to his infirmities, treated with no other care than what is bestowed upon the common run of the children of the poor, remains all his life a wretched ideot, a being scarce human, consuming the labour of others, and altogether incapable of paying for it by any exertion of his own: the same person, brought up in a manner adapted to his deficiencies, may be rendered as valuable a member of society in every sense, the economical one not excepted, as if no such infirmity had fallen to his share.

> A thousand persons labouring under this species of infirmity would, by the help of a suitable education, for which able professors are not wanting, be just as capable of earning their own maintenance … as any other thousand persons that could be named." (2010, p. 161)

Bentham made the same point with reference to the blind (2010, p. 163) and was explicit that the goal of investing resources in development of capacities of people with physical impairments was to facilitate their independence: "here they would be fitted, according to their several measures of ability in other respects, for obtaining employ on a footing of independence" (2010, p. 164).

In all this there was explicit recognition of the social aspect of disability and anticipation of the insights of the social model of disability, which "makes a clear distinction between impairment and disability: the former refers to biological characteristics of the body and the mind, and the latter to society's failure to address the needs of disabled people." (Barnes, 1998, p. 78) It is true that Bentham's attempts to utilize the economies of scale offered by the National Charity Company to provide suitable education and training to persons with physical impairments were all supply-side measures, aimed at making "disabled people suitable for work" (Oliver, 1990, p. 86). Thus these measures did not attempt to challenge the barriers, whether in terms of the organization of work, or of cultural beliefs or prejudices, that might depress the demand for such labour. However, within Bentham's rationale for appropriate establishments is to be found a statement of the central insight of the social model of disability.

It should be noted that Bentham's analysis shares in the alleged weaknesses of the social model, insofar as that model retains a focus on removable obstacles to productivity presented by the material structuring of the world in which people with impairments attempt to function. The social model has been criticized precisely for containing its own hierarchies of disability, derived, like Bentham's, from a materialist ontology. Such an ontology overlooks hierarchies, for

instance of gender or ethnicity, that have very real consequences on individual lives both inside and outside the productive, public sphere (Morris, 1996; Tregaskis, 2002; Vernon, 1996, 1999).

Jo Wolff distinguishes between the medical and social models of disability by the imperatives to which they give rise (2002). The medical model commands "Change the individual," typically by medical intervention or provision of artificial aids, whereas the social demands "Change the world," for instance by legislative requirements for equal access to buildings and transport systems. There are at least two reasons for Bentham's failure to develop his insight into the social nature of disability. First, Bentham's political economy, with its central tenet of individual responsibility for individual subsistence and its understanding that the production of the social surplus depended on incentives to labour, of itself stifles the development of the social model, at least insofar as that model bears implications for redistribution of scarce resources. Bentham would be very wary about any model that might produce a claim for compensatory expenditure on grounds of the injustice of the disadvantages arising from impairment and or disability. Equality of well-being is for him an illusory and dangerous goal, while the social surplus was simply neither large nor robust enough to finance, for instance, the nullification of all such disadvantages (Bentham, 1838).

Second, whilst Bentham understood that the effects of impairment could be exacerbated or mitigated by the context in which people with impairments functioned, he would, I think, assert the existence of an irreducible, biologically verifiable element in the notion of impairment. Bentham might well have agreed that disability was a social construct, but he saw individual impairment as a natural fact. Again, Bentham shares in the alleged weaknesses of the social model, which has itself has been criticized on the basis of its binary division between disability and impairment. This division "de-medicalises disability, but simultaneously leaves the impaired body in the exclusive jurisdiction of medical hermeneutics" (Hughes & Patterson, 1997, p. 330). Further, repeated attempts to transcend the "impairment/disability divide" from a sociological or anthropological perspective, and to reclaim the body from biology (Shakespeare & Watson, 1997, 2002) have themselves been dismissed (as, presumably, would Bentham's entire intellectual enterprise) as "mechanistic and mired in reductionism" (Hughes, 2007, p. 682).

There are significant ironies in the presence of the central insight of the social model in Bentham's poor law proposals. First, one motive for the provision of appropriate establishments was the possibility of profit from the previously unexploited capacity for labour of people with disabilities. Second, Bentham believed the provision of appropriate establishments to be affordable in part because of the profits derivable from the labour of an expanding population of apprentices, indentured to the National Charity Company until the age of twenty-one. These apprentices combined low maintenance costs with high productivity. Productive labour was to commence at four years of age, when maintenance costs were trifling, and reached its maximum return well before the age of liberation. Specific assistance to people with disabilities was possible partly thanks to cross-subsidy from the profits arising from the quite explicit exploitation of child labour (Bentham, 2001).

Sexuality and Disability in Bentham's Industry Houses

There has been significant criticism of the still prevalent myth that "disability and sexuality are incompatible" (Shakespeare, Gillespie-Sells, & Davies, 1996, p. 9; see also

Shuttleworth, 2004). This oppressive attitude has had powerful effects in residential institutions for people with disabilities in terms of the infantilization of residents as childlike, asexual beings: "This failure to prioritize matters which are highly significant to most adults, including most disabled adults, reflects a failure to consider disabled people as fully human" (Shakespeare et al., 1996, p. 87). Conversely, the history of sexual abuse of vulnerable people with disabilities in such settings, by staff and other residents, provides a salutary warning about the problems of closed, uninspected institutions (Shakespeare et al., 1996).

With regard to the danger of abuse, it should be pointed out that the management of the panopticon industry houses was designed to be as transparent as possible, while the size of each house would make it a centre of public attention and interest (Bentham 2010). Bentham believed that sexual abuse in his industry houses would be impossible and included "security against seduction" in his enumeration of "pauper comforts" (2010, p. 657). With regard to infantilization, Bentham would surely have agreed with Shakespeare on the centrality of emotional and sexual intimacy to human happiness. In discussion of the pauper apprentices, he advocated the early commencement of sexual relations and the availability of marriage, limited only by cautions regarding the necessity of a degree of emotional maturity, and the possible effects on physical health. His rationale was simply that an early start meant a longer period during which sexual intimacy might be enjoyed: "every portion of time, which … might have been passed in the social state, and yet is suffered to pass away in celibacy, is so much lost to happiness" (2010, p. 653–4n.).

If Bentham's view on the centrality of intimacy was enlightened, his assumptions about the sexual partners of the indigent with disabilities were less so. In short, he was guilty of assuming that their field of available partners was made up of other people with disabilities. As he wrote with reference to the deaf and dumb:

> "In such an establishment each individual might at a proper age find a companion of the opposite sex to share with it the burden of the infirmities common to both: and the comforts of matrimony may thus fall to the share [of] many a contented being, who … in the cottage in which he might have been put to board at parish expence, would have dragged out a miserable and solitary existence, shunned as a monster, and scarcely regarded as belonging to the society of men." (2010, p. 162)

In so far as the deaf and dumb in an appropriate establishment are segregated from the rest of the indigent population, Bentham might argue that the field of potential partners was necessarily limited to people with the same impairment. However, it seems likely that he shared the still prevalent assumption that people with disabilities were more comfortable "sticking with their own kind" (Shakespeare et al., 1996, p. 92). Thus Bentham commented with regard to the deaf and dumb, "persons of this description are very convenient company for one another, and but indifferent company for others" (2010, p. 160), and saw their "being educated or associated with persons of the opposite sex, partakers of the same infirmity" (2010, p. 645), as an efficient cause of opening to them of the possibility of matrimony.

Hierarchies of Pain and Productivity: Sex, Procreation, and Self-Maintenance

Discussion of sex raises the issue of eugenics directly. Since the concept was not developed until long after Bentham's death, we lack direct evidence for his attitude to either eugenics in theory or to the large-scale compulsory sterilization of people with a range of physical and intellectual impairments to which it led in practice. It does seem clear that Bentham's appropriate establishments, like all his industry houses, would be scenes of significant reproductive sexual activity. While it would be disingenuous not to point out that the offspring of all apprentice unions would be indentured to the Company until the age of twenty-one, thus increasing its supply of profitable apprentices, Bentham clearly did not view physical impairment as a bar to sexual activity. In enumerating the pauper comforts available to the indigent with significant physical impairments, that is those who require appropriate establishments, he refers specifically to "Facility in regard to obtaining the comforts of matrimony." (2010, p. 653) Bentham went on to argue that the education received would have the effect of allowing the marriage to remain economically viable on the couple's departure from the house.

Nevertheless, the issue of sex poses questions to Bentham's view that impairment, insofar as it constituted loss of capacity, was an harm, that is a cause of pain or loss of pleasure. The individual with an impairment could reasonably be expected to wish to be without it, that is, to be possessed of relatively greater capacities. This is to say that impairment is, of itself, something undesirable. Abberley describes the view that "impaired modes of being are undesirable," as "eugenicist," and "in essence, genocidal" (1998, p. 84). But, of itself, the view that impairment is undesirable entails nothing with regard to the treatment of people with impairments. In just the same way, the view that greater capacity—physical, intellectual, or moral—is more desirable than less does not entail a desire to terminate the lives of human beings who experience a relative lack of such capacity.

Some advocates of the social model of disability, recognizing that physical impairments can lead to enduring pain, agree that bodily impairment is very often a negative experience, regardless of society's response to it: "it would be ... wrong to ignore the issue of impairment, and the desire of many disabled people to avoid the pain and discomfort which it brings" (Shakespeare et al., 1996, p. 185). Bentham discussed bodily imperfection as one of twenty-four primary circumstances influencing sensibility, that is, facts relating to individuals that operate to enhance or diminish the pleasure or pain consequent on good or bad experiences (1996). Such circumstances include physical properties (for instance health and strength), psychological properties (for instance intellectual powers and bent of inclinations), and external facts (for instance pecuniary circumstances). In relation to each such circumstance, human agents are distributed along a continuum, while the condition of any individual occupying a position below the median in that particular distribution can be described in terms of a deficit, or impairment, in relation to the statistical norm. Bentham refers directly to the statistical norm in defining people with bodily imperfections as wanting "any of those parts or faculties, which the ordinary run of persons of the same sex or age is furnished with" (1996, p. 55). For instance, I think that my life would go better with a functioning pancreas, and I could certainly do without the herniated lumbar disc. Both these impairments have a negative impact on my capacities, but neither would imply, for Bentham, any denial of my claim to have my pains and pleasures taken into account in framing rules governing interaction with my fellows. Physical impairment thus constitutes, for Bentham, one of an extensive, multi-dimensional range of circumstances that impact on

individual well-being. What, he might ask, is gained by denying that impairment entails loss of capacity?

Abberley correctly cautions that an irreducible core of people with severe impairments will remain unemployed and therefore economically non-contributing, despite all possible efforts to extend economic opportunities to people with disabilities (1998). The view, which infects Marxist and Capitalist theories, together with early versions of the social model, that human beings are defined by their labour, both devalues and questions the full humanity of those incapable of labour. For his part, Bentham would have believed that *ceteris paribus*, a society in which there were no incidence of physical impairment, would be a better, that is happier, society, liable to contain more pleasure and less pain than one in which such incidence was common. However, his reaction to the existence of such impairments was not to propose the elimination of their possessors, on the basis of their imperfection in relation to some ideal standard of humanity. Instead, he first asserted a right to unconditional relief at public expense on the part of those with impairments severe enough to destroy completely their ability to generate value through labour (a right founded precisely in that inability). He then attempted to facilitate the development of the skills, and thereby the value of the labour, of those people with impairments who retained such abilities.

Bentham does not, however, address the issue of whether to encourage or allow procreative sex between two individuals whose offspring is very unlikely ever to earn its own maintenance. He frankly admits that, "Justice and Humanity out of the question" (that is, "in point of unfeeling economy") it would be better for the National Charity Company if every child destined to die before making a return in profitable labour "should perish the instant of its birth." (Bentham, 2010, p. 449) Elsewhere he argues both that accurately identifying such children would require superhuman foresight, and that killing such loss-makers would be ruled out by the transparency of the management: the public would not endorse infanticide (2010, p. 117). He also takes great pains to make the remuneration of nurses in the industry houses dependent upon reducing the rate of mortality amongst the children (2010, pp. 116-18, 516-18).

On the one hand, given the right assistance, Bentham viewed many physical impairments as no obstacle to self-maintenance. On the other—to apply his thought to an anachronistic scenario in which genetic screening indicates that a developing foetus has an incurable impairment that will prevent any possibility of self-maintenance—while he would argue that, for the opulent, any decision regarding termination remained the prerogative of the parents, he might well advise them that a termination was the best, that is, pain minimizing, option. His rationale would be grounded on the inability of the foetus, or indeed the neo-natal infant, to suffer pain from the disappointment of expectations:

> "It possesses not as yet any such faculty as that of reflection: it has no anticipation of the future: it has no recollection of the past: scarcely can it be said to be possessed of so much as the faculty of consciousness. Of life it may, with unerring certainty, be deprived without any sense of suffering: for before it can have had time to suffer, all sensation is at an end." (Bentham, n.d., UC lxxiv. 137)

In accordance with this view, given a choice regarding the prevention of the conception of a fœtus likely to experience a life of disproportionate suffering and certain to be able neither

to maintain itself nor to contribute to their profit, the National Charity Company would surely embrace a strategy of prevention. By parallel reasoning, the company might well reach the same conclusion in relation to a similarly circumstanced fœtus after conception, and indeed in relation to a similarly circumstanced new-born infant. It would be likely, that is to say, to endorse both termination and neo-natal infanticide in such cases, with the caveat that such a policy should not be pursued if it would outrage public opinion. It remains true that Bentham has no desire to remove people with impairments from the public domain simply on the basis of those impairments. However, there is a threshold, defined in part by a likelihood of acute and prolonged pain, and in part by a lack of capacity for productive labour, below which he would be driven to assert the legitimacy of preventing conception, of aborting fœtuses, and indeed of killing infants with severe impairments. In this regard, Bentham would endorse the position of Singer (1994; see also Kuhse & Singer, 1985) and rely in part on the same argument, namely that it is an error to confuse neo-natal infants with persons.

However, given his view that "unprolific sensuality ought not to be esteemed vice" (Bentham, n.d., UC lxxiv. 124), Bentham would argue that the pleasure of sex was logically entirely separable from the production of children, while birth control rendered the separation wholly practicable. In his view, sexual intimacy might well be central to well-being, but parenthood was not. Under the National Charity Company, a eugenicist hierarchy among the dependent poor would be likely to emerge, in that indigent people with a high risk of passing on genetic impairments severe enough to issue in the inability of their children to contribute economically might well be coercively prevented from procreating. It should be noted that Bentham would view the denial of the possibility of parenthood as a much lesser pain than the denial of sexual intimacy: "*After* birth, in how high a degree soever, the child is an object of *love*, *before* birth, to indigent parents, the same child could scarcely have been an object of *desire*" (1983, p. 113).

Conclusion: An Individual or a Social Problem?

In reading Bentham's poor law writings, there are moments when it seems as if Bentham had made a positive effort to demonstrate the close connections between the development of capitalism and the medical model of disability. The insistence on individual responsibility for individual subsistence, the fourfold division of ability, the notion of imperfect hands, and the privileging of medicine in the industry house all show Bentham individualizing disability and making it a medical issue. The problem began with individual impairment, from which indigence often followed. However, at no stage did Bentham advocate the segregation and confinement of people with physical impairments simply on the basis of their impairment. Indigence, not disability, was his criterion for admission to the poor house.

The study of his provision of appropriate establishments provides a different perspective on Bentham's attitude to disability. Here, there are anticipations of the social model of disability and attempts to provide a social response to impairment that might compensate for the barriers operative in the able-bodied, free market world. However, Bentham's thought was both too individualistic and too biologically essentialist to permit either a fully-fledged articulation of the social model or an anticipation of the critiques to which that model has given rise. To his great credit, he believed that the National Charity Company possessed the resources to provide necessary training and assistance to those with physical disabilities, so that imperfect hands

could be rendered profitable. In addition, he was refreshingly frank about sex, neither infantilizing nor asexualizing people with physical impairments. However, it remains the case that like the social model whose central insight he anticipated, he presumed a hierarchy of disability according to productivity which itself remains problematic.

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From Ableism to Accessibility in the Universal Design University

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Abstract: Educational expansion has reached the tertiary level; however, inclusive higher education remains an elusive goal despite the ratification, in more than a hundred countries, of the International Convention on the Rights of Persons with Disabilities since 2006. The Convention mandates inclusive education throughout the life course and thus increased access to universities. Enhancing accessibility requires us to remove barriers and defeat ableism. Analyzing contemporary trends in Europe and North America, this article compares universities' attempts to implement elements of the "Universal Design University." Because universities serve as role models and provide community services, these organizations can and should implement universal design principles. Universities have myriad opportunities and responsibilities to enhance access to their programs. In embracing social and political paradigms of disability, in giving voice to diverse participants, and in implementing universal design principles, the university can engage and change public awareness and attitudes. Advancing the educational and social inclusion of persons with disabilities in higher education provides benefits far beyond the university campus.

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Universities have developed innumerable traditions worth maintaining since the founding of the Università di Bologna in 1088. Among these, research and teaching are foremost. Providing models for the betterment of society is another crucial contribution. Despite the popular image of the ivory tower, university members everywhere engage diverse publics in a range of settings. However, outdated customs in higher education hinder the future of science and society instead of fostering their advancement. These customs, often unquestioned, certainly cast doubt on the university's claim to be a continual source of enlightenment and a perennial engine of innovation. Among the most glaring of these are ableism and institutionalized discrimination, manifest in persistent attitudinal, architectural, and social structural barriers that have excluded disabled and disadvantaged people from most universities for most of their history. Nevertheless, we live in an era in which scholars with disabilities routinely make key contributions to science, for example Stephen Hawking (1998) and Temple Grandin (1996), among many others. Despite barriers of exclusion, segregation, and stigmatization, such scientists demonstrate their talents and perspectives, which society cannot live without. Given this discrepancy, we must ask: How much stronger and more prominent could universities be if they would open their classrooms to diversity and make their programs and campuses accessible to all?

Since the student protests of 1968 that aimed to secure civil liberties, gender equality, and environmental sustainability, the future of the university in many democracies has been at the top

of national political agendas. This is especially so today, during the current transformation of the higher education landscape via such developments as the "Bologna process" of Europe-wide standardization of higher education credits and certificates (Powell, Bernhard & Graf, 2012) over the past decade or as a result of the economic crisis since 2008/09, causing drastic budget cuts in higher education systems in the United Kingdom (Head, 2011) and the United States (Kelderman, 2011). Clearly, myriad barriers to full participation and social inclusion of disabled people in universities persist. Thus, the "barrier removal philosophy" (Shakespeare, 2006: p. 44) of design for all emphasizes that these institutionalized barriers require enhanced attention and concrete efforts by all those groups involved in making higher education a force for innovation and mobility—on the path towards the "knowledge society" (Castells, 1996). A significant tool for such change is the *International Convention on the Rights of Persons with Disabilities* (United Nations, 2006). Mandating inclusive education—at all levels, including tertiary education—this treaty stands to benefit all, not only those persons with currently perceived impairments and disabilities. However, as DePoy and Gilson (2010) argue, while the Convention aims to raise awareness and reduce discrimination and disadvantage, in some Articles it lacks the needed detail and defined mechanisms to reach its policy goals—or to enforce them. Nevertheless, raising awareness about the Convention's principles should explicitly be joined with other on-going reform processes around the world.

In Europe, contemporary initiatives have elaborated a new model of skill formation that derives from durable strengths in education and training systems. Key goals include not only the support of competitiveness in global markets and individual employability or the maintenance and enhancement of the quality and attractiveness of the European Higher Education Area, but also the flexibility of pathways and enhanced permeability or mobility between vocational training and higher education (Bernhard, Graf, & Powell, 2010; Powell, Bernhard, & Graf, 2012). However, the social dimension, including inequalities in access to higher education on the basis of social and ethnic background or individual dis/ability, has less often been discussed in these reforms. Issues of architecture and accessibility in learning environments have hardly been expressed. Yet throughout Europe, as elsewhere, there are lasting disparities among social groups in entering and graduating from higher education (Shavit, Arum, & Gamoran, 2007), and the physical state of university facilities is often appalling. International legal charters, scholarship, and universal design concepts facilitate attempts to address such challenges and improve these systems.

A decisive response would be for universities to embrace the principles of *universal design*: the design of services, products, and environments "to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design" (Mace, 1997: p. 1). Seven principles guide universal design: equitable use, flexibility in use, simple and intuitive, perceptible information, tolerance for error, low physical effort, and size and space for approach and use (Mace, 1997; see Preiser & Smith, 2011 for examples). Given exemplary organizations that embrace such admittedly utopian principles, the Universal Design University is no longer just a figment of imagination. Universal design offers useful tools, described below, to help universities meet expectations held for higher education. Yet to be realized throughout Europe, "design for all" must become a fundamental goal for the remarkable diversity of teachers and learners, planners and personnel, who together guide, sustain, and enrich higher education.

The Universal Design University

To explore necessary steps towards the Universal Design University, this article discusses barriers and identifies strategies already in use to increase accessibility on multiple levels. Firstly, around the world, *attitudinal barriers*, from prejudice and negative stereotypes to stigmatization and marginalization, have seriously limited the contributions of people with disabilities to community life. Social, scientific, and legal changes provide increasing opportunities to challenge such views and improve the reactions to and treatment of people with disabilities—gradually shifting from containment and compensation toward care and citizenship (Drake, 2001; Richardson & Powell, 2011). Yet this likely most tenacious barrier of ableism is exemplified in the taken-for-grantedness of meritocratic myths, such as the faulty belief that only those who are "able" should or could access university education and succeed. We simply do not know how many youth with disabilities would succeed in postsecondary education were their aspirations not voided by low expectations and institutionalized discrimination (Powell, 2011). The Universal Design University would open itself to the idea that individuals, previously excluded, could contribute to it as it simultaneously supports them in reaching their learning goals.

Secondly, *social, cultural and educational structures* exhibit institutionalized selection processes and discriminatory practices that reduce the learning opportunities and expectations of disabled children, youth, and adults or those who are socially and educationally disadvantaged. Having negative effects early in the life course, such structural and cultural barriers have often given universities an easy way out: the group eligible to apply for entrance is artificially kept low (Powell, 2011; Powell & Solga, 2011). As we have witnessed, while women once had to battle to gain access to universities, in many countries they have quickly become the majority in participation as well as attainment (Schofer & Meyer, 2005: p. 909). In contrast to strides made toward gender equality, racism and ableism or disablism,[1] they remain pervasive, despite the fact that with each further social group, the extension of learning opportunities has proved successful. The expansion of the quintessentially private *and* public good of education has been self-amplifying. The Universal Design University would identify groups whose contributions have been artificially limited by oppression and selection processes and ultimately supply bridges for these groups to enter—and participate fully.

Thirdly, students with disabilities who do make it onto campus or can use Internet-based learning platforms are confronted with a range of *environmental and communication barriers* that hinder their academic and social participation. Innovations on many campuses range from adapted signage and disability service centers to diversity-oriented instruction and disability studies, a multidisciplinary field of enquiry that sharpens critical dialogue on the social and political constructions of dis/ability and "ab/normality" (Powell, 2011). Universities around the world have directly addressed such known obstacles and, in implementing new principles and programs, provide pathways to the future Universal Design University.

The following sections discuss such barriers and strategies to overcome them, from the global and national to the local. All universities orient themselves to international norms of scientific advancement and professional development. Whereas Internet-based universities serve users in networks varying in size and shape, brick-and-mortar universities also relate to neighboring spatial environments and diverse local communities. In any case, universities serve much larger and diverse groups than current students because the campus is a source of community services. The public expects universities to both guard established knowledge and

search continuously for discoveries that will improve human well-being and enhance capabilities.

Universities as Role Models

Because of both their cultural influence and economic significance, universities are uniquely positioned to be important role models, to set new standards, and to provide community services. As these organizations carry out the tasks of education and training as well as professional preparation, their responsibility to realize both excellence and equity in their programs is heightened by the considerable state and philanthropic support that they enjoy. No longer reserved for a small minority, university studies have become an integral part of lifelong learning for many. Offering cultural events and intellectual resources open to entire communities, universities that improve accessibility can better achieve their extended mission to provide possibilities for learning far beyond the groups of faculty and staff members or currently enrolled students. All the more reason to rethink how the university can better serve *all* citizens—those who have already passed through its doors as well as those who will in future come onto campus.

Inclusive Education for All

Every level of education has expanded in countries throughout the world, including higher education, since World War II (Schofer & Meyer, 2005). Such educational change interacts in myriad ways with broader societal developments, such as shifting paradigms or models of dis/ability (see Pfeiffer 2002). Concrete legal innovations—such as the prohibitions of disability discrimination in dozens of countries (Quinn & Degener, 2002)—were brought about significantly due to the global disability movement's advocacy initiatives (Charlton, 1998; Groce, 2002) and protest activities (Barnartt, 2010) that emphasize the power of new social movements in bringing about change. But before activists and advocates succeeded in securing their rights and gaining access to integrated public schools and inclusive classrooms in the last quarter of the 20th century, they had to survive asylums, eugenic forces, and educational exclusion prior to World War II and in the first decades thereafter (Powell, 2011: p. 36). Aligned with growing citizenship rights and notions of personhood, the past half-century has witnessed an unmistakable shift in emphasis from medical to social and political models of dis/ability, based on the core idea that not individual deficits but rather cultural and structural barriers disable people. This has facilitated a redirection of research and policy initiatives away from the rehabilitation and treatment of individuals and towards contextual conditions and barrier-filled environments, human rights charters and anti-discrimination legislation, and mechanisms of social control and exclusion. Today, the debate about strategies to reduce educational exclusion has been superseded by those to realize inclusive education for all (Richardson & Powell, 2011).

International organizations and especially the United Nations have been influential in both the establishment of human rights (including education rights) and in calling for equality and social justice for hundreds of millions of disabled people worldwide. To reach such overarching goals, education is assumed to be absolutely vital. In the international calls for "education for all" and then for inclusive education—a range of organizations has provided ideas, standards, and legal texts to facilitate such transformation (e.g. Peters 2004).

Rights to Inclusive Education and Access

On December 13, 2006, a quarter century after the 1981 *International Year of Disabled People*, the United Nations General Assembly adopted the *International Convention on the Rights of Persons with Disabilities* (ICRPD) with similar goals: to promote and protect the human rights, dignity, and freedom of disabled people around the world (United Nations, 2006). As did its ancestors, this first human rights treaty adopted in the twenty-first century—since then ratified by one hundred fifteen countries—aims to raise awareness about disability as it insists on the reduction of discriminatory practices and stigmatization that have limited the participation and contributions of disabled people throughout history.

Educational rights extend to the university via the Convention's vision of accessible environments and an inclusive education system. The ICRPD's Article 24 on education clearly states the conditions needed and the extent to which different levels of access to education are to be guaranteed. Education systems that are inclusive are viewed to be of fundamental importance to the development of individuals and community life. Without such inclusive systems, persons will neither be enabled to become fully participating citizens nor individuals who reach their potential and freely develop their personality in order to maximize their capabilities (Nussbaum, 2006). Lacking prior schooling and credentials, individuals who suffer "cumulative disadvantage" early in the life course (Mayer, 2005) are unlikely to access higher education or to find adaptations or accommodations sufficiently compensatory—and thus have limited access to formal learning opportunities in future.

Alongside debates at national and local levels about how to ensure democratic participation by citizens and how to secure highly qualified workforces, at the international level, the ICRPD sets a progressive and ambitious agenda of learning throughout the life course. However, the steps necessary to achieve lifelong learning for more than a highly educated few depend on concrete reform processes that will democratize access to learning opportunities. To be successful, such reforms must engage the ideas, norms, and policies evident in institutionalized education systems that continue to segregate or separate, such as those in Germany and the United States (Powell, 2011). Without high quality primary and secondary schooling and permeability between school forms or tracks, learning opportunities at the postsecondary level, whether vocational training or higher education, will be limited. Reflecting the stratified societies and educational systems of which they are an influential part, universities and those responsible for their governance have in fact carefully guarded access to these hallowed grounds, upon which elite civil servants and professionals have been prepared for power. Nevertheless, especially over the past half-century, universities have considerably broadened their missions. Among the common trends that have shaped and influence higher education systems are the evolution from elite to mass to universal participation in postsecondary education, increasing labor market opportunities and rising incomes for highly educated experts, the self-amplifying growth of knowledge, and government patronage and supervision (Clark, 1993). Yet the recent and on-going economic crisis in countries with leading higher education systems in the Anglophone world threatens important initiatives to enhance accessibility and provide services for students with disabilities because universities suffer severe financial austerity measures.

Regardless of the financial constraints, the ICRPD emphasizes investments and adaptations (such as the reduction of architectural barriers) not only in primary and secondary schooling but also in vocational training as well as higher and adult education. Without such modifications, the playing field will not be even for all. Even in the wealthiest European countries, such as Austria, Germany, and Switzerland, education and training opportunities beyond primary and secondary schooling are still seriously lacking for individuals with recognized "special educational needs" (Powell, Felkendorff & Hollenweger, 2008). Thus, the persistence of stratified access to tertiary education and the reproduction of class inequalities—based upon elaborate social selection procedures in tracked secondary schooling—is among the most significant challenges facing European universities (Powell & Solga, 2011). Mobility and permeability have become buzzwords of European reform processes in higher education (the "Bologna process") and vocational training (the "Copenhagen process") (see Powell, Bernhard & Graf 2012). But highly stratified secondary schooling and the persistent division between vocational education and training and higher education, in such countries as Germany, determine the life chances of each cohort and hinder higher education expansion (Powell & Solga, 2011). Still, the ICRPD emphasizes that countries:

> "..shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others. To this end, States Parties shall ensure that reasonable accommodation is provided to persons with disabilities." (United Nations, 2006, Article 24, Section 5)

Progressive policies and practices show the way forward to meet global norms of educational equality. As the ICRPD's mandates are carried out on multiple levels of governance, there is still much to learn from others and to transform university campuses everywhere.

Universal Design Principles Facilitate Access

Youth with disabilities who have obtained the certificates necessary to access tertiary education are often hampered in doing so by the lack of available support services they need. Such services have increasingly been provided on campuses in the United States, supported by codified rights to education and such programs as the "Universal Design Initiative" of the Association on Higher Education and Disability (AHEAD).[2] Such policies and innovations in a range of organizations show that the previously taken-for-granted boundaries of student dis/ability were illegitimate, as disabled students succeed and contribute to these learning communities. Aiming to extend the above-discussed changes, the ICRPD demands adjustments in education policies and university programs around the world. Yet to surpass compliance and create a truly welcoming community that recognizes and values diversity requires more than rules and regulations. Equally, if not more important, cultural shifts in attitudes, awareness, and analysis are necessary. Indicators of such shifts include the existence of academic offerings that examine disability as a universal human experience that nevertheless exhibits tremendous cultural and policy differences, even within regions. Next to attitudinal and architectural adaptations, innovative instructors implement "universal instructional design" (discussed below) to facilitate the learning progress of all their students. Usually, such adaptations require few additional resources even as they benefit all participants.

In architectural structures and communicative diversity—such as ramps, wayshowing systems (Møllerup, 2006), Braille signage, sign language interpretation, and accessible websites—improvements have been steady, but gradual. Universal design has focused on the built environment, spatial mobility, and product use. Such considerations are particularly important in campus planning, restructuring facilities, and building projects. Just as ramps facilitate access for a wide range of users, from parents with prams to wheelchair users to delivery personnel, signage can assist everyone to navigate both familiar and unfamiliar spaces. For example, the *International Symbol of Access* facilitates individuals' mobility and provides daily interactions with issues of accessibility, even as it represents the most prevalent symbol of disability worldwide (Ben-Moshe & Powell, 2007).

[Insert Image International Symbol of Access (ISO), 1969 about here]

[Insert Image International Symbol of Access (MoMA), 2009 about here]

The diverse local interpretations of this icon mirror the shift from exclusion to inclusion of disabled people in the human rights revolution: whereas the traditional icon displays an object (the wheelchair), newer icons show the human user as an active rider—asserting the primacy of personhood and participation (Powell & Ben-Moshe, 2009). Symbols, buildings, and legal conventions all indicate the significant transformation in disability paradigms from medical to social models and from exclusion to inclusion.

Towards the Universal Design University

To illustrate contemporary trends in Europe and North America, a few universities' attempts to implement elements of the Universal Design University are discussed here. In the UK, education and social policies addressing barriers that people with disabilities face have matured since the 1990s, when almost all British universities were largely inaccessible to students and staff with disabilities (Barnes 2007). The *Disability Discrimination Act (DDA)* of 1995 was a watershed event that, from 2005, implemented a Disability Equality Duty (DED) and a code of practice to ensure disability equality. These laws were recently joined by the *Equality Act* of 2010, which aims to protect disabled people and prevent disability discrimination by providing (1) legal rights for people with disabilities in education and employment; (2) access to goods, services, and facilities; and (3) property rights.[3] Higher education access for students with disabilities has moved up the agenda, becoming a major priority for recent governments (Hurst 1998; Harrison et al. 2009). Achieving disability equality demands a proactive approach, effective implementation of legislation, and compliance.

An example of current practice illustrates these issues. An urban campus with a range of building types in the heart of the British capital, the *London School of Economics and Political Science* (LSE) has placed campus maps indicating accessible entrances, installed automatic doors, and provided adjustable computer workstations in the lift-equipped library. Decades ago, when Sally Sainsbury was appointed the first Disabled Students' Advisor, she faced antiquated attitudes of staff who questioned the necessity of even minor changes that would enhance accessibility (personal communication, April 14, 2010). Over a dozen years ago, a *Disability and Well-Being Office* was founded that now provides an array of services to over 900 students a year, from advice and counseling to practical study and social supports to a peer/staff network.

Director Nicola Martin says the *Disability Discrimination Act,* which stipulates how public authorities should act proactively on disability equality issues and tackle institutional disability-related discrimination, was crucial in expanding these services, as the university was required to establish a *Disability Equality Duty Action Plan* (interview, September 2, 2010). While other UK universities, such as Leeds, have well established and internationally-known disability studies research groups, the LSE relies on collaboration among many London universities, made possible through the *Disability Equality Research Network*, to bring disability studies scholarship to campus and to involve students from a wide variety of disciplines and countries.

[Insert Image Access Signage (LSE) about here]

[Insert Image Ramp (LSE) about here]

[Insert Image Automatic Doors (LSE) about here]

[Insert Image Disability & Well-being Office (LSE) about here]

[Insert Image Disability Information Board (LSE) about here]

Good practice in the work of service providers that are "barrier-specific" instead of "impairment-based" are transmitted via the *National Association of Disability Practitioners*, a professional association for disability and support staff in further and higher education. More broadly, the UK's *Equality Challenge Unit* (ECU)[4] helps higher education institutions promote equality and realize the potential of all staff and students, across boundaries of race, gender, disability, sexual orientation, age or religion and belief. The ECU does so through such mechanisms as dissemination of evidence and distribution of toolkits on how to implement effective practices in governance and management, estates, research and teaching, and staff and student services. Such tools are part of universal design in education, which builds on principles to increase access to universities and guarantee learning opportunities for all participants.

On a much older and traditional campus, Germany's Georgia Augusta University of Göttingen, many of the newer developments found at LSE have been hampered by lack of awareness, legal stipulations, and financial provisions as well as tenacious educational segregation that seriously limits the eligibility of youth with disabilities to attend universities (Powell, Felkendorff & Hollenweger, 2008; Powell, 2011). However, many individuals with invisible disabilities or chronic illnesses do attend, having never been selected out of the general education system during primary or secondary schooling. For many students with recognized impairments or disabilities who do make it to campus against the odds, barriers hamper their learning opportunities and thus limit their success. In a seminar on "Social Inequality and Disability" that I taught there, students developed a project to evaluate, measure, and catalogue the accessibility of their campus. Using checklists provided by the local self-help organization of disabled people, *Selbsthilfe Körperbehinderter e.V.*, that had already measured the accessibility of the old town center during the Expo2000, the World Exposition in nearby Hanover, the students tested key campus buildings and events to provide an accurate and up-to-date picture of barriers—and to encourage their removal. This provided lessons on types of barriers and the multidimensional construction of accessibility and of disability.

Such insights and empirical findings have been collected and reflected in disability studies, a burgeoning multidisciplinary field with its own journals, conferences, and courses of study.[5] The development of this field of study itself must be considered both an indicator of shifting paradigms of dis/ability as well as a facilitator of such change within the university, even if debates about the utility and potential of universal design and of social model thinking that advocates a barrier-free utopia are on-going (e.g. Shakespeare 2006). The availability of disability studies in the official curriculum facilitates the broadening of learning opportunities and critical reflection of issues of inclusion/exclusion and ableism.

Even where courses of study exist, disability studies courses are regularly offered, and disability services offices have gathered years of experience, such as at Syracuse University in New York, cooperation among administration, faculty, staff, and students is needed to take accommodations and services "beyond compliance" and to build "pedagogical curb cuts" (Ben-Moshe et al., 2005). Applying universal design principles to teaching and learning, scholars at the University of Washington have adapted the original principles developed at the Center for Universal Design at North Carolina State University, conceptualizing "Universal Design of Instruction" (Burgstahler, 2005; see also Bowe, 2000; Burgstahler & Cory, 2008). Colleagues at Canada's University of Guelph have developed the similar "Universal Instructional Design" concept.[6] Such principles reorient the original tenets of universal design (mentioned above) to the specific interactive situations of teaching and learning: (1) accessible and fair (equitable); (2) flexibility in use, participation and presentation; (3) straightforward and consistent; (4) information is explicitly presented and readily perceived; (5) supportive learning environment; (6) minimize or eliminate unnecessary physical effort or requirements; and (7) learning space accommodates both students and methods. As ideals, universal design concepts provide a utopian vision. However, they also serve as important guidelines for restructuring that have been applied and implemented broadly.

Conclusion

Coming full circle, universal design principles emphasize that on multiple levels and in a range of contexts, universal design fosters progress in universities. Given the rise of education for all and inclusive education, the numbers of university students who consider themselves to be disabled or are in need of individualized support to succeed in their studies has also grown rapidly (Powell, 2011). Thus, universities must address the issues discussed here—for current students—even as the population of recognized and socially validated disabilities, and policies and programs to provide support and services, continues to vary considerably across societies.

As generators of knowledge and as centers of community life in towns and cities, universities have an extraordinary chance—and responsibility—to enhance access to the learning opportunities they offer. As they do so, they show their communities how possible it is to remove barriers and the advantages that accrue to all. In embracing paradigms that extend beyond the clinical to include social-political, minority group, and human variation models of disability (see Scotch & Schriner, 1997), in giving voice to diverse participants, and in providing prototypes for the implementation of universal design principles, the university can engage and change public awareness and attitudes. Advancing the educational and social inclusion of persons with disabilities in higher education provides benefits far beyond the university campus.

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Notes

[1] Without reviewing here extensive debates within disability studies, both ableism and disablism have been used

[2] AHEAD's Universal Design Initiative aims to promote universal design concepts in higher education and to identify useful and achievable strategies to promote universal design concepts that will facilitate access to the curriculum for diverse populations as well as reconceptualize disability. See www.ahead.org/resources/universal-design

[3] See www.equalities.gov.uk/equality_act_2010.aspx

[4] See www.ecu.ac.uk/heifunctions

[5] For example, the Society for Disability Studies, the Nordic Network of Disability Research, and the Center for Disability Studies at the University of Hawai'i organize conferences in the Americas, the Nordic countries, and in the Pacific rim. And seminal publications have reviewed accomplished scholarship (e.g., Albrecht, Seelman, & Bury, 2001; Barnes, Barton, & Oliver, 2002).

[6] See www.tss.uoguelph.ca/uid, accessed December 3, 2010

Images and Captions:

Figure 1. International Symbol of Access (ISO), 1969

Figure 2. International Symbol of Access (MoMA), 2009

Figure 3. Access Signage (LSE)

Figure 4. Ramp (LSE)

Figure 5. Automatic Doors (LSE)

Figure 6. Disability & Well-being Office (LSE)

Figure 7. Disability Information Board (LSE)

Employment Opportunities for College Graduates with Disabilities: A Step Forward

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Abstract: Since data show that students with disabilities graduate from college at the same rate as their nondisabled peers, it is time to examine employment of recent graduates. Here we report on a trend toward higher levels of employment for college graduates who were integrated into "regular" educational settings since the 1990s. To illustrate this phenomenon, we summarize our findings of a study on graduates with and without disabilities at three Canadian junior/community colleges.

Key Words: employment, college, students

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Introduction

Our goal is to examine the employment picture of individuals with disabilities, with a focus on recent college graduates. In doing so, we review trends in employment of Canadians with disabilities and highlight aspects of the current realties. Within the disability rights movement, any time the issues of unemployment and poverty have been discussed in the last three decades, the discrepancy between more and less optimistic data has been debated. Here, we focus on discrepancies among our findings on recent junior/community college graduates, census information, and perceptions within the disability community. In particular, we examine the reasons for discrepancies and attempt an integration of views.

The Perception

In the last decade, it has been reported that persons with disabilities make up an economically marginalized group with a high level of unemployment (Shier, Graham, & Jones, 2009). For example, Statistics Canada, a federal government agency that collects census information and analyzes data, reported that between 1993 and 2001, "people who had not graduated from high school were over-represented in the population of 'chronically unemployed,' as were … people with disabilities" (2005, p. 1). Many people, including persons with disabilities, believe that over 70% of people with disabilities are unemployed (see Taylor, 1998). The view that having a disability precludes individuals from employment may influence some nondisabled individuals, including high school and employment professionals, to fail to encourage the current generation of individuals with disabilities to pursue postsecondary education to the same extent as those without disabilities.

The Reality

Statistics Canada (2008b) reported census data for 2006. This showed that in 2006, 51% of Canadians with disabilities, compared to 75% of nondisabled Canadians, were employed and that only 5% of each group were unemployed. However, in the same report they also reported

that 44% of Canadians with disabilities, compared to 20% of nondisabled Canadians, were not in the labor force (i.e., those who "were unwilling or unable to offer or supply labor services under conditions existing in their labor markets, that is, they were neither employed nor unemployed"[1]).

Why is there such a large discrepancy between views of people with disabilities and the statisticians? First, perceptions of "unemployment" may reflect the large numbers of people with disabilities who are "not in the labor force." Difficulties finding jobs, inadequate job accommodations, widespread views about job discrimination (Shier, Graham, & Jones, 2009), such as not being granted a job interview, negative attitudes, lack of support networks, difficulties with adapted transit systems and irregular scheduling of overtime work, and social policies that discourage work (e.g. loss of disability benefits may have prevented people from looking for a job, making them part of the "not in the labor force" group).

Second, the perception of massive unemployment may be based on the period of the late 1990s to early 2000s, during which many persons with disabilities in the 35 to 60 age group found themselves consistently unemployed or underemployed, despite some college or university education (R. Arcuri, personal communication, April 29, 2009).

Third, another justification for the high unemployment view may be that unemployment statistics do not take into account duration of disability (i.e., acquired in childhood vs. adulthood). The group of people with disabilities who acquired a disability during childhood are now part of the baby boomer generation. They acquired less than an equal education at the elementary and high school levels, since large numbers of them attended segregated schools before the "Year of Disabled Persons" proclamation by the United Nations in 1981. This generation, most of whom are still of working age, did not have access to needed educational accommodations or to remedial education, such as literacy programs, available to the rest of the population (Fichten, Bourdon, Creti, & Martos, 1987). One consistent piece of information mentioned within the disability community is the lack of opportunity for persons whose disability was present from an early age (R. Arcuri, personal communication, April 29, 2009).

Social Model Lenses

According to the social model of disability, it is not the impairment, per se, but barriers, such as segregated education, lack of access to mainstream educational opportunities, inadequate financial resources, and problematic attitudes that have negative consequences throughout the life cycle. The consequences extend to areas such as employment, the quality of services for which one is able to advocate, as well as to where one could live and, in some cases, with whom one can live. It is not surprising that the disability rights movement contends that it is the difficulties that are encountered by people with disabilities that pose barriers that disable them and curtail their life chances. These barriers include lack of schooling and higher education and extend to finding work and suitable work environments (Oliver, 1990).

For example, Kapsalis (1999) clearly linked poor literacy skills to unemployment. The Canadian Council on Learning (2009) summarized findings about the barriers adults learners with disabilities encountered, as well as about the strategies and changes they recommended for overcoming these:

- *Physical accessibility*. In many cases, buildings or classrooms were inaccessible, while in other cases accessible public transportation was not available, and learners had no way to get to school.

- *Financial issues*. Programs and courses were often unaffordable for learners with disabilities, who also found it difficult to successfully negotiate the administrative demands of applying for student aid.

- *Attitudes*. Learners with disabilities reported that their instructors did not always allow for the disability related resources they required to learn, such as note-takers or additional time for tests. (p. 4)

A More Optimistic View

On the other side of the coin, in recent years there has been a more optimistic outlook for two groups of persons with disabilities. The first group consists of people who became disabled in adulthood. The second group is made up of individuals who became disabled in childhood and were sent to regular schools – this group would have been students in the primary school system in the 1990s. The first group, having benefited from "regular" schooling, at least had equitable education. They likely also had work experience as well. The second group is the one that we concentrate on here: people with disabilities who had been "integrated" into the regular elementary and high school system. This provided them with better opportunities for subsequent postsecondary education and for entry into the labor market. We must note, however, that integrated education was not inclusive at all levels. Although things had changed in the academic realm, in extra-curricular areas of education, such as student activities, equal access was not always available.

Canadian Efforts to Equalize Opportunities

In Canada, a number of programs have been put in place for persons with disabilities to rectify inequities in education and employment opportunities. Prior to 1980, when generations of persons with disabilities were attending segregated schools, it seemed obvious that dissimilar educational opportunities would be followed by unequal employment opportunities. As one product of this segregated approach explained, "I was slated to enter a sheltered workshop after I finished (segregated) school. But, because of my cerebral palsy, I failed the manual dexterity test. It is this fortunate failure that resulted in 'Plan B,' which ended in further education and a Master's degree in counseling" (F. Schipper, personal communication, December, 1987). It is only since the 1980s that Canada has put into place various programs to improve both the educational and employment situations of persons with disabilities (Federal/Provincial/Territorial Social Services Ministers, 1998; Office des Personnes Handicapées du Quebec, 1984).

In addition to programs related to employment, since the 1980s, as we noted earlier, there has been a trend to "integrate" children with disabilities into the regular educational system (Kierstead & Hanvey, 2001). Consequently, Canadian children with disabilities generally attended elementary and high school with their nondisabled peers. Data from the Participation and Activity Limitation Survey (PALS - a census based survey conducted by Statistics Canada) show that in 2001, 49% of youth with disabilities aged from fifteen to twenty-four and 53% of

nondisabled youth successfully graduated from high school (Human Resources Development Canada, 2003). This qualified about half of both groups to continue to college and university. Although it would be of interest to know what proportion of high school graduates have a disability and what proportion of graduates with disabilities continues its education, we have not been able to find this information for Canada. This is an empirical question and research needs to address this topic.

Although estimates vary, over the last decade the number of students with disabilities attending postsecondary education has increased dramatically (AQICEBS, 2009; Bouchard & Veillette, 2005; CADSPPE, 1999; Wagner, Newman, Cameto, & Levine, 2005), and we estimate that approximately 10% of North American postsecondary students have a disability of some sort (Fichten et al., 2003; Fichten, Jorgensen, Havel, & Barile, 2006; National Science Foundation, 2010; United States Government Accountability Office, 2009).

Work as a Vehicle of Social Participation

A report prepared for the Office des Personnes Handicapées du Québec (Dugas & Guay, 2007) cites several studies acknowledging the importance of employment. These indicate that a job is often seen not only as a means of earning a living and a vehicle for social participation, but also as much more. A job is seen as conferring status or social legitimacy, as well as rights. As such, its absence is recognized as one of the main risk factors of social exclusion (cf. Dumont, 2003). Indeed, lack of job security increases the risk of deterioration of interpersonal relations and various aspects of health. Similarly, unemployment often leads to loss of self-esteem (Beresford, 1996). This insecurity is also directly linked to various indicators of poverty and less favorable housing conditions; studies have shown that income inequality is associated with health inequalities, as reflected in lower life expectancy and premature mortality (Dugas & Guay, 2007; Hainard, 2003). Inadequate education, lack of employment experience, severity of the disability, and poor availability of needed work adaptations are cited as some of the most important causes of unemployment (Dugas & Guay, 2007).

Postsecondary Graduates with Disabilities

A number of studies have shown that postsecondary graduates with and without disabilities have better employment outcomes than their counterparts with no postsecondary education and that the rates of employment for people who have a university degree are higher than that of individuals who did not complete university who, in turn, generally fare better than those who never went to college (e.g. Canadian Council on Social Development, nd, 2002, 2004; Horn & Berktold, 1999; Government of Canada, 1996; Nichols, 1998; Statistics Canada, 2008b; Stodden & Dowrick, 2000). In fact, Horn and Berktold (1999) reported over a decade ago that 67% of university graduates with disabilities and 73% of graduates without disabilities had full-time employment a year after obtaining their diploma. In Canada, recent findings of a study by the Nova Scotia Department of Education (2008) support these findings, as it shows strong similarities in employment between postsecondary graduates with and without disabilities: 82% of junior/community college graduates and 80% of university graduates with disabilities were employed approximately a year after graduation.

Higher Education of People with Disabilities

Many people acquire a disability later in life. For example, in 2001, the PALS census-based survey of the population of Canadians aged 15 and over showed that the proportion of junior/community college (i.e., mainly two year colleges) graduates with and without disabilities was very similar (16% for individuals with disabilities and 17% for those without; Human Resources Development Canada, 2003). The proportion of Canadian university graduates with disabilities, however, was considerably lower (11% and 20%, respectively), even though the sample with disabilities was much older than the general population (Human Resources Development Canada, 2003, Table C.6). By 2006, the percentage of nondisabled university graduates in Canada was 24%, but this represents individuals aged twenty-five to sixty-four rather than the fifteen to sixty-four age range reported in the 2001 PALS survey (Conference Board of Canada, 2009). Corresponding figures for individuals with disabilities are not available, making comparisons difficult.

Data from our studies (Jorgensen et al., 2003, 2005), as well as those of others both in Canada (e.g. Outcomes Group, 1998) and the United States (e.g. Wessel, Jones, Markle, & Westfall, 2009), show that students with disabilities, once they enter postsecondary education, have similar grades and that they graduate at the same rate as their nondisabled peers. Data on postsecondary students and graduates with disabilities indicate that most want to work (Hubka & Killean, 1996).

Recent Postsecondary Graduates: An Illustrative Example

Most people entering postsecondary education do so with two objectives: to continue their education and to eventually find employment. Recently, we examined employment outcomes of junior/community college graduates with and without disabilities. In 2005, we conducted a survey of graduates with and without disabilities from three of our province's largest junior/community colleges (these only enroll high school graduates) about 10 months after they obtained their diplomas (see Fichten et al., 2006 for additional details). We asked graduates what they were doing now and, if they were employed, how closely their job was linked to their program of studies. About one third of the 1,486 graduates from both three-year career/technical programs and two-year pre-university programs completed the survey. Twelve percent (i.e. 182) self-identified as having a disability such as a mobility impairment, a visual impairment, a learning disability, etc. Two-thirds of graduates with and without disabilities were women. Data on race were not collected, but the vast majority of the students (over 95%, we estimate) in the colleges in question are white. Approximately 60% of graduates with and without disabilities had been enrolled in a two-year pre-university program, while the remaining 40% graduated from three-year career/technical programs, such as nursing, mechanical engineering technology, and graphic design. Because over 80% of pre-university graduates, both with and without disabilities, continued their studies following graduation, here we summarize only the outcomes of graduates from three-year career/technical programs.

As can be seen in Table 1, the percentages of career/technical program graduates show few differences between those with and without disabilities. Approximately half of the graduates were working full-time, whether they had a disability or not. An additional 14% to 15% were working part-time, and almost one third of each group was continuing their studies. A statistical test showed no significant difference between graduates with and without disabilities concerning whether their employment was related to their field of study. Indeed, the only important

difference we found between graduates with and without disabilities was that graduates with disabilities in career/technical programs were less likely than their nondisabled counterparts to obtain employment in a field "closely" related to their field of study (Fichten et al., 2006). That employment of graduates with disabilities is related to their studies was also recently found both at McGill University (Wolforth, 2006) as well as in a very early large American study of university graduates (see Horn & Berktold, 1999).

Canadian statistics for people with and without disabilities in 2001 also show little difference in the employment rate of adults with and without disabilities (e.g. 89% vs. 93%, respectively; Statistics Canada, 2001, 2003). There is an important caveat, however, because the overall Statistics Canada (2008b) data show a substantial difference between the proportions of people with and without disabilities who are not in the labor force (i.e. 51% vs. 20%, respectively). Studies, such as the large scale British Household Panel Study (Bell & Heitmueller, 2009), which include individuals not actively in the labor force in their calculations, have shown a large gap between employment rates of people with and without disabilities.

The "not in the labor force" artifact was not present in our study of junior/community college graduates as the proportion of graduates with and without disabilities who were studying or not available to the labor force for other reasons were very similar. It is also noteworthy that our findings about what happens after graduation are similar to the results of a recent survey of Quebec university graduates (AQICEBS, 2006), which found that approximately two-thirds of the 61 university graduate respondents, all of whom had been registered for disability related services from their school, were employed. Similarly, recent data from McGill University show that 60% of a sample of individuals with disabilities who graduated two to three years earlier indicated that they were employed; most of the remaining 40% reported being enrolled in a graduate program, pursuing mainly Master's or Ph.D. degrees (Wolforth, 2006).

Such positive findings are also very similar to the results of a recent survey of 44,309 Ontario junior/community college graduates, most of whom did not have a disability (Ministry of Training, Colleges and Universities, 2006). Here, the results show that, overall, for the entire student population, six months after graduation 55% of graduates were employed full time, 12% were employed part-time, 8% were unemployed and 25% were "Not in Labor Force - Graduates who were not looking for work, including those attending school full-time, traveling, or staying home for health reasons or because of family responsibilities" (p. 18). Results such as these are encouraging for high school graduates with disabilities who may be considering pursuing their education at the postsecondary level as well as for their families.

Moving Forward

For future generations of persons with disabilities, many of whom will have postsecondary education, there will be more opportunities than in the past. Although the 2011 labor market is by no means as favorable as that in 2005, when we conducted our study, nevertheless, there are grounds for optimism. "Declining birth rates, concomitant slower growth of population and labor force is reducing the inflow of new workers. At the same time, aging population and the impending retirement years of the baby boomers will create a huge new demand for replacement workers" (WCG International Consultants Ltd., 2004, p. 119).

The present North American economy is knowledge-based and technology-driven, where physical ability and sensory acuity may not be prerequisites for employment or involvement in community life. Therefore, people with disabilities may have a greater opportunity to participate in the workforce and in all aspects of society. To realize this potential they, like others, must succeed in postsecondary education. Thus, it is vital that colleges and universities do everything they can to remove obstacles and provide conditions that support success for all learners, including those with disabilities. To remove barriers and support success for students with disabilities in our postsecondary institutions while further informing policy development, it is imperative that accurate information reflecting the realities of postsecondary communities is made available to concerned groups and individuals. This information should be made available in the hopes that it will: (a) help recruit, retain, and graduate students with disabilities, (b) ensure that these students have appropriate opportunities for further education and employment after they graduate, and (c) determine factors which influence academic outcomes that are unique to them and that are not evident from studies of nondisabled students. The overall goal of the research of the Adaptech Research Network, which participated in conducting our research on employment (Fichten et al., 2006), is to provide such information which, ultimately, will help students with disabilities graduate and successfully compete for positions in the workplace.

Here, we suggested that there may be a positive employment trend for persons with disabilities who pursue postsecondary education. This trend is already evident from the Canadian census data, which showed improvement for youth with disabilities in employment between 2001 and 2006 (Statistics Canada 2008a). Moreover, recent studies of both university (e.g. AQICEBS, 2006) and junior/community college graduates show positive employment outcomes. For example, a recent report by the Nova Scotia Department of Education (2008) showed that 82% of junior/community college graduates and 80% of university graduates with disabilities were employed approximately one year after graduation. These findings differ substantially from the "70% of individuals with disabilities are unemployed" assumption of the past.

Another encouraging event for our positive outlook is that both education and employment were included as important articles in the United Nations (2006) Convention on the Rights of Persons with Disabilities: Articles 24 (education) and 27 (employment). Recently, Canada has become a signatory of the Convention. This is an important event for Canada where both education and employment are under the jurisdictions of our 10 provinces, resulting in policy lags due to intergovernmental disagreements. The authors expect that the signing of this Convention will reduce administrative snafus and help achieve similarities among the provinces in education and employment policies and practices.

Conclusion

The information we provide here is of crucial importance to all those working in the disability field. A key conclusion is the demonstration that when they are provided with the tools that diminish or eliminate barriers to equal education, individuals with disabilities can have the same opportunities as their nondisabled peers to obtain employment. Thus, our most important recommendation is that members of the disability community, researchers, academics, rehabilitation counselors, campus disability service providers, and all others who work with individuals with disabilities engage in massive knowledge transfer to inform parents, students, and people who work at the high school level that employment opportunities for college and

university graduates with disabilities are very promising indeed.

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Table 1 *Activities After Graduation – Career/Technical Graduates*

Group	Sample Size	Working Full-Time	Working Part-Time	Looking for Work	Studying	Unavailable for Work	Total
With a Disability	86	51%	15%	1%	30%	2%	100%
No Disability	540	49%	14%	3%	31%	3%	100%

Notes

[1]Definitions are those used by the International Labour Organisation (ILO) (see Statistics Canada, 2010).

Towards a Statistical Model for Monitoring the Exercise of Human Rights under the UN Convention on the Rights of Persons with Disabilities – Canadian Case Study

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Abstract: Monitoring the Convention on Rights of Persons with Disabilities (CRPD) is important to ensure full participation of persons with disabilities in society. Statistical information on disabled population is used to develop policies that improve the lives of disabled people. In this article, we propose a model for statistically tracking the realization of CRPD rights.

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Introduction

People with disabilities comprise a large proportion of the population, internationally and in Canada – about 10% internationally (World Bank, 2005) and in Canada, about 14% (Statistics Canada, 2007). In both developed and developing countries, people with disabilities face difficult challenges. For instance, it has been estimated that, internationally, people with disabilities comprise 20% of people living in poverty (World Bank, 2005) – twice the poverty rate of people without disabilities. In Canada, adults with disabilities are also about twice as likely as their counterparts without disabilities to be living in poverty (Council of Canadians with Disabilities [CCD], 2009; Fawcett, 1996; Fougeyrollas et al., 2005). Forms of systemic human rights violations against people with disabilities include lack of access to education and significant levels of low literacy (Rioux et al., 2003; Zubrow et al., 2009; Statistics Canada & OECD, 2005), denial of medical care (Frazee et al., 2005), limited access to adequate and accessible housing (Canadian Mortgage and Housing Corporation [CMHC], 2003), lack of access to transportation and homecare services (Boucher et al., 2003, Fougeyrollas et al., 2008), and the marginalization and exclusion of disability issues and people with disabilities in civil society organizations (Rioux, 2003). Lack of employment and discrimination in the labour force are also daily facts of life for many people with disabilities around the globe and in Canada (e.g. United Nations [UN], 2008; Canadian Council on Social Development, 2005; Roeher Institute, 2004; Human Resources Development Canada, 2002).

In this context, given the commitments of the international community to furthering the human rights of people with disabilities, it is imperative that a more systematic approach be developed to track how these rights are being realized, supported or hampered. This paper presents a proposed model for statistically tracking the extent to which people with disabilities are exercising their human rights as set out in the recently promulgated United Nations

Convention on the Rights of Persons with Disabilities (United Nations [UN], 2006) and the factors that hinder and support the attainment of those rights.

Statistical Monitoring

The key purpose of the CRPD implementation is to gather information on the extent to which people with disabilities have the possibility to participate in society and access their rights on equal basis with others. Statistical information provided by population surveys around disability is key in providing snapshots of the population of people with disabilities and identifying the main issues faced by this population at national and various smaller-scale levels. The knowledge gained from statistical profiles is valuable in designing adequate policy responses. Recognizing the importance of gathering and making accessible information on the situation of people with disabilities, the CRDP asks the States to "collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention."(CRPD, Article 31). Yet, as a recent report by the Secretary General of the United Nations has observed, "few countries collect information on disability through either censuses or surveys. To a significant extent, the dearth of socio-economic data on persons with disabilities reflects the social welfare and/or medical approach to disability that still prevails in many countries" (United Nations [UN], 2009). While there is some activity internationally to monitor the human rights situation of people with disabilities (Disability Rights Promotion International, 2003; International Disability Rights Monitor, 2004; Emerson et al., 2007), there is no systematic approach in place to monitor the implementation of the Convention. In the absence of such a system, how would we know about the extent to which people with disabilities are attaining and exercising their rights?

This paper endeavours to answer this question by looking at how national-level statistical data can be 'mined' to shed light on the socio-economic and human rights situation of people with disabilities. It draws practical examples from Canadian statistical sources to illustrate a methodological approach to *the kind of monitoring* that could be implemented more systematically in Canada were such data sources consistently available in this country and which could be implemented internationally were similar data sources available on the global stage. While the methodological approach is illustrated using the right to work, this approach is also applicable to all the rights articulated in the CRPD.

Disability - Theoretical and Operational Perspectives

In order to map out the conceptual framework and data elements in a statistical system for monitoring the rights of people with disabilities, it is important to understand what is meant by 'disability' on a theoretical level and how the concepts are operationalized by statistical information available. Historically, the longstanding 'biomedical model' has tended to frame disability as an individual pathology to be prevented and cured (Rioux & Valentine, 2006). From this perspective, 'disability' has been framed in light of explanatory factors such as the nature and degree of functional impairment (Judd et. al., 2008) and the availability of and individual participation in clinical and rehabilitation services, or use of medications, prostheses and other

aids and devices, to ameliorate the disabling effects of impairment or underlying health conditions (Cook et al., 2005). This traditional approach continues to inform the design of many income supports, taxation-based and other social programs in Canada (Government of Canada, 2003).

More recently, proponents of the 'social model' of disability have framed disability as the disadvantages that accrue to the individual with impairment as a result of his/her interactions with built-environmental, social, economic and other contexts. In this model, impairment is de-emphasized, and major attention is placed on understanding and addressing the environmental conditions that ignore, stigmatize, devalue, exclude and even oppress people with functional impairments (Oliver, 1990; Finkelstein, 1993). Taking the social model to its logical term, Roulstone & Barnes (2005) argue that, in order to understand disability in a given context, a critical analysis is required of the disabling effects of society, as well as analysis of prevailing levels of human capital among persons with disabilities, market characteristics and the interplay between the state and market. Some, however, see the dualism between the medical and social models of disability as simplistic and have argued for a more nuanced approach that takes into account as fully as possible the effects of impairment on daily living as well as the complex effects of various contextual factors that create obstacles to daily living that people without functional impairments typically do not face (Shakespeare, 2006; Thomas, 1999; World Health Organization [WHO], 2001; Fougeyrollas et al. 1998; Fougeyrollas & Beauregard, 2001).

In practical terms, one of the main difficulties in measuring outcomes for people with disabilities is the identification of those people classified as 'disabled.' Clearly, the way in which people with disabilities are identified has significant implications on the indicators measuring their access to various domains of life, for example, the percentage of people with disabilities who graduate from university or secure employment. For the purpose of an effective CRPD monitoring, ascertaining the population of disabled people is essential. This information is key in order to monitor any progress made in the removal of barriers that hinder the enjoyment of rights. There is currently no international agreement on the definition of 'disabled person,' for which reason the CRPD does not provide an exhaustive definition, but clearly identifies the inequality of social participation as the outcome of the interactive process between individual and physical, social and attitudinal environment (Fougeyrollas, 2010; 2011). This raises interesting questions about the relationship between the CRPD approach and the national definitions. For monitoring purposes, some States might need to broaden their domestic interpretation of 'person with disability' in case this is narrower than the one employed by the CRPD. At the level of statistical sources, this is translated into looking at what approaches are employed by population surveys existent in various countries to flagging disability and whether these approaches are similar across the surveys in order to produce comparable information.

Method

Conceptualizing a Robust Statistical Monitoring System

The CRPD emphasis on realizing in concrete terms the full inclusion and participation of people with disabilities in all facets of society should be key in thinking through the dimensions of a statistical monitoring strategy. The CRPD seeks to realize among other things a high-level,

twofold objective: a) the access of people with disabilities to a range of socially *valued situations* that are – or that should be – open and accessible to all citizens; and b) the full participation of people with disabilities to these situations as *valued equals*. Furthermore, the CRPD expresses the commitment of States Parties to ensuring that the necessary conditions of attaining those outcomes – *enablers* of the outcomes – are in place and that *barriers* that inhibit and prevent attainment of the outcomes are removed.

These key dimensions are translated into a heuristic model grounded in the underlying assumption that people with disabilities, like others, should have access to valued situations and the participation to these situations should maximize the personal autonomy, independence, choices and personal control of people with disabilities as highlighted by various Convention articles (e.g. Preamble n and Articles 3, 9, 12, 19, 20). A visual representation of this model is provided in Figure 1.

Figure 1. Dimensions of the proposed

statistical   monitoring model
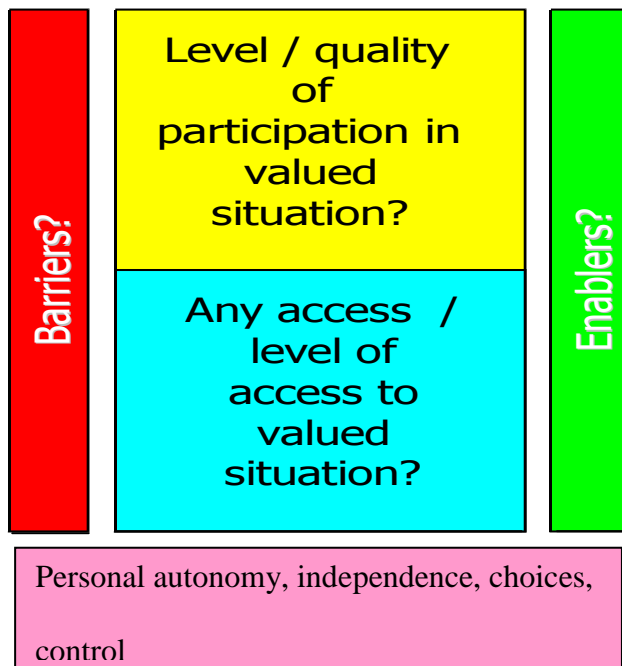
Key Elements of the Proposed Model

The proposed model consists of two main elements to be used in order to assess the statistical information: 1. *access to a valued situation as articulated in the CRPD* and 2. *level of participation once in a valued situation. Barriers/enablers* and *intersectionality* lenses are also key lenses employed across the model components in order to obtain a better understanding of people's experiences in a specific situation.

Equal Access to Valued Situations

The CRPD posits that, like others, people with disabilities should have equal access to the full range of socially valued situations such as decent and affordable housing, employment, education, community leisure and cultural activities and so on. Accordingly, in mapping out the elements of a statistical monitoring system, it is important to identify and track the extent to which people with disabilities have *access* to the socially valued situations articulated in the CRPD.

Level of Participation in Valued Situations

The CRPD also posits that people with disabilities should have scope to participate in those situations as fully as possible as valued equals. In line with this, the statistical monitoring system should track the extent to which the full participation of people with disabilities is being realized, once in one of those valued situations articulated in the CRPD. The participation in a valued situation is seen as an outcome assessed through either or both quantitative and qualitative indicators in the statistical model.

Key Cross-Model Lenses

Enablers and Barriers to Access and Participation in Valued Situations

Across the two main components of the model, an enabler/barrier lens is employed in order to provide a more complex view on the access and quality of participation to various valued situations. The CRPD articulates the commitments of States Parties to ensuring that the necessary conditions are in place for people with disabilities to gain access to valued situations and to participate on equal terms. Accordingly, the model for the statistical monitoring of human rights needs to be attentive to the extent to which enablers of access and sought-for outcomes are in place and the extent to which barriers are operative that impede access and attainment of the outcomes.

In this connection, we argue that 'disability supports' are positive enablers of the attainment of the outcomes and that, where needed, their absence amounts to barriers. We define a 'disability support' as any good, service or environmental adaptation that assists persons with disabilities to overcome limitations in carrying out activities of daily living and in participating in the social, economic, political and cultural life of the community (Roeher Institute, 2002).

At the *individual* level such support 'attaches' to the individual person or his/her immediate environs and includes human assistance (e.g. help with a range of activities at home, school, work, in various activities in the community), assistive aids and devices (e.g. hearing aids, voice synthesised computers, wheelchairs), modifications to the built personal environment (e.g. grab bars, ramps, accessible parking and entrance ways), modification of routines (e.g. different job duties, modified hours or days of work, a modified schedule of study to accommodate issues of mental health or fatigue), medications (e.g. to help manage issues of pain, chronic illness or emotional well-being) and specialized services (e.g. physiotherapy, occupational therapy, speech therapy, personal, school, career and psychological counselling).

At the *community* level such support 'covers' people with disabilities as a broad group and includes: accessible community infrastructure (e.g. accessible buildings, sidewalks, transportation services and public technologies such as computers with adaptive peripherals at schools or libraries); and human capacity at the community level to fully include people with disabilities in regular community activities (e.g. child care workers, teachers and recreation workers who have the knowledge and skills needed to respond to the needs of children with disabilities in regular child care, school or recreational settings; employers and employment consulting organizations who have a sound base of knowledge about how to adapt the work environment and work routines so as to enable job applicants and workers who become disabled to perform essential job functions).

The antonyms of enablers are barriers to people with disabilities gaining access to valued situations and participating as valued equals, there. We define the absence of positive supports that may be needed – the absence of enablers – as critically important barriers. Other barriers include forms of overt discrimination such as being refused a job, job interview or promotion on the basis of disability, being paid less than other workers in similar employment, being refused access to work-related training or to school and so on.

Intersectionality

The rights protected by the CRPD apply to all people with disabilities, regardless of types of impairments, gender, age, and ethnicity. In line with this, it is essential that monitoring processes are designed and implemented in a manner that captures these differences and intersectionality. Particular attention therefore should be given to most vulnerable groups of people with disabilities to ensure that they are not excluded from the monitoring exercises. Article 31, which imposes an obligation on State Parties to collect relevant statistical and research data, also requires that the data collected to be disaggregated to allow the situation of particular groups of people to be extracted and examined. Accordingly, the statistical monitoring model should design indicators that identify particular levels of disadvantage or exclusion that may affect those groups of people with disabilities facing multiple forms of discrimination.

The proposed statistical model can be applied to all valued situations covered by the CRPD such as independent living and inclusion in the community, access to and participation in community recreation and cultural activities, adequacy of living standards and social protection. The rest of the paper provides an illustration of how this model works taking as an example the *valued situation of work* and exemplifying with data available in the Canadian flagship survey on disability. Furthermore, the illustration focuses on the vulnerable group of people with disabilities in low income in order to illustrate how intersectionality can be taken into account in the statistical monitoring.

Case Study – Statistical Monitoring of the Right to Work in Canada

Participation and Activity Limitation Survey (PALS)

PALS has been Statistics Canada's 'flagship' survey on disability. Conducted following the 2001 and 2006 Censuses of population, it gathered a wealth of information about socio-demographic characteristics of people with disabilities – both adults and children; the nature and

degree of functional difficulties experienced, as well as various disability-related issues, such as the types of supports required in various settings and the types of barriers to participation in those settings.

As operationalized in PALS, a 'disability' is any ongoing or recurring difficulty hearing, seeing, communicating, learning, walking, bending or doing any similar activities or, because of a physical or mental condition or health problem, a reduction in the kind or amount of activity that a person can do at home, work, school or in other settings. In order to be selected into PALS as having a disability, a respondent had to indicate any limitation on the disability filter questions of the Census long form, which was administered to about 20% of the Canadian population. A second stage of filtering, that again employed the disability filter questions several months following the Census, resulted in some people who indicated disability at Census time being reclassified as non-disabled because several months later they did not answer "yes" to any of the filter questions. People retained in the PALS sample were those who again answered "yes, sometimes" or "yes, often" to the Census questions, which were asked at the beginning of the PALS interview several months following the Census. The total size of the PALS 2006 sample was 47,793 - 8,954 children (persons under 15 years of age) and 38,839 adults (15 years of age and over). The retained sample represents 202,350 children and 4,215,530 adults with disabilities (Statistics Canada, 2007).

For the rest of the paper, we illustrate with PALS data how the proposed statistical model can be used in practice to track how the right to work is being realized or hampered.

Illustration of Statistical Monitoring

The most recent submission by Canada (2009) to the UN Human Rights Council in the Universal Periodic Review of Canada's compliance with its international human rights obligations is virtually silent with respect to persons with disabilities' right to work, except for the vague and general mention of legal prohibitions against discrimination and brief descriptions of a few potentially relevant program measures at the provincial level (UN Human Rights Council, 2009). Canada has had a fairly robust set of statistical instruments for tracking a range of issues concerning people with and without disabilities. Yet, if even under such circumstances a country as Canada is virtually silent in terms of the attainment and exercise of so fundamentally important a right as employment, how would we know whether and to what extent progress is being achieved in this area? The rest of this section illustrates how the proposed statistical data can be used to shed light on this type of questions.

Access to the Valued Situation of Work

Based on the information provided by PALS, it is possible to gauge the extent to which people with disabilities in general, and those in low income in particular, are in the socially valued situation of 'employment.' As provided by most recent PALS data, the overall labour force participation rate for working-age adults with disabilities is 59.6% comparing to the participation rate of adults without disabilities of 80.2% (Human Resources and Skills Development Canada [HRSDC], 2010). This shows that, in spite of the fact that Canada led the G8 countries in employment growth from 2001 to 2006 and the employment situation of people
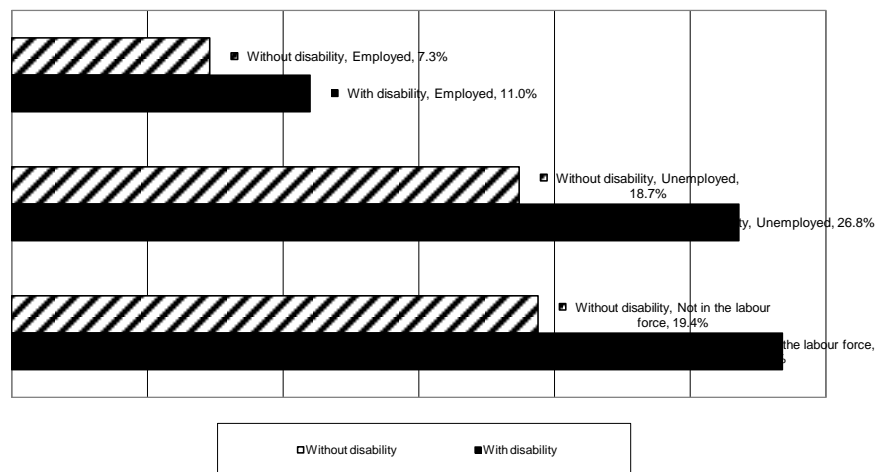
with disabilities improved slightly over those years, Canadians with disabilities have persistently remained much less likely to be employed than their counterparts without disabilities. Using statistical information, it is also possible to ascertain the comparative labour force status of people with and without disabilities. For example, the employment rate for working-age adults with disabilities is significantly lower than that for their counterparts without disabilities (53.5% vs. 75.1%). At the same time, the unemployment rate for those with disabilities is higher than for those without disabilities (10.4% vs. 6.8%) (HRSDC, 2010).

Barriers/Enablers and Intersectionality Lenses

Employing a barrier/enablers lens, we can obtain a more complex profile of those not getting access to the right of work, specifically those not in the labour force. Statistical data provided by PALS shows that in 2006, 43.8% working-age adults with disabilities were not in the labour force. The greatest barriers to get access to work for these people are inadequate training (19.3%), fear of losing partially or completely their current social transfer income if they work (17.6%), and lack of accessible transportation (12.8%). Discrimination, fear of losing access to drug plans and housing subsidies, and lack of accessible information on job opportunities are other barriers uncovered by statistical information (HRSDC, 2010).

Looking at the vulnerable group of people with disabilities in low income, statistical data suggests that the gap between this group and their counterparts in low income without disabilities increases over the progression away from the labor force (Figure 2). Even when working, people with disabilities are more likely than people without to have low incomes (11% vs. 7.3%). The gap widens for those who are unemployed and not in the labor force, with the rates of low income among these people with disabilities being about 1.5 times higher than for their counterparts without disabilities (Crawford, 2010).

Figure 2. After tax low income status by disability status and labour force status (Source: PALS 2006)

- Without disability, Employed, 7.3%
- With disability, Employed, 11.0%
- Without disability, Unemployed, 18.7%
- ...ty, Unemployed, 26.8%
- Without disability, Not in the labour force, 19.4%
- ...the labour force,

□ Without disability   ■ With disability

Economic vulnerability is also highly associated with barriers encountered by this multiple-discriminated group in exercising its right to work. For example, statistical data shows that lack of training is a significant barrier to employment, those with low incomes being significantly less likely to have taken training than their counterparts not in low income (17.3% vs. 34.8%; Adele Furrie Consulting Inc., 2010).

This type of information obtained through 'mining' statistical data available is essential in order to obtain accurate portraits on the access to work for people with disabilities and the main issues they face in exercising this right. The longitudinal trend of statistical indicators as those described above can be used to assess the effect of the CRPD implementation across time in conjunction with legal and other community-based information. Although exemplified with the right to work, the proposed approach can be applied, given data available, in order to assess the impact of the CRPD in relation to each right outlined in the Convention.

Level/Quality of Participation in the Valued Situation of Work

Once in the valued situation of employment, the quality and/or quantity of participation may be reported as an outcome. Based on statistical data, it is possible to ascertain and compare, for instance, the distribution of employed people with and without disabilities across various occupations and industrial sectors, employment earnings and the number of hours per week or weeks per year that were worked for pay. For people with disabilities it is possible to ascertain whether they had to change their jobs because of disability, difficulties changing the jobs and whether their education and skills on the job are underutilized. All these indicators speak indirectly to the issue of participation of people with disabilities as valued equals in paid work. For example, PALS data shows that only about half (48.9%) of people with disabilities do the same work as they did before acquiring their disabilities. Further, because of disability onset, more than three quarters (77.5%) of those who changed their jobs also changed their work responsibilities (HRSDC, 2010).

Barriers/Enablers and Intersectionality lenses applied

The barriers/enablers lens facilitates a further understanding of the quality of participation once in the valued situation of work (those employed). Using this approach, the profile of unmet needs of employed people with disabilities can be determined. For example, PALS data shows that only 60.4% of employed people with disabilities have all their needs for aids and devices met (HRSDC, 2010). Among those who did not receive the workplace accommodations needed, the main reasons for not getting these accommodations were the employers' refusal because modifications were considered too expensive (12.6%) or because they were afraid to ask (14.7%). (HRSDC, 2010). Further, by taking into account the intersectionality, it is possible to ascertain the specific issues faced by the vulnerable group of interest. For instance, those in low income are about a third as likely to receive training as their counterparts not in low income (10.1% vs. 27.8%), with the lack of training representing a significant barrier to better employment and hence to participation of better quality (Adele Furrie Consulting Inc., 2010). Among those who reported employment discrimination in the past five

years, about a quarter (22.4%) are in low income, this percentage significantly dropping among those who did not experience discrimination (12.7% – Crawford, 2010). These numbers speak indirectly about the vulnerability of those in poverty to work-related discrimination. An extended list is provided below with other indicators that can be developed based on PALS in order to assess the quality of participation once in the employment situation (Table 1). The list is, however, adaptable to statistical data available and similar indicators can be extracted for various vulnerable groups, depending on the focus of monitoring process.

Table 1. Barriers/enablers lenses to assess the level/quality of participation of people with disabilities in employment – PALS		
Indicators /measures	Barriers	Enablers
Workplace accommodations	Needed job accommodations not available	Needed job accommodations available
	– **Modified work structures** (e.g. modified workstations; accessible washrooms/elevators; accessible parking; accessible transportation) – **Work aids/job modifications** (e.g. modified days/hours of work; human support; assistive technologies;)	– **Modified work structures** (e.g.modified workstations; accessible washrooms/elevators; accessible parking; accessible transportation) – **Work aids/job modifications** (e.g. modified days/hours of work; human support; assistive technologies;)
Work-related training	Have not recently participated in work-related training	Have recently participated in work-related training
	- **classroom-based training** - **on-the-job training** - **other training**	- **classroom-based training** - **on-the-job training** - **other training**
Educational attainment	Low level of formal educational attainment	High level of formal educational attainment
Workplace discrimination	Discriminatory employer practices based on disability	No discriminatory employer practices based on disability
	- Have been refused a job/job promotion - Have been given less responsibility than co-workers - Have been denied work-related benefits	- Have not been refused a job/job promotion - Have not been given less responsibility than co-workers - Have not been denied work-related benefits

Summary and Conclusion

This paper has provided background on the need for a statistical monitoring strategy to track whether and to what extent the human rights of people with disabilities are being achieved

as set out in the UN Convention on the Rights of Persons with Disabilities. It has taken the right to work without discrimination based on disability as an example. It shows how it is possible to use data that exist in the Canadian context, and that by a reasonable stretch of the imagination would continue to exist in one form or another in this country and that could become more widely available on the global stage, to comparatively track human rights issues along two key dimensions: access to socially valued situations and extent of participation as valued equals in those situations. Barriers to gaining access to the situations and to full participation, enablers of access to the situations and to full participation, and intersectionality were the key lenses applied across the dimensions of the proposed model.

As pointed out by the Secretary General of the United Nations, the international statistical data 'system' for monitoring the human rights of people with disabilities is neither clear nor strong. Even in a developed country such as Canada, where political leaders, government officials, academic and community-based experts on disability, statisticians and policy analysts have dedicated considerable energy and careful thought to developing and analyzing the results of statistical tools for tracking and exploring issues of disability, the statistical data 'system' is far from secure. It has undergone many changes over the years that have been driven largely by concerns about costs to the taxpayer.

A new round of cost reduction measures is in effect, so the 'disability file' in Canada is taking another 'hit.' It is to be trusted that the paper will help decision-makers – in government, in the disability community, in academia and ordinary citizens – to find new paths to effective, efficient and timely monitoring and reporting of human rights issues that are of vital concern to one in seven people on the planet who live with a disability and to the countless others who are their siblings, parents, spouses, children, friends, co-workers and colleagues.

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DISABILITY STUDIES BOOK AND MEDIA REVIEWS

Book Review

Title: *Disability History: Konstruktionen von Behinderung in der Geschichte. Eine Einführung.* ["Disability History: An Introduction to Historical Constructions of Disability"]

Editors: Elsbeth Bösl, Anne Klein, Anne Waldschmidt
Publisher: Bielefeld (Germany): Transcript Publishers, 2010
Paper: ISBN: 978-3-8376-1361-2
Cost: Euro 26.80, 255 pages
Reviewer: Katharina Heyer, Ph.D.

The field of disability studies has taken Germany by storm. With the publication of *Disability History,* we now have a collection of essays written by the who-is-who of German disability studies. Published in a new book series entitled "Disability Studies: Bodies – Power – Difference" [Körper – Macht – Differenz] by the German *transcript* publishers, this book offers a comprehensive overview of central themes in the German approach to disability studies.

So, what's "German" about disability studies? Judged by the first section of the book, which offers methods and theoretical foundations, the German approach to disability studies takes many of its starting points from the cultural turn in Anglo-based, disability studies. All of the authors refuse to translate the English term "Disability Studies" and weave it seamlessly into their (German) text. The bibliography is riddled with English-language disability classics – gesturing towards the globalization of that understanding – and especially the first section extensively cites American and British classics establishing the foundations of the why and how of disability studies (such as the work of Lennard Davis, Paul Longmore, Rosemarie Garland-Thomson, Mark Priestly and others). The volume's first section also makes the case for a "cultural" model of disability. This model, explains Anne Waldschmidt in the first chapter ("Why do we need Disability Studies and Disability History?"), expands the limitations of the social model's orientation towards policy ("how should society treat people with disabilities") (p. 20) by asking more fundamental – and interdisciplinary – questions regarding the construction of disability, difference and marginalization. In that sense, a cultural model, inspired by the Cultural Studies movement, can use disability as an analytical category pointing to "modernity's dark side and unexamined spaces." (p. 23)

Sections Two and Three examine scientific, institutional, and political constructions of disability. Thus, we have studies tracing the construction of "feeblemindedness" in two distinct periods in German history (1900s and 1970s) as well as one that examines the use of controversial cell-therapies for the "treatment" of children with Down syndrome. German postwar history is well represented by studies of institutions and the deinstitutionalization movement, the public work of charities, and a very general overview of Swiss welfare policy. Petra Fuchs offers a fascinating reading of euthanasia medical charts dating from the 1920 through the 1940s, using Roy Porter's call for a "medical history from below." (Porter 1985) She uses medical charts as biographical sources, offering a rare glimpse into the lives of institutionalized patients who became the victims of mass murder during the Nazi regime.

The final section covers arts and culture, such as the relationship between sports and disability during National Socialism and the representation of little people in the fine arts. Many of the chapters in this book are conceptualized as both introductory and comprehensive, meaning that they typically begin with the Middle Ages, walk us through the Renaissance, and end with the modern period. This means we get a sense of general themes that leave us wanting for more. For example, the final chapter on humor walks us through the ages and then jumps to contemporary disability humor, which suggests a move from derogatory jokes to humor that is politically empowering and casts a critical glance on our continuous discomfort with physical difference. Theoretically, the chapter relies heavily on the Anglo discussion on disability humor that was published in a special edition of *Body & Society* in 1999. Surely there must be German theoretical considerations on disability humor? For example, cartoonist Phil Hubbe is the German equivalent of John Callahan, poking irreverent fun at both disability and our reactions to it. And yet Hubbe is barely mentioned in the chapter's footnotes. Readers with German language skills are invited to browse his website displaying his cartoons as well as his transformation from political to disability cartoonist (www.hubbe-cartoons.de). *Disability History* in its entirety offers important glimpses into German-language disability studies that should prompt readers to investigate this growing field more deeply.

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Book Review

I have heard Dr. Millett-Gallant lecture and thought she was brilliant, but I was impressed anew by the depth of her scholarship in this book. Each paragraph is thick with ideas, and each description of art is thoughtful and detailed. Each analysis is meticulously built. The book is intended for scholars, but newcomers to this area of disability studies—such as myself—would be comfortable with its thorough treatment of topics. The density of the text calls for careful reading.

Dr. Millett-Gallant describes many types of visual media here, including photography, performance art, sculpture, and medical displays. While she describes, she simultaneously deconstructs the effects of these media on both the viewer and the viewed. She does not shrink from speculating about the motives of artists who exploit or embrace disability. Many of the artists themselves have disabilities, so this is delicate ground to tread. She appears to be fearless.

The author's analyses are penetrating. In chapter one, Millett-Gallant describes the psychology of the gaze. She discusses Freud and the role of the gazed-upon versus the gazer. She assesses

the gaze as an indicator of status and class, race and gender. She examines iconography versus humanity. In subsequent chapters, Dr. Millett-Gallant analyzes the work of famous artists. Photographer Diane Arbus's work, which is sometimes described as "enfreakment" of those with disabilities due to her exaggeration of their physical characteristics, is analyzed here. So is the work of Marc Quinn, whose sculpture of Allison Lapper's disabled body stood in London's Trafalgar Square alongside monuments to military heroes and statues of royalty. The author also describes the physical pain depicted in paintings by Mexican artist Frida Kahlo and the publicity photos of "human curiosities" commissioned by P. T. Barnum. It is a fascinating variety of art and intentions that Millett-Gallant unravels in these pages.

Sadly, the book is lacking in graphics. As early as the introduction, I was both frustrated and intrigued by the lack of visual reference material. Why would a book about art have so few illustrations? Was it an exercise in imagination? Was it a statement about the objectification of the observed? Was it a budget problem? Fortunately for the reader, Millett-Gallant writes beautifully, and her descriptions of the art are richly detailed. The inclusion of more illustrations, however, would have saved me many searches on the internet.

I was also distracted by a few publishing errors--persistent spelling mistakes, proofreading notes, a printing error--the volume is compact and attractive but not perfect. In addition, a thorough editor might have simplified a sentence here and there to give the reader some relief from the complexity of the paragraphs. But these are irritants, and the book, overall, is a gem.

I will be reading it—carefully—a second time. It is that good. The book is a stew of descriptions, observations, arguments, psychologies, exploitations, empowerments, and complications all exposed in contemporary art that features the disabled body. Millett-Gallant has packed this skinny volume to bursting.

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DISABILITY STUDIES DISSERTATION ABSTRACTS

Editor's note: The information for this section of RDS is provided by Jonathon Erlen of the University of Pittsburgh. A full list of disability-related dissertation abstracts may be found at http://www.hsls.pitt.edu/guides/histmed/dissertations/

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