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Borders, Barriers, and Brains: Issue Definition in Rights Based Policy Related to Autism

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Abstract

In issue definition related to rights based policy, Canada has been stereotypically understood as taking a more positive, human rights centered approach whereas the United States has been expected to take a more negative, civil rights based tact. While this difference in approach is expected to be a key to a broad base of differences between the two nations and societies, the difference is arguably unusually relevant in the disability policy arena. After all, recent changes in the understanding of disability is transforming disability from an issue of personal culpability overseen by medical professionals and tempered by charitable efforts to an issue of shared social and personal construction for which society at large is responsible. As the incidence of disability continues to rise, broad changes in social, political, and economic infrastructures are the expected result of recent innovations in disability related policy. These changes will affect society well beyond the lives of individuals with disabilities.

Over the past decade, Canada, the United States, and several other counties have experienced a surge in the reported incidence of autism. The public management of needs related to the autism baby boom is an unfolding process. This year the Canadian Supreme Court is scheduled to hear the case of *Auton v. British Columbia*, which is focused on the question access to intensive therapy

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(specifically Applied Behavior Analysis or ABA) as a medical right. This case is especially interesting in the North American context both because of its inherent implications for the construction of rights and because of the compelling difference in the definition of the therapy from the United States (where students have a rights based access to special education and ABA is consistently defined as an educational right). To examine this question of the relationship between neurodiversity and the construction of rights I am conducting surveys of issue stakeholders including parents, agency workers, school district representatives, and practitioners in the medical community. The surveys are correlated with the Participation and Activity Limitation Survey run by Statistics Canada. I examine how the current definition of rights in the realm of autism policy fits into the ongoing history of the definition of human and civil rights in North America.

Borders, Barriers, and Brains: Issue Definition in Rights Based Policy Related to Autism

Public policy responses to social challenges resulting from disability were recast a generation ago as being rights based (Hernandez, Keys, & Balcazar 2004; Rimmerman & Herr 2004.). Disability was once understood in the western world as a quintessentially personal or familial challenge resulting from a fault in the physical, neurological, or emotional composition of an individuals' body or mind. To be disabled was to be handicapped and therefore a locus for pity, perpetual professional supervision, and, often, poverty (Bagenstos 2004). The policy solutions most often used to address this definition of the challenges surrounding these types of human difference were acts of social, community, or public charity and medical care (McCarthy 2003). During the mid-twentieth century era of scientific optimism, policy solutions rooted in medical treatment were especially favored. Individuals with disabilities were expected to play the "sick" role in society and, as a result, were systematically stripped of the ability to participate as full citizens in society (Bagenstos 2004; Herzog 2004).

Since the 1960s, however, disability has become understood as being jointly created by personal characteristics and public infrastructures designed—intentionally or not—to exclude

those whose bodies or minds deviated from the norm (Herzog 2004; Hertz 2003). Although many policy (and other) decisions are still being made using other understandings of disability (including some in relatively influential areas such as bioethics) (Wolbring 2003), in both Canada and the United States, challenges related to disability are increasingly defined as problems rooted in inadequate protection of the rights of populace on the part of government (Bagenstos 2004; Hurst 2003; Rimmermann & Herr, 2004).

However, in issue definition related to rights based policy, Canada has been stereotypically understood as taking a more positive, human rights centered approach whereas the United States has been expected to take a more negative, civil rights based tact. While this difference in approach is expected to be a key to a broad base of differences between the two nations and societies, the difference is arguably unusually relevant in the disability policy arena, especially with regard to the administration of programs and policies designed to address non-physical disabilities (Gerber et al. 2004).

The following is an examination of the relationship between rights based policy and challenges related to neurodiversity using the case of autism spectrum disorders (hereinafter referred to as autism). This case was selected because of the rising profile of autism in both Canada and the United States and because of the inherent diversity within the diagnosis. The primary research question is: to what degree does the stereotypical difference between the Canadian and American approach to the construction of rights manifest in the issue stakeholders' experiences? In examining this question, the ultimate goal is to shed light on how the current definition of rights in the realm of autism policy fits into the ongoing history of the definition of human and civil rights in North America.

Between Human and Civil

Democracies share a fundamental commitment to the provision and protection of their populaces' rights. However, the conception and construction of rights varies significantly between systems. Arguably one of the most fundamental divisions is in the justification for rights. From at least a stereotypical standpoint, one outcome of this difference has been along the axis of human vs. civil rights (Fraser 2003). Human rights are typically defined as those rights that are held simply by and because of human existence (Bangrath 2003). Human rights are often provided for and protected at the level of the society at large, with the unit of concern and analysis being the human collective (Grover 2003). Civil rights, on the other hand, are typically defined as those rights that are acquired through the fact of citizenship and contingent (to a certain degree) on the responsible exercise of that citizenship on the part of the individual human being. For example, in the United States, an individual citizen can lose the right to vote if convicted of certain crimes, since this constitutes a violation of the citizen's responsibility to be law-abiding.

One root of the distinction between human and civil rights is the difference between systems based on the Westminster model (such as Canada) and those based on judicial review (of which the United States is the prime exemplar) (Bangrath 2003; Hiebert 2004; McMillian & Tatalovich 2003). As a result, parliamentary democracies, including Canada, were traditionally reluctant to adopt a bill of rights focusing on individual rights (Hiebert 2004, 1964). A cornerstone of civil rights based system has been the judicial review that "allows judges to invalidate legislation when it is inconsistent with judicial interpretations of constitutional rights" (Hiebert 2004, 1964) on the individual level.

Another aspect of the difference in conception of rights in North American systems is around the question of positive versus negative rights (Fraser 2003; Brodsky & Day 2002). Positive rights do not imply a normative description in this context. Positive rights are not necessarily “good.” They describe a right to have the circumstances for the exercise of a right in place as opposed to the negative right of not being unjustly prevented from exercising a right (Brodsky & Day 2002; Gowri 2000). Positive rights are more naturally incorporated into systems and philosophies using a human rights basis whereas the (so-called) negative rights dovetail more conveniently into civil rights based systems. For example, in the United States, the positive rights associated with affirmative action are frequently contested (if not abhorred), most often because the provisions designed to protect positive risks at the social or community level tend to infringe on the civil rights of specific individuals attempting to engage in the system in an given way. The difference between positive and negative rights can be of particular significance for those with emotional or neurological differences (Fennell 1999).

The exercise of the difference between human and civil rights is, of course, far from absolute. Both the histories of Canada and the history of the United States contain examples of public policies seemingly more in keeping with the conception and creation of rights on the other side of the border (Gee 2004; Grover 2003). Canada encoded a basic bill of rights in 1960 and then, in 1982, adopted the Canadian Charter of Rights and Freedoms (Hiebert 2004). Similarly, much of the language surrounding American social policy initiatives, most notably the New Deal and the Great Society, invokes human rights based understandings of the role and importance of the collective in the exercise of democracy. Nevertheless, this stereotypical distinction is expected to be generally observable in the differences in character and content of policies in the two countries.

In recent years there has been discussion of a convergence of approaches to rights, particularly since the passage of the Charter of Rights and Freedoms in Canada and the reconsideration of affirmative action and inclusion policies in the United States (Gee 2004; McMillian, & Tatalovich 2003). *Auton vs. British Columbia.*, which is being currently considered by the Supreme Court of Canada, is quintessentially civil rights oriented, with the question of concern squarely rooted on the individual rights of specific children with a selected condition. Court decisions related to the creation and construction of rights both motivate and reflect political action on the part of minority groups (Troy 2004). Similarly, though the policy is fundamentally a civil rights based one, some of the arguments made in support of the Americans with Disabilities Act of 1990 were rooted in collective human as opposed to individual interests (Hernandez, Keys & Balcazar 2004). Furthermore, among the scattered and substantial effects of the terrorist attacks of September 11th in the United States has been some reconsideration of human rights in the United States—if only in the consideration of privileging the human right of survival over certain civil liberties.

Autism Policy History

The public and governance aspects of autism are located across a broad scope of traditional policy areas. As is the case with most types of disability, challenges related to autism that have been defined as public issues are usually addressed using civic education, services or purely rights based policy solutions (McCarthy 2003). In addition to its inclusion as part of this overarching and rapidly developing disability policy area (Herzog 2004), policies and programs specifically addressing autism have also been developed in both Canada and the United States in recent years. Especially at the state/provincial and local levels of governments, there is a growing plethora of specific autism policies including, for example, personalized license plates, training

programs for teachers, and tax breaks for individuals with autism (Piorthier and Devlin, forthcoming).

Recent Autism Policy in Canada

The most significant development in autism related policy in Canada during the past few years has been the *Auton vs. British Columbia*. This case, which was heard by the Canadian Supreme Court during the summer of 2004, focuses on the question of access to intensive therapy (specifically Applied Behavior Analysis or ABA) as a medical right. Applied Behavior Analysis is an intensive (and expensive) therapeutic program in which a child works one on one with a trained professional for up to forty hours per week (Choutka, Doloughty & Zirkel 2004).

Although ABA is currently one of the most scientifically proven treatments for autism, these promising preliminary results do not represent a consensus within the academic and scientific communities studying autism (Schoen 2003). Proponents of other treatment strategies both called the results into question and have begun to generate evidence of the efficacy of other strategies (including, for instance, changes in diet). Furthermore, parents of children with autism are deeply divided over ABA: whereas many parents believe that ABA therapy has provided a unique opportunity for their child to recover from autism, others believe that ABA does not work for their child, particularly for older children and adults with autism. Finally, some members of the disability community, including some adults with autism, have objected to the ABA on the grounds that the ultimate goal of the therapy is to destroy the natural personality and thinking patterns of the individual. As a result of *Auton vs. British Columbia*, questions surrounding neurodiversity have been brought to the foreground of current decisions about the formulation of a broad scope disability policy and programs in Canada, particularly in British Columbia.

Recent Autism Policy in the United States

While there has been nothing quite so fundamental as a Supreme Court case centered on autism in the United States in recent years, there have been both macro changes to the composition of disability policy (Hurst 2003) and intriguing appearances by autism in seemingly unexpected areas of public policy in recent years. For example, many of those within the disability policy community thought (or at least hoped) that the Supreme Court decision in *Olmstead vs. L.C.* would be “the so-called *Brown vs. the Board of Education* of the disability rights movement” (Bagenstos 2004, 49). This decision essentially held that individuals with disabilities should not be in institutional or residential settings unless absolutely necessary to protect the individual or others from harm or if it was the preferred mode of treatment of the individual with the disability. Community based services were to be provided whenever possible. Whereas the implications of this decision have been less dramatic than was initially anticipated by disability advocates and state service providers alike, the decision effectively signaled the long-anticipated death of the routine institutionalization of individuals with autism.

An example of an intriguing appearance of autism related issues in public policy was in the Homeland Security Act of 2001. One of the last minute additions to the bill was a restriction of a parents’ ability to sue for injuries or ill effects of childhood vaccinations. This was motivated by a growing suspicion on the part of some members of the scientific community that some part of the rise in incidence in autism came as a result of the use of a mercury based preservative in childhood vaccines (Baker & Stokes, forthcoming). Though this causal theory remains hotly debated and the vaccine provisions in the Homeland Security Act were ultimately tempered, the policy is intriguing for the standpoint of the construction of rights. After all, a primary reasoning for the policy was the protection of the public health (through access to low

cost vaccines) at the expense of the civil rights of a specific subset of children who had (or would) developed autism perhaps as a result of the vaccination.

Project Methods

To examine this question of the relationship between neurodiversity and the construction of rights I am conducting surveys of issue stakeholders including parents, agency workers, school district representatives and practitioners in the medical community. The surveys are correlated with the Participation and Activity Limitation Survey (PALS) run by Statistics Canada. Unlike other disability survey instruments, PALS was deliberately created to examine the social construction of disability experiences.

The data collection process was begun in July 2003 and is still underway. As a result, the sample is as yet incomplete, consisting of a total of 540 responses from one province (British Columbia) and one state (Missouri). In the coming year, the data collection will be expanded to include other parts of the United States and Canada. In addition to the survey, a representative sub-sample is being asked to participate in a follow-up semi-structured interview designed to gain more specific qualitative and contextual information about individual's impressions and experiences. Thus far 31 interviews have been conducted. Because the majority of the data collected thus far has been from parents and primary caregivers, their point of view will be the one more predominantly discussed below.

The Families Experiences with Autism Survey is being used to collect data in the United States. The survey includes 45 questions asking about the experiences with autism, family structure and finances, socio-economic and community participation and impressions of elements of the public infrastructure such as public schools, targeted programs, and public information sources. Several of the questions also included space for additional comments from

which a wealth of more qualitative data was generated. Thus far, the survey has been administered to 440 parents and primary caregivers of children with autism in Missouri. The surveys were administered between July 2003 and March 2004. Of those who were administered the survey, 428 consented to participate after the informed consent process.

The Survey of Parents and Primary Caregivers and Survey of Practitioners and Policymakers are being used to collect data from Canada. Thus far the data includes responses from British Columbia only. The surveys include most of the same questions (asked in an identical fashion) as the Families' Experiences with Autism Survey. The surveys being used in Canada also include a series of questions directly related to the *Auton* case and about comparative impressions of policy between Canada provinces and vis-a vis other western democracies. A few of the questions were also altered to better fit the Canadian context (for example, the categories of ethnic identification and the type of community in which the family resides). These differences are expected to enhance rather than diminish the basis for comparison between survey responses from both countries. Furthermore, unlike as has been the case in the United States thus far, a parallel survey of professional and policy makers is currently being used to collect the impressions of other stakeholders. Thus far the survey has been administered to 97 parents and primary caregivers of children with autism and 3 practitioners/policymakers in British Columbia. An additional 12 practitioners/policymakers have also participated in the semi-structured interview process. The survey was launched in June 2004 and is ongoing. 100 percent of those who have been administered the survey have consented to participate after the informed consent process.

Borders

The Canada-United States border has long been unique but has, during the late twentieth and early twenty-first centuries, been of renewed interest. This occurred first in the free trade agreements of the early 1990s and then as an element of the aftermath of the terrorist attacks on September 11, 2001. This increased focus on the longest undefended border in the world has reshaped impressions of the differences between the cultures and nations on either side. In looking at the question of how the current definition of rights in the realm of autism policy fits into the ongoing history of the definition of human and civil rights in North America, it is first necessary to explore whether or not those exercising rights under conditions of neurodiversity represent differently constructed subpopulations.

The first element of experience to be examined is the degree to which there are differences in the populations identified as having autism in Canada and the United States. Autism is a spectrum disorder with an entirely behavior based diagnosis (Schoen 2003). As such, in spite of the uniform diagnosis standards located in the DSM-IV, autism not only goes by multiple names with varying connotations, but the exact nature of, for example, Pervasive Developmental Disorder versus Aspergers' Syndrome versus Educational Autism can be differently interpreted, especially given a difference in cultural context. While the symptoms of autism are generally far from subtle, its status as a pure descriptor of behavior thought to be caused by underlying differences in neurological composition (as opposed to condition diagnosable by other more "medical" means) highlights the importance of social construction in disability.

The populations of children with autism were found to be remarkably similar in both countries, especially at first glance. The higher prevalence of autism in boys was reported as

about the same in both nations. In Canada, 81% of the parents and primary caregivers had boys. Similarly, in the United States, 84% of the respondents had boys. The composition of families involved were also quite similar on both sides of the border. For example, approximately 70% of the families in both countries reported that they had two adults in the household. Furthermore, unlike what was believed to be the case in the middle of the twentieth century, the ethnic backgrounds of the families in both countries more or less mirrored those of the general population. The same was true of the income distributions (though a higher percentage of the Canadian families indicated that their family's yearly income was in excess of \$60,000 a year).

The novelty of autism experience (in spite of a suspected genetic component) was also similarly manifested in both Canada and the United States. 74% of the parents and primary caregivers from Canada reported that no one else in their family had ever had autism. In the United States, 70% of respondents indicated that no one else in their family had ever had autism. The majority of parents in both countries began to suspect a developmental difference in their child between the ages of 6 months and 2 years and the majority of the children in both countries were formally diagnosed by a medical professional sometime between their first and third birthdays. Despite the element of social construction believed to play a role in the creation of disability at the dawn of the third millennium, the populations of children identified as having autism share striking similarities across the Canada-United States border.

One of the key borders in policy questions related to neurodiversity has to do with the divisions between the types of professionals working with children with autism and their families. When asked who first mentioned autism as a potential diagnosis of their child, parents and primary caregivers in Canada responded that they had been the ones most often (22% of the time), which was followed by a medical specialist (15% of the time) and another family member

(10% of the time). In the United States, on the other hand, these percentages were lower. The respondents still reported that they were the most often the one to have mentioned autism first (16% of the time), but the family physician was second most often (at 13%) and early childhood educator was tied with medical specialist the third most often (11% of the time).

There were also differences between experiences with public infrastructures in the two nations. Perhaps somewhat surprisingly, only 79% percent of Canadian parents and primary caregivers reported that they had received publicly funded services for their child's autism (another 8% were not sure) whereas 88% of respondents from the United States indicated that they had received such services. Nevertheless, a higher percentage of parents and primary caregivers from the United States (78%) indicated that their families' community activities were restricted as a result of having a child with autism than in Canada (70%). Interestingly enough, when asked about service needs the percentage of parents and primary caregivers reporting that they had unmet service needs was identical (70%) in both countries, as was the percent (2%) reporting that their child or family was receiving services that they did not need.

Barriers

As part of both the Families' Experiences with Autism and Parents and Primary Caregivers surveys, respondents were asked directly about their experiences with their children with autism's rights. In both Canada and the United States, disability specific rights protections and policies embedded in a rights based philosophy are necessary only because of a historical failure on the part of the societies to ensure or protect the rights of individuals with disabilities vis-à-vis the level of rights enjoyed by the general population. An examination of these barriers as reported and described by parents and primary caregivers of children with autism is expected

to shed light on the lived experiences of individuals with disabilities and their families, especially because non-physical disabilities are often more challenging to extant infrastructures.

As is mentioned above, a similar percentage of parents and primary caregivers in both countries indicated that their families’ community activities were restricted as a result of having a child with autism. The percent of parents and primary caregivers reporting that their child’s rights had been violated as a result of his or her autism was substantially different—whereas 38% of parents and primary caregivers from the United States indicated that their child had had such an experience, 55% of percent of Canadian parent and primary caregivers indicated that it had happened to their child. When cross-tabulated by whether or not the parent considered their families’ community activities to be restricted the results were as shown in Table 1:

Table 1

Reported Restriction of Activities Cross Tabulated with Violated of Civil Rights				
	Of those with Activities Restricted, % with Rights Violated	Activities Restricted and Rights Violated (% of total)	Of those with Activities Not Restricted, % with Rights Violated	Activities Not Restricted and Rights Violated (% of total)
Canada	58%	40%	56%	12%
United States	41%	32%	28%	6%

As is mentioned above, Canada has been understood as having taken (stereotypically at least) a human rights as opposed to civil rights approach to the provision and protection of rights for its populace. Though it might initially be somewhat surprising to find a higher reported incidence of rights violations on the individual level reported in Canada, this is less surprising when one considers that perhaps the articulation of the civil right on the national level in the

United States (the Americans with Disabilities Act) as having had a positive influence on the social inclusion of children with disabilities above and beyond that which is experienced by having their rights protected as part of a collective.

It may also, however, be (more) indicative of a desire on the part of the parents of children with autism in Canada for policy approaches that take a more civil rights stance and which resemble what they believe to be the condition of social policy in the United States. The simple existence and intent of *Auton vs. British Columbia* suggests this. Several of the litigants in the case are Canadians who were educated at universities in the United States and developed their impressions of the ideal construction of special education systems there.

These differences also reflect Canadian impressions of American policy. When asked to compare the quality of public policy and public programs related to autism in Canada with those in the United States, 40% of Canadian parents and primary caregivers rated the United States as much better than Canada. These ratings are compared to 0% for France, 14% for the United Kingdom and 8% for Australia (even though Australia is considered by many international disability groups to be on the forefront of disability policy development). Furthermore, only 4% of the parents and primary caregivers believed that the policies and programs were better in Canada than in the United States (33% did not know).

There were also intriguing implications of the types of rights violations that parents and primary caregivers reported their children had experienced. As Hernandez, Keys & Balcazar point out, public opinion about rights matter at least as much as the presence of the right in a particular system (2004). This is arguably particularly true for those who are issue stakeholders. After being asked whether or not their child had ever had their rights violated as a result of his or her autism, parents and primary caregivers who answered “yes” were asked to briefly describe

the most recent incident. Several of the Canadian respondents described being forced to pay for medical treatment (whereas none of the parents and primary caregivers from the United States described this as a rights violation). Because the vast majority of the respondents from the United States also had public or private health care insurance, this speaks not only to the presence of an available health care system but to a focus on a human right. On the other hand, responses from parents and primary caregivers in the United States were most often focused on the process associated with developing an Individual Education Program (IEP) plan. Under the Individuals with Disabilities Education Act, every child with an identified disability has the right to have an IEP plan developed to ensure that civil rights to a free and appropriate education are protected.

In addition to the direct exercise of rights, one of the key areas in which individuals with disabilities and their families have traditionally run into barriers to their participation in society is in employment. The experience of disability was once so intimately connected with the experience of poverty that the popular term used to describe such conditions—handicap—was a description of a beggar holding out his or her cap for money. In order to gain an understanding of current manifestation of this aspect of disability in Canada and the United States, the parents and primary caregivers were asked a series of questions related to their finances and employment. The percent of parents and primary caregivers who indicated that their families had had financial problems as a result of their child's autism difference: 60% of Canadian respondents said that they had whereas only 43% of respondents of the United States reported financial difficulties caused by autism. These difficulties could, of course, be either on the income or cost side of the family finances equation.

When asked about the specifics of employment difficulties experienced as a result of a child's autism, the percentages of Canadian parents and primary caregivers reported were the

same or lower than their counterparts in the United States for almost all types of difficulties including: not taking a job to take care of the child; taking leave in addition to normal parental leave; changing jobs; turning down a promotion; changing work hours to a different time of day; and being reprimanded at work. The one exception was in the percent of parents and primary caregivers who reported that they had worked fewer hours due to their child's autism. Whereas 63% of Canadian respondents reported having made this choice, only 46% of respondents from the United States had done so.

Another difference was in the distribution of employment effects within the family. The parents and primary caregivers who reported that their child's autism had affected work outside the home were asked which members of the family were the most affected. In the United States, the majority of the families (64%) indicated that the mother was the most affected, followed by both the father and the mother (17%) and the father only (7%). In the Canadian sample, however, 48% of the respondents indicated that the mother was the most affected, followed by both the mother and the father (32%) and the father only (14%).

Brains

Up until the late twentieth century children with neurological differences were typically not allowed to attend public educational programs with their peers. A movement toward first mainstreaming and then inclusion began to take hold in both Canada and the United States during the late 1980s and early 1990s. From the standpoint of a constructivist understanding of disability, the interpretation of special education services is somewhat complex. If the services are used as a means of excluding the child from general education environments on the basis of discrimination against individuals with disabilities, special education services are undesirable. To the extent that special education services represent needed or at least helpful accommodations

within the education system special education services become desirable mechanism by which children with disabilities become more incorporated into society (especially, in many cases, if the services discretely are provided in the general education classroom).

Inclusion appears to be working differently for children with autism in Canada as compared to the United States. 26% of the parents and primary caregivers from the United States indicated that their children were educated in general education classrooms (with or without special education services such as an aide or classroom modifications). However 68% of parents and primary from Canada indicated that their child was in a general education classroom. When cross-tabulated with reported family income, these percentages where not found to vary dramatically by level of income in either nation.

A frequently voiced justification for inclusion involves the argument that the presence of the child with the disability benefits all children in the classroom (and society at large) by better representing the breadth of human experience and creating conditions wherein all members of society are better equipped to understand one another. The finding that children with autism in Canada were much more likely to be included speaks to the stronger presence of a human rights basis in Canada.

Other intriguing aspects of difference in the Canadian and American experiences were found in the answers given to question about programs and strategies parents and primary caregivers have used in the management of their children's autism. As is mentioned above, in the United States, federal policy (uniquely) provides for an individualized civil right to a free and appropriate special education plan for children with identified disabilities such as autism. Presumably as a result of this policy, parents and primary caregivers reported that they had used special education services in the management of their child's autism twice as often in the United

States (84%) as in Canada (40%). The drop off between those who had ever used special education services and those currently using them were, however, similar in both countries, with 14% fewer currently using special education in Canada as compared 17% few in the United States.

Finally, despite the fact that the *Auton* case is seeking to define ABA therapy as a medical right, only 27% of Canadian parents and primary caregivers indicated that they had ever used a medical intervention even though 67% indicated that they had used Applied Behavior Analysis at some point in time. Though the treatment is more often described (especially in court documents discussing a child's educational civil rights) as an educational intervention in the United States, 63% of American parents and primary caregivers indicated that they had used a medical intervention, which was a much closer percentage to the 57% who reported having ever used Applied Behavior Analysis.

Concluding Thoughts

The inclusion of those with autism and other types of neurodiversity in society is a complex and multifaceted challenge. In the case of autism, as it is being experienced by the families of young children in Canada and the United States, the historically expected difference between human and civil rights based traditions appears to have influenced families' experiences with the public infrastructure. However, this difference has not had a shaping influence on the construction of disability in either nation. Furthermore, as has been found in previous studies, the preliminary results of this study suggest penetration of the rights based understanding of disability is as yet incomplete (McCarthy 2003).

This penetration is expected to increase over time. One of the key challenges in all policies relating to neurodiversity in children is the absence of reliable comparison groups in the

adult population. The vast majority of adults with conditions currently understood as reflecting neurodiversity grew up in situations remarkable different from those experienced by children today. In the past, neurodiversity was either unrecognized (or, at least, misunderstood) or was managed through systematic removal from society in either institutional or “special” settings where the children’s potential was underestimated and, frequently, undermined (Hurst 2003). Though there are a substantial number of outspoken and dedicated individuals with disabilities engaged in disability advocacy, both the potential and perspectives of the population at large remain relatively unknown but will likely speak to the differences in construction of rights in North America in years to come.

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