

**THE ILLUSION OF INCLUSION FOR CHILDREN WITH INVISIBLE DISABILITIES
IN ONTARIO PUBLIC SCHOOLS**

by

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Abstract

The current study examined inclusive education in Ontario public schools, as it is experienced by students with invisible disabilities and their families. Invisible disabilities are those that are not immediately visible to the naked eye. Some invisible disabilities that commonly affect children include (but are not limited to) high functioning autism spectrum disorder, attention deficit disorder, externalizing behaviours, depression/anxiety, and oppositional defiant disorder. Most literature to date focuses upon teacher/administrative perspectives of inclusion, while experiential data from families is absent. Parents, recruited through various community organizations and Quintilian Private School, completed a survey on their families' experiences within the Ontario public school system. Students with invisible disabilities completed an adapted photovoice exercise, where they shared a visual and textual summary of their feelings about public school and specialized private school, respectively. It was discovered that inclusive education for children with invisible disabilities is more an illusion than a reality in Ontario public schools.

Preface

Why Me? Why This Issue?

As the mother of two children who have exceptional needs, including autism spectrum disorder (ASD), cerebral palsy (CP), attention deficit disorder (ADD/ADHD), anxiety/obsessive compulsive disorder (OCD), sensory processing disorder (SPD), and severe learning disabilities, I have worn many hats over the years. Physiotherapist, behavioural therapist, psychologist, child advocate: these are only a few of the unofficial mantles I assumed as a stay-at home-mom, attempting to give my kids every opportunity for a fulfilling life. I have experienced first-hand the fight to ensure that the rights of my children to receive a decent education are being met within the public-school system. It has often seemed an unwinnable battle. Despite policies that espouse inclusion, I witnessed numerous systemic and applied examples that disavow inclusive education policies. I am unsure if inclusion is the best way to approach educating exceptional children; however, since inclusion is the official policy and ideology, it should at least be implemented and funded properly. Such is currently not the case.

I advocated and fought for my children's rights for years; nothing changed. I realized, after frustration and heartbreak led to the drastic decision to withdraw my RRSPs so that I could 'afford' to enroll my children in private school, that I was fighting with the wrong people, and using the wrong weapons. Teachers, principals, the schoolboard—all whose hands were tied by limited resources/funding, lack of knowledge, and conflicting agenda's—were as frustrated as I was. I well recall discussions with school administrators who communicated to me that public schools are designed to be generalists and how they didn't have the resources or knowledge to accommodate my son. In my opinion, the problem is intrinsic to our educational pedagogy; the

fight needs to be on an institutional level, and progressive change needs to be systemic and widely implemented to prevent at risk children (like mine) from falling through the cracks.

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List of Abbreviations

ASD: Autism Spectrum Disorder

ADHD: Attention Deficit Disorder with/without Hyperactivity

EA: Education Assistant

HFA: High Functioning Autism

IEP: Independent Education Plan

IPRC: Identification, Placement, and Review Committee

LD: Learning Disabilities

ODD: Opposition Defiant Disorder

OPEC: Organization of Petroleum Exporting Countries

PDD: Pervasive Developmental Disorder

SPD: Sensory Processing Disorder

Chapter 1

Introduction

The diagnosis of high functioning autism spectrum disorder (ASD), attention deficit disorder with hyperactivity (ADHD), anxiety/depression, and other developmental, psychiatric, and learning disorders has increased exponentially in recent years (Public Health 2009; Ouellette-Kuntz et al. 2014;). In this thesis, these disorders are referred to, collectively, as “invisible disabilities.” Invisible disabilities are defined as “conditions, illnesses, and structural or biomechanical anomalies that are life limiting, but not readily discernable to others” (Davis 2005). The scope of this category of illnesses is much broader if adult disorders (such as multiple sclerosis or fibromyalgia) are included; however, for this paper invisible disabilities refers exclusively to childhood presentations of neurological/ behavioural/learning disorders that are pervasive, but invisible to the naked eye. While the increase in the incidence of these disorders affects many aspects of public policy, my research will focus on how the Ontario public elementary school system accommodates children presenting with invisible disabilities.

In Canada, we are signatories of the Convention on the Rights of the Child, which contains sections pertaining to educating those with disabilities. Provincial legislation lays out a framework for an ideology of inclusive education (UNICEF 2007). There is a marked difference, however, between the legislative and bureaucratic ideology of inclusion, and the reality of life in the Canadian classroom (UNICEF 2009). While severely impaired children have relatively easy access to the supports required for them to be schooled alongside their peers, children with invisible disabilities have a vastly

different experience. These kids do not appear as needy as do children with visible exceptionalities, and therefore there are less (often no) supports or resources available to them (Jahnukainen 2011). Despite good intentions, the experience of inclusion for exceptionally needy children with invisible disorders within the classroom is often more an illusion than a reality (Lupart 1998; Moore and Slee 2012; Florian 2014). In addition, there is a lack of understanding and agreement regarding the practical implementation of inclusion and its effects on invested parties, as well as a spirit of collective indifference that does not fuel political will to make necessary changes (The Roeher Institute 2003; Lupart and Webber 2012; Moore and Slee 2012; MacFarlane and Woolfson 2013). These factors affect the ability of the public-school system to meet its obligations regarding education of children with invisible disorders.

A quality education is a major stepping stone to Canadians' being able to exercise their substantive citizenship (Prince 2009; Crawford 2013; Erevelles 2014; Cahill et al 2012; Boman 2015; Levesque 2016). Those with disabilities are more likely than are their able-bodied peers to live in poverty or to be unemployed, and they are less engaged in political processes (Prince 2009; <https://www.ldac-acta.ca/>). In addition, persons with invisible disabilities are less likely to graduate high school and/or to attend a post-secondary institution. This population is also more likely to be incarcerated, on public assistance/disability benefits, and to suffer with addiction (Crawford 2013; Underwood 2013; van de Glind et al 2014). There is no single factor that, addressed in isolation, can guarantee the likelihood of persons with invisible disabilities exercising substantive citizenship; however, early intervention and the provision of a quality education have the potential to change the trajectory for children with invisible disabilities (Annamma

Morrison and Jackson 2014; Abidi Javed and Sharma 2014). Current discursive formations surrounding education, inclusion, public attitudes, and government funding/responsibilities impact the implementation of effective educational policies that marry the reality and the ideal for all Canadian children.

Receiving input from families affected by the delivery of inclusive education in Ontario, I expect to find that the negative experiences of those with invisible disabilities who struggle through the public-school system in Ontario are significant and follow them over time. In addition, I expect to find that inclusion is not implemented well in the Ontario public-school system. The issues with inclusion as a concept, from definition to implementation, will be documented in my literature review. It is very true that kids with invisible disabilities who do not receive an education that taps their potential are at risk of missing the opportunity to exercise substantive citizenship (Prince 2009). What that means in layperson's term is that, as adults, they don't have the social or academic skills to be independent, employed, married, homeowners, voters etc. In some cases, disability is so severe that independence is not possible. In many others, the potential is left untapped. Education is key to unlocking the potential of all children to exercise their rights in the province of Ontario.

Many of the studies on inclusion have been done from a purely theoretical standpoint, or from the point of view of the educational system itself (i.e., what is required to succeed as inclusive *teachers*). What is largely missing from this discussion is the perspective of the affected children and their families. Blum (2007, 2011) did address invisible disabilities from a feminist, mother-blame perspective; however, she did not give voice to specific information regarding the school experience of these families.

Pivak et al (2002) elicited parental opinions on inclusion, but this study only talked to the parents of children with visible disabilities. Burge et al. (2017) conducted a survey to assess adult perceptions of inclusive schooling for children with intellectual disabilities. Their results were interesting, as 42% of those polled supported special needs classrooms as opposed to inclusion, but they talked with adults who had no experience as a special needs parent. Tétreault et al. (2014) solicited information from parents of special needs children in Quebec. Their results were highly critical of inclusive schooling; however, this study was designed to assess the efficacy of a specific program in Quebec (the *Agreement for the complementarity of services between the health and social services network and the education network*) that is not implemented in Ontario. Therefore, it is impossible to draw direct comparisons. There are other studies that interview parents regarding how it feels to be a special needs parent, but schooling is one facet of that experience, not the focus of the studies (Neff and Faso 2014; DePape and Lindsay 2015; Collier Keefe and Hirrel 2015).

I am interested in focused, firsthand accounts of parents and children who experience inclusion in Ontario public-schools. Mom and dad may not know what “inclusion” is, but they can see their child struggling and bear witness to their pain; they receive umpteen calls from administrators to discuss behaviours or learning needs; they know the individual education plan is not working; they shake their head when asked if it is “ok” if their child sweeps the hallways during math class, because they are deemed too disruptive to other students. These personal experiences present the most accurate picture of the reality of inclusion, but they are nowhere to be found in the glossy public relations manuals presented by the province, nor the academic work on his topic. The affected

families themselves are the best messengers to document the fragmentation between the ideals of inclusion and the reality of Ontario's education system.

To give a brief description of my thesis layout, the document will be organized as follows: In chapter two, the literature review and theoretical underpinnings, I will unpack the concepts, ideas, and applied examples that elucidate why inclusion is problematic and improperly applied in Ontario public schools, as well as delving into the influence of inclusion on the exercise substantive citizenship. It is important to explore inclusion and citizenship at the grassroots level, to clarify the effect of the current 'inclusive' practices on children with invisible disabilities and their parents who are struggling with the implementation of inclusion policy. There is a plethora of theoretical literature on why inclusion as a concept and practice is problematic, much less so from the perspective of those who are affected by it. Michel Foucault's discourses on power, knowledge, neoliberalism, and bio-politics are the primary theoretical ideas behind my study. Neoliberalism, disability studies, advocacy, and political action will also be explored.

Chapter three will discuss methodology of the current study. Finally, the data will be unpacked in chapters four through six (results and discussion), where I will analyze outcomes and extrapolate on conclusions and further research ideas.

Chapter 2

Literature Review

Perspectives on Literature and Theory

“Fairness is not giving everyone the same thing. Fairness is giving each person what they need to succeed” (Unknown)

What are Invisible Disabilities and Just How Common are They?

Invisible disabilities are those that are hidden from public view; when you see someone with an invisible disability you may not immediately know that there is something ‘wrong’. Invisible disability is a catch all phrase that captures a wide range of hidden disabilities and challenges. Some examples of invisible disabilities that commonly affect school age children include, but are not limited to, high functioning autism spectrum disorder (ASD), attention deficit disorder with/without hyperactivity (ADD/ADHD), apraxia, dyspraxia, sensory processing disorder (SPD), anxiety, depression, oppositional defiant disorder (ODD), conduct disorders, learning disabilities, behaviour problems, and other developmental and psychiatric disorders (<https://www.disabled-world.com/disability/types/invisible/>). When an exceptionality is visible, it is likely, in contemporary Western society, that the necessary supports will be provided for the care and well-being of the disabled person. Invisible disabilities are more problematic; the reality of the disability can be difficult for others to recognize or acknowledge. It is often difficult to understand the cause of a problem, if evidence of it cannot be seen in a visible way (<https://www.disabled-world.com/disability/types/invisible/>). Thus, supports and

services may not be forthcoming, or they may be more difficult to access (Jahnukainen 2011).

Invisible disabilities are common amongst Canadian children. Statistics Canada has a haphazard practice of collecting statistics regarding the incidence of disabilities, especially disabilities affecting children (Strong-Boag 2012). There is no one statistic that represents the prevalence of invisible disabilities in Canada; it is necessary to search each potential disorder that is carried under the “invisible disability” umbrella. A piecemeal compilation of various sources, most of them decentralized academic studies, is required to paint an accurate picture of the prevalence of invisible disabilities. Further complicating the history of statistical analysis is the variability in definitions/ labelling of disorders, methods for diagnoses, and methods of reporting these disabilities. Meta-analyses are difficult when there is no historical consistency in identifying and defining invisible disorders (McKenzie et al 2016).

The prevalence of pervasive developmental disorders, including ASD, Rett syndrome, and Asperger syndrome (high functioning autism), is estimated to be between 27.5 and 70 per 10,000 children aged 1 to 14 years. Canadian government statistics regarding autism suggest that prevalence rates have increased 10 to 17 percent in recent years (Public Health 2009). A study on the incidence of autism in three Canadian provinces reported that the estimated average annual percent increases in prevalence of autism among children 2–14 years of age ranged from 9.7 % (95 % CI 7.8–11.6) to 14.6 % (95 % CI 11.3–18.0) (Ouellette-Kuntz et al. 2014). That is quite a substantive rise if 9.7–14% more kids are presenting each year with this disorder.

According to the Learning Disabilities Association of Canada (2017), one in 10 Canadian children has at least one form of learning disability (<https://www.ldac-acta.ca/>). Learning disabilities are among the fastest growing disorders in Canada that are not related to aging, increasing among Canadians aged 15 and over by almost 40 per cent between 2001 and 2006 (Statistics Canada 2006).

The final report of the Canadian Standing Senate Committee on Social Affairs, Science and Technology estimated that 15% of Canadian children and youth are affected by a mental disorder at any given time (Public Health 2009). Waddell et al. (2014) conducted a survey of international epidemiological studies and generalized to the Canadian population; according to their study, approximately 677,900 Canadian children between the ages of 4–17 were diagnosed with a mental disorder. The most widespread mental disabilities affecting Canadian children are ADHD, anxiety/depressive disorders, and conduct disorders. “Epidemiological studies and meta-analyses have reported that about 5% to 12% of school age children and adolescents experience ADHD” (Wu Ohinmaa and Veugelers 2016, 1). Waddell et al (2014) estimate that 134,500 kids were diagnosed with ADHD in 2014. Anxiety and depression, also known as internalizing disorder, were estimated to occur in 290,511 Canadian children and conduct disorders were estimated to occur in 113,300 children. These numbers regarding the prevalence of ASD, ADHD, internalizing and conduct disorders reflect the primary diagnosis of the children; however, co-morbidity is extremely common with many invisible disabilities. The invisible disabilities discussed above commonly occur with each other, and with a host of other hidden disorders such as sensory processing disorder, apraxia, dyspraxia,

sleep disorders, language disorders and (many) more (Helland et al 2014; Pfeiffer 2015; Mayes et al 2015; Gregory and Sadeh 2016).

Why are these statistics on incidence important? Because they demonstrate the incredible number of kids who have invisible disabilities, and how that number is on the rise. Whether this increase is because of better diagnostic tools, over-diagnoses, or an actual increase in cases is a matter of great debate. The bottom-line is that these children have been assessed and diagnosed, and they need to have access to an education that meets their needs and allows them to exercise substantive citizenship. To solve the puzzle of how the school system is failing children with invisible disabilities, it is first necessary to elucidate the nature of education for children with invisible disabilities; the fact that I can demonstrate the increasing number of students, and their increasing need, within the school system is of paramount importance as a building block to my study.

What is Inclusive Education?

The historical context for special education in Canada was rooted in segregation; children were frequently sent to live in residential schools if they exhibited ‘abnormal’ symptoms from deafness to “mental retardation.” Even when education for exceptional children was provided within a school setting, the children were kept in special classes, with no access to their able bodied/minded peers (Jahnukainen 2011). Special needs classrooms within public schools limited social and educational interaction between children who have special needs and their peers who do not. In recent years, hiding disabled kids away in “special” classes became socially and politically unacceptable. The difference between inclusion and special education is that inclusion is based on the premise that all children

can be instructed in the same class, using the same curriculum with accommodations provided to those who need them. Special education removes these kids to a different room with a resource teacher and a different curriculum and agenda that is more tailored to meet the needs of the students (Black-Hawkins Florian and Rouse 2007; Berg 2012). The move away from special education is based on human rights and the assumption that labelling and “dumbing down” curricula is unfair to children with exceptionalities (Lupart 1998). These concerns gradually saw the popularity of segregated classrooms decline.

How to educate children with special needs appropriately was taken up at the UNICEF Convention on the Rights of the Child, as well as the Convention on the Rights of Persons with Disabilities (unanimously affirmed by the UN in 1989 and 2006 respectively). Inclusive education was declared to be a right of every child (UNICEF 2007). It should be noted that, while my thesis focuses on inclusion as it pertains to the education of children with invisible disabilities, the ideology applies to all marginalized persons in the classroom setting. Race, sexuality, socio-economic status, gender—all forms of potential discrimination are included in this designation. There is also cross-over between different marginalized groups that can put some children at further risk (Lupart 1998). Inclusion is meant to equal the playing field for all these groups (UNICEF 2007; Government of Canada 2010). Canada was a signatory on both UN resolutions and has since directed the provinces (who have legislative purview over education) to codify inclusion as the guiding principle for education in our country. Therefore, inclusion is not just a preference in Canada, it is a legislated right for all children in this country.

But what is inclusion? This very basic question may seem pedantic; however, it is causing a conundrum for educators and legislators the world over. Inclusive pedagogy “is an approach to teaching and learning that supports teachers to respond to individual differences between learners, but avoids the marginalization that can occur when some students are treated differently” (Florian 2014, 289). This concept seems simple enough, in theory, but the implementation of inclusive pedagogy in a school setting has a multitude of meanings and applications. In its most basic form, inclusion can be understood as physically placing children with special needs in a “regular” classroom. Inclusion can also be defined in terms of meeting the needs of children with special needs within a typical classroom. Another possible application of inclusion is attempting to meet the social and educational needs of all students. Yet another possibility is viewing and treating the classroom as a community, that can “nurture the qualities of equity and care” between all children and adults within the classroom” (Goransson and Nilholm 2014, 270). These very different applications of inclusion stem from differences in what The Roeher Institute (2003) refers to as “access” and “support.”

Access is simply a having place within a typical classroom for an exceptionally needy child. In the Western world, most children with special needs have a place to go to school in a class with their able-bodied peers; special needs programs and classrooms no longer exist, all but 2% of children in Canada are educated within the average public-school classroom (Government of Canada 2010). Support, on the other hand, is much more problematic. Once children were re-routed from a special needs classroom to a “normal” classroom, budgets, teacher education, and curriculum design should also have been changed to support both the kids coming into the class, and the teachers who are

responsible for helping them learn. This is where the breakdown begins in the delivery of inclusive educational policy because the latter never happened (Roehrer Institute 2003). The adage “it takes a village to raise a child” would have been best applied (Gorranson & Nilholm 2014). The vision of inclusion as a community, where schools are well funded, and teachers are well trained to provide a classroom environment that is inclusive, encourages students to care for each other, and meets the social and educational needs of all children is the optimum implementation of this concept. In this configuration, access and support for each child would be considered and provided for. Gorranson and Nilholm (2014) conducted an extensive literature review to study the application of inclusion, and they only found one instance where the classroom as a community was successfully applied. That there are few empirical examples of this expansive definition of inclusion belies the fact that most pundits advocate for just such a learning environment as the ideal. One possible explanation for the split between reality and the expressed ideology may be that inclusion has been buttressed against “collective indifference,” a neoliberalist ideal whereby most people are so focused on what they need, that they become indifferent, at a policy and individual level, to what can be done to help others within the community—the village has been closed and it is every man, woman, child for him/herself (Moore & Slee 2012). Prince (2009) echoes these concerns, noting that there is ambivalence regarding the overall attitude towards disabled people in Canada. On the one hand, people espouse politically correct views about the rights of every person to equality, while on the other they feel that the responsibility for a solution to the lack of equality for persons with disabilities is the responsibility of the individuals (and their families) whom are affected by the systemic discrimination in the first place. “In a

society in which individualism is perhaps the main ideology, proposing an ideal in which the community is seen as a model does seem to amount to a challenge” (Goransson & Nilholm 2014, 276).

Inclusion is interpreted in many ways, across different countries, states/provinces, and even school boards (Florian 2014). Therefore, trying to find one concise and applied definition is very difficult. This confusion at the upper levels, where decision makers write policy, filters down to the classroom level because teachers are rarely prepared to develop an understanding of/plan for implementing inclusion in their classroom (MacFarlane & Woolfson 2013). The inability to establish a cohesive understanding of inclusion is rooted in different beliefs regarding what schools can and should accomplish (Goransson & Nilholm 2014). These decisions become even harder to make in a multicultural nation like Canada, where everyone’s’ ancestral past is different and therefore many different cultural expectations are at play in the decision-making process (Jahnukainen 2011).

Deciding what schools are responsible for providing introduces issues of power into this discussion. Who decides? It is not the research community, or even the educational community who make policy decisions; how inclusion is implemented within a country/state/province is a political decision. Changes require a shift in the political will of a region. As researchers, our role is to provide studies and academic dogma that shows why and how communities within the classroom can be established. Goransson & Nilholm (2014, 276-77) found a “scarcity of research that succeeds in establishing factors and/or interventions that increase levels of inclusion in schools and/or classrooms in relation to a specified definition of inclusion.” They recommend further research of this

vein must be undertaken if inclusion is to become anything more than an ideological construct.

To complicate matters further, inclusion was introduced to the school system at the same time as provincial testing. The testing affects everything from the school/board/city/countries reputation, to funding decisions (Florian 2014). One way to interpret this is to say that inclusion, which requires a community or collective approach has been pitted against the individualism and politicization of general testing. Teachers are put in untenable positions. They have limited resources and/or training regarding the education of children with exceptionalities. They are required to assimilate special needs kids into their classrooms, at the same time they need to have class wide results on standardized testing that demonstrate academic excellence (Florian 2014).

The current information on inclusion leads to more questions than answers. “The operative meaning of inclusion in reviews and empirical research should be much more clearly defined and ... new types of studies are needed” (Florian 2014, 286). It is unrealistic to expect the principles of inclusion to be fully realized if there is no cohesive definition of what it is, and how to implement it as best practice in public schools. Florian (2014) also points out that the implementation of inclusion often materializes as special education renamed. She makes the important point that “talk of ‘including’ can only be made by those occupying a position of privilege at the center. In so doing, they made it clear that by relying on what it sets out to dismantle, renaming special education practices as inclusive education inevitably colludes with rather than challenges the status quo” (287). This train of thought dovetails with the discussion of neoliberalism that will be addressed in future sections of this document.

What is the Official Ideology of Education for Exceptionally Needed Children in Ontario?

Education funding and policy are executed by the provinces and territories in Canada (Basu 2004). Although there are some over-arching principles that connect provincial policies, there is also incredible diversity in the implementation of education policy within the country (Lyons Thompson and Timmons 2016). In Ontario, neoliberalism has become the underlying ideology behind the delivery of healthcare, education and most other public policy departments. The so-called “common-sense revolution” in the early 1990’s cemented the intractability of this ideology (Rasu 2004). This revolution was “driven by a perceived need to improve the efficiency of the public sector while cutting costs and simultaneously by the need to increase educational standards, improve outcomes, and ensure accountability in order to remain globally competitive in a knowledge-based market economy” (Rasu 2004, 621). Although the faults found with education to that point were largely manufactured to sell the neoliberal agenda, the solutions appealed broadly to the population and have since become an integral principle in education policy in Ontario (Rasu 2004). While Ontario espouses inclusive rhetoric in their education policy, Thompson, Lyons, and Simmons (2015) note that there is considerable flux between the ideology and the delivery of inclusion in Ontario public-schools.

In the provincial document, *Equity and Inclusive Education in Ontario Schools: Guidelines for Policy Development and Implementation* (Government of Ontario 2014), the official policy implemented by school boards/schools in our province is described. At risk of some repetition, I think is worthwhile to itemize the policy, while keeping in mind

the points made in the previous section. An inclusive educational environment is described as “one in which all students, parents, and other members of the school community are welcomed and respected, and every student is supported and inspired to succeed in a culture of high expectations for learning” (Government of Ontario 2014, 5). To achieve this end, the policy focuses on three goals. First, the cooperation between the ministry, school boards, and schools is recognized as imperative to the successful delivery of inclusive education. Second, the ministry espouses the goal of delivering “an environment that is caring, safe, inclusive, and accepting of all” (Government of Ontario 2014, 7). Last, the ministry is committed to accountability and transparency and therefore will report to the public the success of their policies “based on established indicators” (Government of Ontario 2014, 7). The role of school boards is outlined, generally stating their responsibility to consult with parents, teachers, and experts in their region, the flexibility that they have been given to alter policy to reflect the needs of their student population, the power to disperse funds, and the expectation that the board will consult with lawyers and freedom of information professionals to ensure that they are meeting the standard of inclusion expected by the ministry. While the board reviews policy and makes changes as necessary, schools are responsible for implementing this policy.

The guiding principles are set out as follows:

Equity and inclusive education

- is a foundation of excellence; In a diverse society, equity is a fundamental requirement for educational excellence and high standards of student achievement.
- meets individual needs; Equity does not mean treating all students in the same way but, rather, responding to the individual needs of each student and providing the conditions and interventions needed to help him or her succeed
- identifies and eliminates barriers; All students are supported

equitably through the identification and removal of discriminatory barriers that limit their ability to achieve to their full potential.

- promotes a sense of belonging; Equity and inclusive education contribute to every student's sense of well-being
- involves the broad community; Effective and meaningful school community partnerships are an essential component of an equitable and inclusive education system.
- builds on and enhances previous and existing initiatives; Sound research and analysis of successful policy practices form the basis for the development and sharing of resources.
- is demonstrated throughout the system; The ministry, school boards, and schools will incorporate principles of equity and inclusive education throughout their policies, programs, and practices (Government of Ontario 2014, 15).

Finally, the ministry addresses curriculum policy by stating that the inclusion and equity will be considered in all review of curriculum. The delivery of information about indigenous peoples has already been changed to reflect a more diverse and culturally appropriate message. Content is periodically reviewed to ensure it is sensitive to the concerns of marginalized groups. "All curriculum documents are checked by academic experts to ensure that they reflect principles of equity and inclusive education" (Government of Ontario 2014, 24).

At numerous places within *Equity and Inclusive Education in Ontario Schools: Guidelines for Policy Development and Implementation*, there is reference to what school boards, schools and teachers are supposed to do to ensure that visions inclusion and equity are realized. For example, "All boards now have an equity and inclusive education policy in place and are *expected* to continue implementation to further embed the principles of equity and inclusive education into all aspects of their operations and learning environments" (17) or "Each board *may use its own* approved process and format for further policy development or revision" (16) or "discriminatory biases and systemic barriers to equity and inclusive education *should* be identified and addressed so

that students can see themselves represented in the curriculum, programs, culture, and teaching, administrative, and support staff of the school” (18). The italics in the above quotations are mine (I could use approximately 20–30 similar quotes to make this point), to highlight the language of direction from the province to school boards, schools etc. What is missing from this directive is a formulation to enforce and regulate the suggestions made throughout the piece.

This document adds legitimacy to the concerns noted in the previous section. The goals, practices, and principles stated are very general, with a lot of positive references to the rhetoric of inclusion, but no real substance on how to create environments that are inclusive, while meeting the social and academic needs of students in Ontario classrooms. Inclusion is espoused as the policy that will guide education; the provincial government sets its guidelines and determines the funding that each schoolboard will receive, the school board is responsible for following guidelines and dispersing the funds to each school, and schools are to use these funds to ensure that the delivery of education, at the classroom level, is inclusive, equitable, and meeting the academic needs of all students. This model for inclusion in Ontario puts a lot of pressure on those that do not have the power to make the decisions; allowing the ministry and school boards to hold the purse strings, while relying on schools and teachers to implement inclusion with very little training and support. But how are schools supposed to do so? How are these goals to be met? What are the steps to be followed to ensure inclusivity? Beyond being a supportive and creative environment, what is inclusion in Ontario schools? What are the “established indicators” of the success/failure of inclusion? What are the “academic experts” looking for to guarantee that the principles of inclusion are represented within curriculum design?

The nonexistent detail within this policy document lead to more questions than answers. This lack of specificity could be partly due to the definitional problems surrounding inclusion, or they could reflect that there is more of a commitment to attractive rhetoric than reality when it comes to implementing inclusion in Ontario schools.

Reality Check: Does the Implementation of Inclusion Mirror the Reality?

Ontario espouses inclusive educational rhetoric, as do all other provinces in Canada. The reality, however, is far from inclusive. The problems with implementing inclusion, from an ideological perspective have been discussed above, but to fully comprehend the issue, a glimpse into the Ontario classroom, and the Ontario family, is required. It may seem odd to look at the family before the classroom, but the truth is that a child's access to the necessary supports within the classroom is directly related to the geographical and socio-economic location of their families. Gallagher-Mackay and Kidder (2014) point out that the parental knowledge or ability to advocate for services from assessment to accommodations is dependent upon these factors. In rural or Northern areas of the province, many of these supports do not exist. Even in densely populated areas of the province, these services are either hard to access, have extremely long waiting lists, or are cost prohibitive (Gallagher-Mackay and Kidder 2014). In many cases, special services need to be sought out, which can be problematic, especially if parents are not aware of their existence. Statistics Canada (2006) noted that 35% of the parents of special needs kids have difficulty accessing the necessary supports for their child (<http://www.statcan.gc.ca/pub/81-004-x/2007001/9631-eng.htm#a>). Public Health (2009) points out that, although specialized treatment services exist for invisible illness, less than

one-quarter of children receive those services. The ‘People for Education’ parent hotline receives many calls from parents who “continue to struggle with seemingly intractable challenges to ensure that all children have a chance to learn up to their potential—with adequate, effective, and timely programs and services” (Gallagher-Mackay and Kidder 2014,1). The Canadian health and social systems (including education) are inadequate when it comes to access, support, education, and treatment for many types of invisible disabilities ([http://www. Invisible disability.ca/](http://www.InvisibleDisability.ca/)). Judy Lupart (1998) points out that the perpetuation of traditional attitudes regarding disability tends to place the responsibility for improving education and standard of living on the individual or their family. When one imagines extending this kind of pressure to other marginalized groups (women, people of colour, LGBT for example), the ridiculous nature of this belief becomes glaringly apparent. In 2018, it is certainly not acceptable to expect a woman to have to fight legally for her basic human rights—this expectation would be ludicrous—yet such is a prevailing attitude about persons with disabilities and their families.

In the classroom, it is somewhat harder to assess the reality of inclusion. There are many studies that note shortcomings in inclusive education (Hanvey 2002; The Roeher Inst. 2003; Black-Hawkins Florian and Rouse, 2007; Moore & Slee 2013; Florian 2014; Gorransson and Nilholm 2014), but far fewer that assess the policy from the perspective of teachers/principals who are actively engaged in the education of children with exceptional needs. Gallagher-Mackay and Kidder (2014) conducted a study that asked principals directly about the implementation of inclusion in their schools. A statistical analysis of available services supported the principals’ comments. The input from the principals is too vast to fully report here; however, their perspective on several key issues

is relevant. The authors note that “funding for special education has been a perennial problem in Ontario. Finding an appropriate method to provide funding that will address the wide variety of needs, programs and services across Ontario has proved difficult, if not impossible” (Gallagher-Mackay and Kidder 2014, 9). Many of the principal’s frustrations relate to funding; for example, many principals queried stated that it was impossible to meet the needs of special needs children without adequate support from educational assistants (EA’s). “Meeting the needs of all students is a challenge. We are told that EA’s are “generated” through behaviour or medical reasons. With so many students with academic needs and so little support personnel it is difficult to ensure everyone gets what they need” (Elementary School, Thames Valley DSB5; cited in Gallagher-Mackay and Kidder 2014, 3). Forty-four percent of the elementary school children whose IEP recommends assistive technology do not receive it. Principals cited identified cost, lack of equipment, and lack of EA’s/teachers trained to incorporate such devices into the classroom as causal reason for this deficit. Less than 2% of Canadian children with special needs are being educated outside the classroom; this causes stress to teachers who, per their principals, do not have the training (and therefor the comfort level) to instruct these children along with the rest of their pupils. Close to 50% of elementary school principals admitted to having asked parents to keep their special needs child at home for all or part of the day. Despite the legislation designed to ensure every child remains in school all day every day (unless unwell or otherwise excused), principals are also mandated to have a child removed from school if they are having an adverse effect on their classmates. In addition to walking this tightrope, many principals admitted

that they have sent kids home simply because they do not know what to do with them (Gallagher-Mackay and Kidder 2014).

Even getting children with exceptionalities assessed is problematic within the school system. Firstly, the child is not legally guaranteed accommodations if they do not go through the Identification Placement and Review Committee (IPRC) process. The province discourages schools from initiating this process, as it is costly, instead recommending the student get an independent education plan (IEP). Currently, 41% of the families whose children require special services at school go through the informal IEP process, and this number is steadily rising. The IEP is not legally binding, reducing the family's ability to insist on appropriate accommodations for their child, and it is completed by teachers, who often have no training or expertise in this venture. There is a 30-day window at the beginning of each year to complete IEP's, which puts a lot of pressure on teachers and further reduces the efficacy of a rushed document. In their exhaustive review, Gallagher-Mackay and Kidder (2014) found only 5 of Ontario's 72 school boards used IPRC's most of the time. The reason IEP's are preferred? As noted, the prohibitive cost to the province, as well as the waiting list for assessments within the province. Many principals have families who have been waiting for up to four years to have their child receive the necessary assessment to get a diagnosis for PDD's or learning disabilities. An assessment is a required element for an IPRC. A parent either needs to get a private assessment (at a cost of \$3,000–4,000) or wait. For those waiting, a 2013 school survey, showed 47% of elementary schools in the province have a cap on the number of assessments (two) that principals could recommend in a year (Gallagher-Mackay and Kidder, 2014). A telling quote sums up the reality of inclusions for Ontario principals in

this province: “Every other child is coming to the school with some type of need/diagnosis /label/ etc., and the parents are demanding support for their child. The school is not equipped to adequately provide service for all the students who need the help—but we do the best we can” (Elementary school, Simcoe Muskoka DSB; cited in Gallagher-Mackay and Kidder 2014, 11). Gallagher-Mackay and Kidder (2014) suggest that many of the problems cited by the principals in their study are not due to lack of knowledge, or lack desire to do better at the ground level, they are simply budget/funding related obstacles that cannot be solved by schools. Until the Ministry of Education allocates more funding to educating exceptional students, these shortcomings are likely to persist.

The perspective of principals is providing valuable insight into the problems of implementing the inclusive ideology legislated in Canada. Teachers are another source of important information. Sharma, Forlin, and Loreman (2008) and Sokal and Sharma (2014) conducted studies on the attitudes of teachers regarding inclusion in general, as well as their ability/training to instruct successfully in an inclusive classroom. These studies found that, for both pre/in-service teachers, the more education they had regarding how to teach in an inclusive classroom, and the more personal experiences these teachers had with special needs children, the better they felt about inclusive schooling. In many teacher’s colleges, there is only one course on teaching children with special needs. For those who graduated years ago, there were none. There is not enough in-service education either (Sharma, Forlin, and Loreman 2008). Teachers have become a poorly utilized resource. They are expected to deliver instruction that is inclusive, complete IEP’s, manage behavioural problems, and help kids with special instructional

needs/assistive learning technology, all with little to no training. Again, it seems that funding (in this case funding teacher education) is the key to improving inclusion in Ontario elementary schools. Lack of funding, lack of cohesive definitions, unrealistic expectations—the reasons that inclusion is not working need to be clarified, because inadequate education for special needs children has far-reaching effects on prosperity and citizenship in this country.

The Exercise of Substantive Citizenship

Citizenship, as a concept, has changed in recent years. There has been a move away from the belief that citizenship is individual, legal belongingness to a country, towards a focus on a broad scope of rights and freedoms. The belief that different groups deserve rights and freedoms is not new, that has been a hallmark of Western civilization for centuries. What has changed are the political, economic, and social conditions that make possible organized expression of the concerns of marginalized groups, and the manifestation of these concerns in the context of citizenship ‘rights’. Citizenship is viewed "as a social process through which individuals and social groups engage in claiming, expanding or losing rights" (Isis and Turner 2002, 4). Thus, citizenship has morphed into a more sociological concept where the focus “is less on legal rules and more on norms, practices, meanings, and identities" (Isis and Turner 2002, 4). The neo-liberal concept of citizenship has been ruled inadequate by those critical of the status quo for disabled citizens; the focus on individualism at all cost, intrinsic to neo-liberal thought, whereby both rules and rights are applied equally to every single person can no longer be accepted on its face if every individual is to recognize their substantive citizenship (Lister 2007). This

application of citizenship paints a portrait of equality through individual rights, without considering how that picture will look for those who are marginalized and cannot equally access the full contingent of rights and freedoms. Differentiated, substantive citizenship is now widely accepted, although its implementation remains problematic (Isis and Turner 2002; Lister 2007).

The freedom and ability to exercise rights to vote, be educated, be employed, and to have human rights protections are examples of substantive citizenship. If there are systemic barriers to the exercise of these rights, full and substantive citizenship is not possible (Prince 2009). Many Canadians take their citizenship rights for granted, living their daily lives without thinking of the freedoms and services they access with ease. Disabled persons are frequently unable to exercise substantive citizenship, and the consequences for Canada's economy, democracy, and the personal freedoms of disabled Canadians can be devastating (The Roeher Institute 2003; Cornwall and Schatten-Cohelo 2007; Prince 2009; UNICEF 2009; Fritsch 2015). Persons with disabilities are under-represented in the labour force. Per the Council for Canadians with Disabilities (2013), the unemployment rate for disabled persons is 10.4%, as compared to 6.8% in the non-disabled population. Battle (2002) noted that 44% of the disabled population in Canada is not employed, a statistic that has remained static. Disabled persons are over-represented when it comes to living in poverty; 10.6% of non-disabled Canadians live in poverty, while 14.4% of disabled persons live in poverty in this country. Crawford (2013) reported that persons with disabilities are twice as likely to live in poverty in Canada. Some 38.4% Canadians with disabilities who live in poverty had not graduated from high school compared with 24.6% of their counterparts without disabilities ([Council for Canadians](#)

[with Disabilities, 2013](#)). High school completion rates for disabled persons is 80%, while able-bodied people have a completion rate of over 90%. University degrees are earned by 23% of non-disabled persons, while those with a disability earn a university degree only 14% of the time (<https://www.rickhansen.com/Our-Work/School-Program/Resources/Disability-statistics>). Voting likelihood increases with both education and employment; any group that experiences barriers in those areas is less likely to vote. This fact, coupled with issues of accessibility, make it less likely for disabled persons to exercise their right to vote (Uppal and LaRochelle-Côté 2012). Voting is power, in that it gives people the right to advocate for a person/party that best addresses their concerns. Those who are less likely to vote are also less likely to organize and fight for their rights in the various democratic venues available for such political action. Collective action shapes public policy, therefor one of the most effective ways to influence policy and practice that affects disabled persons is to get involved in politics at this level (Prince 2009). Discussions of citizenship go far beyond legal membership in your country of residence and affect the disabled (and other marginalized groups) at every level of substantive membership in their country of residence.

Questions of citizenship are relevant to the discussion of inclusion and the education rights of children with special needs on several levels. First, once the concept has been unpacked to reveal the validity and extent of substantive ‘lived’ citizenship, it becomes very easy to see gaps in the system whereby children with exceptionalities are not being treated with equality in Ontario public schools. Second, within the context of this discussion, equal opportunity education for all Canadian children is clearly a right. It is not a preference, or an ideological principle that plays well in a politically correct

dialogue. It is a right; codified internationally, legislated within our province. If one accepts that these two statements are true, then it is logical to question how the reality of inclusive education in Ontario can be so different from the textual version espoused in public policy documents. Last, the relationship between education, employment, and voting highlights the necessity to provide a quality education to all Canadians so they can exercise their rights, not only to vote, but to live a full, complete, inclusive life.

Changing Minds, Changing Policy

Invisible disabilities are frequently harder to see than visible disabilities, especially in the case of high functioning children (particularly those on the autism spectrum). Children with ADHD, high functioning ASD, learning disabilities, and behaviour disorders (for example) have numerous struggles in school, which stem from both social and learning issues, leading to frustration and behavioural problems that can cause them stress and exacerbate their core diagnoses (Ambler, Eiders and Gregory 2015; McKenna et al 2015; Seymour Macatee and Chronis-Tuscano 2016;). These issues can also frustrate and overwhelm teachers (Sokal and Sharma 2014). What these kids also have is potential. If a delivery system for education was designed and funded appropriately, these kids could learn to read and do arithmetic. They could go on to college or university and become full and productive members of our society. In other words, they could exercise substantive citizenship.

Currently, the Ontario Ministry of Education espouses inclusion as the ideological basis for delivering education in our province. But the “inclusion” that gets delivered in the Ontario classroom is not meshing with the ideology that inspires it. The query into

“why not” is fraught with complicated and, as yet, unanswered questions. The problem is not lack of knowledge, private schools such as Quintillian Private School, where my son attends, have been employing methods that work for many years with significantly improved outcomes for students with invisible disabilities (McDonnell 2016). There are issues of funding, teacher education, hiring practices, allocation of resources, conflicting agendas, and lack of concise policy that accurately establish what inclusion is and how to implement it in the public-school system. Lack of political will to address these issues and make the changes necessary to ensure that children with exceptional needs receive the same caliber of education as their able-bodied peers compounds these issues.

Inclusive education is essentially a political issue. Those who have the power to make decisions at the highest levels need to be educated about what is required, where the system breaks down, how this break down affects children, families, teachers, and other invested, ground level, parties. How best to achieve this end? The answer to this question is also far from simple; as the issue is political, so must be the solution. Many disenfranchised groups have achieved parity between texts that purport to represent them and the daily reality of their lives. For example, women, people of colour, and more recently, the LGBTQ community, have paved the way for other groups to become a political force that activates change (Prince 2009). The key to changing how children with exceptionalities are treated within the Ontario school system is also organized, political action. Prince (2009) points out that before political activism can become relevant, the issues need to be clear, pertinent, and well researched. Before discussing disability activism as it relates to inclusion in Ontario’s public schools, it is imperative to understand some over-arching trends and practices in our society that affect attitudes,

practices, and abilities to organize and advocate for change. The most important of these is the influence of neoliberalism and global capitalism.

Neoliberalism: Fabricating Social Freedom

Neoliberalism is often-contradictory, and it is complex. Is it an ideology? A theory? A political/social practice? In fact, neoliberalism is all of these and more. It is often hard to establish where the ideology and the practice diverge. Beck (2002, 122) characterizes neoliberalism as a “nebulous phenomena ... an ideological ‘thought virus’” (cited in Peck and Tickell 2002, 281). This description is particularly apt. Neoliberalism has moved beyond an ideological movement and invaded every corner of the economic and social world, as well as the human psyche, within capitalist countries. Ironically, such rigid social control encourages citizens to believe themselves to be acting with freedom (Lemke 2010); because there is no totalitarian dictator using fear and force to control their actions, citizens unknowingly become the agents for the implementation of neoliberal control.

Disabled persons are, effectively, “othered” in mainstream neoliberal thought. Based on their reduced ability to produce and consume commodities, disabled persons become dependent on state-sponsored resources. Dependence of any sort is frowned upon in neoliberal rhetoric. Given that many disabled persons require extra support to realize substantive citizenship, this “other” or “deviant” status automatically assigned those who have a reduced ability to participate in capitalism is problematic. Othering negatively impacts disabled persons ability to exercise rights and freedoms, advocate for change,

and thrive in mainstream society. Thus, the tenants of neoliberal thought, as well as the relationship between ableism and neoliberalism must be examined closely.

The Modern Historical Context of Neo-liberalization

How did an ideology assume so much power over the Western (and more recently the pan-Asian) world? The logical place to look for answers is with the birth of neoliberal ideas themselves. The Chicago School of Economics began theorizing about neoliberal ideals in the 1970s as a response to Keynesianism. Keynesianism took root in the post-war West and embraced the notion that the state is a caretaker of its citizens. Social programs, education, health care, and other government-funded programs invested in citizens because they were viewed in an almost parental way; people who were healthy and well cared for were a happier and more productive population. Keynesianism built citizens expectations to be provided certain benefits from their government; individual roles could be reduced to becoming a recipient of government benefits (Palley 2004). The economy, like most other institutions, was governed by Federal regulations designed, in theory, to facilitate growth and economic stability. Keynesianism managed the economy based on the principle of aggregate demand. “Aggregate demand is the total level of demand for goods and services in an economy. Keynesians believe that firms produce on the basis of their expectations of the level of aggregate demand and that the level of aggregate demand thus determines the overall level of economic activity” (Palley 2004, 2).

Conservative groups objected very strongly to the ideology and agenda of Keynesian policy makers. The social programs provided by the state were expensive, the

emphasis on aggregate demand, with no attention being paid to its interaction with production conditions were problematic, and excessive regulations, in the opinion of conservative thinkers, limited the free-market economy. While economists developed ideas contrary to those of the so-called “welfare state,” Keynesianism developed an identity crisis from within. This crisis was partly in reaction to poorly handled current events/economic crises of the time (for example Vietnam War, OPEC crisis), in addition to “the intellectual divisions of Keynesianism and its failure to develop public understandings of the economy that could compete with the neoliberal rhetoric of “free markets” (Palley 2004, 2).

While Keynesianism was beset with internal and economic problems, neoliberalism as a widely-implemented government policy, stemmed from more than a push-back against this economic policy. In *The Crisis of Democracy*, Crozier et al. (1975) posit that certain segments of society, previously docile and easy to control, were becoming both problematic and less able to service capital. In a time of increased social protests, social upheaval, and radical new ideas, it became apparent that a mode of governance to control this population, and to protect the financial interests of “big business” was needed. Neoliberalism fit this bill and those with vested interests in social and economic governance pushed it to the forefront of government practices. But the move to neoliberalism was never presented as a way to control the populace; that would have been a hard-sell at any point in history. Rather, Keynesianism’s failure was touted as the inspiration for the extensive and fundamental changes (Davies and Bansel 2007).

Neoliberalism began in the 1970s as a “utopian intellectual movement” (Peck and Tickell 2004, 380). In the 1980s, Ronald Reagan and Margaret Thatcher, influenced by

the conservative rhetoric cited above, employed the economic theories of neoliberalism politically, drastically changing Western economic and social conditions. Government policies began disassembling social programs and regulations, in favour of implementing a free-wheeling market economy. Keeping in mind that political transparency was not a priority, Bronwyn Davies and Peter Banzel note that the “tactics of government through which [the implementation of neoliberalism] is achieved are generally not made visible or analyzable to the subjects regulated by those practices” (2007, 251). This point is very important to the further discussions of neoliberalism within this thesis.

Jamie Peck and Adam Tickell (2002) describe the initial phase of neoliberal policy as “roll-back” neoliberalism, which entails the widespread trend to defund and dismantle Keynesian social and economic programs in the Western world. Once Keynesian institutions had been effectively condemned within the political sphere, “roll-out” neoliberalism was entrenched. Roll-out policies introduced organized neoliberal policies of governance, regulation, and statehood. Therefore, the welfare state would cease to exist, to be replaced by individualistic, free-market economies.

Free markets and capitalism are at the heart of neoliberalism. To allow capitalism to function as it should, neoliberal policy recommendations include “deregulation of business, privatization of public activities and assets, elimination of or cutbacks in social welfare programs, and reduction of taxes on businesses and the investing class” (Kotz 2002, 65; cited in Jones and Calafell 2012, 2). As opposed to viewing the populace as a collective group in need of government regulation and support, neoliberalism places responsibility for success on the individual. Neoliberal theories assume that “the market ensures that factors of production are paid what they are worth, obviating the need for

institutions of social protection and trade unions. Indeed, institutions of social protection can lower social well-being and cause unemployment by interfering with the market process” (Palley 2004, 3). As an economic theory, neoliberalism is relatively straightforward. Its influence supersedes the economic sphere, however, and this relationship is far more complex and anything but simple.

Neoliberalism: Influences Beyond the Economy

Neoliberalism represents an economic policy shift; however, consequences of the internalization of neoliberal dogma affect a plethora of policies, practices, and individual beliefs/responsibilities that over-reach the economic domain and alter social, political, and individual life for millions of Western citizens. “Through discourses of inevitability and globalization, and through the technology of choice, responsibilized individuals have been persuaded to willingly take over responsibility for areas of care that were previously the responsibility of government” (Davies and Bansel 2007, 251).

It seems counter-intuitive for a populace to accept such drastic changes and embrace an ideology such as neoliberalism; however, to implement policies that might be unpopular in their entirety, governments used what Sklar (1980) called “piecemeal functionalism.” Instead of offering up the new policies in their entirety, piecemeal functionalism breaks them into smaller, more palatable, policy. By doing so, the overall policy goals are obscured, thus reducing in-depth policy analysis and/or active resistance by the populace. Therefore, the government can “produc[e] the illusion of each institution inventing the processes for itself, voluntarily taking neoliberal strategies up in the interests of competing in both the local and global market as well as competing for

increasingly scarce government funding” (Davies and Bansel 2007, 251). This logic applies to economic and social policies, as well as to the production of individual beliefs. Because public and private lives have been conflated in terms of the individualistic, free-market economy, neoliberalism creates a pervasive mind-set that far exceeds its origins as an economic policy. “Through...the installation of moral absolutes, democratic debate and discussion are obviated, rendering a kind of moral-economic totalitarianism” (Davies and Bansel 2007, 251). Through these tactics, the neoliberal citizen was born.

Passivity was the trademark of the welfare state citizen; the neoliberal citizen is “the autonomous ‘active’ citizen with rights, duties, obligations and expectations—the citizen as active entrepreneur of the self; the citizen as morally superior” (Davies and Bansel 2007, 252). This new citizenry capitalizes upon human existence by embracing free-market principles as a moral/economic mantra and rejecting communal accountability for the disenfranchised, marginalized populations within its ranks (Lemke 2010). This is not to imply that free-market principles came into play with the rise of neoliberalism; these principles have always been an integral part of capitalism. Their implementation within neoliberalism is amplified and the ideas are enshrined to promulgate a vision of society where production and consumption are hallmarks of citizenship and dependence and/or deviance are delineated as universal negatives (Davies and Bansel 2007).

A final note about the generalities of neoliberalism: neoliberals do not like to be referred to as neoliberals. Capitalists, conservatives, free-market economists, fiscal conservatives, neo-conservatives, are all labels worn with pride. Strangely, “neoliberal” is not a desirable moniker (Venugopal 2015). When I began my journey to understand

neoliberalism, I wondered at my lack of familiarity with it as a concept. It seems to me that invisibility is not a coincidence; trying to slip beneath the radar and convince the “regular joes” of the world that they are free, independent thinkers is a hallmark of neoliberal strategy. I recall wondering who the “neoliberals” were? I still wonder, as the ideology surpasses political affiliation, ethnicity, religion, etc. Yes, the political right wing is most commonly associated with neoliberalism; however, the policies and rhetoric have outlasted liberal and conservative regimes. One line that does not appear to get crossed within neoliberal policies is class. Economic prosperity is a common goal amongst all citizens, but the policies from the top favour the very rich, regardless of the political party in power. To further the discourse about neoliberalism and lay the groundwork for its influence upon disability activism, Michel Foucault’s ideas are particularly relevant. In the next section, Foucault’s ideas, as they feed this discussion, will be unpacked.

What Does Foucault Have to Say?

In *The Birth of Bio-Politics*, a series of lectures given in 1978–79 at the College de France, Michel Foucault offers a discourse on neoliberalism. The definition in the previous section of this paper is in keeping with Foucauldian thought. I deign to be repetitive; however, I would like to highlight briefly several important Foucauldian ideas regarding what neoliberalism is, before entering a discussion on several themes common within Foucauldianism (power, knowledge, and governmentality) as they relate to neoliberalism and disability activism. Foucault (2010) posited that the delineation between the economic and the social is ignored or omitted in neoliberal practice.

Systematic economic interpretations are super-imposed on the social domain. There is no authoritarian, violent regime pushing these changes; the populace believes that they, using their rights and responsibilities, have chosen the ideology and policies themselves. “To the extent that the individualized subject of choice understands itself as free, and the choices of government are based on moral absolutes and on inevitabilities, the visibility of the workings of government is able to be significantly reduced” (Foucault 2010, 193). In this way, neoliberalist factions proceed with their agenda without employing obvious control mechanisms. Citizens are expected to be rational actors who maximize a free-market economy in their professional and personal lives (Foucault, 2010).

One cannot discuss Foucault without understanding several important concepts that he continuously references as they relate to neoliberalism. The first of these is power; who has power and how they exercise it, is relevant to any discussion within the social sciences. Foucault (2010) is not interested in power struggles, as much as he is in how power is exercised and what this means for the relationship between the citizen and the state. “Foucault argued ... that power is not something that is exchanged, given, or taken back, but rather is exercised and exists only in action” (Tremain 2015, 4). When questioning political philosophy, it is pertinent for Foucault to question how power is exercised in a specific context/era.

Neoliberalism has a particularly interesting power dynamic, because powerplays within neoliberalism are cloaked in invisibility. In *Power and Knowledge*, Foucault (1980) discussed the exercise of power using the spatial analogy of prison structures. This is a perfect example of disciplinary power; making exercises of power more efficient, invisible, and complete. In an historical context, a prison was a dank, dark dwelling; a

windowless dungeon with stale air and no sunshine. Inmates knew from their accommodations that they were being punished; their spirits were expected to be broken by the horror of their lodgings. Foucault uses the utopian ideal of Bentham's Panopticon to demonstrate a different way that spatial design effects power dynamics. In the Panopticon, cells are more spacious and above ground, with windows facing the guard towers, as well as the outdoors. An inmate has the illusion of a brighter, more hospitable cell; a hope that those in power have considered their needs in the spatial elements of institutional design. The cell has actually been designed to give the inmate less freedom than the dungeon like cells; the guards in the tower can see every movement and control every situation with greater ease due to the increased visibility. Per Foucault, "Visibility is a trap" (2012, 200). Although there are few examples in which the Panopticon has been built to Bentham's exact specifications, his ideas influenced the spatial exercise of power in institutional settings around the world. In fact, this phenomenon, which Foucault called "isolating visibility" (1980, 147), is yet in play in prisons, military establishments, government institutions, and schools. The Panopticon example speaks to the way neoliberalism exercises power in general; rather than ruling through overt force and darkness, power is applied through light and deception.

Power seems a simple concept in the distant past. Royalty and aristocrats exercised power through customs and practices that had been in play for generations (for example, feudalism). As social constructs began to change, and revolutions toppled the power of kings, power began to change as well. "A form of power comes into being that begins to exercise itself through social production and social service ... it becomes a matter of obtaining productive services from individuals in their concrete lives" (Foucault

1980, 125). This process can be tied directly to neoliberalism, because the power exercised in its name is intrinsically tied to one's ability to be an economic producer/consumer. Thus, modern day conceptions of power are many layered and complicated, both by the different levels of ability to produce and the consequences thereof implemented by the government.

Foucault wrote extensively on struggles to attain or exercise power. He notes that the struggles aren't really between this group, or that, but rather assaults on a method/practice of power. "This form of power that applies itself to immediate everyday life categorizes the individual, marks him by his own individuality, attaches him to his own identity, imposes a law of truth on him that he must recognize, and others have to recognize in him. It is a form of power that makes individuals subjects" (Foucault 2000, 331). From a neoliberal perspective, this is an accurate summary of the ways in which the neoliberal state subjectifies its populace; citizens are expected to be producers, consumers, active in politics, the exercisers of various 'rights' given them by the government. This technique of power is the fuel by which neoliberalism functions and exercises power over capitalist economies/countries. Per Foucault: "The individual is the product of power" (1984, xii). Power both controls the populace and functions through their thoughts and actions.

One final aspect of power that I feel relevant to a discussion of Foucault and neoliberalism is power and the body. Foucault (1980, 2012) speaks of Bio-power (power the state exercises over the body) and its relation to bio-politics (when governance of the populace is achieved via bio-power). Just as the move away from monarchies changed the way power became a social commodity, it also changed the power relations between

state and body. “Sulpice” (torture to control the body) is replaced by “asepsis” (state control over sickness, degenerate behaviour, physical/mental “other”ness) (Foucault, 2012). The state advocates a clean, healthy, morally acceptable ideal, and takes steps to see that the populace embraces state priorities (Foucault, 1980). Behaviour that is criminal, degenerate, sexually inappropriate, or inexplicable (given knowledge available in certain eras) is either punished, sanitized, or institutionalized. For Foucault, social constructs are 100 percent subjective, based on the ideology behind the exercise of power at any given time. For example, in ancient Greek and Roman cultures, sexual relations between same gender couples is considered commonplace, yet stricter (semi)modern mores regarding sexuality sent this behaviour “into the closet.” Homosexuality, as we define it today, is a construct that has been created according to era-specific norms and mores. The same behaviour (male sexual relationships) is constructed in very different ways depending on the power dynamics of the time. “Meaning and meaningful practice ... is constructed within discourse” (Hall 2001, 73).

This point is very important in the context of this paper, because neoliberalism discourages any type of “other” that cannot optimize their own consumption or production of market goods. Persons with disabilities do not possess the opportunity to maximize either, therefore neoliberal power brokers don’t invest resources in these “broken” bodies. Keynesian politics, on the other hand, attempted to take care of those who struggle to help themselves. This point, regarding power and the body, and power in general is pertinent; constructs are created once we attach meaning to them; the same construct with different interpretations has different social/power ramifications. For

Foucault (1980), subjects' perceptions of power (or anything else for that matter) is what has the power to transform the social, structural reality in which they live.

A secondary concept that goes hand in hand with power in a Foucauldian context is that of knowledge. Knowledge is used to justify human action; targeting which knowledge ascends to popularity and general acceptance is an exercise of power. "Knowledge [is] inextricably enmeshed in relations of power because it [is] always being applied to the regulation of social conduct" (Hall 2001, 75). Knowledge is a tool to control and normalize the behaviour of others. Foucault tried to make evident "constant articulation of power on knowledge and of knowledge on power," especially with respect to the subject. Power—that is, its exercise—he argued, perpetually creates knowledge and knowledge constantly induces effects of power" (Tremain 2015, 7)

Foucault often used spatial terms to discuss knowledge (i.e. region, domain, implantation) because he thought that knowledge considered in the context of spatiality made it possible to clarify how "knowledge functions as a form of power and helps to disseminate the effects of power" (Foucault 1980, 69). Foucault suggested that an exclusively temporal analysis of knowledge/power would lead to the development of a "collective consciousness as the scene of events" (1980, 69). Spatial analysis allows for precise identification of the points at which change occurs in discourses of knowledge and power. Foucault's discourses on knowledge, and the spatial relationship between knowledge and power, pertains to neoliberalism because it allows for connections to be made between how a remote economic theory became the dominant discourse in capitalist societies for the last 30 years. Using strategies previously discussed, such as piecemeal functionalism, those in power managed to dupe the populace into embracing

their beliefs and policies. Conservatism took sway after a long period of liberal Keynesianism, and policies previously known only in economic terms were suddenly accepted “knowledge” in a social and public policy context. It is not a coincidence that schools and public service organizations were the first to embrace neoliberal ideation (Davies and Bansel 2007); this was a deliberate move by those in power to exercise control over the spread of knowledge, to make facts out of rhetoric. “The key feature of the neo-liberal rationality is the congruence it endeavours to achieve between a responsible and moral individual and an economic-rational actor” (Lemke 2010, 201). This is accomplished via the promulgation of knowledge by the powerful to influence the citizen.

Finally, it is necessary to discuss Foucault and governmentality. In a casual context, governmentality refers to a central governing body and the implementation of their policies. Foucault used this term differently; government does not “refer only to political structures or to the management of states” but also styles “the way in which the conduct of individuals or of groups might be directed” (2000, 341). Rather than regarding regimes as static institutions, Foucault described it as an interplay between the government and the governed; a co-dependent dichotomy whereby both groups depend on each other for survival. The government is tasked with managing citizens behaviour (primarily to achieve their own ends), and citizens with governing the behaviour of themselves, their families etc., in accordance with governmental directives, subtly enforced in bits and pieces, and internalized by citizens as beneficial and empowering. Normalcy is embraced as the new “means through which to identify subjects and to make them identify themselves in order to make them governable” (Tremain 2015, 7). Thus,

deviation from the norm, from the perspective of those who exercise power, is equated with an inability to govern (control). “All in all, in his history of governmentality Foucault endeavours to show how the modern sovereign state and the modern autonomous individual co-determine each other’s emergence” (Lemke 2007, 191). New discourses are introduced with to “structure the possible field of action of others” (Foucault 2000, 341). These discourses are internalized by citizens and projected as the new standard/ideal. Thus “newly appropriate and appropriated subjects of the new social order” (Lemke 2007, 248) are born through a combination of power, knowledge, and governmentality.

Neoliberalism and Disability Activism

This is not the last we shall hear from Foucault, but, having discussed the foundations, I will switch gears a bit and focus on neoliberalism as it pertains to disability activism and the construction of the “other.” The disabled have been “othered” long before neoliberalism became the governing rationale in the Western world. Disability has been assumed to be a medically predetermined condition; those with an affliction, disease, or deficit are assumed to be damaged goods (Strong-Boag 2010). The word itself “disability” evokes a lack of abilities, an individual who is sick in some way and requiring medical intervention. The disabled are contrasted with the able bodied ideal and found wanting (Fritsch 2015). In response to this impairment, governments, through charity, programming, or incarceration, exerted their power over the bodies of disabled citizens. Foucault (1980) noted the carceral power of the government to treat or institutionalize people who did not conform to societies ideal. Foucault coined the term

heterotopia, to describe physical spaces where deviant, “othered” groups are excluded from society (Johnson 2016). He was referencing prisons, rest homes, and asylums; however, his thoughts can be extended to include the more ephemeral, non-physical spaces whereby deviant groups are categorized as a unit and pushed into boxes that limit their rights to exercise substantive citizenship and equality with their able-bodied peers (Fritsch 2015). The “space” allotted to the disabled by neoliberal governments is that of a dysfunctional “other.” The disabled are imagined as a medically unfit, undesirable contingent of society. While, in many cases, medicine can (and should) help those who have physical/mental impairment, the disabled community, in general, are more than their impairments. “When disability is taken as a simplified, biological, and undesirable “monolithic fact of the body,” what disability really is and really can do is delimited by the very historical configurations of knowledge/power that depoliticize how disability came to be naturalized as such in the first place” (Fritsch 2013, 48).

It is interesting to note that, as neoliberalism gained influence over the last three decades, the medicinal view of disability, whereby the disabled were to be pitied, helped, and fixed by authoritative, state sponsored organizations, transformed into a social/rights model of disability (VanHala 2014). Instead of being the recipients of charity, the social model advocates for the disabled individual making their own decisions. Disabled people wanted their own voice in the policy making that pertained to disability programs. Certain rights and obligations were internalized by those with disabilities, and those became the guiding priorities for disabled life and programming (VanHala 2010). Disability activists who support the social model made great strides in improving physical accessibility and altering rhetoric to be more inclusive. If applying Foucauldian

perspectives to this phase of disability activism, however, they did so by buying in to the neoliberal imagining of disability theory. The disabled are yet “othered” and undesirable by government practice, giving rise to the illusion that impairments are pre-determined and natural, an idea that came from the government so that it could marginalize a non-productive (and therefore deviant) group (Tremain 2015).

Anyone who cannot produce/consume to support a free-market economy is considered “other than” a good neoliberal citizen. Many disabled persons do not meet the *métier* of worthy neoliberal subjects. Per Kelly Fritsch, “the neoliberal hegemonic social imagination both works to curtail who is considered desirable and informs the production of a good, individualized neoliberal subject that limits disabled and able-bodied people alike” (2015, 45). This practice cements the undesirability of disability in any form, so much so that there is speculation that many people would rather be dead than be disabled or be saddled with a disabled child (Kafer 2013; Fritsch 2015). Within the social model, changes in the reality of life for the disabled did change for the better, however, there is no obligation for the state to provide ‘charity’ or specialized programming. Rather, the individual (or their family) is expected to figure out how to help themselves. This lack of state assistance is combined with an environment that discourages activism for change. Of course, the disabled have ‘rights’, to disability pensions, tax credits etc. (VanHala 2010), but these investments by the state are minimal and leave the affected person living a subsistence lifestyle with little hope for improvement because they can’t compete in the free-market economy as well as their able-bodied peers (Fritsch 2015). According to disability theorist Alison Kafer, this amounts to “an ableist failure of imagination” (2013, 4). While access and inclusion have become the pervading rhetoric in the social model,

attitudes towards disability persist in being negative and unfavourable; ‘other’ regardless of context or practice.

Framing disability using a medicinal or social/rights model illustrates that societal power dynamics create the discourse around disability. As Foucault would note, disability is a social construct in the same way that (for example) homosexuality is. The discourse that is popular at a given moment in history sets the parameters and consequences of disability. A person who limps, or has learning disabilities, mobility issues etc. presents with the same physical reality in any era; yet social constructs determine labels, policies, and guiding principles for the way such impairments are handled. “Disability ... is given meaning through the neoliberal hegemonic social imagination that defines disabled people as unworthy, inadequate, and dependent, while naturalizing disability as excessive, contaminated, indicative of helplessness, pitiable, deviant, tragic, and inferior” (Fritsch 2015 48).

One might think that the description above would cause consternation and organized resistance amongst the disability community themselves. It is true that some members of the community fight against such monikers; however, a great many more have fallen into the neoliberal trap of internalizing such ideas about themselves and others like them. That is not to say that ableism is a new or strictly neoliberal phenomenon; rather, the type and ferocity of ableism is amplified within neoliberal constructs (Fritsch 2015). Power relationships within neoliberalism are effective because “individuals ... have been seduced by their own perceived powers of freedom and have, at the same time, let go of significant collective powers ... individual subjects have thus welcomed the increasing individualism as a sign of their freedom and, at the same time,

institutions have increased competition, responsabilization, and the transfer of risk from the state to individuals” (Davies and Bansel 2007, 259). Disabled citizens are no exception; although their individualization remains problematic, their buy-in to ideas of state versus individual responsibility is not (Fritsch 2015). The disabled internalize the “other” status and associate it with certain rights and responsibilities that go hand and hand with it. Accessibility, tax credits, and disability pensions are accepted and seen as the rights for the disabled group (Fritsch 2015; VanHala 2014). The acceptance of such things precludes fighting to change the status given by neoliberalism, because the disabled community is utilizing the “largesse” provided for them through the system. It is a form of institutional bribery to appease a disadvantaged group with minimal rights and benefits, primarily to buy their silence and passivity regarding the possibility of improving those rights/benefits in the future. Silence and passivity are the antipathy of organized advocacy. The tendency to shy away from collective action and overt questioning of the government cements the status quo for disabled people, just as it does for the able-bodied. When Foucault (1980) focused on disability, he queried how the disabled are materially constituted in a gradual and progressive process to embrace, as their own, a definition of themselves assigned by the state. “An argument about disability that takes Foucault’s approach would be concerned to show that there is indeed a causal relation between impairment and disability, and it is precisely this: the category of impairment emerged and, in many respects, persists in order to legitimize the governmental practices that generated it in the first place” (Tremain 2015, 9). This creates a self-perpetuating cycle whereby the government sets the tone and

simultaneously ensures it is embraced by the community it affects, regardless of whether the policies and ideas are in that community's best interests.

What kind of relationship between disabled citizen and neoliberal state does this cycle foster? The disabled embrace their "rights" as assigned by the government. If, as expected, disabled citizens accept the "rights" ceded them by neoliberal policy, they reinforce the neoliberal idea of them as needy, dependent, and undesirable (Fritsch 2015). Worse still, the status quo makes it increasingly difficult for disabled persons to exercise substantive citizenship. Rather than merely legalized status in a country, substantive citizenship implies the ability to access cultural, social, and economic elements that are implied benefits of citizenship (Prince 2009). "Canadians with disabilities are absent citizens. Compared to persons without disabilities, persons with disabilities experience significant cultural, material, and political disadvantages" (Prince 2009, 4). If one is "absent," it becomes even more difficult to access equal rights and advocate for oneself in the face of incredibly bad odds. Neoliberalism functions under the premise that there is no need for organized resistance; or at least the idea that the subjects shouldn't be able to identify this need (Tremain 2015). The reality of the interplay between government and the disabled citizen may not be remarkably different than that of the relationship with the able bodied; neoliberalism exercises power in a universally deceptive and secretive way for all; however, the quality of life and citizenship between the two groups is remarkably skewed. The disabled struggle more economically; they are less likely to finish high school and/or university, to be gainfully employed, to go to a community event, to vote, or to organize to advocate for improvements to their lot in life (Prince 2009; Kelly 2013).

To suggest ways in which the quality of life can change for disabled people, it is necessary to look at how the disabled are defined. There is a tendency to address this group as a homogeneous entity, but the disabled, like any other group, are heterogeneous; vibrant with differences (Prince 2004, 2009; Kelly 2013). Disabled people are feminists, persons of colour, indigenous, gay, straight—innumerable intersections change the fabric of the group. There are also many ways to be disabled: physical disabilities, psychiatric disorders, neurological disorders to name but a few. The social/rights model differentiates between disabilities but fights for rights and/or acceptance focus on the group in totality (VanHala 2014). There is still a focus on helping a group of people who are broken or defective in some way with specific programs and government benefits. “The disability rights movement has done a great deal to politicize the ableism that disabled people experience; in doing so, however, the disability rights movement tends to replace the heterogeneous world of impairment with a homogenized (and homogenizing) disability identity” (Fritsch 2015, 49).

With all respect to movements that draw attention to (and gain results for) basic concerns many disabled people face, especially issues of physical accessibility and inclusive government rhetoric, it is now time to change the social constructs surrounding disability that have been limited by the “neoliberal hegemonic social imagination” (Fritsch 2015, 50). Fritsch (2015) describes a movement to desire disability differently; to move beyond the idea of broken bodies and minds that are incapable of producing and consuming in a neoliberal context. “Challenging the undesirability of disability is a shared responsibility and goes beyond the inclusion of disabled people within the exploitative and individualized relations of neoliberal capitalism” (Fritsch 2015, 44–45).

Such a challenge requires moving beyond the homogeneous “we” and rethinking the constructs that have been enshrined to define disability in the neoliberal era. New ways to act collectively, while maintaining individual differences, are required to rewrite the reality of how disability is constructed.

How is it possible to change a social construct, especially one that supports the neoliberal agenda? It is conceivable that the disabled could look to many state funded agencies for direction and collective action to change the social reality of life with disabilities. In the pre-neoliberal past, these agencies actively advocated for change, often with great results, especially in increasing physical access. As Federal funding for social programming became increasingly piecemeal, [under neoliberalism] social groups and agencies were relied on to implement disability programs previously administered by the state (Kelly 2013). This was not simply a shift of funding from one agency (the government) to another; the government shaped the ideology and scope of these organizations by removing core funding of not-for-profit (NFP) organizations and offering money for specific programs only. What does this mean for disability activism in Canada? It means that the large well-established NFP organizations purporting to advocate for the disabled are no longer able to do so effectively. In fact, most of these organizations do not fight the status quo at all and have eliminated the word (and the practice) of activism from their vocabularies, in fear of losing what funding they receive if they appear to lack complicity with government rhetoric (Kelly 2013). Terms such as “advocacy, disability movements, [and] empowerment” (Kelly 2013, 4) are absent from mission statements and any other public material. Instead these documents espouse terms such as public-education and self-advocacy.

One of the greatest victories for disability activists was the inclusion of disabilities as a specified ground protected in the Charter of Rights and Freedoms, only after concerted lobbying by Canadian disability groups. Equality for the disabled was guaranteed, along with gender and race equality (VanHala 2014); however, this victory was weakened when the government, to further dissuade NFP organizations from challenging the status quo, eliminated the Court Challenges Program in 2006. This program helped NFP organizations fund challenges under the Canadian Charter of Rights and Freedoms. It is now “increasingly difficult for disability groups to afford to raise challenges, thereby limiting the potential benefits of the historic inclusions of disability as a defensible category of the Charter” (Kelly 2012, 4). This scenario paints a rather bleak picture of the potential for change via Charter challenges. The government gave with one hand, while taking away with the other.

If one assesses the situation from a Foucauldian perspective, it becomes clear that focus on benefits and disability programs is an inadequate approach to changing the reality for disabled folks. “Governance arrangements and discursive techniques ... need to be the focus of advocacy and scrutiny by the disability movement and by scholars in disability studies” (Prince 2004, 58). Prince (2004) analyzed 25 years of government action on disability issues. He identified a “deja vu discourse of disability. It entails the official declaration of plans and promises by governments and other public authorities, followed by external reviews of the record, and then official responses with a reiteration of previously stated plans and promises” (67). Surface gains are touted without addressing structural policy gaps, decisions are postponed indeterminately, human rights issues are downplayed, and future action is offered with unspecified timelines. The result:

nothing changes except rhetoric. Foucault (1980) posits that governments utilize déjà vu discourses to justify and rationalize inaction. There is also an argument made by neoliberal governments that citizenship and inclusion is not the prelude of the government; shrugging off responsibility for action further justifies the inaction noted by academic and secular studies (Prince 2004/09; Kelly 2012/13; Fritsch 2015). Prince also notes the lack of statistical data and government studies on disability issues. “Policy is often based on the knowledge derived from data. No data, no problems to address” (2004, 72).

Governmentality, in the Foucauldian context, adds clarity to Canadian disability policy. There are structures by which power is exercised by the Canadian government that influence the ability of disabled persons to exercise substantive citizenship or experience an inclusive society (Prince 2004). The current government discourse “naturalizes the limited scale and pace of reforms in disability policy and services” (Tremain 2001). It also allows for slow, incremental change and “conceals the erosion and decline in existing programs and benefits to persons with disabilities” (Prince 2004, 77). The essential point is that current discourses and means of exercising power allow for the maintenance of the status quo at a time when fundamental change is required.

Given that government appetite for change appears limited, and the NFP organizations have their hands tied by neoliberal policy, perhaps the best potential for change lies outside of the government arena. In 1999, a parliamentary committee noted that “the Canadian public needs to be educated or disability issues will fall off the public, and political agenda” (House of Commons 1999, 1; cited in Prince 2004, 72). To date, that education hasn’t happened. Collective indifference remains the prevailing ideology

(Prince 2009; Kelly 2013). Kelly (2013) suggests that change is best accomplished through alternative activism. Instead of acting through NFP's, there is the potential for disability activism that is "radical, creative [and] sometimes confrontational" (Kelly 2013, 4). Using artistic, cultural events and campaigns, such as the *Vibrant Mad Movement* or the *Disability Pride March*, a different form of activism is possible. Rosemary Garland-Thompson calls this "visual activism", which she suggests "is the first step towards making people think and act differently" (2009, 193). The measurable, material information valued in scholarly studies is not available with this type of activism, which may explain why academic accounts of activism don't include it (Garland-Thompson 2009; Kelly 2015). It has the potential, however, to paint a new picture of life as a disabled person in Canada. Heterogeneous, visible, non-charity, self-naming, and adaptable, creative, cultural activism has the power to engage and educate the public in interesting and educational ways, outside of restrictive, government environment.

Creative activism has great potential to rescript disability activism in Ontario, however, where does this route for change leave academia? Do we, as scholars, have a role to play in informing public opinions and policy changes? Cooper and Levine (2013) suggest that the answer to this query does not lie in reshaping the content of academic research, per se, but the mobilization of that knowledge. Research abounds on many topics that can improve the quality of life for the disabled, but much of it remains closed within academic journals that are rarely circulated outside of academia. While it may seem counter intuitive, "research is rarely the determining factor either of policy or of professional practice" (Cooper and Levine 2013, 4). Instead, policy choices are

“frequently based on hope and fear, what others seem to be doing, what senior leaders have done and believe has worked in the past, and their dearly held ideologies – in short, on lots of things other than facts” (Pfeffer and Sutton 2006, 5).

What we know can become irrelevant if those enacting policy do not base their decisions/practices upon it. Perhaps measurable change can best be achieved with creative endeavours to increase public awareness pertaining to disability issues, coupled with initiatives to make what “we,” as academics, know accessible to those introducing grassroots disability rights projects and those in governmental environs who shape relevant policy. Framing disability scholarship in this way means changing how we design, complete, and deliver academic research to enhance its usefulness in the formation of policies to enhance the life of the disabled in Ontario.

But What Does Any of this Have to do with Inclusion?

This widespread disdain for the disabled is short-sighted; at one point in every person’s life they will become less than able, even if only depleted by the ravages of age. All people should have an equal stake in disassembling the exemplar of able-bodied perfection (Kafer 2013). Instead, despite personal inclinations of individual politicians, the state has a personal interest in “othering” the disabled; whatever values this group might add to society, individualism and economic production are not imagined to be among them (Fritsch 2015). Foucault (1984) notes that as the exercise of social power becomes synonymous with maximizing economic production, citizenship becomes a reward for the able-bodied. Work to increase equality and citizenship for the disabled have been on-going for over 30 years with few measurable results beyond creating

physical accessibility and the adoption of empty rhetoric about inclusion. Academia, in my opinion, needs to open itself up to qualitative, forward facing, creative forms of resistance to make visible the realities of life as a disabled person. Change does not happen in *abstentia* (Prince 2009). The disabled need to find creative ways to surpass their invisibility and collectively lobby for changes in policy. Even more importantly, the disabled, academic, and political communities must lobby to create spaces for change in public perception and understanding of disability issues (Kelly 2013). Neoliberalism regimes will not foster these changes in political, educational, or NFP environments. The question of how to organize within this climate is complicated; the answer may be as simple as becoming a more visible group and using knowledge mobilization to ensure that visibility activism takes the leap from a public to a policy discourse (Garland-Thompson 2009, Cooper and Levine 2013). The relationship between disabled persons and the state will remain intense and complex until this happens. Substantive citizenship remains elusive (Prince 2009; Kelly 2013); disability remains an undesirable economic and social reality (Fritsch 2015). Neoliberal rhetoric is still pervasive; it is still an “ideological thought virus” (Beck 2002, 122; cited in Peck and Tickell 2002, 281).

What does this mean for children with invisible disabilities in Ontario public schools? It has been established that educational resources for children with invisible disabilities are inadequate (Florian 2014). Attractive rhetoric regarding inclusion is not supported by the reality of life in the public-school classroom (UNICEF 2009; Moore and Slee 2012; McFarlane and Woolfson 2013; Goransson and Nilholm 2014; Florian 2014; Gallagher and Mackay-Kidder 2014). Many of the shortcomings stem from collective indifference and lack of political will to change Ontario’s public education policy in

dramatic ways (Prince 2009; Moore and Slee 2012), fueling the funding and teacher-training shortfalls, inadequate staffing, and policy issues that influence the delivery of ‘inclusive’ education. The proliferation of neoliberal ideals explains the lack of interest and investment in children with special needs. “Neoliberalism ... unlike liberalism, withdraws value from the social good. Economic productivity is seen to come not from government investment in education, but from transforming education into a product that can be bought and sold like anything else” (Davies and Bansel 2007, 254). If education is organized as a production line to equip future neoliberal producers/consumers with the tools they need to be successful global capitalists, is it any wonder that children with special needs, who are less likely to achieve this moniker, receive less resources from a government that views them as deviant and unproductive?

My project aims to give a voice to those on the front-lines of inclusive policy delivery, from the perspective of children and parents who experience it. The current status quo in Ontario is that there is no problem with inclusive policy delivery. As Prince (2009) noted, if there are no studies with the potential to discover a problem, then there is, effectively, ‘no problem’. I believe that the most effective way to investigate the reality of inclusion for kids with invisible disabilities in Ontario public school is to avoid the glossy public relations manuals and work directly with those that can express the occurrence of inclusion (or lack thereof) from experience.

Chapter Three

Methodology

The study utilized a variety of research methods to express the voices of parents and children who experience/have experienced inclusion in the Ontario public-school system. Survey data and an adapted version of photovoice were used to address my problematic. Using multiple methods can allow researchers to triangulate results and validate findings (Aldridge and Levine 2001). In part one of this study, parents who self-identify as having children with invisible disabilities will be asked to complete a survey through Survey Monkey. The survey took 15–20 minutes to complete and respondents remained anonymous, as no identifying information was collected. The survey asked questions about inclusion as it is implemented in Ontario public schools. The inquiry covered diagnosis of invisible disabilities such as high functioning autism spectrum disorder, ADHD, sensory processing disorder, learning disabilities, and behavioural/neurological disabilities. In addition, student accommodations, education assistant support, acceptance by peers in an inclusive classroom, and the effects of going to public school on their child's psychological health, behavioural issues, and learning progress were assessed from the parental perspective. As there is no existing measure, I have compiled a survey to assess these issues. This survey is based on an extensive literature identifying questions and concepts pertinent to the issue of inclusion (Black-Hawkins Florian and Rouse 2007, Prince 2009, Moore and Slee 2012, Gorranson and Nilholm 2014, Gallagher-McKay and Kidder 2014). As no previous work has been done with this survey, it is an experimental study to gauge both the responses of the respondents and the efficacy of the measure.

Because I attempted to document a schism between the ideology and the practice of inclusion, I opted to use survey data to enumerate portions of the phenomenon with closed ended questions. I chose to pursue survey analysis for a portion of this study because it allowed me to reach a wide respondent sample with cost and time efficiency. Per Aldridge and Levine (2001), surveys are an ideal first step; a precursor to more intensive studies. Surveys “establish ... the general outlines of the researchable problems” (28). Surveys are an effective vehicle to gather “comparable information from respondents across a wide range of different social groups” (Aldridge and Levine 2001, 28). Quantitative analysis is inadequate to explore the very personal experiences that best demonstrate the reality of inclusion in Ontario public-schools; therefore, qualitative, open-ended questions will also be a part of the survey. Although surveys have historically been primarily quantitative, there is movement towards assessing qualitative data as well (Aldridge and Levine 2001). Due to the time constraints of a master’s thesis project, follow-up interviews and focus groups were limited in the context of the current project, but participants were asked if they are willing to participate in future in-depth qualitative analysis of the survey data. Anonymity of respondents in the current project was protected by having the email submitted via a link that is not attached to survey response information, and the source codes will be deleted from the responses.

Parents were recruited through Quintilian Private School, as well as through Pathways for Children and Youth, Autism Ontario, and The Reading Clinic. A sample pool should be selected to maximize coverage of target population (Tourangeau Conrad and Couper 2013). The recruitment for this study is targeting people who self-identify as parents of children with invisible disabilities; the recruitment sources are organizations

that attract a wide variety of persons of variable socioeconomic, racial, cultural, and educational statuses who are members of the target group. One short-coming of an online survey is that it is only available to those that have access to the internet. In 2017, most persons have access to the internet; however up to 30% of the adult population may not have personal access (Tourangeau Conrad and Couper 2013). This digital divide is an integral problem with web-based survey studies; the population lacking in internet tends to represent those with lower socio-economic status and geographical restrictions. To overcome this limitation, recruitment materials were posted in public spaces of the recruitment organizations, and this material included notices of free internet access at public libraries in Ontario.

Some organizations will distribute the letter of information through group email servers; others will post a recruitment poster on their website and/or in office locations. Parents who chose to respond did so by following an attached URL to the survey. The survey was completed once the respondent reads and indicates informed consent by clicking on an appropriate section of the survey.

In part two, children participated in an expressive art project. They were asked to draw several pictures depicting their feelings/memories about attending both public and private/special needs schools in Ontario. In addition, drawing from Castleden and Garvin's (2008) study of photovoice in the Huu-ay-aht First Nation, the children were asked to interpret their own art project by writing a short (one to two sentence) interpretation of their pictures. Younger children were asked to speak rather than write about their pictures and responses were scribed. Photovoice is traditionally a community-based research method that combines the use of photographs and verbal responses to

allow a marginalized group to share their life experiences and feelings as a basis for changing policy that affects some aspect of their experience (Castleden and Garvin 2008; Wang 2006). Per “John”, a participant in Castleden and Garvin’s (2008) Huu-ay-aht First Nation photovoice project “It was a good way for us to express our thoughts and feelings. A picture is worth a thousand words” (1401). The addition of dialogue to support the photo/picture reduces interpretation errors regarding what the photo represents to the photographer or artist.

While embracing the principles above, the current project used expressive visual *art* projects instead of photos to represent children’s feelings at various times in their lives. “Expressive arts have long been used with children to promote psychological health and social support. They offer children a way to express their feelings, perceptions, thoughts, and memories in ways that words cannot” (Malchiodi 2005, 9). Studies indicate that expressive arts provide “opportunities to share experiences in an empathic environment through symbolically expressing emotions in a concrete way” (Smilen 2009, p. 381). Bagnoli (2009, 547) argues that “applying ... drawing methods in the context of an interview can open up participants interpretations of questions, and allow a creative way of interviewing that is responsive to participants’ own meanings and associations”.

Traditional structured interviews can be problematic for children; they do well when replying to factual questions, but have a harder time responding to questions about their feelings or past experiences (Herjanic 2004). This is especially true for boys, whose emotional recall is harder to tap into in a structured interview setting, than that of girls. This point is particularly of note in the present study, as boys are more strongly represented amongst children with invisible disabilities (Mahone 2012; Cortiella and

Horowitz 2014; Center for Disease Control 2016). Expressive arts, with explanatory dialogue, present an opportunity to assess student interpretations of their educational experiences. This method also has the potential to validate the survey information provided by parents.

Students were recruited through Quintilian Private School. Although it may seem counterintuitive to sample children in a private school to inquire into public school services, this method was chosen for the following reasons: (a) All children will be gathered in one place, with relatively easy access; (b) All children have invisible disabilities; and (c) all children have both experienced “inclusion” as it is delivered in the public-school setting and student-centered learning as it is delivered in their private school. The ability to compare the two experiences of the children will illustrate the gaps (if any) between the education currently being offered children with invisible disabilities in Ontario public-schools and the existing alternatives in special learning private schools. It would have been valuable and interesting to conduct this project with children in public school as well, however, due to the time constraints of a master’s project it was not feasible to adjust the study to apply to public school students and go through the lengthy and complicated ethics process within the Limestone School Board.

After informed parental consent was received, a teacher with knowledge of the project will give a simple request to the students regarding their experiences in public school and oversee the project for 15 minutes. Teachers were chosen to complete this exercise (rather than the researcher) because they already have a rapport with the children that facilitates the comfort and well-being of the participants (Irwin 2005). The teacher did not look at the pictures but made sure students did not experiencing emotional

distress from the assignment. All children were told their participation is voluntary. After 15 minutes, a different teacher with no knowledge of the experiment will pick up the drawings, which will be face down on desks with no names attached. The drawings were placed in an envelope and no teachers saw the pictures. One week later, the same procedure was followed, asking the children about their experiences at Quintilian.

To analyze the data in part one of the study, the survey, the first step was to review closed-ended questions. There is a definitive answer for each and the analysis is a simple and straightforward percentage calculation. To investigate the open-ended questions, the respondent's answers were categorized using grounded theory to assess general themes. Grounded theory is inductive; the conclusions, and sometimes the questions themselves, are born of the information gathered in the study (Kirby 2006). As bits of information are identified and categorized, relationships become apparent. As these relationships repeat, they become the basis for theory formation. Thus, as opposed to beginning with a theory and making deductions based upon it, grounded theory begins with phenomena and builds a theory to explain it (Kirby 2006).

Once the information was coded, percentages were applied to elucidate the direction in which the data was trending. Combined insight from both open- and closed-ended questions provided general answers to the study questions, for example, do most parents feel that the public school is inclusive? Do most respondents think that the IEP process, and forthcoming accommodations, meet the needs of their children with invisible disabilities? After studying the overall tendencies, the data was further broken down to provide information on each trend. It was impossible to predict the direction of these inquiries, as they were gleaned from the overall analysis. In general, this phase

delved deeper into the responses and investigated why subjects answered as they did. Once this was complete, it was possible to extrapolate whether this portion of the project supports (or not) the thesis that inclusion is not well implemented for children with invisible disabilities in Ontario public schools, and theorize as to why, or why not.

In part two, the adapted photovoice activity, analysis was quite straightforward; each child who responded was asked to explain their drawing of their emotions/memories of both public and private specialized schools. Children were asked to describe their experiences in both written and visual format to reduce the risk of interpretative bias. These drawings/descriptions were coded for trends in the same way as the open-ended questions in part one.

Finally, the trends in parts one and two were examined for correlations in the perceived success of inclusion for kids with invisible disabilities in Ontario public schools. This analysis is not intended to imply a generalizable relationship between the two parts of the study. Each section targets different populations and acquired information in vastly different ways; however, as the whole project has been designed to give voice to families/children affected by invisible disabilities, I was curious to see if there are any trends in the responses of the two groups, i.e., do the children view school in the same way as their parents?

Chapter Four

Results-Part One Survey Analysis

Thirty-four respondents began the process of completing the survey in part one of this study; however, 12 of the surveys were incomplete (little to no response to the questions beyond consent), therefore the number of respondents analysed is 22. The results to be discussed in this section are preliminary and speculative, due to the small number of respondents and the untested survey measure. This project does not aim to fully explicate the concepts discussed; rather, it is a first step in a larger project that will continue to give voice to parents and children living with invisible disabilities.

In the sample population, 60.89% of the respondent's children were diagnosed with high functioning autism (HFA), 69.57% have attention deficit disorder with/out hyperactivity (ADHD), 53.17% have learning disabilities (LD), and 52.71% have sensory processing disorder (53.71%). These are only the most common diagnoses. It is worth noting that only four respondents have children diagnosed with one disorder. This finding echoes the well-documented supposition that comorbidity is very common in those with invisible disabilities (Casonova and Casonova 2015; Mayes et al. 2015; Mansour et al. 2017). Most of the families involved in part one of this study sent their kids to public school (65.22%), as opposed to specialized private school (34.78%). This pattern is important to note, as it is representative of the reality of education delivery trends in Ontario; private schooling is not the norm.

As this study is designed to give voice to parents/kids with invisible disabilities regarding the implementation of inclusion within the public-school system in Ontario, I

asked parents to indicate whether the concept of inclusive education had been explained to them. As inclusion is the official policy of the Ontario Ministry of Education, parents should be informed of what this means to facilitate accountability to those ideals. Unfortunately, 77.27% of respondents had not been told that their child's education should be inclusive, the concept was not defined, and the parents didn't really know the meaning. Only 22.73% understood inclusion, as it is meant to be implemented in Ontario public-schools. The definition provided by the Ministry of Education was included in the survey, so parent's responses regarding inclusivity are based on definitions provided by the education system itself, even though no one had shared it with most of them to date.

The diagnostic process was long and expensive for most families in this study; 90.91% of the respondents had their children assessed privately, with no assistance or guidance from the school. The cost ranged from \$1,500 to \$12,000, with higher cost being associated with more diagnoses per child and more children within the family. The average cost per child was \$4,000 in fees for various private assessments (i.e., ASD, ADHD, SPD) and several thousand more for specialized, private treatment (i.e., occupational therapy, specialized programs for children with LD etc.). Some of this cost could be offset by private insurance or coverage offered by employers, however, a good insurance plan would cover between \$300 and \$2,000/year (Nunes et al 2014 ; http://www.pshcp.ca/glossary.aspx#t_1135). One assessment often exceeds this coverage and most children will need to be assessed separately for different issues, so the cost to families can be incredibly high. Many parents were disillusioned with the school's role (or lack thereof) in helping to identify a problem and/or have it assessed by professionals

associated with the school board. For example, one respondent describes her struggle to get help for her child in the following way:

I requested the school do an OT assessment for my daughter as recommended by her previous psych assessment and after two years of waiting they finally informed us there was an error and she was bounced off the list. By this time my daughter was crashing and needed an updated psych evaluation. After two years of pushing them for it, they again gave me the story that she was somehow no longer on the list. We ended up calling an emergency mental health organization and taking her to the intake meetings there. By this time, she was suicidal and only 9 years old. Thankfully they were able to push and have both assessments done within a two-month period. The public-school board has done NOTHING but fight me on the validity of my daughter's disability despite the many obvious difficulties she was having.

This seems an extreme example, but there are many others within our sample that speak to the difficulty in getting diagnoses for their children in a timely and effective way.

Another parent reports that “We involved the school initially, but the wait times were insane (in excess of one year). We did assessments privately, at a cost of \$12,000 between the two boys.” Yet another respondent commented: “He had been having school issues up to grade 5, school said all behavioural. I suggested dysgraphia to them and they'd never heard of it. We had him see a psychologist and do private tutoring. We have to this point spent around 5–6000\$. He got his diagnosis last fall.” Only 9.09% of the sample were referred by the school to access cost free assessments.

Once a diagnosis was in place, the next step for most parents was to seek accommodations for their children within the public-school system. An accommodation is a change that helps a **student** overcome or work around the disability; they range from EA support, specialized lesson and behaviour plans (IEPS), technological support etc. Most respondents reported that this was a process fraught with frustration. Only 18.18% indicate that accommodations were successfully implemented without having to fight for

them. 59.09% fought for accommodations, but none were forthcoming, while 13.64% fought to have minimal accommodation provided, and 4.55% fought but were happy with the accommodations when they were finally provided. One parent shared that “We fought, to no avail. The need was acknowledged, but the supports were never put in place. Excuses ranged from lack of funds, lack of teacher training, to lack of EA staffing, to lack of knowing what to do.” This quotation is representative of the responses of parents who were displeased with the accommodation process. Those parents who reported that they were happy with the accommodation process/results made comments that underscore a more complicated dynamic at play. For example, one of those parents stated: “the help they provide is minimal and I'm not sure it helps much.” Another respondent who indicated their child received accommodations with no “fight” commented that: “strong advocacy and participation by me led the charge for services. I am a lucky parent who can take time off work to go and have meetings during School hours to follow up and make sure the IEP's are followed.” If accommodations are only implemented if a parent polices the school and insists, is that the provision of accommodation with no struggle?

Accommodations within the public-school system are identified and organized within an IEP. The best practice of the IEP production is an Identification Placement and Review Committee (IPRC) meeting. IPRC's are requested (in writing) by parents. Then, a group of professionals review the child's case and come up with recommendations that are incorporated into an IEP. Accommodations developed through the IPRC are the only ones that the school board is legally required to enforce. There were no respondents who

went through the IPRC process in this sample. IEP's were completed by teachers, with input from principals and parents.

Most respondents indicated that the accommodations offered in IEPs were not sufficient to meet the needs of the students with invisible disabilities. 47.62% of respondents felt their kids were not being met at all, 19.05% felt the accommodations slightly met the needs of their kids, and 28.57% felt the IEP somewhat met those needs. Only one respondent (4.76%) felt that their kid's educational needs were met very well by the IEP.

The ability of the teacher to implement the IEP directives was somewhat more positive, with 23.81% indicating that the teacher implemented these "very well"; however, the majority felt the teacher struggled to implement the IEP; 28.57% felt IEP's were not implemented well at all, 19.04% responded with "slightly well," and 28.57% indicated that IEP's were implemented "somewhat well." When asked what they thought about the teacher's ability to instruct people with invisible disabilities, 33.33% said that they perceived the teacher's ability as "not at all well," 33.33% indicated "slightly well," and 23.81% responded "somewhat well." Only 9.52% felt that teacher was able to instruct kids with invisible disabilities "very well".

When asked how beneficial the IEP was to the overall experience of children with invisible disabilities, the responses were consistent with those above; 23.81% indicate it was 'not at all beneficial', 33.33% responded that it was 'slightly beneficial', 28.57% said it was 'somewhat beneficial', 9.52% felt it was 'very beneficial', and 4.76% thought it was 'extremely beneficial'.

Technology has become an important tool to help children with special needs succeed in the classroom. When asked to discuss their child's access to assistive technology, only 15% indicated that it was in use and working effectively for their child, while 10% responded that it was in use, but not effective for their child. Most respondents (50%) were not offered assistive technology at all, and 25% say that they have been offered tech via their IEP but it is not in use in the classroom. One parent shares:

My child is quite adept with computers and is 7. He is basically kept away from technology at school because they don't understand how to properly direct its use for him. My female child (8) needs things like dragon dictate and the school has yet to provide or train her to use these technologies. She cannot read on her own and has very rudimentary writing skills and short-term memory deficits and yet NO assistive devices recommended for her have been provided.

Another parent commented that “the programs do not work for younger children and there is absolutely no support from teachers who are not trained. Even as a parent, we did not understand the choices to do a writing assignment let stand the child who is under the demands of time constraint.” These responses indicate frustration that assistive technology is under utilized and most teachers are not given the resources for these accommodations to be effective; however, if implemented correctly, assistive tech can be a game changer for a child with invisible disabilities, as indicated by the comments of this parent: “yes, they have access, were trained to use it and it has improved their ability to function in school.”

Another accommodation offered by the public-school system in Ontario is support from an EA. When asked to indicate how much access their child(ren) had to an EA, 28.57% reported that they had no access whatsoever, 33.33% indicated that access is

always shared between multiple children, 9.52% were unsure, and 4.72% said that their child does not require EA support. Only 9.52% have full-time access to an EA and 14.29% have an EA for half a day. 85% of respondents are unhappy with the amount of time their child spends with an EA. One parent shared the following regarding EA access: “My daughter only spends 20 minutes a day with her EA. She needs much more assistance than that. School has become a free daycare system for us because she isn't learning anything but sits at her desk all day unable to follow.” Another parent says: “My child doesn't complete her work at school. When I look in her desk, so many pages are barely completed, so she doesn't get help or can't follow. ... Nobody seems to care.” There were 15% of the respondents who indicated that they were happy with EA access. For example, one parent says: “she seems to do very well with my son and spends the most time she has mostly with him.” The respondents with a positive opinion regarding EA access are the same ones whose children have full or half-time access.

When questioned about social inclusion, most respondents indicated that their children struggle with this aspect of school. The potential for their child to blend in with his/her classmates, despite visible accommodations was rated as “not at all possible” by 23.81% of respondents, 9.52% indicated that it was “slightly possible,” 38.10% responded that it was “somewhat possible.” On a positive note, 19.05% deem it “very possible” and 9.52% “extremely possible.” Still, of 21 respondents, 15 responded with a response of equal to or less than “somewhat possible.” Similarly, when asked about their school's success at facilitating friendships between kids with invisible disabilities and their able-bodied peers, 33.33% indicated that the school was “not at all successful,” 23.81% responded with “slightly successful,” and 23.81% “somewhat successful.” Only

14.29% responded that such relationships were “very possible” at their child’s school.

There is no common denominator that predicts the success of social inclusion; the families who reported a positive experience had differential diagnoses, EA access, and comorbidity.

An important facet of inclusivity is the school/teacher’s ability to deal with behavioural and/or academic exceptions without disturbing the flow of academic information for all students. When questioned about whether they receive phone calls asking them to pick up their children because the school can’t handle their behaviour, 10 of 22 respondents replied in the affirmative. Of these families, 30% only receive this call once a week, 20% get a call to remove their child three times per week, 30% are contacted four times per week, and 20% are called five times or more per week. Regarding phone calls to discuss behavioural/educational challenges, 14 of 22 respondents said that they receive calls from the school routinely. One call per week was reported by 21.43%, 14.29% get two calls of this nature per week, the same number get three calls. Four calls a week were the norm for 21.43%, and five or more calls per week were reported by 28.57%.

When asked if their child has been asked to absent self from class during academic time due to behaviour/comprehension issues, 55% of the respondents answered in the affirmative, while 45% were not aware of their child being asked to leave the classroom. One parent stated that her son was “often removed from his classroom to do menial tasks so that he would not disrupt his peers.” Another parent reported that her son “was not encouraged to learn with his peers and was constantly sent to the principal’s office for his lack of impulse control.” Yet another parent shared: “My children are frequently asked to

leave class or school because they disrupt other kids, are having a meltdown, the material is too hard, and they get frustrated etc. They are given menial tasks, asked to sit in the hall, or sent home if we are able to get them.” And another parent describes that her son was “kicked out of JK. Then put in a special education room for SK before they said he was too high functioning for it, so they just called every day for me to pick him up. He wasn't allowed in gym, recess, or any activities or award shows.” Respondents who did not report this phenomenon were not as apt to leave a comment on this question, although one parent responded that their daughter “attends and does her best.”

When asked if their child’s frustration levels increased as they graded up through the Ontario public-school system, 86.86% responded that it did so. Of the other responses, 4.55% each answered “no,” “not yet,” and “only somewhat,” respectively. One parent said that “the lack of peers is a large factor which causes frustration and having to eat and play alone every day and not be able to share.” Another shared: “Yes, problems become more predominate with the progression of school and age of kids. fitting in becomes harder the older they get.” Still another parent says that “the grade up comes with higher learning expectations and higher behavioural expectations and even though the children are "special needs" it seems that the school expects their "maturity level" to match their peers.” A final quotation on this question:

the older my daughter gets, the harder it gets to get her to attend school. Last year she dropped out of school in December (grade 4) because it simply caused her too much anxiety and she had a total breakdown. She began to revert and was not able to function. Sleeping, eating, and self care became an impossible challenge for us. Each day begins with an anxiety attack, tears, and fear. Each day I have to physically bring her to school as she begs and pleads with me not to leave her at that place.

These examples of parental responses were representative of the overall answers to this question.

Parents were also asked if, in their opinion, their child's experiences in public school exacerbated behavioural conditions/diagnoses, 81.2% reported that they did indeed exacerbate conditions, while 18.18% indicated that they did not. When explaining their response, one parent said that "their diagnoses stayed the same, but their ability to respond to it deteriorated. Frustration and being ostracized socially led to more behaviour problems, labels, and further social exclusion." Another indicated that: "as my child fell farther behind he became less involved and frustrated. He was bullied in public system and although witnessed by staff they did nothing to prevent it." Additionally, a parent recalls that "the way the school treated him like he was just an awful kid gave him anxiety. He started chewing holes in his clothes and refusing to eat." In a shocking, and hopefully isolated, case a parent stated that: "they routinely locked my 5-year-old son in a padded cell in senior kindergarten without our knowledge and he has autophobia / monophobia now which I directly attribute to this experience. We removed our son from the public system the day we found out about this practice."

When asked to rate how well inclusive education is delivered in Ontario public-schools, 33.33% indicated that it is "not at all well" implemented, 19.05% responded with "slightly well," 28.57% said inclusive education was "somewhat well" implemented, while 9.52% think it is "very well" implemented, and 9.52% responded "extremely well." When asked if they would transfer their child to a specialized private school if they could, 68.18% said that they would, while 9.0% said "maybe" and 22.73% indicated that they would not remove their kids from public school.

In the final questions, parents were asked to share additional thoughts about public school and (if applicable) specialized private school. It is interesting to note that 100% of the comments about public school were negative. One parent indicated that they were “tired of the negative emails, texts, meetings where you are hammered with many staff versus one parent. Medication comes up, keeping her home, again.” Another parent noted that the public system:

wants parents to pay to have needs identified but then just make excuses as to why they have no funding to provide those needs to your child. The services go to those that become a danger to other students and teachers, those who threaten the actions of teachers or those with visible severe disabilities that struggle to make grade but are supported and pushed forward. The process does nothing to support those that could be successful with the appropriate supports.

The frustration is evident in all responses to this question. One respondent wrote “It's a disaster - period. Totally unequipped to manage special needs kids in regular classrooms. Inclusive classrooms don't work in my experience. No resources, no comprehension, no training, no reasonable solutions when problems arise.” Another noted that ““It has been a rocky road ever since my first child started. I am always expecting a phone call about one of the kids.”

As one of the recruiting agencies involved in this study was a specialized private school, I decided to ask for some insight into the experiences families had in private versus public school. One parent, recalling their decision to switch children from public to private school, shares that their kids

were suffering academically, socially, and emotionally at public school. They were in a regular class but had no friends. They were being passed along, grade for grade, without learning. Their behaviour problems were increasing, and their psychological health decreased. We made the choice to remove them from public school out of desperation.

Another stated that “the patience and ability for the private school to focus on the individual child really motivates and supports the child to learn and develop with self esteem.” While another reported that

the experience is night and day. Our son is happy, engaged, learning, making friends, has very few frustrations or meltdowns at specialized private school—which is the polar-opposite of his experience in public school. Public school involved daily anxiety, tears, meltdowns, no friends, overwhelm, and ultimately, abusive treatment that has resulted in long term damage to our son.

Similarly, one last parent recalls that “our children have thrived in a specialized, private school setting. They are accepted by peers, have friends and play dates. Despite a lack of assistive technology, they are learning to read, write, do math, science etc. Most important, they feel happier and struggle less behaviourally.”

When examining the data trends overall, it became obvious that, while most respondents had a negative relationship with the public-school system, several reported a more positive experience. Within those who responded more optimistically about the public-school system, there was a great deal of variance within their own survey responses, for example, one parent indicated that the school/teacher had implemented the accommodations very well, but later said academic and social inclusion were not at all well implemented. Another parent responded that all measures of inclusion (i.e. accommodations, IEP, technology, social inclusion) were poorly implemented, but then responded that inclusion itself was ‘very well’ implemented at their child’s school. Amongst the 22 parents who completed the survey, 18 responded with consistently negative answers. Two respondents indicated that the school had done “very well” at implementing accommodations, IEPs, and educational inclusion. Two respondents were unclear (as described above). I wondered what variables influenced this relationship,

postulating that perhaps those whose children only had one invisible disability were more likely to flourish in public-school. In the sample, 19 of 22 families had children with comorbid invisible disabilities, and three of 22 report relative satisfaction with the public-school system. Within those three respondents, only one indicated that their child had a single diagnosis. The others indicated comorbidity, thus this variable cannot explain the positive responses.

Next, I considered access to an EA; of the three families with a positive experience, three of them had access to an EA either full or half time. It appears that EA access is a good predictor of opinions about public school. However, two families with half time access were not happy with inclusive, public school education, therefore EA access is not always able to predict experience. Parents who report satisfaction with the school system often reference a specific teacher or EA. For example, one parent notes that “his EA is very knowledgeable and of great benefit to him,” another says that their child has “one superb teacher who could teach to everyone in that class of regular students and those with so many different learning disabilities.” These educators are reported to immediately implement accommodations, and these families do not report being asked to pick up their child or that their child is asked to absent themselves during academic time. It is too simplistic to say that inclusion is implemented by either a “good” or “bad” teaching staff; only four of 22 respondents were consistently positive, and those who were negative noted many systemic problems with the education their kids received in the public system, however, having a good relationship with teaching staff did influence overall satisfaction with public schooling. It remains unclear what precipitates

satisfaction with public education amongst parents of children with invisible disabilities, but it is likely a combination of variables that are individual to each family experience.

There is a much more cohesive and collective picture regarding the respondents who reported negative experiences within the public-school system in Ontario. In the responses above, most of the families were not happy with IEP/accommodations, teachers/EAs, and social/educational inclusion. The most common undercurrent amongst these respondents was frustration. As they are reporting their child being asked to complete menial tasks during school time, or being called repeatedly by school administration, or being told that their child needs help but will not be receiving it, the parental frustration was palpable. Eighteen respondents indicate frustration and dissatisfaction with the public-school system. These families say things such as “[my child was] sent to a padded cell during instruction time in public school without our knowledge” or “my son was only attending half days and I was expected to pick up at any given time,” and “they were not being helpful and just pushing for what they wanted rather than what would help my son.” Nine families indicated that they were desperate with concern for their children.

These families express feelings of futility and lack of hope. One parent indicates that “his teacher last year was the head of special needs and she was useless,” another says that “The system seems under-resourced. We kept hearing that ... others with more severe needs would be prioritized.” These parents make other comments such as: “the psychiatrist made recommendations and they wouldn't follow them” and “still waiting for IPRC meeting requested a year ago.” It is impossible to transcribe all the parental comments, but these selections are representative of the responses generated by the

survey. It is very clear that, amongst our sample, inclusive education does not measure up to the ideals espoused by the Ontario Ministry of Education.

Chapter Five

Results Part Two: Adapted Photovoice

Eleven children participated in part two of this study. They were tasked with drawing a picture and writing a sentence or two describing how they felt about attending public and private school, respectively. I wanted to see if children with invisible disabilities felt differently about their relationship with public versus private specialized schools. If they did, then what difference is there? Most if not all these kids have never had inclusion described to them, but they are the most effective barometer of how it feels to be in these environments, and their depictions/comments on various things allow for an extrapolation on how they experience inclusion. Grounded theory will be used to analyse the drawings, which will be cross referenced with the written explanations. This will reduce interpretive bias and substantiate the validity of the findings. To keep researcher bias at a minimum, I will not be interpreting the meaning of the children's pictures beyond a comment on what they drew and/or wrote. It is interesting to note that four of 11 participants did not draw a picture, expressing their feelings in a written format instead. I didn't expect this but analysed the written work and coded it as per the methodology. In one case the subject only drew a picture of experiences at public school, although the same respondent completed visual and written offerings for their experience at Quintilian. In these cases, there was no triangulation of visual and written material.

The first element examined was an overall positive/negative response to public versus private schools respectively. To assess positivity/negativity in the image-based portion, simple elements of the images were studied. For example, nine of 11 children

indicated emotions with a happy or sad face. This is a straightforward expression of positive and negative emotions. In this case, all the children who utilized faces in their depictions used a happy face regarding Quintilian, and all of them, save one, used a negative face about public school (please see appendix one to examine the children's drawings).

The drawings were, in most cases, very simple and monochromatic, so it was difficult to make any extrapolations using an analysis of colour selections, symbolism etc. Several participants drew more detailed pictures, with multiple subjects and colours. Subject "I" choose to draw a bird breaking free from a previously locked box in their portrayal of schooling at Quintilian; the same subject drew the locked box, with rain and lightening falling on unhappy faces to depict their experience at public school. Even without reading their comments, it is apparent that the subject feels more positively about Quintilian and more negatively about public school. Subject "J" expressed his/her feelings about public school with an unhappy face, with a gun pointed towards it, while private school was portrayed with sunshine and kids playing outside. Again, even without the text, this subject clearly expressed his/her experiences via imagery. Such clarity was not always the case, especially without adding textual analysis into the mix. Subject "H" drew what appears to be a happy face to represent experiences at public school. For his/her depiction of private school, there was a detailed picture of friends interacting on a school yard. Based on the imagery, this subject had an equally fulfilling experience in public and private schools. If one adds an analysis of the text, however, it paints a different picture. With the apparent happy face, the participant wrote about having no friends at their old school but having friends at Quintilian. The smiling happy face in the

picture may be attached to the memories of having friends at private school, instead of representing happiness at public school. Indeed, most of the pictures were very difficult to analyse without simultaneously looking at the text and imagery combined. Subject “G” drew a picture of what appears to be a small school in their depiction of how it felt to be at Quintilian. There was no emotive indicator in the picture: however, the accompanying caption read “I feel happy. People are nice to me.” The text allowed me to see how this subject felt in a way that the image alone did not.

Textual analysis also allows me to break down the experiences into categories other than positive/negative private/public. Three categories were developed for further analysis: academic experience, social experience, and personal feelings (about themselves). Academic experiences were an interesting revelation for me, as I did not expect kids to recognize the differences in quality of education/learning. Subject “A” drew a picture of multiplication times tables, captioned “happy to be here.” Subject “C” did not draw a picture, but when writing about public school he talked about how his teacher had called him a loser and commented that: “people were being mean to me and I did not have any help and no education and I feel bad about what happened at my old school.” The same student wrote the following about Quintilian: “I feel awesome in this school and it gives me more education and focus on what I am working on and I love the teachers here they are real nice to me and I.” Clearly, this subject felt that the quality of the education that he/she receives is better in a private, specialized setting. Subject “D” also wrote a textual response without drawing a picture. He commented that his educational experience at public school was “horrid,” while his experience at Quintilian was marked with fewer kids per class, more teachers, and a better education. Subject “K”

mentioned a future career as a writer in their Quintilian picture, but referred to themselves as “stupid” when discussing public school.

Social experiences were also markedly different in the textual analysis of public versus Quintilian school. The most salient social experience that the children reported was bullying. Only one drew a picture of themselves being bullied at public school, but five others reported it in the texts accompanying their picture. For example, subject “C” stated that he/she “didn’t like to get beaten up all of the time” at public school. Subject “B” noted that at Quintilian, he/she was “great, happy, *not bullied*” (italics mine). Subject “G” drew a picture of him/herself being bullied, while writing in a speech bubble the bully saying “haha loser.” In addition to bullying, subjects also reflected on friendships; subject “H” talked about his/her lack of friends in public school but drew a picture of interacting with friends at Quintilian. He or she made sure to label each person in the picture as “friend.”

Another interesting category that developed in this portion of the study was the children’s portrayal of how they feel about themselves. The overall trend in the text pertaining to public school was negative, self-deprecating comments such as “dumb,” “lonely,” “horrible,” “mad,” and “loser.” There were no positive self statements made by children describing public school. The opposite is true of the representations of how the subjects perceived themselves in the Quintilian context, where children reported feeling “happy,” “great,” “awesome,” and “free.”

The children’s perceptions, expressed visually and in text, demonstrate that (a) they feel the difference between private/public school experiences and (b) their

experiences in public school were negative and their experience in private school were positive. These results mirror the survey data collected in part one. Although the participants in both portions of the present study were not necessarily related (i.e. for confidentiality purposes, I did not ask whether the parents of the kids in part two filled out the survey and could not compare specific results against each other), it is obvious that children with invisible disabilities and parents of such children perceive public school as 'dis'inclusive and negative. This may be for different reasons, with kids drawing on personal feelings and impact on self-esteem and parents commenting more on systemic issues, lack of funding etc., but the perceptions of the experience itself are the same. Public schooling in Ontario does not meet the ideals of inclusion espoused by the Ontario Ministry of Education according to those who are best positioned to opine.

Chapter Six

Discussion and Conclusion

The results clearly indicate that, when given a voice to do so, parents of/children with invisible disabilities report a different experience within public schools than the official ideology espoused by the Ministry of Education. This conclusion is not surprising, given that the Ministry does not acknowledge a problem at all (Ontario Ministry of Education 2014) and, as the literature review indicates, inclusive education for children with invisible disabilities is fraught with many conceptual and applied issues (Black-Hawkins Florian and Rouse 2007; Florian 2014; Gorranson and Nilholm 2014; Gallagher-Mackay Kidder 2014; Burge 2017). When a concept is misunderstood at the theoretical level, it is very difficult to imagine it being successfully applied. Indeed, within the current sample, it became clear that inclusion is failing at several levels.

Survey respondents did not have a clear understanding of what inclusive education was supposed to look like, thus making it easier for the Ministry of Education to deliver it haphazardly within the province of Ontario. All parents, not just those of the disabled, should be informed regarding what education is supposed to look like, as such information would keep the Ministry of Education accountable to the recipients of “inclusive” education in Ontario. Once inclusion had been defined for them, respondents to the survey reported that they were significantly dissatisfied with public-schooling regarding diagnosis procedures/costs, accommodations, access to an EA, the capacity of teachers to instruct ability diverse classes, and the overall social/academic experiences of their children within Ontario public schools.

Parental opinions were only part of the current study, the children, while not well versed in the meaning of inclusion, made illusory contributions to a complete picture of the reality versus ideology of inclusive practices; clearly, children perceive dis-inclusion in public schools and have the opposite experience in specialized private schools. Children report bullying, by students and teaching staff, perceptions of being left out, realizations of the incomplete provision of education and more. Social and educational inclusion were not described as successful by any of the children who completed the adapted photovoice project.

Studies exhorting the opinions of teachers and principles regarding the implementation of inclusive education mirror this dissatisfaction (Macfarlane and Wolfson 2013; Gallagher-Mackay Kidder 2014; Sokal and Sharma 2014), so it is not shocking that parents and children are noticing the same deficits. Teachers and administrators denote insufficient funding, support staff, and professional development to adequately implement the inclusive ideology espoused by the province.

It is surprising that, when both parents, children, and educational professionals are expressing concern about the ability of Ontario public schools to educate all children inclusively, no changes to the system are being made, no political activism for change is underway, no acknowledgement of a problem by the Ontario Ministry of Education has been forthcoming. Why is the government resistant to change when all interested parties identify areas of the system that do not function as intended? Answering this question involves revisiting the concepts of neoliberalism and disability activism.

In a neoliberal economy such as Ontario's, good citizens are those who can produce and consume, fueling capitalism's unquenchable thirst for wealth and commercial activity in a free market system (Davies and Banzell 2007; Foucault 2010). Education becomes less a road to enlightenment and more so a production line where children are instructed in how best to become responsible citizens (a.k.a. generate wealth and use it to purchase resources). It is expected that these citizens will do so independently, without overtaxing the government with social welfare responsibilities (Foucault 1984; Fritsch 2015). In this climate, the disabled are "othered" by the system itself, regardless of what politically correct platitudes get mouthed.

Regarding children with invisible disabilities and inclusive schooling, kids with disorders such as high functioning ASD, ADHD, learning disabilities, anxiety and depression etc. present with behavioural and academic issues that are quite complex, especially given the comorbidity of such childhood disorders (Helland et al 2014; Pfeiffer 2015; Mayes et al 2015; Gregory and Sadeh 2016). Even if resources are expended upon children with special needs within the education system, there is no guarantee that they will grow up to become financial affluent neoliberal producers and thus no impetus for the government to invest in them (Davies and Banzell 2007). The "other" or "deviant" moniker that seems to attach itself automatically to the invisibly disabled is applied by design to serve the ends of those in power and limit the waste of resources on a dependent segment of society. It is worth noting that private, specialized schools, such as Quintillian Private School, that do invest time and resources into children with invisible disabilities have substantially better outcomes for these kids. Since its inception in 2005, only one student has decided not to further their education and/or get a job (McDonnell

2016). Therefore, the wheel does not need to be reinvented; the information on how to fix the system already exists; all that is lacking is the political will to see it implemented.

While some agencies may want to agitate for changes to this system, they have a difficult time doing so, because it has become very difficult to advocate for change within the traditional avenue of not-for-profit (NFP) organizations because those groups are funded by the government and will find themselves without a mandate if they do not pull the party line (Fritsch 2015). There are no Ministry of Education studies that identify a problem, no NFP groups pushing to organize and execute change. Therefore, where there is ‘no problem’ there need be no solution (Prince 2009). As such, documenting the existence of “the problem” was the primary goal of the present study.

This project was a first step towards bringing parents and children into the discussion and telling the story of how *they* experience the delivery of inclusive education in Ontario. By adding the voices of the families most affected, the existence of ‘the problem’ becomes a salient reality. This adds a new dynamic to the discussion and opens new possibilities for exercising change. Parents and children are uniquely able to speak to this issue in that they are inherently affected by the status quo and they are not under any pressure to blindly agree with policymakers or risk funding. Families are better positioned than teachers to spearhead this discussion, because they don’t have to risk losing their jobs if they advocate for meaningful (and possibly expensive) changes.

Within academia, we are uniquely situated to use the power of the pen (figuratively speaking) to undertake research projects that tap the voices of parents and children who experience inclusive education and give them an avenue for expression. Be it traditional

scholarship, alternative activism, or forward facing/knowledge translation projects, it is possible to uncover and share the minutiae that encapsulates the issue of inclusive education for children with society at large. This will potentially encourage grassroots activism, and ultimately policy changes, to address holes in the education system that prevent giving each child in this province the opportunity to maximize their potential and (eventually) exercise substantive citizenship.

The current study was merely a tiny drop in a very large bucket regarding what is needed to make sweeping and structural changes to the education system in Ontario. This project was limited in scope by the time constraints intrinsic to a master's degree. There were many moments when I wished I could interview my participants personally and have them extrapolate upon a salient point or a contradictory series of responses. But time did not allow for such follow up investigations. The survey format seemed like an efficient way to potentially reach a larger sample population and quickly get their input, however, in hindsight, it was too passive and hands off; it would have been incredibly valuable to be able to make the process more fluid and representative of lived experiences.

It would have been wonderful to have the time and resources to enhance my sample sizes in both parts of the study. While a survey has the potential to reach a larger number of respondents, there is no guarantee that it will. In this case, despite having several reputable organizations advertising the survey across the province, the response rate was very low. In addition, the enhanced photovoice experiment would have been so interesting to implement on a larger scale. The kids had such thought-provoking

perspectives, it would have been amazing to have time to recruit from other specialized private schools within the province and expand this portion of the study.

My future research efforts will expand on the scope and depth of the current study. I am interested in developing various projects to increase the voice of families personally affected by inclusion and children with invisible disabilities. Greater numbers of parents and children contributing in a more fluid and detailed manner would be most impactful. Once the problems are loudly acknowledged by families and those on the front lines of inclusive education delivery, the task of sharing these voices would become paramount. Translating knowledge gleaned from academic research into useable information for social/policy changes is an important “next step.” Per Bennett (2000) “The greatest wisdom or discover in the world will go unheeded if its not read” (1). It isn’t enough to discover and document a problem with how kids with invisible disabilities are educated in Ontario, policy needs to be changed, political will needs to be nourished; it isn’t possible to inspire this kind of revolution with published articles in an academic journal exclusively. Everything learned needs to be shared; participatory, reciprocal, forward facing scholarship is a must to implement change, not just recommend it. Cooper and Levin (2013) indicated that education policy and delivery in Ontario is not based on research, but on accepted dogmas and institutional norms, many of which have already been proven ineffective. This is a systemic failure of all children being educated in this country, especially those with invisible disabilities. We can, and must, do a better job of making knowledge about educating children accessible to those with the power to implement it if children are to be provided with the tools they need to exercise

substantive citizenship. “In an age where we know so much, why are we applying so little of it?” (Bennett 2000, 1).

In conclusion, the literature indicates the inclusion is a concept fraught with theoretical and applied difficulties. The current study demonstrates that inclusion, as it is offered to children with invisible disabilities, is dysfunctional in Ontario public schools. This conclusion is not gleaned from the glossy manuals espousing inclusive rhetoric, nor is it based on the experiences of teachers/administrators who are trying to implement this concept. These results are based on the lived experiences of children with invisible disabilities and their families. Yes, the scope of this study must be enhanced to be able to generalize these findings, however, the results strongly support taking the next steps in this research. No family should feel that school can only serve as a babysitter for their child. Every child deserves the change to reach their maximum potential and exercise substantive citizenship. I would close with the words of a parent who quite nicely captures the rationale for continuing to study, and act to improve upon, the delivery of inclusive education for children with invisible disabilities in Ontario schools:

“If there is another province with a school system that is willing to offer her the support she needs I will pack up and move without hesitation.”

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Appendix 1

Adapted Photovoice Project



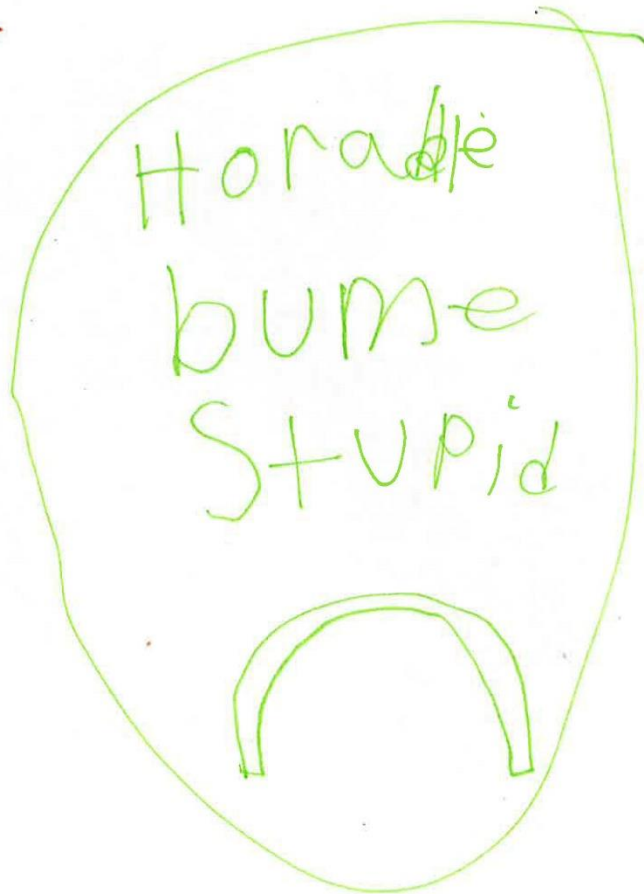
Private School
Subject A

Public School
Subject A

lonely



Sometimes
happy



Public School
subject B

I react Happy

FUN ~~not~~ not Bullied

Private School
Subject B

I feel awesome in this school and it give
me more education and focus what I'm working
on and I love the teachers here they are
really nice to me and I.

Private School
Subject C

I fell horrible at my old School because.
People treat me like a baby and treat me like
dirt and i didnt like to get beaten up all of the time
and people called me bad names at my other School.
and i didnt like it so i moved here and i love it a lot and
I dont like the bullies at my other School and i dont like
the teachers at my old School. And she called my
a loser and a bad warrior and people are being mad to me
and I didnt have any help and no education and I feel
bad what happen at my old school.

Public School
Subject C

I feel that this school is a good deal more according to the ~~idea~~
of other schools, as there are competent teachers and due to the state per class room.
However, it is a little bit more unnecessary and, quite frankly, unnecessary
expensive, as my parents have to shell out \$14,000 dollars a month (also,
I am rather well adjusted).

Private School
Subject D

When I was at my old school, I felt it rather hoarse. However, upon reflection
I feel that it would be more beneficial as the notes are more to your benefit and it is much
much less expensive and a great deal less in stress as it is rather "risky."

Public School
Subject D

Happy
about
being
here

$\begin{array}{r} \times 129 \\ \hline 6 \end{array}$

$\begin{array}{r} \times 129 \\ \hline \times 129 \end{array}$

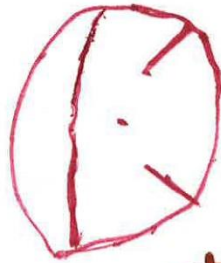


Private School
Subject E

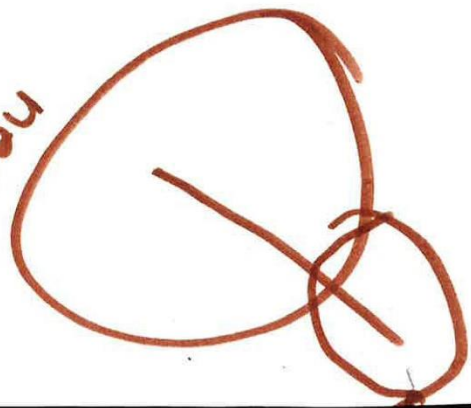
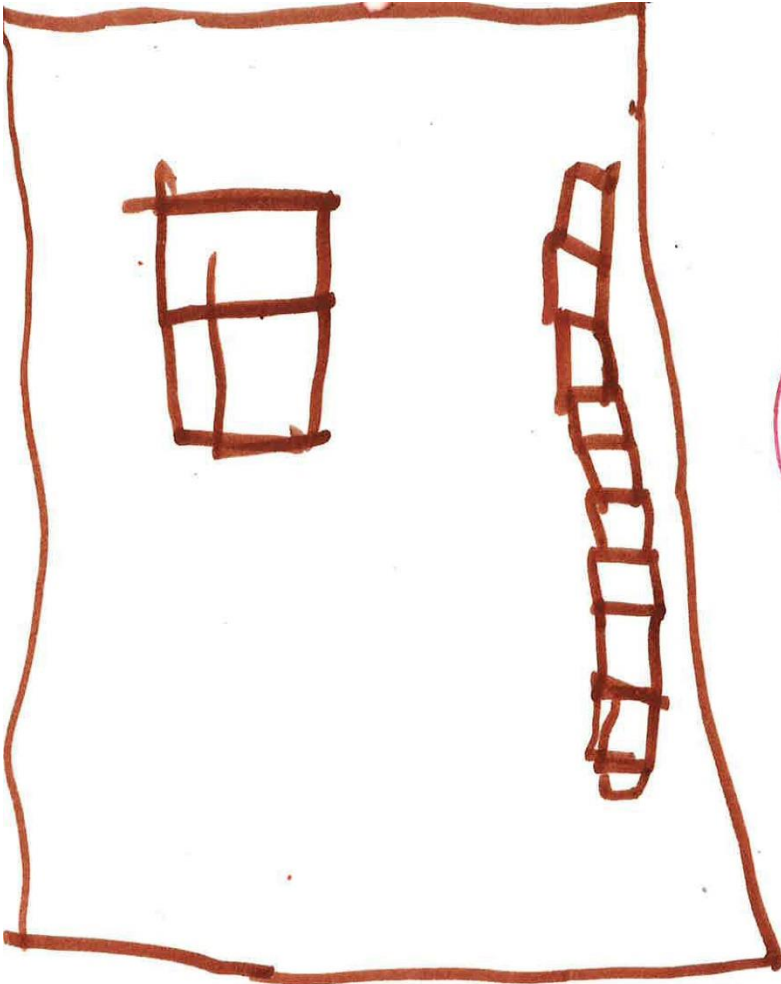
My Old school
made me very
Sad and i used
to get mad
and always get
sent to the
office for no
reason

Public School
Subject E

Mord

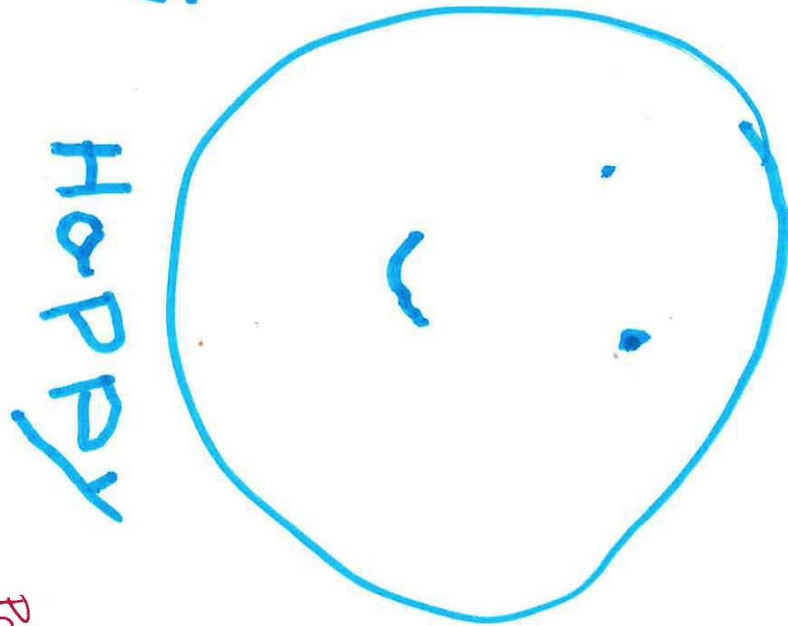
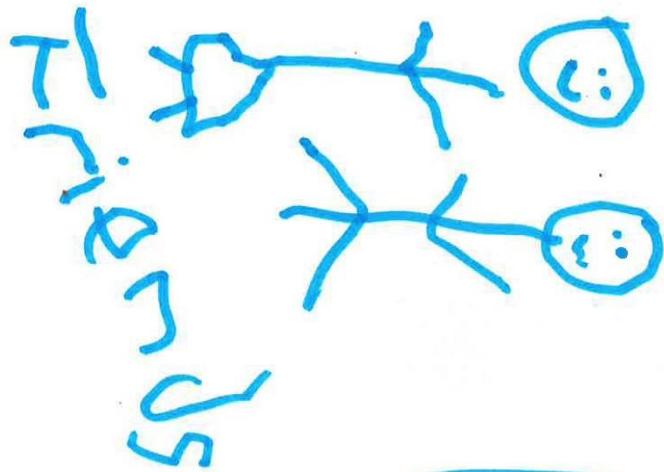


to B'ig



needed
have
Peremca
to
have
friends

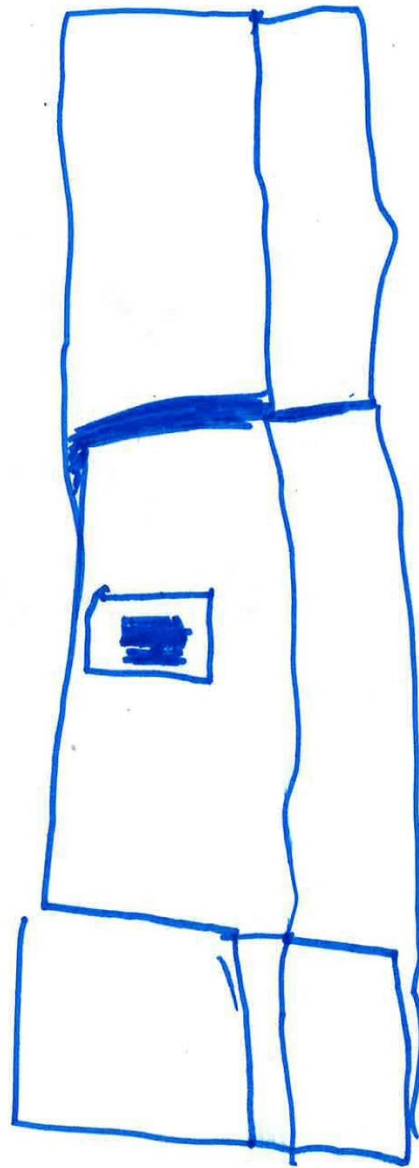
Public School
Subject F



Private School
Subject F

CDA

I feel
happy
people
are
nice
to me

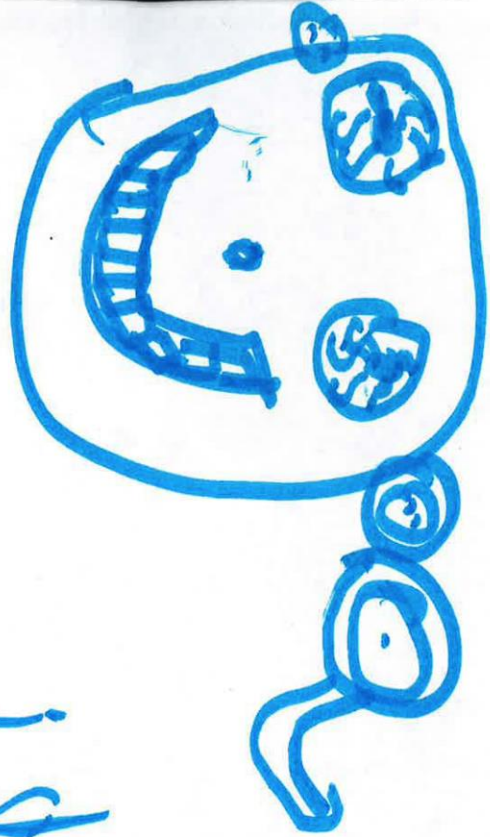


Private School
Subject G



Public School
Subject G





I

I did not
have friends
at school
but now
I have
many
friends.

Public School
Subject H

Public School
Subject I



All my feeling felt locked
I felt like I couldn't do
anything

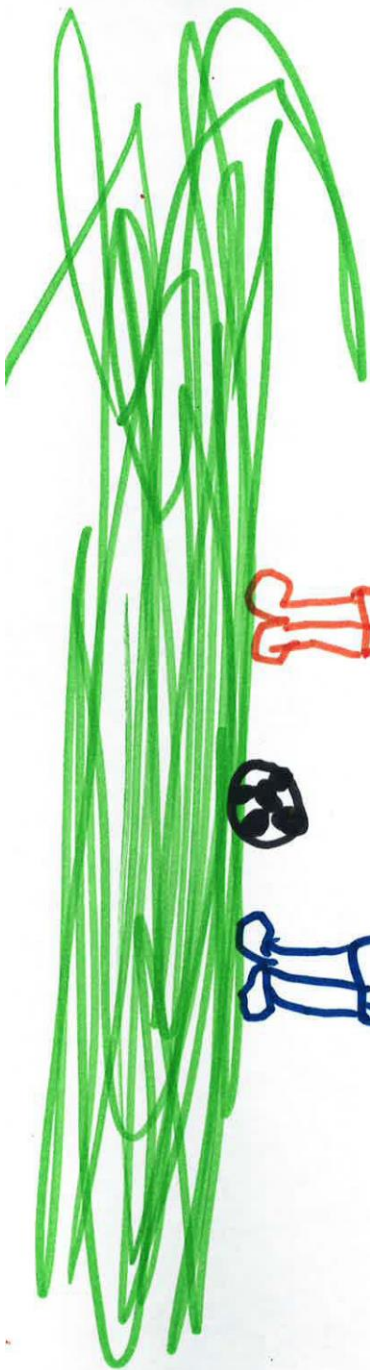
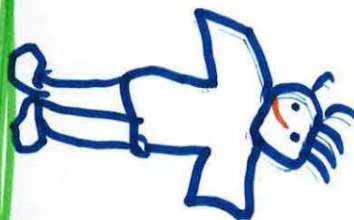




when I came to quinn & lillian
I felt free like a
bird soaring higher and higher

Private School
Subject I

Friends
like
me

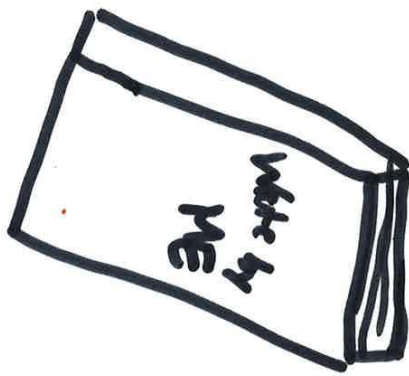


Private school
Subject J



Public School
Subject J

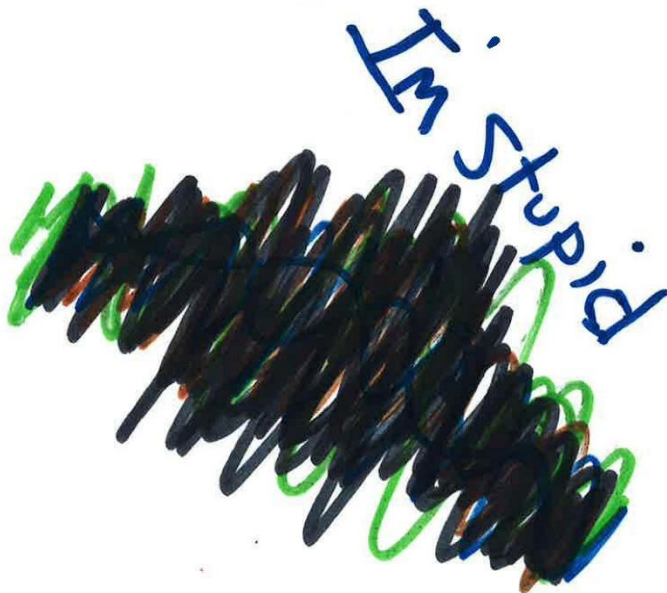
'I'm learning to be a writer when I
grow up'



Private School
Subject: K

'How mad feels'

It's stupid



Public School
Subject K

Appendix II

Survey Questions

1. How many children do you have with invisible disorders (for example: ASD, ADHD, SPD, learning disabilities, conduct and other behavioural disorders)?

One

Two

Three

More than three

2. Could you please specify how old your child(ren) with these disorders are?

3. Could you please specify the invisible disorder(s) your child(ren) have been diagnosed with, or that you self-identify your child(ren) as struggling with?

High functioning autism spectrum disorder

Attention Deficit Disorder with or without hyperactivity

Learning disabilities

Oppositional defiant disorder/conduct disorder

Hearing loss/speech impediments

Sensory processing disorder

Depression, Anxiety, other psychiatric issues

Other (please specify)

4. Please indicate the city (within Ontario) in which you reside?

5. Does your child attend public school, private (specialized) school, home school, or other (please specify)?

6. If your child attends a specialized school, is homeschooled, or other, has your child ever attended a public school?

Yes

No

7. Was the school involved in your child's diagnostic process? If yes, please explain how they were involved and what the timeline of the process looked like. If no, please share the cost to your family for the private consultations and give details about how long it took.

8. Once (if) your child was diagnosed, how long did it take the school to offer accommodations to improve your child(ren)'s learning experience?

Immediately

Within months

Within the year

Never

Other (please specify)

9. Did you have to fight/are still fighting for the school to provide special services/accommodations for your child(ren)? Please explain.

10. If your child has an independent education plan (IEP), who completed it?

Teacher

Educational psychologist

Other (please specify)

11. How well do you feel the accommodations offered by Ontario public schools address(ed) your child's learning/behavioural needs while in school?

Not at all well

Slightly well

Somewhat well

Very well

Extremely well

12. How well did the school/teacher implement the recommendations in your child's IEP?

Not at all well

Slightly well

Somewhat well

Very well

Extremely well

13. How beneficial was the IEP to your child's Ontario public school experience?

Not at all beneficial

Slightly beneficial

Somewhat beneficial

Very beneficial

Extremely beneficial

14. Were you ever told by school professionals that your child was incapable of learning to read/write and assistive technologies would replace those skills?

Yes

No

15. Please explain your child's experience with assistive technology. Do they have access to it? Are staff trained to use it? Do you think it is helpful to your child?

16. Please rate your perception of the ability of your child's teacher to adequately instruct children with a variety of learning/ behavioural/ neurological needs.

Not at all well

Slightly well

Somewhat well

Very well

Extremely well

17. How much access does your child have to an EA?

Full time

Half time

Quarter time

Always shared with multiple children

Other (please specify)

18. Do you know the number of EA's in your child's classroom compared to the number of kids who have identified exceptional needs? If yes, please specify.

No

Yes, the ratio is one to one

Yes, the ratio is one to two

Yes, the ratio is one to three

Yes, the ratio is one to four

Yes, the ratio is one to five or more

Other (please specify)

19. Are you satisfied with the amount/quality of time your child spends with an EA? Please explain

20. Do you know if the EA's in your child's class help children who struggle, but are not diagnosed with any exceptionality?

Yes

No

I don't know

Other (please specify)

21. Does your child receive his/her education in a mainstream classroom with peers or in a segregated classroom? (some combination of the two also possible)

22. As the parent of a child with invisible disabilities, has inclusion, as it is implemented in your child's classroom, been defined/explained to you? If no, please refer to above for the definition of inclusion by the Ontario Ministry of Education.

Yes

No

23. How possible is it for your child to blend in with their classmates in an inclusive way, taking into consideration the visible accommodations they receive?

Not at all possible

Slightly possible

Somewhat possible

Very Possible

Extremely Possible

24. How successful are the efforts within your child's classroom to encourage friendships between children with exceptional abilities and their peers?

Not at all successful

Slightly successful

Somewhat successful

Very Successful

Extremely successful

25. Have you ever been asked to keep your child at home for all/part of the day because the school can't accommodate their special needs?

Yes

No

26. If you answered yes to the previous question, approximately how many times/week does the school request that you pick up your child during regular school hours?

Once

Twice

Three times

Four times

Five times or more

27. Do you live close to the school to facilitate quickly picking your child up in case of emergency?

Yes

No

28. How often per week does your child's school call/contact you regarding your child's behaviour/learning challenges?

Once

Twice

Three times

Four times

Five times or more

29. Has your child ever been asked to absent themselves from academic instruction time due to behaviour/comprehension problems? Please explain.

30. How well do you feel that 'inclusion' is being implemented at your child's school?

Not at all well

Slightly well

Somewhat well

Very well

Extremely well

31. Have/did you notice changes in your child's frustration levels as they graded up within the Ontario public school system? Please explain.

32. How well do you feel inclusive schooling positively affected your child's psychological health?

Not at all well

Slightly well

Somewhat well

Very well

Extremely well

33. How well do you feel inclusive schooling positively affected your child's behavioural success?

Not at all well

Slightly well

Somewhat well

Very well

Extremely well

34. Has your family consulted with psychiatric personnel, Pathways for Children and Youth, or other organizations to receive advice/help to deal with your child's struggles at Ontario public schools?

35. As a parent, do you feel that your child's experience in public school exacerbated their behavioural issues/diagnoses? Please explain.
36. In your opinion, what is the ideal schooling environment for your child?
37. If you removed your child from public school to a specialized private school, please describe the precipitating events that led to that decision?
38. If you had the opportunity to remove your child from public school and enroll them in a private, specialized school, would you do so? Please explain?
39. Please share any other thoughts/experiences your family has had within the public-school system in Ontario.
40. For all parents who have (at any point) enrolled their children in a specialized private school, please summarize the differences btw public/private schools and how this has affected your child's learning and behavioural experience in school.

Appendix III GREB Approval



August 23, 2017

Ms. Nichol Kaiser Master's Student

Cultural Studies Program Queen's University Kingston, ON, K7L 3N6

GREB Ref #: **GCUL-068-17; TRAQ # 6021556**

Title: **"GCUL-068-17 The Illusion of Inclusion for Children with Invisible Disabilities in Ontario Public Schools"**

Dear Ms. Kaiser:

The General Research Ethics Board (GREB), by means of a delegated board review, has cleared your proposal entitled **"GCUL-068-17 The Illusion of Inclusion for Children With Invisible Disabilities in Ontario Public Schools"** for ethical compliance with the Tri-Council Guidelines (TCPS 2 (2014)) and Queen's ethics policies.

In accordance with the Tri-Council Guidelines (Article 6.14) and Standard Operating Procedures (405.001), your project has been cleared for one year. You are reminded of your obligation to submit an annual renewal form prior to the annual renewal due date (access this form at <http://www.queensu.ca/trag/signon.htm> l/; click on "Events"; under "Create New Event" click on "General Research Ethics Board Annual Renewal/Closure Form

for Cleared Studies"). Please note that when your research project is completed, you need to submit an Annual Renewal/Closure Form in Romeo/traq indicating that the project is 'completed' so that the file can be closed. This should be submitted at the time of completion; there is no need to wait until the annual renewal due date.

You are reminded of your obligation to advise the GREB of any adverse event(s) that occur during this one year period (access this form at <http://www.queensu.ca/traq/signon.html>; click on "Events"; under "Create New Event" click on "General Research Ethics Board Adverse Event Form"). An adverse event includes, but is not limited to, a complaint, a change or unexpected event that alters the level of risk for the researcher or participants or situation that requires a substantial change in approach to a participant(s). You are also advised that all adverse events must be reported to the GREB within 48 hours.

You are also reminded that all changes that might affect human participants must be cleared by the GREB. For example, you must report changes to the level of risk, applicant characteristics, and implementation of new procedures. To submit an amendment form, access the application by at <http://www.queensu.ca/traq/signon.html>; click on "Events"; under "Create New Event" click on "General Research Ethics Board Request for

the Amendment of Approved Studies". Once submitted, these changes will automatically be sent to the Ethics Coordinator, Ms. Gail Irving, at the Office of Research Services for further review and clearance by the GREB or GREB Chair.

On behalf of the General Research Ethics Board, I wish you continued success in your research . Sincerely,

A handwritten signature in black ink, reading "Joan Stevenson". The signature is written in a cursive style with a horizontal line at the end.

Joan Stevenson, Ph.D. Interim Chair

General Research Ethics Board

c: Dr. Audrey Kobayashi , Supervisor Dr. Richard Day, Chair, Unit REB Ms.

Danielle Gugler, Dept. Admin.