

A Critical Examination of Pedagogy and Ways of Knowing of People with Autism

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This major paper is dedicated to my family,  
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## Abstract

Traditionally, autism has been treated as a disability in that individuals with autism have been thought to have deficits that need to be remedied. This notion has been perpetuated by the definition of autism provided by the medical model, as well as notions of the “norm.” “Environmental thinking,” as defined by the Faculty of Environmental Studies (FES), allows for the examination of autism outside of this predominant common sense view that pathologizes it. From a critical disabilities perspective, the hegemonic view of autism serves to oppress individuals with autism and other so-called disabilities. Alternatively, the social model of disability proposes that the environment is what enables or disables individuals. One important environment is the pedagogical environment. Given the prevalence of autism and the high costs associated with providing the necessary support, education has become a social and political issue. Pedagogical approaches currently used can be controversial. The fields of critical pedagogy and critical special education offer insights that could serve to inform and improve educational practices. These critical fields suggest the alternative perspective that people with autism have a different way of knowing that is different from predominant western ways of knowing, but is equally valid. This study is guided by several questions that emerge from this notion, including questions about the ways in which people with autism “know” the world, as well as the appropriateness of certain pedagogical approaches. In addition, this inquiry is structured around themes from critical disability studies including: honoring the experience of “disability,” inclusion versus exclusion, visibility versus invisibility, and “disability” as a political and social issue. These themes serve to highlight some of the current issues facing people with autism, their parents, and educators. The qualitative study, which is part of this work, provides important first-hand information from these different groups. This study concludes that as individuals with autism

comprise a heterogeneous population, there is no single best pedagogical approach. Rather, the method should be tailored to address the needs of the individual. In addition, it is suggested that there are problems with current conceptions of the "norm," intelligence, and pedagogical approaches as these can be too narrow and often serve to exclude individuals with autism as well as those with other exceptionalities. A broader definition of intelligence is needed, such as the one proposed by Dr. Howard Gardner's concept of multiple intelligences, which recognizes different abilities and respects multiple ways of knowing. Furthermore, pedagogues should be mindful of the hidden curriculum as this is universally difficult for children with autism to grasp. Ultimately, through the challenging of current hegemonic notions of autism, it is possible to envision a world where the common sense will be shifted to see autism as an opportunity for individuals to live out a unique way of being, and for society to learn from their gifts and experiences.

## Foreword

The purpose of this major paper was to explore current conceptions of autism as well as prevailing pedagogical approaches, from a critical perspective. This paper challenged the hegemonic notion of autism as a disability that needs to be “cured.” The examination of these issues through “environmental” thinking as defined by FES, allowed for the exploration of autism from a counter-hegemonic lens, outside of the view of the predominant medical model that pathologizes it. In addition, this paper brings together many of the connections I have discovered through my studies at FES between fields of study which are often kept separate. In so doing, this paper is an integration of all three of the components of my Plan of Study which are: critical pedagogy, education for children with autism, and ways of knowing.

Critical pedagogy was the first component that I explored in my major paper, along with the related field of critical special education, through literature reviews. This fulfilled two of my components, namely becoming familiar with the field of critical pedagogy as well as acquiring an understanding of the issues of power in education based on the work of critical theorists. Two of the theorists whose ideas I found influential were Paulo Feire and Douglas Biklen. I saw that my third objective, gaining experience in practical applications of alternative pedagogical approaches, was fulfilled through studying popular education at FES. This informed my views and inspired me to resist the prevailing common sense notions surrounding conceptualizations of autism in my own work.

The second component of my POS, education for children with autism, was approached environmentally by explicitly considering the context of the school. Through examining the theory and practice of education for

individuals with autism, I gained insights that enabled me to fulfill my learning objective which was to examine different methods used for teaching children with autism, with a focus on deconstructing the power dynamics implicit in each. I also fulfilled the objective of investigating the question, “Whose interests are being served in education for children with autism” through the information that I gained from the qualitative interviews I conducted. My studies at FES in quantitative as well as qualitative research methods provided me with the foundation that enabled me to conduct this study, with methods that respected and represented the counter-hegemonic view I was taking.

My next objective, the examination of the political milieu around education for children with autism, was fulfilled by considering socio-political pressures, such as neoliberalism, and how these pressures affect funding for programs for individuals with autism. This idea emerged from my FES coursework on Local Government Organization and Operation. The final objective for this component, to envision a liberating practice of education for children with autism based on notions from critical pedagogy, was addressed by the conclusions I drew and recommendations I was able to make in the final chapter of this major paper. Recommendations include a broadening of notions of intelligence, and are centered on acknowledging the uniqueness of each individual with autism. In addition there is a warning given to educators that things such as the hidden curriculum should not be taken for granted as they are often extremely difficult for individuals with autism to understand.

My third component, ways of knowing, was explored through first-hand accounts of individuals with autism as presented in the literature, as well as through my qualitative interviews. Examination of these accounts



enabled me to achieve two of my components, which included gaining an understanding of other ways of knowing and legitimizing these alternative means of acquiring knowledge. My exposure to a course at FES in Native Canadian Relations as well as a course in Embodied Learning at OISE/UT, challenged and disrupted my conceptions of predominant western ways of knowing, in particular notions of the “norm.” With this knowledge to guide my inquiry, I was able to see that individuals with autism have many unique and well developed talents; in particular they often possess much kinesthetic intelligence and highly developed visual skills. The qualitative study I conducted completed my process of understanding that if the different ways of knowing of people with autism were granted legitimacy by society, it could serve to greatly benefit everyone.

Overall, this paper represents my personal growth through my studies at FES, and is meant to contribute to an alternative, counter-hegemonic view of autism and in turn to a more liberated society.

## Chapter 1: Introduction

Disability was once thought of as a punishment from God for the past wrongdoings of an individual's parents, a punishment that most often served to confine an individual to a life of misery and social exclusion (Albrecht et al., 2001). In recent times this conception has been challenged due in large part to the counter-hegemonic notions argued for by the Disability Rights Movement, one of the 20<sup>th</sup> century civil rights struggles which began approximately thirty years ago (Bennet, Grossberg & Morris, 2005). This movement fought for the social inclusion of people thought of as disabled, and the re-examination of disability as socially constructed rather than individually determined (National Museum of American History, 2005). In line with this, critical disability studies "considers the examination of the societal participation of persons with disabilities and the social determinants of disability" (graduate program information pamphlet, 2007-08). Critical disability theory, in particular the Social Model of Disability, sees disability as socially constructed where the environment is what disables (Rocco, 2002).

People with autism<sup>1</sup> have often been thought of as disabled. Until recently, these individuals were thought to be doomed to a life of isolation, as the common understanding was that they were incapable of emotions (Sacks, O. as cited in Grandin, 1995). Prior to the publication of the first autobiographies by people with autism in the late eighties, "it had been medical dogma for forty years or more that there *was* no "inside," no inner life in the autistic, or that if there was it would be forever denied access or expression" (Sacks, O. as cited in Grandin, 1995: 11). This conception is changing as understanding is improving, and there is now less of a feeling that people are disabled by autism. One sign of this is that under the

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<sup>1</sup> Autism is sometimes thought of as a subset of autism spectrum disorders (ASDs), as will be discussed later in this chapter. In this work, the word autism will be used interchangeably with the term ASDs.

medical model, autism is now considered a developmental delay rather than a Pervasive Developmental Disorder (PDD), as it was once seen (Bruey, 2004). Despite improvements in social awareness, there is still an overriding sentiment that there is something wrong with the person with autism that needs to be fixed, as evidenced by educational and therapeutic approaches taken with these individuals. In contrast, this work aims to demonstrate that people with autism have a unique way of interpreting, understanding and relating to the world. In many ways, this way of knowing is different from that of neurotypicals<sup>2</sup> (NTs), but is no less valid. From this, it follows that information will be explored through a critical disability studies framework, where autism will be seen as a way of being, rather than a disability.

This exploration will be informed by themes from critical disability studies including:

- Honouring the experience of “disability”
- Inclusion versus exclusion
- Visibility versus invisibility
- “Disability” as a political and social issue

These themes are elaborated upon in this first chapter, and will also appear throughout this work.

In addition, some questions will be used to guide and organize the inquiry. This first chapter provides an introduction to autism and the concept of disability, in order to familiarize the reader with these terms as they will be major components of this work. This information will be used to

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<sup>2</sup> The term “neurotypical” is used to refer to people without autism, since autism is thought to affect the Neurological System. It must be noted that this is a somewhat problematic term since it raises issues of who qualifies as a NT. For example, Gisella Slater-Walker (2002) notes that as a person with epilepsy, she feels the term NT excludes people such as herself. Despite not being ideal, NT is a convenient term which is commonly used in autism literature, and thus it is also be used in the present work.

problematize the question, "How does western society typically view autism, and is this view accurate and respectful?"

Chapter two focuses on the question, "Do pedagogical approaches taken with children with autism adequately address their unique ways of being?" In order to answer this question, the fields of critical pedagogy and critical disability studies will be explored.

Chapter three discusses ways of knowing in people with autism, and explores whether or not pedagogical approaches address these ways of knowing. This chapter will also assist in providing an answer to the question, "What knowledge can be accessed through autism that could not be accessed by perceiving in a neurotypical way?" A broadening of the typical notion of intelligence will be sought to assist in this exploration. In addition, the influence of film on society's understanding of autism will be examined.

Chapter four provides a qualitative study which aims to access the experience of autism, from first and second-hand perspectives. Furthermore, this chapter aims to address the questions: "How does the world appear from the perspective of an individual with autism?" and "How can a NT understand this perspective?"

Finally, chapter five includes a discussion and conclusions along with recommendations for parents and educators of children with autism, as well as for all educators and society at large.

#### *Background to Disability and Autism*

*In New Keywords: A Revised Vocabulary of Culture and Society,*

Bennet, Grossberg & Morris (2005) explain that the use of the term disability in the political and personal identification sense is relatively new. The term disability was adopted rather recently and was meant to replace older terms such as "cripple" and "handicapped" (p. 87).

From the perspective of critical disability studies the definition of "disability" should recognize that it is a political and social issue, a notion that is evident in the following definition of disability:

The disadvantage or restriction of activity caused by a contemporary social organization that takes no or little account of people who have physical (and/or cognitive/developmental/mental) impairments and thus excludes them from the mainstream of society (as cited in Gabel, 2005: 113).

In Canada, there have been several initiatives that protect the rights of people who are considered disabled. For instance, the Charter of Rights and Freedoms, which is contained within the Canadian constitution, is intended to provide equality and protection for all citizens, including those with disabilities, under the law. The Canadian Human Rights Act prohibits the discrimination of people who are disabled. In 1998 it was amended to include a section that requires employers (federal and service providers) to accommodate persons with disabilities (American Foundation for the Blind, 2006).

In Ontario, as well as other places throughout Canada and the United States, there have been several court cases between parents and the government along with school systems, surrounding the issue of funding for special education. These provide evidence of the tensions that surround education and services for children with autism. In 2004 children under the age of six were eligible for funding for autism intervention programs; the government fought parents in court against the extension of these services

for older children ("As it Stands," 2007). In 2005 the Liberal government extended funding for children up to the age of eighteen. In part, this created the problem of a substantial increase in waiting lists for autism interventions from 89 children in 2004 to 382 children in 2005. Though these interventions usually take place outside of the school, training is underway for educators to learn skills to support Applied Behaviour Analysis (ABA), an autism intervention, in the schools ("As it Stands," 2007).

In 2004, a group of parents sued the Ontario government claiming that it was failing to provide sufficient funding for the schools to cover the costs of appropriate education and treatment of their children with autism. This can cost anywhere from \$30,000 to \$80,000 per child each year (CBC News, 2007). Many families have had to spend their life savings, re-mortgage their homes and take extra jobs in order to pay for their children to receive special education in private schools. In April 2007 they lost this case, but will continue to pressure the government to provide improved services for children with autism in the schools (CBC News, 2007).

### *What are Autism Spectrum Disorders (ASDs)?*

Autism is a pervasive developmental disorder which typically affects three key areas including, "language, social behaviors, and behaviors towards objects and routines" (Evans, 2006: 6). The term 'autism' was first introduced in 1911 by the Swiss psychiatrist Eugene Bleuler. The first individuals to document the syndrome of autism were Leo Kanner (1943) and Hans Asperger (1944) (Martos Perez et al, 2007: 9). The term 'autism' comes from the Greek word 'autos,' which means self (Kavale & Mostert, 2004: 99).

Autism disorders are currently believed to occur on a spectrum,

ranging from low to high in level of functioning of the individual. The autism spectrum is very broad, and can range from an extremely brilliant and capable professional to a non-verbal individual. There are five subtypes of autism: autistic disorder, Asperger's disorder, childhood disintegrative disorder (CDD), Rett's disorder, and pervasive developmental disorder – not otherwise specified (PDD-NOS).

Autism first appeared in the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III) (APA, 1980 as cited in Mesibov et al., 2001: 21). However the definition provided was criticized for being too narrow, failing to include those with higher functioning autism. Thus, the definition has been expanded in the text revision of the DSM-IV. The new definition states:

Autism is a devastating developmental disorder in which children present with core deficits in verbal and nonverbal communication, social interaction, and pretend or imaginative play...typical problems are observed regarding limited eye contact, an absence of appropriate facial expressions and gestures, a lack of developmentally appropriate peer relationships, an absence of shared attention, and a general lack of emotional or social reciprocity... No one behavior serves as a definitive diagnostic indicator; children with autism present with a variety of symptoms across cognitive, emotional and behavioral domains (also see Kabot, Masi, & Segal, 2003). Language and nonverbal communication skills are either absent or significantly delayed (American Psychiatric Association, 2000) (as cited in Hillman, 2006: 349).

The term "devastating", used to describe autism in the description above illustrates the prevailing view that autism is a terribly negative and undesirable condition. This fails to respect the experience of autism as a different way of knowing the world, a point that will be elaborated upon later in this work.

The prevalence of ASDs has dramatically increased in the past twenty years (Martos Perez et al., 2007: 21). Sicile-Kira (2004) notes that the rise

in autism cases has been so marked that "ASDs are clearly becoming the fastest-growing disability of this decade" (p. 12). In 1990, it was estimated that autism affected approximately 1 in 10,000 children, whereas recent studies have shown that this figure has climbed substantially. In 2003-2004 the Montreal Children's Hospital conducted an epidemiological study with preliminary results showing that there was a prevalence rate of 1 per 147 children with autism (Library of Parliament, 2006).

ASDs typically appear within the first three years of life (Sicile-Kira, 2004). Many researchers feel that autism is likely present from birth, or very soon after; however, because of its nature the specific disorders of developmental progression will not necessarily be obvious for several months or even years. Humphries (2000) explains that it is difficult to diagnose autism in infants due to the fact that all behaviour is immature.

Autism has become a prominent theme in developmental psychopathology though there are still many unanswered questions about its causes and best treatments. ASDs differ in the intensity of behavioural symptoms and the number of behavioural symptoms that an individual exhibits; there is no "standard" individual with autism, just as there is no "standard" neurotypical (Sicile-Kira, 2004). There are, however, many characteristics that are common to all individuals with this condition. One example is that individuals with autism frequently focus on the details, and tend to miss the larger picture. It is often difficult for these individuals to integrate different cognitive functions, such as hearing and seeing. One individual reports on his experiences:

Helplessly I sit while mom calls me to come. I know what I must do, but often I can't get up until she says, 'Stand up'...The knack of knowing where my body is does not come easy for me. Interestingly I do not know if I am sitting or standing. I am not aware of my body unless it is touching something...Your hand on mine lets me know where my hand is. Jarring my legs by walking tells me I am alive



(Chandira Rajapatirana as cited in Wallis, 2006: 36).

This inability to know where his or her body ends and the rest of the world begins is a characteristic that is common to some individuals with autism.

Autism spectrum disorders (ASDs) are four times more common in boys than in girls (Sicile-Kira, 2004). Currently, there are no medical tests which can diagnose autism; rather, autism is diagnosed as a result of behavioural tests, which sometimes results in confusion around the diagnosis as these tests are subjective (Bruey, 2004). Bruey (2004) recommends that in diagnosing autism, it is important to search for clusters in behaviour, as one or two behaviours alone do not indicate an ASD. There is no particular "autistic behaviour", but rather the underlying patterns of behaviour make the individual "autistic" (Jordan, Jones & Murray, 1998: 15). Clinicians look for what is generally known as a "triad of impairments," where the individual has behavioural differences in social relationships and interactions, language and social communication, as well as imaginative thought (Biklen, 2005).

### Causes

Currently, the cause of autism is unknown. However, researchers have found strong evidence that there is a genetic component and a biological basis, suggesting that autism is due to biological and neurological differences in brain structure or function, and individuals with autism have particularities in several areas of the brain. It is suspected that a disruption in fetal brain development may contribute to the condition. Furthermore, researchers have not been able to ascertain why the prevalence of autism has increased so drastically over the past few years (Sicile-Kira, 2004).

## Understanding Autism in the Context of Learning at FES

Autism can be understood in two basic ways. Under the prevailing medical model, autism is generally seen as a brain-based congenital condition (Durig, 2005). However, this is a limited view of autism, which views it as a condition that resides within the individual. Alternatively, autism can be understood from the perspective of critical disability studies “like other categories of disability...based on a particular and fluctuating construction of reality, varying with one’s goals, audience, frame of reference, and point of view” (Duchan, as cited in Biklen, 2005: 14).

This latter perspective of autism is consistent with the way that issues are examined in the Faculty of Environmental Studies, where things are understood contextually and in complex inter-relations. In his article *Thinking, Learning and Acting Environmentally* (2003) David Morley outlines the organizing concepts for teaching, learning and researching at FES<sup>3</sup>. He explains that

Environmental is viewed as both a *complex, dynamic and open system of relationships* (‘everything is connected to everything else’) and as a conceptual filter through which problems are viewed and addressed – studying in, with, and through environments (Morley, 2003: 1).

In line with the above definition, the Social Model of Disability views disability as defined by society and the environment (Albrecht et al., 2001). Scholars of disability studies have argued against the idea that a disability is something that a particular person has in his or her own body; rather, they identify the issue as “a problem located in the interaction between bodies and the environment in which they are situated” (R.G. Thomson, 1997: 296

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<sup>3</sup> This study examines autism by using several of the criteria for studying environmentally proposed by FES. For example, context is considered explicitly in that the school environment is analyzed in terms of how it serves the needs of children with autism. Furthermore, autism is viewed holistically and from multiple perspectives including those of activists, parents and educators. Studying autism in this manner can help to elucidate the significance of FES’s approach of “thinking, learning and acting environmentally.”

as cited in Erevelles, 2005: 67). For example, an individual is thought to be “with” a disability, but they are not merely the disability (Albrecht, 2001: 403). This field rejects the medical model of disability because it does not fully explain the lived experience of the individual, and furthermore it pathologizes individual differences and relies on experts to “fix” these differences (Society for Disability Studies, Guidelines for Disability Studies” 913 as cited in Gabel, 2005, 2-3).

FES’s pedagogy takes a contextual approach where it seeks “the understanding of a situation by placing it in the context from which its meaning is derived: societal, temporal, cultural, ecological, ideological, political, community, institution, etc.” (Morley, 2003: 2). This notion, in echoed by research on autism which has shown that it is problematic to search for over-arching explanations of autism because these types of theories propose that autism is central to the person, and ignores the importance of the environment (Biklen, 2005: 44). For instance, one common symptom in autism is echolalia, which is the repetition of speech made by another person. In one example cited by Biklen (2005) echolalia disappeared when a student felt engaged in a lesson and the classroom environment.

Morley (2003) emphasizes that studying environmentally means that whatever is being studied is part of a system and should be studied in relation to that system because it cannot be fully understood if studied in isolation. He further emphasizes the transdisciplinary nature of Environmental Studies. Based on these guidelines, it would be a mistake to view autism merely as a condition of the particular brain chemistry of an individual. Rather, autism can be more fully understood as a complex way of being and interacting with the world. In keeping with Morley’s

explanation of environmentalism as interdisciplinary study, the present work draws from several different disciplines including critical disability studies, as already discussed, and critical pedagogy and critical special education which will be discussed at length in chapter two.

### Themes in Critical Disability Studies as Related to Autism

Earlier a number of different themes relating to critical disability studies were identified. The following is a discussion of some ideas that emerge out of these themes.

#### *Honouring the Experience of "Disability" by Problematizing "Disability"*

Disability is not an absolute condition (Rocco, 2002). Characteristics that are considered impairments depend on the conditions that exist in society, for example it could be advantageous to be deaf in a society where loud noises abound (Albrecht et al, 2001: 224). Some conditions classified as diseases or impairments at one point in time, cease to be considered as such when norms sway or change. Critical disability theory emphasizes that a person has a disability only with respect to a certain environment, it is not an absolute state of being in the individual (Albrecht et al, 2001). For example, autism is said to affect "verbal and nonverbal communication, social interaction and pretend or imaginative play" (Hillman, 2006: 349). However, this can be taken to mean that typical Western communication styles are at odds with the communication styles of children with autism. Thus, many western environments disable the person with autism.

### Visibility versus Invisibility

An important term in the field of disability studies is visibility. Gere (2005) provides the example of classroom gaze, a term coined by Michel Foucault, where the instructor and students are involved in observing one another's physical body thinking that it will reveal truths about the other's way of being (p. 54). Certain disabilities appear invisible because there are no physical features to accompany the disability. Gere tells about her own daughter's experiences as a 19-year-old student with Fetal Alcohol Syndrome. Gere writes that frequently teachers complain that her daughter does not try hard enough or apply herself sufficiently, not realizing the enormous effort that it takes her to merely pass a course because of the challenges presented by her disability. When informed of her daughter's condition, many teachers express surprise and disbelief, protesting that she looks so normal.

Visibility is also an issue for people with autism, particularly those students with high functioning autism. The lack of physical signs to indicate autism leads some teachers to conclude that the child is rebellious, rather than unable to comply with classroom rules and instructions (Williams, 1992). Gere explains that "Invisibility demonstrates the limitations of the gaze of the teacher, showing how easy it is to misinterpret in the act of reading another's body" (Gere, 2005: 58). Critical disability theory emphasizes that there is a continuity between the impaired and the temporarily able-bodied. Individuals who are born able-bodied are often only temporarily able-bodied, where age, accidents and disease can change this. Furthermore, the process of aging links able-bodied individuals to disabled individuals. Similarly, neurotypicals may not always be this way. This fact makes it even more important to understand and appreciate life from the perspective of people with exceptionalities (Gable, 2005).

Invisibility of disabilities challenges typical ways of knowing. Gere claims that, "Specifically, our tendency to give power to the visual leads us to construct discourses that depend upon equating what we can see with what is real" (p. 61). Furthermore, Gere notes that "Research based on a medical model of disability rarely includes the voice of the person with impairment" (p. 60). Advocates of disability studies have argued against this as something that acts to further marginalize the disabled/differently abled community.

Erevelles (2005) examines how differences in terms of disabilities are organized in the schools. She argues that in order for disability studies to be truly emancipatory, there must be a recognition that people of all abilities are members of the same continuum. The present study is centered on the belief that if society does not learn about autism, and the unique ways of knowing and being of people with autism, not from a clinical perspective which pathologizes these individuals, but rather from the perspective of wanting to understand and appreciate the differences, then everyone will lose out on the unique gifts of people with autism as well as an expansion of the current predominant understanding of the world and reality. This would signify a great cost to society.

### *Inclusion versus Exclusion*

Social networks are vital in the lives of people with disabilities, especially people with autism, as often these individuals are excluded from society (Albrecht et al, 2001). In his book *Autism and the Myth of the Person Alone*, Douglas Biklen disputes the prevailing notion that individuals with autism do not desire any social contact. He explains that it is often difficult for these individuals to communicate with neurotypicals because

they do not communicate in the same ways. Biklen conducted a qualitative study where he interviewed several individuals with autism. He found that communication and the feeling that others were listening was important to these individuals. One major concern is that people with autism often have great difficulty in establishing and maintaining friendships because of their difficulty with reading and understanding social cues. Frequently family and professionals who work with them are their only connection to society (Biklen, 2005).

### *Disability as a Political and Social Issue*

Disability politics suggests that the disabled are systematically excluded from participation in everyday life. Erevelles (2000) notes that in 1995 the World Summit on Social Development reported that disabled people constitute one of the world's largest minority groups facing poverty, unemployment, and social and cultural isolation. Disabled people are among those who are most marginalized and abused; they have the greatest need of advocates and the least ability to advocate for themselves (Ware, 2005).

### Conclusion

This first chapter provided some background information as well as an outline of the structure of this work. This paper will explore autism through the counter-hegemonic notions provided by a critical disability studies framework. This inquiry will be guided by the four themes elaborated upon above, as well as questions mentioned earlier in the chapter.

## Chapter 2: Review of the Literature

Education for children with autism has become an important issue for the school system. Since the 1970's there have been several movements to create inclusive classrooms where children with disabilities such as autism are educated in mainstream classrooms in their neighborhood school. Inclusion has been taking place in Canada and internationally, due in large part to several different initiatives and treaties including the United Nations (UN) Convention on the Rights of the Child (1989), the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993) and the United Nations Educational, Scientific and Cultural Organization (UNESCO) Salamanca Statement (1994) (Klar-Wolfond, 2006). Inclusion brings with it many issues that will be discussed in this chapter.

This chapter aims to explore the question, "Do pedagogical approaches taken with children with autism adequately address their unique ways of being?" To answer this, the chapter begins by examining the concept of normal as it is often taken for granted in the school system as well as in society. Following that, there is a brief discussion of critical pedagogy along with a literature review of critical special education. After this, the question of how autism is being approached by researchers and what kind of information this is garnering will be examined through a discussion of trends in autism research.

### Problematizing Normal

In examining the history of disability in the west, Albrecht, Seelman & Bury (2001) note that disability has raised questions of normality, and the differences represented by people with disabilities have been perceived as a threat to the established social order as well as mechanisms of social control



(p. 5). In an effort to re-establish social control, many individuals were institutionalized for being different (Foucault, 1973). In general, people with disabilities have experienced much rejection and been denied a sense of full belonging in society.

One means by which people have typically been identified as different is through comparison to what is “normal.” The concept of the norm is integral to modern society, and often goes unquestioned. In fact, the concept of normal has driven disability research (Albrecht et al, 2001). Critical disability studies points out that the notion of the norm is a statistical concept that emerged out of nineteenth century Europe, while the field of statistics was developing (Davis, 1997 as cited in Gere, 2005).

Statistics assumes that the population can be normed, and divided into standard and nonstandard deviations, where people with exceptionalities such as autism as well as other disabilities lie outside of the desired norm. Davis (1997) points out that there was a strong connection between statistics and eugenics, which is the field that is concerned with improving inherited human traits by selective reproduction, out of a belief that this would improve human life and create a “healthier” society (as cited in Gere, 2005).

The behavioural symptoms given for autism are based on behavioural norms, and normal developmental milestones. This is potentially problematic as it creates an opening for labeling individuals who do not meet these milestones as abnormal and deviant. In fact, Amundson (2000) argues that “the doctrine of biological normality (used by philosophers and medical practitioners) has been used to rationalize neglectful (or intrusive and demeaning) social responses to disability” (as cited in Albrecht et al.,

2001: 225).

The normalization principle was taken up by the psycho-medical model of disability. It was limited in that it assumed that only one set of norms was appropriate and necessary for all groups (Jensen, 1980 as cited in Albrecht et al., 2001: 281). The disabled person was given the sole responsibility to change to be more acceptable and “useful” to society (Albrecht et al, 2001).

Through evaluating the notion of normal it is evident that one major problem with normalization is that it failed to recognize the uniqueness of individuals, and to celebrate these differences. In an effort to achieve greater tolerance, it is important for neurotypicals (NTs) to examine their own preconceptions of normal, and to attempt to understand the world from the perspective of individuals with autism. In the words of Durig (2005)

We need to be able to see the world through the eyes of a person who has autism. We need to reexamine our assumptions of normalcy, because implicit in our assumptions of normalcy lies hidden the idea that the autistic person is an inferior person (p. 15).

There has been an attempt to move away from the normalization movement as there is an increased recognition that it “supports the objectifying and commoditization of persons with intellectual disabilities” (Albrecht et al., 2001: 281). As part of this increased social awareness, there have been many changes to the nomenclature used to refer to people with differences, where many old terms are now considered unacceptable resulting in a search for new, less stigmatizing terms (Albrecht et al., 2001).

### Critical Pedagogy and Disability

Critical pedagogy and critical theory are topics which have received a substantial amount of research attention by several disciplines, particularly

in the past few decades. Critical pedagogy argues that school curriculum should be informed by practices that empower the lived experience of all students, rather than just a privileged few, and is primarily concerned with “understanding the relationship between power and knowledge” (McLaren, 2003: 83). A central issue in critical pedagogy is the notion of power in the teaching and learning relationship. In contrast, mainstream curriculum seems to separate knowledge from power. Another central aim of critical pedagogy is to promote education that contributes to the development of a world that is socially just (Breunig, 2005).

Several critical pedagogy theorists have said that education and research are always value-laden (Giroux, 1997). One example of this is that in Western society, much education for children with autism attempts to manipulate behaviour to make it appear “normal.” This approach is not only disrespectful, but also not possible. This point is illustrated in a quote by an individual with autism:

People do seem to have trouble realizing that we can learn a compensatory skill, but not how to be 'normal' (even if we wanted to be totally normal). They can't realize that our brains and thought processes are different and that we can't change that any more than the blind can learn to see with their eyes. Or that what is adaptive for normal may be maladaptive for us (and vice versa), and that, in most cases, our ways can be better for us (and can allow us to function quite well in certain situations and at certain tasks). I think a cure for 'normalcy' would be a much better goal than a cure for autism; normalcy is much more prevalent! (Jared (1993) as cited in Jordan, Jones & Murray, 1998: 15).

Individuals with special needs, such as autism, are generally taught in a way that assumes that they have “deficits,” and ignores the fact that these students may learn in a way entirely different from the mainstream population (Gabel, 2005).

Paolo Freire, one of the early proponents of critical pedagogy, felt that

the purpose of education was to raise an individual's consciousness from a state of oppression. Freire rejected the "banking" model of education where the student is considered an empty vessel to be filled (Freire, 2005: 72). In fact, he felt that students who were filled with the knowledge of others while rejecting their own way of being were not actually learning (Gadotti, 1994: 42). Furthermore, he felt that the banking model of education maintains a harmful power hierarchy with the teachers in power, and the students subordinate (Gadotti, 1994). Freire felt that students should not be regarded as people who know nothing, but rather as individuals who have the knowledge of their own life's experiences (Gadotti, 1994). He advocated for a more egalitarian or "co-intentional" approach where teachers are learners and learners are also teachers (Freire, 2005). In applying this concept to special education, NTs would learn from individuals with autism, as well as teach them tools for communicating in a NT way. This would demonstrate more egalitarian and respectful communication than the current unidirectional teaching mode.

### Literature Review of Critical Special Education

Critical pedagogy has tended to overlook issues related to special education. Thus, related to the field of critical pedagogy, but less well known, the field of critical special education has emerged. One of the important figures in this field, Nirmala Erevelles (2000), notes that:

Even though critical theorists of education have privileged the theorization of the body along the axes of race, class, gender and sexuality, they have consistently omitted any mention of the "disabled" body. Such omissions reflect the historical practices within American public education that continue to marginalize the issue of disability by maintaining two educational systems – one for disabled students and one for everyone else. Based on these discriminatory educational policies, more than five million students with disabilities have experienced segregation in special education programs that are,

in effect, both separate and unequal. This has contributed to the continued unemployability of disabled people in a highly competitive market economy and thus the conditions of poverty in which many of them live (p. 25).

In the above quotation Erevelles is discussing the issue of inclusion. There are some who have argued that mainstreaming is not always appropriate and can in fact be detrimental to the child (McGregor & Campbell, 2001). The experience of being in a predominantly NT class can be frustrating and confusing for the child who realizes he or she is different, and does not understand what is happening around him or her, or is overwhelmed by the constant stimuli in the classroom environment.

The fact is that most children with autism are educated in specialized schools, though this is not necessarily the best place for them (Bruey, 2004: 184). With specialized schools, it has been argued that one of the main disadvantages of specialized schools is that the children with ASDs are separated from their NT peers, and thus do not learn to communicate with them by modelling their behaviour (Bruey, 2004). It can further be argued that NTs are disadvantaged by being separated from children with ASDs as they do not learn to communicate with them.

Inclusive education, where NTs and children with ASDs are schooled together, addresses the above critiques. This model is gaining popularity in school boards across Ontario. The idea is based on the Salamanca Statement of UNESCO which claims that "regular schools with this inclusive orientation are the most effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all" (UNESCO, 1994 as cited in Broekhof, 2007).

In order to receive special education, the Ontario Ministry of Education policy requires that a child first be identified as having an exceptionality, and

subsequently assigned an Individual Education Plan (IEP). This IEP, which is supposedly developed to aid the child in learning the curriculum, is a double-edged sword as it also “allows the educator to follow a policy that was developed to exclude children from the regular classroom, on the basis that a protected environment is necessary for the child to learn effectively” (Broekhof, 2007: 3). This again excludes the child from the mainstream classroom by relegating ASD children to a special education class.

Environmental accommodations must be made for children with ASDs to be successfully included in mainstream classrooms. For example, most children with ASDs require the one-to-one assistance of an educational aid in order to be successful (Bruey, 2004). Renzaglia et al. (2003) note several practices to promote successful inclusion that are primarily aimed at equipping disabled individuals with necessary skills to match the demands of their environments. This, along with appropriate supports, can successfully promote inclusion into virtually any environment (as cited in Yell & Katsiyannis, 2003).

Critical special educators have challenged issues of assessment and the labelling of students and questioned whether these actually produce placements that are in the child’s best interest (Gabel, 2005). One reason is that special education has historically been seen as a “dumping ground” where pupils that the classroom teacher does not want to deal with are babysat rather than taught (Dorn, 2002: 279).

There are several issues around diagnosing and labeling children as having an ASD. On the one hand, labeling creates stigma, thus some parents resist a diagnosis for their child (Sicile-Kira, 2004). In order to

access government funding, a label is necessary. For this reason, some parents even exaggerate symptoms so that the label is more severe and the child is entitled to better services, or does not have to wait as long to receive services (Nadesan, 2005). It can be argued that the real problem lies in how society reacts to labels. Society must learn to understand and value differences rather than fearing them.

Learning how to deal with differences is becoming an increasingly important issue as there has been a dramatic increase in the number of children with autism who are educated in public schools (Yell & Katsiyannis, 2003). In reviewing the literature, it is evident that there is a lack of sufficient scientific evidence to support any of the particular educational approaches to teaching children with autism enough to conclude that it is the best method or even that it is the most indicated and correct method to use with a particular subgroup of children with autism (Jordan, Jones & Murray, 1998; Ware, 2005). Linda Ware (2005) further argues that the focus on “evidence based” research employing scientific methods have not contributed to real improvements for programs for children with special needs (p. 107). Currently there are a variety of methods of education that can be effective for different individuals. It is important to choose methods that cater to the needs of the individual. Some studies conclude that the teacher’s commitment and ability to engage with the individual with autism is often more important than the method of education (Jordan, Jones & Murray, 1998; and Grandin, 1996). More work remains to be done.

Though there is no single “best” educational program, research shows that intense instruction (twenty hours or more per week) has shown positive results in research as well as enabling half of the students treated to be included in mainstream classrooms (Jordan, Jones & Murray, 1998). One

drawback of these studies is that they lacked the scientific criteria of random assignment (Gallagher, 2002: 57).

Iovannone, Dunlap, Huber and Kincaid (2003) have identified vital elements with empirical support that should be included in programs to teach children with ASDs, including:

(a) Individualized supports and services for children and families, (b) systematic instruction, (c) comprehensible/ structured learning environment, (d) specialized curriculum content, (e) functional approach to problem behaviour, and (f) family involvement (as cited in Yell & Katsiyannis, 2003: 138).

This last element of family involvement which is particularly important is further elaborated upon in Harding, London & Safer's (2001) article entitled "Teaching Other People's Ideas to Other People's Children: Integrating Messages from Education, Psychology, and Critical Pedagogy." They emphasize that instead of blindly following curriculum, teachers should consider the needs of the particular students in their class (autistic and non-autistic), before preparing lessons. In addition, they should incorporate material that the family thinks is important for the child to know, rather than assuming that as a teacher he or she knows best. These authors acknowledge that children and teachers of diverse backgrounds can enrich education. Since autism is present across cultures and socio-economic groups, cultural elements should be considered.

In teaching children with autism, teachers must examine many things that they take for granted with neurotypicals. As part of this, critical pedagogy identifies and analyzes the hidden curriculum that is



composed of unstated values and hegemonic norms that are transmitted invisibly in students' everyday worlds (Kanpol, 1996). This hidden curriculum is present in what is being taught without the teacher even being aware that he or she is teaching it. Some actions taken for granted by teachers as insignificant can have negative results when used with children with autism. For example, many students with high functioning autism who have language skills can interpret things literally, so it is important that teachers avoid using sarcasm, slang and idioms with these students as these can be interpreted literally and result in teaching the opposite of what the teacher intends to teach (Hardman, Drew & Egan, 1996: 380 -381).

### Autism Research

Dawson and Osterling (1997) note that in autism research there is a paucity of truly scientific experimental studies with random assignment of children to different groups, as well as researchers who are blind to which group the children are assigned (as cited in Gallagher, 2002: 57). Most autism research is quasi-experimental (Biklen, 2005). One of the main problems with doing research in autism is that as autism is a highly medicalized field, it is difficult to step outside of this conceptualization, in fact "most of the language of the field assumes a shared, normative perspective of an observable reality" (Biklen, 2005: 11). An example of this is evident in the definition of autism provided by the DSM-IV which includes a description that is judgmental, calling actions displayed by people with autism "ritualistic" rather than "consistent, and referring to "persistent preoccupations" rather than "interests" (Biklen, 2005: 12). This objectifies and "others" the individual with autism, with the implicit view that the NT state is superior.

Clinical reports show that intense early treatment of children with autism has resulted in one half of these children being incorporated into a general classroom (as cited in Gallagher, 2002: 57). There are high costs associated with intense intervention programs, and this has created tensions between parents and the school systems (Lord, 2001 as cited in Gallagher, 2002: 57). Some have suggested that careful studies should be designed and conducted around claims of treatment programs for children with autism to determine whether these programs truly merit the high costs (Paul et al., 2002). This idea is emphasized by the Jordan, Jones & Murray (1998) report that reviewed educational approaches for teaching children with autism. This study concluded, "No approach has been entirely successful in producing a methodologically sound evaluation of its work" (p. 121). In addition, it appears that there is no consistent pedagogical method that is successful in all cases (Jones & Murray, 1998).

In terms of research paradigms, there has been an evolution from the old to the new paradigm of disability and families in disability research. The old paradigm emphasized disability as a characteristic of the individual, whereas the new paradigm focuses on the differing abilities of the person and disability as an interaction between the individual and the environment. Disability is now seen as a social creation that is based on the interaction between the person and the environment, where the environment is responsible for the disability as it limits the agency of the individual (Albrecht et al, 2001: 171). Although the new paradigm is evidently more enlightened than the old, society at large does not appear to have taken on these liberating values and attitudes in dealing with people with disabilities. Many still blame the person with a disability for his or her condition.

The old paradigm of research and service provision views disability as

resulting from deficits within the individual, which cause impairments in daily activities. Thus, the old paradigm viewed the disabled individual as needing to be “fixed.” There was no mention of modifying the environment to suit the needs of the individual (Turnbull & Turnbull, 2002). The old paradigm was composed of three parts including: the psychotherapy model, the parent-training model, and the parent involvement model (Turnbull & Turnbull, 2002).

The psychotherapy model of the 1950’s and 60’s treated the birth of a child with autism as a tragedy (Turnbull & Turnbull, 2002). Psychotherapy was done with the mother in the hopes that it would “fix” her relationship with her child, and thus “cure” her child of the autism (Paul et al., 2002: 84). There was no support given to the mother in her day-to-day dealings with the child. There was the notion of the “refrigerator mother” where mothers were blamed for being cold and unfeeling, failing to nurture their child, thus causing the child to withdraw inwards, an idea that was popularized by Bruno Bettelheim (Sicile-Kira, 2004).

The change in psychiatry’s perception of autism can be attributed to the work of Dr. Bernard Rimland. Dr. Rimland was a psychiatrist and researcher who also had firsthand experience with ASDs as his son had autism. He concluded from his research that autism was biologically based, rather than emotionally based (Sicile-Kira, 2004).

The parent training model started in the 1970s and continued in the 1980s, with the focus being on training parents, rather than psychotherapy. However, this model also considered that the child had autism due to the deficits of the parents (Paul et al, 2002). The goal was to

“Fix” the child with the disability by “fixing” the parents’ competence. Once again, professionals maintained a power-over relationship with

parents as they instructed them and guided them in skill acquisition (Turnbull & Turnbull, 2002: 86).

The parent involvement model was started around 1975 and it focused on involving the parent in academic decision-making (Turnbull & Turnbull, 2002). One critique is that it has meant primarily the involvement of mothers.

In the new paradigm of disability and families, the emphasis changed from professionals having power-over families to having power with families, where families are to decide and demonstrate their own priorities (Turnbull & Turnbull, 2002: 92). The entire family is now viewed as the unit of support, not just the child and his or her mother.

The new paradigm of research and service provision focuses on adapting all environments to make them favorable to the person with a disability, rather than focusing on the mother-child dyad (Turnbull & Turnbull, 2002). Furthermore, this paradigm focuses on empowering the family by focusing on their strengths, rather than exerting power over them. There is a focus on participatory action research with this model. The focus of this paradigm is on modifying the environment, with two key themes being:

- “Fixing” the broad environment (from macro to micro levels) so that all of society, including families of children and youth with disabilities, take actions to ensure quality of life outcomes.
- A transformed ecology ... in order to enhance family quality of life outcomes (Turnbull & Turnbull, 2002: 96 –97).

It is evident that environmental accommodations are a key theme in the evolution of the old to the new paradigm of disability research. This is in line with the social model of disability which views disability as a product of the environment, rather than a characteristic of the individual. The qualitative study conducted as part of this major paper is consistent with the

new paradigm.

### Chapter 3: Ways of Knowing in Autism

The predominant view that individuals with autism have a deficit which needs to be remedied will be explored and challenged in this chapter. There will be an effort to understand ways of knowing in autism, in an attempt to resist ways in which they are disappeared, disrespected and misunderstood. In particular, this chapter will examine the following questions:

- Does mainstream education address the ways of knowing of people with autism?
- What knowledge can be accessed through experiencing the world through autism that cannot be accessed by experiencing the world as a neurotypical?
- What recommendations do individuals with autism have for educators working with children with autism?
- How does the portrayal of autism in film influence society's understanding of autism?

One method of exploring these questions is through investigating the means through which children with autism acquire and create knowledge. In particular, "ways of knowing" can be defined as "a composite construct that incorporates one's understanding about the nature and source of truth, decision-making processes, justification of perspective and attitudes toward dilemmas" (Botella and Gallifa, 1995 as cited in Reybold, 2002: 537). In this work, ways of knowing will be used to refer to the ways in which individuals acquire and process information about the world, and how they use this information to interact with the world.

The concept of intelligence is a construct that has been used to describe knowing. For centuries, scholars have been interested in

understanding different ways of thinking. In spite of this, for many years intelligence was understood in narrow terms, as a uni-linear trait that was static over time (Gardner, 2006). Standardized tests, such as the IQ test, arose out of this notion to measure a particular type of intelligence (Gardner, 2006). People whose minds work differently from what these tests privilege are at a disadvantage in terms of success in school (Gardner, 2006).

The theory of multiple intelligences (MI), developed by the educational psychologist Dr. Howard Gardner, arose to challenge the limited conception of intelligence provided by standardized tests. MI theory was developed from research in the fields of developmental and neuropsychology. It provides a framework to understand the different and unique competencies of individuals, many of whom fall outside of the dominant Western conception of intelligence. This theory recognizes that people have many different strengths and styles of learning (Gardner, 2006). It argues that peoples' cognitive ability is better described as a set of "abilities, talents or mental skills" rather than a uni-dimensional entity (Gardner, 2006: 6). The multiple intelligences outlined include: "verbal/linguistic, visual/spatial, musical/rhythmic, logical/mathematical, body/kinesthetic, intrapersonal and interpersonal, and naturalistic intelligences" (Checkley, 1997 as cited in Simms Shepard: 210).

In examining education for children with autism, one sees that some of the current approaches to teaching fail to reflect the different ways in which these children learn. For example, the popular Applied Behaviour Analysis (ABA) attempts to use the principles of behaviourism to reprogram the behaviour of individuals with autism, without recognizing individual styles of learning. This is in part due to the fact that traditional schooling is not flexible in addressing different styles of learning because in general it "acts

to perpetuate dominant ways of knowing" (Breunig, 2005: 112).

In this way, schools are environments which can disable individuals. Simms Shepard (2004) notes that the Western educational system "relies heavily on a traditional verbal-linguistic approach" that assumes that all students "are fluent in English and comfortable with spoken and written language" failing to make accommodations for those who are not (Simms Shepard, 2004: 210). As has already been discussed, and will be illustrated by the following examples, many individuals with autism have difficulty with spoken and written language.

The following sections will provide some specific examples of individuals with autism in the literature to examine ways of knowing. Their accounts of experiencing disability through the limitations of particular environments will also be discussed.

### First-Hand Examples of Knowing through Autism

Over recent years, there have been several first-hand accounts of autism that are useful in elucidating knowledge acquisition. Although each individual is unique, there are some characteristics which are common to many people with autism which make individual cases useful. This section includes an examination of two famous individuals, Temple Grandin and Donna Williams, who were among the earliest figures to write about their experiences with autism.

#### *Temple Grandin*

Temple Grandin is a professor of animal behaviour who has designed two-thirds of the livestock handling facilities in the United States; she is also an individual living with autism. In her book, *Thinking in Pictures*, Grandin (1995) explains that she is a visual thinker, in fact she can only understand

things as visual images. Thus, when she is spoken to, she must translate the words into pictures in order to make sense of what is being said. In describing her thinking process, Grandin says that:

Unlike those of most people, my thoughts move from video-like, specific image to generalizations and concepts. For example, my concept of dogs is inextricably linked to every dog I've ever known. It's as if I had a card catalogue of dogs I've seen, complete with pictures...My memories usually appear in my imagination in strict chronological order, and the images I visualize are always specific. There is no generic, generalized Great Dane (Grandin, 1995: 27-28).

Grandin recalls that she was nonverbal until the age of three, though she understood everything that was said to her. This was a very frustrating experience for her, which resulted in numerous behavioural outbursts. Grandin attributes her learning to her mother's unfailing commitment to finding her tutors who were able to teach Grandin in a way she could understand (Grandin, 1995).

In Grandin's career, this apparent disability of thinking only in visual images has served her as she has been able to solve many problems in the design of cattle handling facilities by using this way of thinking. She has been able to view her mental images of machinery from many different perspectives to discover flaws and figure out ways to fix them (Grandin, 1995).

As difficult as autism has been for people without it to understand, and still presents a challenge for parents and professionals as well as lay people, it is evident that people with autism also find the predominant ways of thinking and understanding the world strange and perplexing. Temple Grandin reports that while she was growing-up, she did not realize that others without autism were not visual thinkers to the extent that she was. She says that even in her job she often fought with other engineers at the meat packing plants where she worked designing equipment because she



could not understand why the other engineers did not see mechanical errors before installing the machines. This was a source of intense frustration for Grandin, as she “ran” the machines in her mind and could pick out errors before the machines were physically installed. She later realized that the other engineers did not use this same process out of ignorance rather than carelessness. Grandin explains that, “Now I realize it was not stupidity but a lack of visualization skills. They literally could not see” (Grandin, 1995: 26). Grandin’s comment is an interesting spin on the predominant NT assumption of ability, because from the point of view of a person with autism with gifted visualization skills, NTs who do not have them are disabled.

### *Grandin’s Recommendations for Educators*

From her own experiences, as well as from working with others with autism, Grandin has several recommendations for educators. When working with the many individuals with autism who are visual thinkers, Grandin notes that it is easiest for them to learn things that can be taught visually. For example, it is useful if a schedule can be written down. Teachers can help students with autism by writing the schedule on the board everyday, or writing it individually for the student to have at his or her desk. In terms of language, Grandin mentions that it is easiest for children with autism to learn nouns because they can be put into pictures. In contrast, words that cannot be associated with a picture often have little or no meaning (Grandin, 1995).

Grandin further explains that frequently people with autism have a different sense of their body boundaries. She provides the example that they are unable to judge by using the sense of touch where their body ends and the chair begins. Rather than being a disability, at times this provided Grandin with the ability to operate cattle equipment as an extension of

herself. She could effortlessly concentrate on the cow's subtle movements and respond to these by making minute adjustments to the machinery so that the cow would be comfortable (Grandin, 1995). This is a representation of Gardner's kinesthetic intelligence.

Not all behaviour should be accepted or encouraged in children with autism. Grandin cites the example of rocking, which is a common characteristic of children with autism. Grandin claims that though rocking caused her to feel calm, it was addictive as the more she engaged in it the more she wanted to continue to rock rather than doing anything else (Grandin, 1995: 44). Another characteristic that people with autism have is difficulty adjusting to change. Many insist on keeping their routines exactly the same from one day to the next as new situations can be frightening and confusing. If caregivers give into this desire and attempt to maintain everything consistent without introducing the slightest change, it can be disastrous when there is an unavoidable change in the child's schedule.

Grandin states that people with autism often lack what others term "common sense." They can learn a series of steps, but cannot make a creative solution if one step is missing. Many also are not able to generalize well, thus the skills they learn to apply to one situation are not usually transferred over to a different situation. Teachers must be aware of this and tailor lessons to develop strengths and work on weaknesses.

In Grandin's instructional video entitled *Sensory Challenges and Answers* (1998) she explains the importance of a good teacher in helping and educating a child with autism. She says that it is necessary for teachers to engage children in the learning, as by nature children with autism attempt to withdraw into themselves, and if allowed to do this completely, they could acquire secondary brain damage from being under-stimulated. Thus, it is necessary for the teacher to keep the attention of the child. However, it

must be noted that some children cannot pay attention to spoken words and visual stimuli at the same time. In this case, care must be taken to present only one stimulus at a time. Lack of eye can be a way of dealing with this inability to attend to multiple stimuli, or it can result from finding direct gaze too personal and frightening (Grandin, 1995).

Despite the challenges Grandin faces in living as a person with autism in a predominantly neurotypical world, she claims that, "If I could snap my fingers and be nonautistic, I would not – because then I wouldn't be me. Autism is part of who I am" (Grandin, 1996: 16).

### Donna Williams

Another famous individual living with autism is Donna Williams, an author, artist, screenwriter and composer. In her first book, the bestselling autobiography entitled *Nobody Nowhere*, Williams describes the experience of growing-up in Australia in the 1960s and '70s as a person with undiagnosed autism. She explains that from a young age she was aware that her habits and ways of exploring the world were considered strange and rejected by others. In describing her early understanding of others and the world, Williams writes that "The world seemed to be impatient, annoying, callous, and unrelenting. I learned to respond to it as such, crying, squealing, ignoring it, and running away" (Williams, 1992: 4).

Autism was almost unheard of while Williams was young. Medical professionals who examined Williams were unsure of what to make of her. They encouraged institutionalization, but Williams' father was against it thus she was kept at home (Williams, 1992). It was not until she was in her twenties that Williams received the formal diagnosis of autism.

On Williams' website, she describes the experience of growing up as

someone who did not belong anywhere, was not understood by others and in turn did not understand others or the world around her. She felt as though she was in a 'feral' state, and one of constant chaos where before the age of nine she was unable to even understand three sentences strung together (Williams, n.d.).

In identifying her abilities, Williams writes that she has always been gifted at pattern recognition, though she has not always been able to interpret the meaning of the patterns. For a long time, she claims she was "largely meaning deaf and meaning blind as well as face-blind" (Williams, n.d.). She could not understand why people acted the way they did, everything seemed random, which meant she was wary of people invading her world (Williams, n.d.).

In describing her own thinking and way of relating to the world, Williams says:

I don't think in pictures. I'm a kinesthetic thinker, a systems thinker, a musical thinker. Mine is a physical and sensory world of pattern, theme and feel (Williams, n.d.).

The thinking Williams describes is evident in the writing style of her autobiography, which is written in a nonlinear fashion with changes in time periods and characters which are not prefaced by any explanation. It is important to note from the above description that Williams is not a visual thinker, in contrast to Temple Grandin. This emphasizes the point that individuals with autism do not have only one way of thinking, though they may have some similarities in their thought patterns. However, similar to Grandin, Williams also possesses kinesthetic intelligence.

Williams points out that individuals with autism often feel a lack of connection to the world because of their differences which isolate them from

society. She discusses her own difficulties with forming connections, relating these to behaviours she exhibited which seemed odd and unusual to NTs. Contrary to what many NTs around her thought, these behaviours were useful as they enabled her to conceptualize ideas, such as connectedness. In the following passage, Williams provides a description of the behaviour followed by an explanation of the function it served:

The ordering of objects and symbols  
Proving that belonging exists and giving myself hope that I, too, could one day feel this same special and undeniable place where I, too, fitted in and belonged in 'the world.' Also creating order and thereby making this symbolic representation of 'the world' more comprehensible (Williams, 1992: 189-190).

It is evident in the above examples that a kinesthetic way of knowing is being employed to understand the world. Furthermore, it is evident that behaviours that appear random and useless to NTs are often useful and necessary for individuals with autism to relate to the world.

### *Williams' Recommendations for Educators*

Williams explains that the meanings and motives of behaviour should not be taken for granted by educators. She cites the example of laughter, which is usually taken to mean enjoyment. Williams mentions that for her, "Laughing can mean enjoyment, understanding or fear" (Williams, 1992: 188). This is also so in NTs, as different individuals may demonstrate the same behaviour, but mean different things. Educators should be aware of this in interpreting behaviour.

Williams also recommends that the educator should gain the child's trust by making it clear that the educator accepts the child as he is, before attempting to teach anything that will take the child away from this way of being. She notes that this acceptance frees the child to reach out, rather than having to adopt conforming behaviours out of fear, which creates "role-

playing robots" (Williams, 1992: 180). She further notes that a delicate balance is important in the intonation of the voice of the educator. The voice should be predictable to a degree, but not overly so that it would be

drowned out, or so unpredictable that it would be frightening to the child (p. 188).

### Other Voices from Individuals with Autism

Temple Grandin and Donna Williams are excellent resources in describing ways of knowing in autism. However, they are individuals with high-functioning autism which does not represent the entire spectrum. In his book *Autism and the Myth of the Person Alone*, Douglas Biklen draws on the perspectives of people who are lower functioning, meaning that they display more pronounced characteristics of autism. The book is a qualitative study, written from a critical disability studies framework, where individuals with autism are primary contributing authors. A basic premise of the book is that people classified as autistic, even those who cannot speak, are thinking people with ideas about their lives and their relationship to the world. Biklen calls this approach the *presumption of competence* (Biklen, 2005: 1).

Biklen's role in the research was to gather the information and ask clarifying questions, but not to impose his own meaning on the information the participants provided. He allowed them to speak for themselves, and was aware that he could not assume he knew what they meant until they confirmed that he had understood correctly. A problem with NTs is that they often attempt to speak for the labelled person in research and education. It is common to analyze the behaviour of people with autism in terms of standards of communication and etiquette laid out for NTs by western culture. For example, NTs frequently interpret the lack of a verbal response

to a question as meaning that the other lacks awareness. This is not always the case. In Biklen's work it is evident that the people with autism often were hyper-aware of their surroundings, as well as questions that were asked, but they were unable to voice their response. One individual relayed his experience that for a long time, when he was offered a selection of breakfast cereals the choice he really wanted did not match the choice his finger would inevitably point to (Biklen, 2005). This lack of an ability to coordinate movements to thought should be taken into account when attempting to understand autism, rather than presuming that understanding will automatically lead to a response.

In terms of learning, the individuals with autism in Biklen's study cite several suggestions which they attribute to having enabled their learning. One is modeling behaviour, another is the value of practice and repetition, and a third is the "usefulness of games with discrete steps" (Biklen, 2005: 269). Games carry the caution that they can appear random and difficult to understand or relate to, making it a frightening experience for the person with autism. Thus games must be predictable, and taught in small increments. For people who are non-verbal, and are able to point, this kinesthetic ability enables them to communicate to a great extent. All styles of learning must be respected, without a preconceived notion of a "correct" order. For example, some children may learn mathematics before they learn to speak because numbers carry more meaning for them. Although this is not a typical sequence of learning, these differences must be respected by educators. To facilitate learning, educators should use teaching tools which are sufficiently interesting to draw the child's attention to them, such as brightly coloured blocks (Biklen, 2005).

Among all the many recommendations that the contributors of Biklen's study made, and all the things that they credited in helping them to learn,

Biklen makes the interesting observation that behaviour modification was not among these. The process of learning seems to have been more flexible, though it involved practice “as a key element of success” (Biklen, 2005: 280). Overall, inclusion was the most important factor, rather than training, and parent involvement also played a key role (Biklen, 2005).

### Autism in Film

This section will examine the portrayal of disability in film as this medium provides a unique perspective of how society views people with disabilities. Negative portrayals of the disabled in film and other media not only fail to honour the experiences of the disabled, but also perpetuate false stereotypes. In his 1998 study, Safran investigated trends in the portrayal of people with disabilities in Academy Award winning films. He notes that there has been an increase in the number of awards involving disabled characters over the past few decades. Many people have limited experience with and knowledge of disabilities, so movies portraying disabilities become their source of information (Safran, 1998). Films are often inaccurate as they focus on one interesting feature of a disability, rather than on portraying the whole person (Safran, 1998). One of the problems with this is that students being integrated into mainstream classrooms face preconceptions from their peers and teachers, which are instilled by the mass media (Safran, 1998).

Though there are several films that portray characters with behaviours on the autism spectrum, this section will focus on two famous examples, Rain Man (1988) the first movie to portray autism in a main character, and Snow Cake (2006) a more recent example.



## Rain Man

Rain Man is likely the best known Hollywood movie that portrays an individual with autism. In this movie the protagonist, Raymond Babbit, is an individual with autism who has a special gift for memorizing numbers. When his brother recognizes this, he takes Raymond on a road trip to Las Vegas to gamble. Safran (1998) mentions that Rain Man

Provides viewers with a generally accurate profile of autism, (but) it also focuses on the uniqueness of a savant, which may create the belief that all individuals with autism have a "hidden genius" (p. 228).

It is interesting to note that the character of Raymond Babbit was inspired by the real-life man, Kim Peek, who is described by doctors as a super savant, and considered an expert in fifteen different areas, though he cannot dress himself, turn on a light switch or understand social skills (Cueni-Cohen, 2003). Peek was born with brain damage, in particular macrocephaly, cerebellum damage, and agenesis of the corpus callosum (Cueni-Cohen, 2003). He was originally diagnosed with autism, but this diagnosis was later changed though his behaviours show characteristics that could be considered on the autism spectrum. The savant syndrome presents the paradox of severe mental handicap and gifted mental ability. Most savants have only one dominant area of interest, but Kim Peek has multiple areas of expertise. He reads at a rate of a few seconds per page, and completes several books a day with excellent memory retention (Extraordinary People, 2007). Interestingly, when Peek reads he uses one eye to read one page and the other to read the other page (Cueni-Cohen, 2003).

On a standard IQ test, Peek scored 69 (less than the average 100). According to his father, Fran Peek, "His inability to understand metaphors knocked him out of having a decent IQ because he's always literal," When

his IQ test was modified, leaving out reasoning or abstract elements, his score jumped to 184 (as cited in Cueni-Cohen, 2003).

After meeting Kim, Barry Morrow was inspired to write the script for the movie "Rain Man." Prior to the success of the movie, Kim Peek had contact with barely 20 people, and never looked anyone in the eye (Cueni-Cohen, 2003). After the success of "Rain Man," Peek gained greater contact with the outer world as it became more interested in him. He became the topic of many articles, and traveled with his father to give numerous talks around the United States, often at autism conventions. Peek's mission statement is: "Learning to recognize and to respect differences in others and treating them like you want them to treat you will bring the peace and joy we all hope for. Let's care, share -- be our best!" (as cited in Cueni-Cohen, 2003). This is an important attitude for society to adopt towards all people of varying abilities.

As in the case of Rain Man, Safran (1998) notes that films can have a positive influence in shaping social opinion and awareness and can be used by educators as teaching tools. They have the power to educate and lead to positive social change. He further comments on the positive trend that children and adults with disabilities are increasingly integrated into the community, which is mirrored in the increasing presentation of people with disabilities in Academy Award winning films (Safran, 1998).

### Snow Cake

Snow Cake (2006) is a film about a friendship between Linda, a woman with autism, and Alex, a NT man. The movie begins with Alex giving Linda's daughter, Vivienne, a ride to her hometown when a truck accidentally strikes Alex's car, killing Vivienne. Subsequently, Alex goes to

visit Linda in order to pay his respects for her loss. Upon meeting Linda, he senses that something about her is different as she shows no signs of grieving. Instead, she is obsessed with keeping her house clean, and with the shiny objects that Vivienne had purchased for her. In addition, Linda is terribly afraid of germs and one of her main concerns is what will happen with the garbage when the truck passes by the following week as it was Vivienne's job to take it out. Alex agrees to stay and take out the garbage, and also arranges Vivienne's funeral. While he is staying with Linda, Alex enters her world and is able to gain greater perspective on his own life. One of the gifts of autism that shines through Linda's character is an honesty that stems from an inability to comprehend, much less manipulate, social conventions. Alex grows to appreciate this honesty. Before leaving he says to Linda, "You're the only person I ever met who I didn't have to justify myself to." In this admission, he acknowledges the gift of being allowed to merely be, which is rare in a predominantly NT world where social conventions can be stifling.

Linda is fortunate to live in a supportive environment as the townspeople of Wawa try to accept her uniqueness. However, it is evident that they lack a real understanding of the characteristics of people with autism. As a result, Linda's lack of adherence to social conventions creates an uncomfortable situation when Linda puts on loud music and dances at Vivienne's wake. She is asked to stop by one of the mourners who considers this behaviour disrespectful, but Linda's mother who understands her better orders the music left on so that Linda can dance and express herself in a way that is right for her.

Sigourney Weaver's portrayal of Linda is sensitive and critically acclaimed as an accurate representation of a woman living with autism.

However, a danger of the film is that by portraying only one character with autism it could give the false notion that this person can represent all people with autism. Another critique of the film is that autism is presented in a simplistic way, without many of its accompanying complexities. Burki (2006) complains that *Snow Cake* presents autism as a “form of extreme quirkiness, its rough edges conveniently smoothed away” resulting in a picture that does not appear complete (p. 910).

On the other hand, provided the audience can remember that people with autism are individuals, having unique challenges that vary from one person to the next, Linda’s character seems a good introduction to high functioning autism, challenging the notion that all people with autism are uncommunicative. Furthermore, the film portrays Linda’s way of relating to the world in a positive light, and presents her way of knowing as an enhanced appreciation for things that neurotypicals find mundane, such as flashing lights and eating snow. Overall, this movie demonstrates the power of friendship, beyond the labels of able and disabled; Alex and Linda establish a friendly understanding which touches both of their lives and helps them on their respective healing journeys.

### Problematizing Film as a Pedagogical Tool

Film is an important medium for examining messages about autism, and other so-called disabilities, that are distributed and consumed by the broader society. Important questions emerge which can aid in the problematization of film. One such question is, “Does film construct reality or reflect it?” In answering this, it can be argued that film, like other media, is both an expression of reality, and a projection of an idealized world indicating that this is a “chicken-and-egg” question. The classic study by Bandura, Ross & Ross (1961) demonstrated how film can influence social

conduct by showing that when children are exposed to violent behaviour on film, there is a high chance that they will mimic this violence. Movies produced by Hollywood are made with the intention of profit. Thus, views and values portrayed remain conservative in order to reflect the views of the audience.

Film blurs the lines between reality and fantasy. Some examples have been cited where people send gifts to fictional television characters when they accomplish important milestones on the show, and some fans write characters letters asking for advice with problems, as though the characters were real people (Buckman, 1992 as cited in Galician & Merskin, 2006).

Film presents the public with selective images of events and characters which can result in the formation of opinions of reality based on incomplete information. Furthermore, some stereotypes which are presented are so subtle that they often go unobserved. The more people are exposed to images in film and other media, the more likely they are to believe them. Long argues that, "Images, by their sheer omnipresence, can shape and affect viewers" (Long, 2003). Thus, the more audiences are exposed to characters that are portrayed in roles that reflect the stereotypical conception of disability, the more likely it is that the audience will accept this as true.

Sometimes liberating messages about disability are presented in film. However, these cannot stray too far from the accepted public opinion or they risk being ignored (Woollacott, 1982). The reason for this is explained by the theory of cognitive dissonance, which says that people aim to reduce the psychological discomfort of having contradicting thoughts, values and beliefs by purposely avoiding the unconscious decoding of media messages that challenge their beliefs (Woollacott, 1982). For this reason, it is even more

important to deconstruct films viewed in educational environments to ensure that potentially positive messages are not ignored.

The experience of disability can be glamorized in film. Characters should be analyzed and deconstructed to ensure that hegemonic ideas are challenged. If they are not, and if the film portrays a negative, stereotypical character, then this can act to reaffirm inaccurate stereotypical and negative notions of disability. Images portrayed in film can feed into common sense notions without challenging them. Timothy Lenz, a professor of political science at Florida Atlantic University, argues that film is important in the socialization of young minds as images are a part of today's classroom, just as they are prevalent throughout society. He further states that they provide a valuable teaching tool as they shape and are shaped by societal views and values of the present (as cited in Long, 2003).

Images are reflected and communicated showing a dichotomy of mirroring and a potential for instructing or molding audience views. When watching a film, which often moves quickly, stimulating the visual and auditory systems, people have less time to think and reflect as compared to reading text. Furthermore, when watching a film, people must suspend disbelief, rather than distinguish between what is real and what is not. This danger can be reduced if films are engaged critically, regardless of whether they present positive or negative portrayals of "disability" (Probst, 1983).

### Conclusion

Though the experiences described by the individuals mentioned in this chapter are personal and therefore may not be generalizable to others with autism, the difficulties facing people living with autism in a NT world and the need for respectful inclusion are universal. A common message that unifies

these is that people across the autism spectrum have a meaningful way of understanding and relating to the world, which should not be ignored or looked down upon. Educators and parents should not be engaged in trying to change a child with autism into a 'normal' individual, but rather they should appreciate the child's unique perspective and provide strategies for her or him to function and manage within situations in which he or she needs to participate (such as in the family, the school, and later on in the workplace). Such strategies might include teaching children with autism ways of understanding others as well as communicating effectively and managing situations which they find stressful (Jordan, Jones & Murray, 1998: 14). It is clear that autism is not a disease that a person has, but rather it is a different way of knowing and experiencing the world.

Film is an important pedagogical tool in educating sensibilities around autism and other so-called disabilities. People must be aware of the relationship between the images they see and the reality these images represent, and the fact that these do not always match perfectly. Any portrayal of disability, whether positive or negative, can be turned into a positive learning experience if it is engaged critically. For example, if students are exposed to a film about disability they can then be asked to research the reality of the particular disability. This can be a positive experience as it can serve to expose the stark contrast between negative stereotypes of disability and reality. Questioning the interests that are being reflected in maintaining the hegemonic notions of disability can further the benefit of the activity. Thus, all films can provide a positive learning experience, the main danger lies in an uncritical consumption of the film as harmful stereotypical images of autism and other disabilities could be assimilated without resistance.

## Chapter 4: Qualitative Study

This section consists of a qualitative study in four parts. The purpose of this study is to explore and examine the ways of knowing of individuals with autism, with the aim of attaining a deeper understanding of these means of experiencing, interacting with and coming to understand the world.

This study aims to pick out themes in ways of knowing of individuals with autism, as well as the issues in current methods of education.

Questions examined include:

- How are some of the life experiences of people with autism qualitatively different from the experiences of NTs?
- Do the current methods of education reflect and respect the experience of autism or do they discriminate against people with autism?
- What are some ways in which education could be changed to better reflect the ways of knowing of individuals with autism?
- Do individuals with autism feel included in society?
- How can society help to increase the sense of inclusion of individuals with autism?
- How does the physical invisibility of autism affect individuals and their families?

### Methodology

In this study, understanding of the above questions is sought from a firsthand approach of the lives of the individuals themselves, and the people whose lives are touched by them, rather than from a detached perspective typical of laboratory investigations. This study chose to privilege this firsthand information by using a qualitative approach, rather than a quantitative study that would have transformed the data into numbers in a statistical report. A qualitative approach is appropriate to the subject of autism as there is no single type of person with autism, rather each person



is a unique individual. Autism is not something that can best be known objectively, it is the individual subjective experience that is most important. In line with this, a qualitative researcher “seeks multiple truths” and can consider autism’s “layered, subjective identities” (Biklen, 2005: 3) as no two people with autism are exactly the same.

This study includes interviews with four different groups consisting of:

- 5 relatives of individuals with autism (3 parents and 2 grandparents)
- 1 individual with autism
- 5 educational assistants (EAs)
- 3 special education teachers

In this study, special education teachers were individuals who taught in contained classrooms exclusively for children with exceptionalities, one of which was autism. EAs were individuals who worked one-on-one with children with autism, breaking down lessons into manageable segments. They worked with children in mainstream inclusive classrooms as well as special education classrooms. These groups were chosen because of their firsthand experience with autism.

Based on preliminary research and a perusal of the literature, questions pertaining to the themes in the present research were compiled as part of a package that was submitted for ethics approval through FES. The main questions used to direct the interviews are provided in Appendix B, however, it should be noted that these questions were merely used to guide interviews, and were not intended to limit discussion.

Once ethics approval was received, agencies were contacted to determine whether recruitment would be possible through them. Most subjects were obtained from personal referrals, because agencies were slow to review the research and ethics proposals submitted, and the study

needed to proceed due to time constraints. Participants were approached by email and/or telephone and the study was explained briefly. Preliminary consent was obtained verbally, followed by the signing of informed consent forms.

The interview data was organized and analyzed around the following four themes, which were explained in chapter one, but with a greater emphasis on autism in this chapter:

- Honouring the experience of "disability"
- Inclusion versus exclusion
- Visibility versus invisibility
- "Disability" as a political and social issue

In the interest of maintaining confidentiality, names and some identifying details have been changed.

### Honouring the Experience of "Disability"

In his study entitled *Constructing Inclusion: Lessons from Critical Disability Narratives* Douglas Biklen (2000) notes that the experience of individuals with autism significantly varies from that of NTs, and it is worth understanding the specific variations in order to show respect for these differences. With this in mind, in the present study participants were asked questions aimed at accessing experiences of autism or being closely associated to someone living with autism. Various lessons learned are provided in this section.

All special education teachers and educational assistants (EAs) interviewed agreed that they have gained much from working with their students with autism. They spoke of "taken-for-granted" assumptions that cannot be ignored in teaching children with autism, versus neurotypicals. One EA, Tom, described his experiences working with Jenny, an eight-year

old girl who is on the lower end of the autism spectrum, meaning that she displays a greater intensity and number of characteristics of autism. He remembered making many mistakes as they began their work together because of things he took for granted as being common abilities to NTs. For example, when asking Jenny a question, he expected her to respond immediately and if she did not, he would rephrase the question and ask it again, thinking that he was clarifying the question. Overtime Tom realized that this had the opposite effect of further confusing Jenny as it takes her a long time to process the words being asked, and even longer to form a verbal response.

Tom claims that working with children with autism has made him “A more aware and better teacher in general.” In particular he has realized that he should not take anything for granted as “common knowledge” that does not require an explanation because anything “is fair game in terms of needing to be broken down.” Tom has learned to be more aware and in-tune with the particular individual he is working with, so that he can assess his or her needs individually.

It is common for teachers to teach etiquette along with the curriculum. Tom noted that many words that are included in requests to serve the purpose of being polite are unnecessary, such as “please can you” and “now would you kindly.” These words add confusion to the essential message that needs to be processed by children who have difficulties with processing. When Tom began working with Jenny, he tried to encourage her to pay attention to his instructions by raising his voice, as he would with NTs, in an attempt to regain her attention when it appeared that she had mentally wandered away from the material of the lesson. He soon noticed that this disturbed Jenny, and a quiet voice was much more effective. He points out

that there is a delicate balance of sensory stimulation that keeps Jenny engaged versus that which overloads her sensory system. Too much stimulation is overwhelming and confusing, whereas too little stimulation will cause Jenny to withdraw and lose interest. While he is teaching her, Jenny needs to squeeze or rub an object with her hand so that it provides the right amount of additional neural stimulation that she needs to help her pay attention.

Alison, another EA, also spoke of the delicate balance of sensory stimulation needed by some of her students with autism. She gave the example of a boy who needed to make minute adjustments to the audio and visual contrast to a particular level. These were fine adjustments that did not appear significant to Alison as a NT, but she noted that when she allowed her students to make these adjustments “all of a sudden they responded as though they could really see and hear what was happening.” Overall, EAs reported that computer programs can serve as wonderful teaching tools, especially for children who have an easier time interacting with machines rather than people.

Tom commented that he has noticed that from the point of view of a NT, the world of the person with autism is a world that “focuses less on meaning, and more on experiencing.” Teaching environments are very important. He finds that because his students often have heightened senses, they like to touch many things as they are learning about them. This often appears strange and confusing to their young NT peers who are taught by parents and educators that it is wrong to fidget or touch things in a way that is considered excessive.

The need for sensory stimulation is addressed in a school where

Marianne, an EA, teaches. This school is a part of the Toronto District School Board but because it is specifically for teaching children with exceptionalities this school is equipped with teaching environments to suit the needs of these children. One such environment is the multi-sensory room called the Snoezelen Room, which contains items meant for sensory stimulation such as cushions, bouncing balls, aromatherapy material, and tactile stimulants among other things.

Marianne spoke of the wonderful teaching space that this produced, where children were interested and engaged. She noted that the fact that the school is exclusively for children with exceptionalities presents the issue of segregation and the problem of the lack of inclusion of students with so-called disabilities into mainstream society. Marianne claims that similar environments can be created in classrooms in mainstream schools through knowledge of sensory objects important for children with autism. She also notes that minor adjustments need to be made in mainstream schools, such as the volume of the school bell which needs to be adjusted as this can be painful to the ears of children with autism. Also, fluorescent lights and the amount of lighting can be a problem. However, accommodations are a tricky issue because children with different exceptionalities require different accommodations, which is something that needs further exploration.

In some instances, sensory experiences were used to reward learning. Erika, an EA teaching in a special education classroom, had a student who loved the sensation of the carpet on his skin. This experience was used as a reward for good behaviour, where he would be allowed to lie on the carpet at the end of the day if he had complied with the teacher's instructions. Rewards such as this are not simple, and need to be deconstructed. First, the withholding of an experience that the child likes until he or she complies

with the required behaviour is manipulative and coercive in a sense, as it does not offer a range of behavioural options, but rather forces the child to act a certain way for a desired outcome. Alison talked about her observation that children with autism are frequently encouraged to assimilate at a level that is not meaningful or purposeful for them. It is not merely that they are being taught to communicate with NTs, rather there is an attempt to change these children. This is problematic in western society which values freedom and democratic decision making. The use of coercion to motivate learning is not only an issue for children with autism, but is also true of education in general. Rewards are complex as they can present unintended issues with motivation. Psychologists studying motivation divide it into two types, intrinsic and extrinsic (McClelland, 1985). Intrinsic motivation occurs when the reward for doing something lies in the experience itself. For example, studying because the material is interesting and produces a sense of satisfaction in the learner represents intrinsic motivation. In contrast learning for the purposes of obtaining an external reward such as a sticker, praise, or the experience of lying on a carpet, represents extrinsic motivation. Intrinsic motivation is highly associated with success in school, which is not the case with extrinsic motivation (McClelland, 1985). However, extrinsic motivators are commonly used in teaching though it has been known for several decades that they are not as effective as intrinsic motivators. Extrinsic motivators seem to be particularly used in educating children with autism, though this does not have to be so. If the interests of these children were respected, lessons could be based on sensory objects such as learning about different textures which would represent learning about something that was intrinsically rewarding.

Educators' understanding of the experience of autism was hindered by lack of knowledge. Parents participating in this study complained that

several regular classroom teachers demonstrated a lack of understanding and support for their children with autism, which failed to honour the experience of the children. This was echoed in interviews with EAs and special education teachers who reported that there is not enough training on autism provided by schools. This is especially the case with regular classroom teachers who often have no training in working with these children. Elaine's story illustrates this point. Elaine, the mother of a boy with high functioning autism, told of her son Cody's experience in grade one. Cody is a beautiful young boy who has extreme difficulty in greeting people and initiating social contact. To NTs he often seems aloof and "spoiled" as it appears that he does not like to compromise. Though Cody's teacher was aware of his diagnosis, she did not seem to have more than a superficial understanding of autism. At the beginning of the year, Elaine offered this teacher some literature on autism, however the teacher was reluctant to accept it, claiming that she is very busy and does not have time to do additional readings along with all the marking and lesson preparation that she needs to do. At one parent-teacher interview, the teacher commented that Cody has an "attitude problem" because he spoke out of turn and often failed to comply with instructions. The teacher was indicating characteristics that are part of Cody's autism which made it clear to Elaine that this teacher did not understand her son, or autism.

Elaine's experience is not unique. Alison, an EA, reported that in the school where she was working, often teachers would assume that the children with autism would not comply with requests because they did not want to, rather than because they were unable to. One very important theme that came out of discussions around respecting the experience of autism was the idea that in order to show respect there must first be understanding. Educating educators and others who interact with people

with autism is vital. This is in line with the comment made by one individual with autism from Durig's (2005) study who said that "the single biggest problem we have suffered in the world of autism is a lack of understanding" (p. 14).

Closely following understanding, parents cited the need for acceptance. This is something that needs to be achieved by everyone who comes into contact with people with autism, and other differences. One mother, Suzanne, lamented that for a long time, she had hoped that her son's autism would disappear. She related that:

For years I yearned for my son to be normal. In fact, I always felt like I was on the verge of a breakthrough with him, where we'd be able to actually talk normally. Over the years, I've realized that this breakthrough isn't coming and I've had to learn to accept Jason for who he is, rather than trying to force him to be like me.

Happily, Suzanne notes that this acceptance has been liberating. She is less frustrated with Jason's differences, and has been able to become more attuned to his gifts.

Contrary to this enlightened attitude, the predominant message in society is that there is a need to take children out of the autism, as though autism is a screen hiding the child. This can be seen in the media such as on popular talk shows like *The Oprah Winfrey Show* (September 18, 2007) and *Larry King* (March 31, 2007), when they feature autism. These two recent shows in particular presented the message that parents and society must "fight against autism" to save these children. The birth of children with autism was discussed as a tragedy that had to be fixed quickly, rather than an opportunity for new learning. Despite this limited view, there were some interesting points made that will be presented later in this chapter.



While autism presents a unique opportunity for learning, this study does not wish to pretend that the lessons are easy. It is important to respect and appreciate the difficulties that can be associated with raising a child who is different. As a researcher, one can enter and exit the world of autism at will, but for parents of and individuals with autism this is not the case. In chapter three, it was noted that, several spokespeople for autism said that they would not give up the autism, even if this were an option, because it is an essential part of who they are. In contrast, Frank, the individual with autism interviewed for this study, would choose to give it up "in a second." He claimed that he does not see how the experience of autism benefits him, and he has only experienced it as a hindrance in his life.

Challenges are an unwelcome daily reality for many people living with autism, however this does not mean that there is anything wrong with the individual. As previously noted, from the perspective of the Social Model of Disability, it is society that is at fault for not accepting these people and for creating environments that do not appreciate their exceptionalities. Part of the problem is that society tends to take the accepted worldview of NTs as the only true one, despite the fact that worldviews change with time and place (Durig, 2005). Alison notes that this "taking for granted" of NTs could be made obvious if a person on the autism spectrum were allowed to enter the classroom of NTs and make adjustments to the environment to accommodate his or her sensory needs such as shutting off the lights, and adjusting the volume of the intercom making it barely audible to NTs. She notes that "this experience would disturb neurotypicals, yet we constantly expect them to live in our world."

A part of honouring the experience of disability is being open to

learning from the different qualities and abilities of autism, rather than looking down upon them because they are different from those of NTs. This experience was commonly reported by family members as beneficial in gaining perspective on their own life. Two grandparents, Judy and Greg, of an adolescent on the autism spectrum talked about how this experience has benefited them in that they have had to learn to communicate in a way that is different to what they were accustomed to. Greg related a story of taking his granddaughter to the doctor because she was experiencing severe cramps. In reporting to the doctor how this had been treated, he relayed that the youth's grandmother had bought her some Advil for pain relief. The girl became agitated and corrected him saying that it had been her mother, and not her grandmother, who had bought the Advil. This refreshed Greg's memory, and he agreed. However, the child was upset and pursued the matter, asking why he had said it was Judy rather than her mother who had made the purchase. At the time, Greg felt that this child was being intentionally rude and overly particular about a minor detail that did not make a difference; he became annoyed. However, on re-examining the experience, he reflected that perhaps she needed this precision because of the way her mind works where she pays a great deal of attention to detail, and is disturbed if there is an inconsistency.

Along the same line, Judy spoke of the fact that her granddaughter required her to provide detailed explanations even for minute instructions and changes. This tested her patience and that of the rest of the family. However, over the years Judy explained that she has learned much about relating to her granddaughter in a different way from the one she has been used to with NTs, while learning not to judge her. In looking back, Judy says that this experience has been beneficial to her not only in relating to her granddaughter, but also in being more forgiving in her interpretations of

behaviour in NTs that previously would have caused her to feel impatient and slighted. To summarize the benefit of her experiences, this grandmother says, "I learned to get down off my high heels." If more NTs were able to learn this same lesson, we would have a much happier world. In the end, noted the EA Alison, NTs and individuals with autism are more alike than they are unlike, "We all need to be loved, appreciated and cared for, but what differs is the ways in which we communicate our needs, and the ways in which we need others to express this love and appreciation."

### Inclusion versus Exclusion

As discussed in previous chapters, inclusion is an important topic in critical disability studies and autism. There is a debate over whether it is better to educate children in inclusive versus segregated environments.

Cathy talked about her role as an EA for a 24 year-old male, Bill. This role involved the unique task of teaching this young man skills to be able to become integrated into society. Part of this involved the teaching of a functional curriculum where Bill would learn essential life skills. They had been trying to work on his social skills because he wants to communicate with others, but his difference in communication style inevitably pushes them away. As part of his functional curriculum, Bill had been instructed to say hello to people and ask them a question about their own experiences, instead of always talking about himself. The application for this backfired on their trip to Harbourfront when Bill waved to all the people stepping off the ferry and attempted to ask how they had liked the experience. Cathy noticed that he was hurt and confused when the patrons ignored him or were rude in their responses. This reflects the reality that the wider society tends to exclude people who are different. People often do not realize how

hurtful this can be.

The feeling of exclusion is an issue for parents too. One mother told of feeling excluded from experiences of bonding with her child that are normal for NTs. She related an anecdote of observing other mothers at the park laughing and talking to their children. She lamented that her own child does not seem interested in talking to her, and prefers to play with objects and be on his own, or watch the cars that pass by on the street in front of the park. She has often felt isolated because of a lack of commonality with the other mothers who were able to talk to each other about experiences with their own NT children. She was reluctant to talk to them because she felt that they would not be able to relate to her experiences with her son. Furthermore, in comparing their children to NTs, parents of children with autism encountered much frustration when they noticed that their child was interested in things that other children found odd. One mother mentioned that her son had a fascination with watching his electric trains circle round and round on the tracks, and could watch them for hours. This was not appreciated by his NT peers when she invited them for play dates with her son.

Another feeling of social exclusion reported by parents was that of feeling financially and emotionally drained, as well as having little to no free time, all of which left them unable to participate in everyday social activities. Often the mother had to stay at home to be able to cater to the needs of her child. Many times they had to be "on call" in case their child had to be brought home if he or she was having an excessively difficult day at school. Mothers expressed their fear of marital breakdown because of the devastating financial and emotional implications that often come with caring for a child with special needs.

One mother reported that she felt excluded by pediatricians and neurologists, who did not listen to the gut feelings she had about her children even before they were diagnosed. This shows an undervaluing of the mother's way of knowing, when it comes from a felt sense rather than physical proof. Western society generally frowns upon this as unscientific and therefore invalid. This point was also emphasized by the guests, Jenny McCarthy and Holly Robinson Pete, on the Oprah Winfrey show "When Autism Strikes: A Wake-Up Call for All Parents." These two mothers emphasized that in their own experiences and in the experiences of other mothers they have spoken to, professionals consistently dismiss what mothers know to be true of their children. They argued that professionals often fail to heed mothers' early suspicions that their child is different, dismissing this as overanxious maternal feelings. They claimed that this contributes to the fact that the diagnosis of a child with autism takes too long, and could be made sooner, which would benefit the family in understanding the child sooner and making necessary adjustments.

Seeking knowledge about their child and bonding with other parents was one of the most important things that parents did for support, as it helped them feel they were included in an accepting community. A diagnosis of autism was at least initially very difficult for all parents interviewed, as well as for their spouses, and the extended family. In one case, the extended family had a more difficult time adjusting to the diagnosis than the parents themselves, but this delayed family adjustment was difficult for the parents who felt that not only did they have to cope with their own situation, they also had to help their families to understand the child.

In considering the question, "How do people on the autism spectrum achieve inclusion?" one father, Keith, emphasized the importance of having a NT peer mentor, someone in the "in group," to break the ice and help a child with autism to become incorporated in the class. He said that this had been an important experience in his son's life which had helped him through elementary school. This mentor acted as a buffer between his son and the other children, and enabled his son to navigate the spontaneity and confusion common in the NT world.

Often children with autism suffer exclusion because schools fail to provide environments that cater to their unique ways of knowing, such as their sensory needs as discussed in the previous section. Another form of exclusion evident in the schools is through segregating children with exceptionalities into separate classrooms (Broekhof, 2007). This topic is debated in the literature. In this study, parents generally thought that it was important to educate children with autism in mainstream classrooms where they could have contact with NT peers, while special education teachers felt they fared better in separate classrooms. EAs who had experiences working in both segregated and inclusive classrooms, claimed that there was no simple answer as to which one was better. A problem with segregation was that children were kept from interactions with their NT peers, and were in a sense forgotten. At recess there was no interaction between the children not only because of the difficulties of social interaction that are a part of the experience of autism, but also partially because they did not have the commonality of the classroom experience. Two of the special education teachers interviewed reported that the special education classroom often contains children with various exceptionalities, and it is a great challenge to meet the needs of each child. The reality is that often these needs go unmet, and the classroom becomes an environment where

the children are looked after, rather than taught. On the other hand, some noted that children are less frustrated as demands in special education classrooms are more flexible than in mainstream environments.

### Visibility versus Invisibility

As discussed in chapter one, visibility is a central notion in disability studies. Autism is often invisible because of the lack of physical features to indicate its presence. Autism manifests itself behaviourally, and mainly in social interactions. Classroom gaze was mentioned as an important way in which teachers and students assess each other and form initial understandings of the other. Other members of society also use this gaze, and frequently it is involved with decisions about who is entitled to behave in a certain way and who is not. When an individual shows obvious physical signs of being different, such as in Down's syndrome, society seems to be more accepting of behaviour that is not the norm for NTs.

Keith, a father interviewed, broke down as he told of the difficulty his son, Peter, experiences as a result of the physical invisibility of autism. He explained that as there are no visual cues to indicate that his son is different, people make assumptions about his behaviour. Keith fought back his tears as he lamented, "When you have a child in a wheelchair, people make allowances. But when your child looks normal, but keeps missing social cues, people start to think he's a jerk." The lack of visible cues results in less allowances for behaviour which deviates from the NT norm.

Keith claimed that his family is supportive, but others sometimes are not. As a businessman, he often has work contacts visit at his house, and has found it unnecessary in the past to talk about his son's autism. However, he said he has often felt hurt and embarrassed by his son's

inability to relate as a NT. Keith cited the example of Peter's atypical sense of humour. Often he cannot let go of a joke, long after NTs have stopped finding it funny. Sometimes he tells inappropriate jokes or makes odd remarks. It is extremely hurtful for his father to see the negative impression this causes on guests who think Peter is intentionally breaking social norms. The realization that his son is unaware of why people do not like him and is unable to modify his behaviour is devastating.

Vash (1981) explains that, "Invisible disabilities can be difficult, interpersonally, simply because you appear to be what you are not" (p. 13). People expect things to be as they appear, though they know this is not always the case. Frank, the adult with autism interviewed for this study, explained that when he is standing with a group waiting for a bus, his autism is completely invisible. However, if someone starts to talk to him, it becomes obvious and people soon move away. He says he feels angry at peoples' intolerance, and wishes others would be more patient and slower to judge him.

Frank claims it was easier to have an exceptionality in primary school because people were more supportive. As children grow up, failure to conform to NT norms is less tolerated. In addition the differences in the behaviour of people with autism and that of their NT peers become more obvious. A special education teacher noted that in high school youths are unsure of themselves and their own place in the world. They are afraid of being rejected and thus often fear being seen with an individual who is stigmatized with an exceptionality. Frank confessed that he was frequently teased in high school and college by students who did not like him because he was different. He felt that he had little support, and few allies. This individual's experiences reinforce the idea of a need for greater tolerance of



differences in society.

Since behaviour in autism is human behaviour, two of the parents identified their own characteristics mirrored, though often in an exaggerated way, in their children with autism. This made their own traits visible, thus difficult to ignore. The fact that they had to face their own challenges through seeing them in their children enabled them to learn about themselves. For example one mother reports that she was an extremely shy and quiet person before having her children. In seeing these characteristics mirrored in her two children with autism, and in having to fight to get services for them, she has become a more extroverted person. Now she cares less about what others think of her, as she feels freer to express herself in her behaviour as well as her physical appearance.

A diagnosis makes individuals more visible for several reasons. First, it provides a framework around which the family can “see” the individual, as opposed to being bewildered by the person’s differences. The grandparents in this study noted that it was difficult for their family when their granddaughter was born. For a long time, nobody knew what to make of her behaviour, despite the fact that she was taken to several different specialists in an effort to determine why she behaved so differently. Finally when the granddaughter was diagnosed with an ASD, the family was provided with a way of seeing her, and also understanding her. Her behaviour no longer seems random and erratic.

Mitchell (2001) talks of another form of visibility, a way of “seeing.” He speaks about Temple Grandin and the fact that her different way of seeing, from a perspective other than that of NTs “gave her the capacity for seeing the world from alternative points of view – for example, that of

panicked cows being herded down the chutes of slaughterhouses" (p.394). As mentioned in chapter three, this enabled her to redesign cattle handling facilities to reduce the cows' fear, and make them more comfortable (Mitchell, 2001). In the interviews conducted, several participants cited examples of the ways in which individuals with autism are able to see in a way that is invisible to most NTs. Some children could see minute details in visual images, even when they only caught a glimpse of the image for a split second. A mother reported that her child noticed that some scenery had been slightly modified in the sequel of a movie he saw once, and this disturbed him. His mother and other family members did not notice the difference as it was so slight, however when they conducted research on the matter it confirmed the boy's astute observations.

### Disability as a Political and Social Issue

Autism is a hotly debated political topic in Canada, largely because of the high costs associated with educational needs as well as other service needs of individuals with autism. Government funding is limited, and there are long waiting lists. As a result, one mother, Susan, reported that on applications for services and funding, parents must often exaggerate their child's autism and claim that the child is "lower functioning" than he or she actually is in order to qualify for assistance. Who gets assistance is an interesting question. Though there are grants available, parents must be highly educated to know how to apply and to be able to write applications that receive funding. As usual, people who are already privileged in terms of education receive the resources and people who are less educated continue to be excluded.

In general, parents feel that the government is not doing enough to

meet the needs of their children as the burden of properly educating a special needs child tends to be put back on the parents' shoulders, though they may be exhausted and overwhelmed. Susan, a mother of two children with autism, complained that the government gives her an allowance of five hundred dollars a year to put towards extra-curricular programs for each of her two children with autism. She has found many valuable programs covering a wide range of useful topics at the Geneva Centre for Autism, but each one of these generally costs the entire sum that she receives. On the other hand, the Geneva Centre offers free classes for parents on how to teach their own children, but she says that she is exhausted from the personal care that she already provides for them and the rest of the family. Sadly, she feels guilty about this. It seems that this is an example of the implementation of the ideals of neoliberalism. Instead of providing adequate services, the government gives citizens the responsibility of addressing their own needs and those of their children.

### *The Challenge of Neoliberalism*

In the mid 1970s, there were shifts in the world economy and an economic crisis of inflation and high interest rates, government deficit and rising debt. The pressures of the global economy "made it necessary to overcome local and national barriers to accumulation" (Teepie, 1995: 78). The direct response of governments to this crisis was a set of policies aimed at putting more responsibility onto the citizens rather than the state. Neoliberalism, the retrenchment of government from many social programs resulted, in Canada, in diminished federal and provincial responsibility for the less privileged.

In his article entitled "Creating Difference: Neo-Liberalism, Neo-Conservatism and the Politics of Educational Reform" Michael Apple argues

that critical pedagogy needs to adapt to the changing socio-political times so that it may be effective in addressing important issues in education. He further argues that there are differing social interests that have varying educational and social visions and these “compete for dominion in the social field of power surrounding educational policy and practice ...These complexities and imbalances ... tend toward the reproduction of both dominant pedagogical and curricular forms and ideologies and the social privileges that accompany them” (Apple, 2004: 12).

Currently there are several issues facing the public school system. One of these problems includes the emphasis that there is on accountability and “measurable student outcomes,” which puts much pressure on students and schools. The result is often standardized tests rather than programs to support teaching. This is in line with the ideals of neoliberalism that demand demonstrable results that one is “making an enterprise of oneself” (Olsen, 1996 as cited in Apple, 2004: 24). In his article, Apple (2004) emphasizes that neoliberalist policies are not neutral. These policies as well as neo-conservatism put increased pressure on schools to produce students with high performance standards. The State shifts the blame of access to programs and outcome of education onto the schools, parents and children. This is the case in standardized testing such as that administered by the Education Quality and Accountability Office (EQAO). The EQAO conducts province-wide assessments for students in grades 3, 6 and 9 with the aim of measuring the achievement of students against the curriculum (EQAO, 2006). These data are widely used to compare schools and make recommendations for curriculum. While the results of this test may seem unbiased, these tests do not fully take into account different ways of knowing, such as those of children with autism. Neoliberalist and neo-conservative policies have been

Accompanied too uncomfortably often by a shift of resources away from students who are labelled as having special needs or learning difficulties, with some of these needed resources now being shifted to marketing and public relations. "Special needs" students are not only expensive but also deflate test scores (Gillborn & Youdell, 2000 as cited in Apple, 2004: 20).

Yet this is not recognized by the school system or the EQAO administrators. As is common with neoliberalist policies, the responsibility is placed back in the hands of the teachers and parents who are not in a position to help themselves. Borg and Mayo (2006) point out that neoliberalist policies put the onus of economic survival on the individual and/or group rather than the state, and "self-help" is recommended for those who are victims of these policies (Mayo, 1999 as cited in Borg & Mayo, 2006: 2).

McLaren and Leonard argue that "Traditional education orients students to conform, to accept inequality and their places in the status quo, and to follow authority" (McLaren & Leonard, 1993: 28). In contrast, it seems that the kind of ideal education argued for by critical special education is one that goes against this over-riding political system. Often there is resistance to this type of education which attempts to provide liberating education for all, regardless of way of knowing, level of ability or social class. Apple comments on this issue, noting that middle class parents have an easier time navigating the school system, as do their children (Apple, 2004: 21-22). These needs are systematically ignored.

Apple (2004) notes that neoliberalism has not had the same degree of negative effect in all countries. Countries with longer histories of socially supportive policies, such as Norway and Sweden, seem to have fared better, as these policies have tended to provide a protective effect from the

pressures of neoliberalism (Apple, 2004: 27).

Parents are not the only ones feeling over-burdened. According to one special education teacher, Nancy, these teachers “have too much on their plates.” She explained that in a contained classroom for special needs students, there are children with several different diagnoses. In addition to providing each one with lessons that will suit his or her individual needs, there is a heavy emphasis on documentation in the schools which takes up much of the teacher’s time. This documentation is meant to make educators accountable for teaching the students, but Nancy complains that the excessive documentation consumes the time she could otherwise spend teaching the children in her special education class.

Parents in this study cited the common theme of becoming advocates for their children with ASDs. Some were involved in groups that advocated for increased government funding for their children’s needs, and all had to be advocates in the school, being firm about how they wanted their children educated. They often had to fight difficult battles to get the schools to provide their child with the resources he or she needed. Despite their best efforts, many still reported that they felt much frustration as they were unsure of how to best navigate the system. Many times, they learned important pieces of information later that they would have liked as they could have greatly benefited from having this knowledge earlier. Furthermore, they felt there was a lack of complete disclosure of information from professionals. Many would have liked to have been provided with a step-by-step guide by the school as well as the medical professionals working with their children. The information exists, but it needs to be compiled and organized to make it useful for parents.

Educational assistants also had some complaints. They spoke of the uncertainty of their job, as several of their colleagues have been laid off over the past year due to insufficient funding. This is a political issue which has appeared in the media, and is echoed in a recent article in the Toronto Star (Oct 4, 2007). It was reported that "Ontario Schools have 6,000 fewer education assistants than they need to help the province's most needy children, the physically disabled, autistic and students with extreme behavioural problems" (p. A27). The Star also reports that despite the twenty million dollars invested in August of this year by Queen's Park for salary increases for EAs, one hundred and eighty-nine million more would be needed to hire the adequate number of EAs. At the moment, EAs are stretched beyond capacity in terms of their work load. Many are now only able to use part of their time for teaching, and the rest of their time is spent in personal care duties for these students ("Educational Assistants," 2007). Of the teaching time they have, EAs are also forced to divide this time among more students, working with one child in the morning, another in the afternoon. Each child receives the EA for half a day, though they would greatly benefit from having an EA with them for the full day. These children are still fortunate as not all children with autism have access to an EA, several are on waiting lists.

Overall, the parents interviewed reported that higher functioning children, and children without behavioural issues tend to fall through the cracks because it is easy for schools and government to brush them aside. Children with serious behavioural issues must be assisted because they are disruptive to others; in contrast children who are quiet and keep to themselves are often ignored, and do not have EAs assigned to them, though they may not be reaching their full potential as a result.

Finally, there was the issue of training. When asked if they had received formal training, many EAs claimed that they had received minimal training through the school. They had taken it upon themselves to learn about autism on their own. This training included attending seminars, and internet research. Sometimes parents provided them with useful literature, but schools in general were not considered a significant source of information. Special education teachers did have more training, but they also felt that it did not include enough information about working with children with autism in particular. This lack of sufficient training raises questions about the priorities of schools, and society. One wonders whether teachers of NTs would be allowed to work with these children if they did not have sufficient training, yet insufficient training is accepted for EAs who work with children with autism.

### Conclusion

This chapter provided a qualitative study of the experiences of people with autism, and those close to them. The information was organized into four themes including,

- Honouring the experience of “disability”
- Inclusion versus exclusion
- Visibility versus invisibility
- “Disability” as a political and social issue

Each theme attempted to answer questions proposed at the beginning of the chapter.

In learning to honour the experience of disability, it is necessary to acknowledge that people with autism have different abilities, which can be quite different from those of neurotypicals. Two components are vital, first understanding autism and then accepting it. Schools should demonstrate this by having environments that support important ways of knowing in



autism, such as sensory experiences. These should be used as part of the curriculum rather than as rewards for learning.

Inclusion is important for individuals with autism as well as their parents and other family members. Parents of children with autism can feel excluded from experiences that seem mundane to parents of NTs. Further exclusion comes from professionals who do not listen to mothers' instincts about their children. Individuals with autism suffered social exclusion by people who were impatient and did not want to take time to understand them. NT mentors are important in enabling inclusion in classroom environments, as well as in society.

Visibility is a major theme in disability studies, and it is especially relevant to autism as there are few accompanying physical signs which affects how NTs treat people with autism. Often the lack of physical indicators of autism means that NTs fail to recognize that they should show understanding and patience for the different ways of knowing of people with autism.

Autism is an important political topic. Government funding is limited and seems to privilege highly educated parents. Educational aids are a necessary but limited resource. Many EA jobs have been cut over the past year due to insufficient government funding. Neoliberalism has created a powerful political climate where the government has been able to offload social responsibilities onto over-burdened parents of children with autism.

Overall, individuals interviewed cited many challenges as well as benefits that accompanied the experience of autism. Many of the challenges are a result of an environment that does not facilitate the

experience of autism, as argued by the Social Model of disability. The four themes used to organize the information from the interviews in this study allow one to have a more complete understanding of the experience of autism. The recommendations suggested under the four themes discussed could result in an improved reality for people with autism, as well as the whole of society.

## Chapter 5: Discussion and Conclusion

The aim of this exploratory research study was to gain a better understanding of the ways of knowing of people with autism, and whether or not education for these individuals is adequately addressing these ways of knowing. Critical pedagogy, critical special education and critical disability studies make it evident that the dominant or hegemonic common sense regimes of power promote the world view that able-bodied, neurotypical is the “norm” and that all else deviates from that norm. The examination of autism from these radical pedagogical approaches reveals many problems with this perspective.

The previous chapters provided information that explored a broad range of questions relating to the experience of autism. The examination of these questions through “environmental” thinking allows for the exploration of autism from a counter-hegemonic lens, outside of the view of the predominant medical model that insists on pathologizing autism. FES makes this critical perspective possible, something which might not have been feasible in another academic environment. The pedagogical approach at FES is one of “thinking, learning and acting environmentally” (Morley, 2003: 1). From Morley’s (2003) article it can be seen that some of the criteria for this include: explicitly considering context, examining things holistically, taking multiple perspectives as well as actively engaging with a diversity of interests. As suggested by FES’ pedagogical approach, studying “environmentally” implies “the study of contextual relationships; studying the particular as it is defined by the whole” (Morley, 2003:2). In applying this to the current study, people with autism and NTs have been studied in relation and in particular educational contexts, rather than merely as separate entities. The importance of this point is further emphasized in the

criteria that states that “studying environmentally relates to its holistic/systemic manner of seeing things as a whole; the whole being more than the sum of the parts” (Morley, 2003: 2).

In addition, groups such as NTs and individuals with autism affect each other and it is appropriate to study them in relation to each other as well as separately both groups stand to gain from respectful dialogue. The following recapitulation and discussion will provide a further illustration of how the above mentioned criteria greatly informed this study in terms of the material examined as well as the methods taken.

To begin, Chapter one laid the groundwork for this exploration by providing a summary of the tasks that would be undertaken in this work. It also outlined the behavioral characteristics that make up autism as well as notions of disability. These ideas were problematized from the perspective of the Social Model of disability, as well as the pedagogical approach of FES. Four guiding themes were identified and explained including: honouring the experience of “disability,” inclusion vs. exclusion, visibility vs. invisibility and “disability” as a political and social issue. These themes, which are important to disability studies, provided a framework around which to organize information, particularly information obtained through the qualitative study.

Chapter two examined the field of critical pedagogy and found that much of what is proposed by critical pedagogy is relevant to students with special needs, though the connection is not always mentioned explicitly in the literature. The field of critical special education, which has emerged from the field of critical pedagogy, is more explicit in its application of critical notions to education for children with exceptionalities. In chapter two as

well as in subsequent chapters, the school context was explicitly considered in terms of how it supported or failed to support the learning of individuals with autism. Chapter three explored the first-hand accounts written by individuals with autism, and their descriptions of how they acquire knowledge and relate to the world in light of Gardner's multiple intelligences. In this chapter, examining the narratives of individuals with autism contributed to the challenging and interruption of predominant ways of thinking. The debate over whether to educate children with autism in inclusive classrooms versus contained classrooms is an important topic, which does not seem to have a simple answer. As seen in the literature examined, as well as the qualitative study conducted in chapter four, there are pros and cons to both. The best strategy appears to depend on the individual, though it is crucial that the overall school environment feels inclusive in both cases.

Further implications follow from the information obtained through this inquiry, and recommendations can be made for the education of several different groups including: parents, educators of children with autism, educators in general as well as all of society. To begin, recommendations for parents center on the interpretation of autism and attitudes towards their children. The reigning common sense notion of NTs as the "norm" has great power, which is evidenced by the unfortunate sense in parents that their exceptional child has been "stolen," is living behind an impenetrable wall, or is being held captive (Jordan, Jones & Murray, 1998). Instead of adopting this hegemonic attitude, parents could attempt to understand and appreciate the differences that their children with autism demonstrate. Rather, autism is an integral part of the individual and as such, there should be an embracing of these differences.

It must be recognized that this important task would be easier if there were social structures in place to assist parents with the challenges of daily support of their child with special needs. Individuals with autism and other exceptionalities face systemic exclusion from the protectionism normally granted to NTs through the denial of adequate government funding and resources. In addition individuals with autism are denied expression in schools that fail to provide them with appropriate environments that would privilege their unique ways of knowing as most pedagogical approaches aim to “normalize” the behaviour of these individuals, rather than allowing them to be as they are.

As victims of this pressure to conform, individuals with autism can be thought of as the oppressed that Paulo Freire (2005) speaks of in his work. In *Pedagogy of the Oppressed*, Freire (2005) emphasizes the need to liberate the oppressed as well as the oppressor as both are victims of the oppressive relationship. In western capitalistic society, the predominant value system promotes profit and protects citizens who can contribute to this profit. Freire continues by discussing the idea of “false charity” where the oppressor provides handouts to the oppressed, rather than enabling them to live and function independently in society (Freire, 2005: 45). In this way, limited government funding provides the notion that there is generosity and good fortune to people who receive this funding. Educational programs that focus on modifying the behaviors of individuals with autism to cause them to appear normal seem to be generous in that they are attempting to integrate individuals with autism into society; however this is a façade of beneficence as it denies the unique experience of autism while imposing a rigid notion of normality.

Children with autism are generally treated and educated by a

multidisciplinary team. One problem with this team approach is that it can be extremely costly (Sicile-Kira, 2004: 185). As previously mentioned, parents and other caregivers must struggle to obtain funding from the government to help with services for their children with autism. In addition, there have been job cuts to Educational Aids who work with children with autism, and often enable them to participate in inclusive schools by providing the extra one-on-one attention needed by these children. In light of these cuts, it seems that it would be important to examine and assess the predominant social values which ignore the worth of the talents and ways of knowing of people with autism that are not in line with those of NTs. This lack of appreciation for differences resulting in social exclusion can arguably lead to a society that is impoverished by its narrow-mindedness and ignorance of the myriad perspectives that are possible through experiencing the world differently.

Another issue raised by the team approach to education for children with autism is that it defies the common conception of the individual as autonomous. Contrary to the term 'autism' which comes from the Greek 'autos' meaning self (Kavale & Mostert, 2004: 99), the individual with autism relies on others to fulfill many tasks for him or her. If this is viewed from a positive light, autism can be thought to provide an important social and historical "moment" for increased community living in a society with thinning social threads. In western society, there has been a breakdown in social structures which supported community living (Cushman, 1995). Environmental structures such as town halls and meeting places no longer provide the communal spaces they once did. Furthermore, people have moved away from organized religion which provided a structure and dictated social roles. Cushman (1995) argues that this has resulted in the "empty self," where people feel alone and isolated, but do not realize how to

ameliorate this since modern society promotes the independent individual. As mentioned, exceptionalities, such as autism, make community living vital as they often require the effort of a team or group of people. This necessarily brings NTs and people with autism together as a social group working for a common purpose, forming a social system. This provides an important moment with a potential to knit a tighter social fabric where people need to help one another and be more understanding, shifting the focus away from excessive individualism. The increasing number of individuals with autism being born makes this opportunity one that cannot be ignored.

From the perspective of a liberatory practice, any efforts to help the individual, such as therapeutic efforts, should have the goal of “helping the ‘autistic mind’ adjust productively to its unique capabilities and disabilities. Therapy should target only those symptoms that directly impair the individual” (Nadesan, 2005: 207-208). Emphasis should be primarily placed on social accommodations to help individuals. Parents have an important role in advocating for their child to ensure that he or she receives the most appropriate education and sufficient funding. Proper advocacy could foster a deep sensitivity where NTs would recognize the crucial need to establish social accommodations for individuals that lie outside of the NT norm.

It is important that parents are educated about autism and the resources available to them and their children. Parents often feel overwhelmed by the abundance of unorganized information that is difficult to make sense of. In line with this, it was reported that “In a survey of more than 500 parents, negative experiences reported both inside and outside of the educational system included significant difficulties in gathering information about treatment options and then obtaining and monitoring



related services" (Johnson & Hastings, 2002: McWilliam, Lang, Vandivere & Angell, 1995 as cited in Hillman, 2006: 351). This lack of organization serves to complicate the formation of parent groups that can rise up to resist a social order that is oppressive to themselves and their children.

In terms of education for children with autism, counter-hegemonic pedagogies such as embodied learning could be pursued by educators as they are suggested by the kinesthetic intelligence that is common to several people with autism. Embodied learning privileges the intelligence of the senses, and knowledge which can be acquired through it, while moving away from the division of mind and body, something which is done naturally by some people with autism who cannot distinguish the boundary between their own body and the rest of the world. In this way, embodied learning disrupts traditional notions of intelligence by "challenging western ways of constructing knowledge" (Gustafson, 1998: 52), and proposes an appreciation for the knowledge that comes from the experiences of the body, rather than intellectual knowing.

Educators working with children with autism should first ensure that they themselves have a thorough understanding of autism and how people with autism learn best. It is crucial that schools take a more active role in providing this training. From the information analyzed in this study it is evident that the world through the eyes of an individual with autism is rich in many areas including texture, colour, sight, sound and smells. This richness is often overwhelming, and not experienced as pleasant. Additional ways of knowing can include synesthesia, where senses intermingle resulting, for instance, in the ability of some people to "see sound" (Buten, 2004: 59). Other ways of knowing include the experience of being "mono channel" where individuals can receive and process stimuli to one sense organ at a

time, for example they can either look at a speaker's facial expressions or hear the sound of the speaker's words, but they cannot do both at the same time (Grandin, 1996). Educators of children with autism need to be aware of these special ways of knowing, and tailor lessons to accommodate these ways, meaning that curriculum should be student-centered. It is important to acknowledge that educators also need support themselves as they are often overworked. Employing more educational assistants would be of utmost importance for special education teachers, mainstream inclusive classroom teachers, as well as students.

In addition, educators of children with autism should realize that each child is unique, implying that there is no single model that works best in terms of education. As a result educators must resist the predominant "banking" concept of education" which turns students into empty vessels to be filled (Freire, 2005: 72). This banking concept raises the question of whether or not the student is truly learning since the information taught is memorized rather than internalized (Freire, 2005).

The fact that education should be individually tailored can be frustrating for educators, but it can also free them from the rigidity that a single method would imply, enabling them to be creative. For example, a lesson could begin with something that individuals with autism find intrinsically motivating, such as a subway system or a bus route, and expand upon this (Grandin, 1996). In addition, it has been noted that the curriculum should not be overly simplistic because individuals with autism need to be stimulated intellectually, just as neurotypicals do.

General recommendations emerging from this study that are applicable to all educators centre on resisting "taken-for-granted"

assumptions. Educators should not be fooled by a “classroom gaze” which takes only physical appearances into account making it seem that all students are NT, as there are often no outward physical signs of autism. Furthermore, educators should familiarize themselves with their individual students and consider the needs of each one in order to design and implement lessons that address these needs, rather than teaching a general curriculum that may not be as useful. In addition, educators should be mindful of the hidden curriculum which is comprised of the rules, regulations and guidelines, around codes of conduct and behaviour which are not overtly taught, but are assumed to be understood by all individuals (Garnett, 1984; Hemmings, 2000; Jackson, 1968; Kanpol, 1989 as cited in Smith Myles et al, 2004: 5).

In order to facilitate the learning process, greater communication among parents, educators and individuals with autism would be beneficial. Support for this notion can be found in Freire’s (2005) suggestion that dialogue is one essential means of overcoming oppression. This dialogue can begin with exposure to films on autism and their subsequent deconstruction, possibly with the assistance of an informed pedagogue. This could challenge NTs to engage with the counter-hegemonic and liberating notions of people as “differently” abled rather than disabled. A critical process such as this could assist in destroying the boundaries between able and disabled, normal and abnormal, which could be instrumental in disrupting the predominant social structure that excludes so many members of society and continues to keep them in a position of oppression.

The examination of autism through the perspectives of critical pedagogy and critical special education enable the identification of “cracks in consent” (Marino, 1997: 23) or spaces where hegemonic notions are

interrupted, providing critical alternatives. For example, alternatives to the view of autism provided by the medical model available through the Social Model of disability which views disability as something that is socially constructed. This implies that society has a large responsibility to create environments where people with autism could be appreciated as integral members, rather than being disabled by environments that are exclusive. In considering multiple interests, as prescribed by FES's pedagogical approach, including the current predominant sociopolitical milieu as well as the interests of individuals with autism, parents and educators, at times these interests appear to be at odds with each other. However, through the challenging of the current social organization and the envisaging of a new, more enlightened and liberated society for all, these interests could become complimentary. Through learning to understand and appreciate the differences of people living with exceptionalities such as autism, NTs, who also do not comprise a homogenous group themselves, could learn to understand and appreciate their own differences and exceptionalities. In the words of one special education teacher, "We're all different, it's just that the differences in people with autism are more apparent."

Stepping outside of these limited common sense notions of autism as a disability makes it possible to envision a world, though it may exist in the distant future, where the hegemonic common sense will have been shifted. Autism, along with numerous other so-called disabilities, will be seen as an opportunity for individuals to live out a unique way of being, and for society to learn from their gifts and experiences. With this vision in mind, increased awareness and sensitivity towards differences would help to create a more inclusive society and in turn, a better world.

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## Appendix A



## Ways of Knowing of People with Autism: Informed Consent Form

### Information for Participants:

I am a graduate student working on my master's degree at York University with the Faculty of Environmental Studies. The proposed investigation will explore and examine "ways of knowing" of individuals with high functioning autism, with the aim of attaining a deeper understanding of these means of experiencing, interacting with and coming to understand the world.

The study design is composed of three parts. Three different groups will be interviewed:

- 1) Parents of children with autism
- 2) Educational aids working with children with autism
- 3) Adults who have autism

You will be asked questions relating to ways of knowing and understanding the world during an interview with the principal investigator. The duration of interviews will be approximately one to two hours.

### Anonymity and Confidentiality:

Your information will be gathered and stored in a locked filing cabinet. The principal investigator will be the only person with a key to this cabinet. Your data will be retained for two years following the completion of this study, and will subsequently be destroyed.

Your identity in this study will be treated as confidential. All information gathered will be kept confidential. In any material that is written about this study, your name as well as any identifying details will be changed to conceal your identity.

### Benefits and Risks:

There are no perceived benefits or risks associated with participating in this study.

Please note that participation in this study is strictly voluntary, and you will not be penalized in any way if you choose not to participate. In the event that you choose to participate, please also note that you have the right not to answer any questions as well as to withdraw at any time. Should you choose to withdraw from this study, all data generated as a consequence of your participation will be destroyed at that time.

### Reporting of Results:

The current study is part of the research for my major paper. This research has been reviewed and approved by the Faculty of Environmental Studies (FES) Human Participants in Research Committee on behalf of York University.

Contacts:

If you have any questions or concerns about this research, please do not hesitate to contact me at:

Daniela Kibedi (Principal Investigator)  
Master of Environmental Studies Candidate  
York University  
4700 Keele Street  
Ph: 647-400-9619  
Email: dkibedi@yorku.ca

Should you have any questions prior to or following the study about the Faculty of Environmental Studies, York University, ethical concerns regarding this research or your rights as a study participant please contact the following:

Faculty Supervisors:  
Professor Chris Cavanagh  
story@web.ca

Professor Honor Ford-Smith  
hoperoad@yorku.ca

Manager, Faculty Governance, Environmental Studies:  
Diane Legris  
416-736-2100 ext. 33783

Manager of Research Ethics for York University:  
Office of Research Services  
Ross S414, York University  
416-736-5055

## Ways of Knowing of People with Autism

Consent to participate in this study:

I (your name) \_\_\_\_\_ have read the above information and fully understand the nature and the purpose of the study in which I have been asked to take part. I understand that I will be free to withdraw from the study at any time. I voluntarily consent to participate in this study.

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Investigator

\_\_\_\_\_  
Date

## Appendix B

*Questions to Guide Interviews with Adults with High Functioning Autism*

1. As a child, were you part of an inclusive/mainstream classroom or were you placed in a special classroom/school?
2. What was this experience like for you?
3. What are your interests?
4. Do you have any hobbies? If so, what are they?
5. What do you enjoy doing the most?
6. How does this make you feel?
7. Could you describe to me how you learn best?
8. Do you think there is something that you understand about the world that others without autism do not understand?
9. If you had to describe the world, what kind of a place would you say it is?
10. What is it like to interact with others who do not have autism?
11. What would you like others to know about you?
12. Is there anything you would like to let others know about the way you learn/experience the world?

*Questions to Guide Interviews with Parents of Children with Autism*

1. Could you please describe the overall experiences of your son/daughter with the school system as he/she was growing up?
2. Do you feel that your son/daughter felt included in the school?
3. Under what conditions did your child learn best?
4. Where there any teachers who brought out the best in your child, and encouraged him or her to learn effectively? If so, what were some of the teacher(s) important characteristics?
5. How did the teacher(s) address and respect the unique “ways of knowing” of your child?
6. Could you describe your son/daughter’s main interests?
7. How would you say your child interacts with others? The world? You?
8. Under what conditions does your child learn best?
9. What things would you say get in the way of your child’s learning and experiencing the world?
10. If you had to describe the way your child thinks (as compared to others without autism) how would you say that they think? (For example, Temple Grandin, an individual with autism, describes herself as “thinking in pictures” which is to say that she can only think with visual images, rather than words).
11. As an infant, how did your child learn best? What were some challenges?
12. Does your child use associations to express and communicate about things? (For example, some children would say “partly heard song” to mean “I don’t know.”)
13. How would you envision an ideal environment for your child to experience and learn about the world?
14. What has your child taught you about learning/experiencing the world?
15. Do you feel that the physical invisibility of your son/daughter’s condition has affected the way he or she has been treated? Please explain.
16. Do you feel that the government is doing enough to support your son/daughter?
17. If you were to imagine a world designed for the needs of your son/daughter, what would this world be like?

*Questions to Guide Interviews with Educational Assistants Working with Children with Autism*

1. Please describe the work you do/have done with children with autism.
2. What do you think this experience was/is like for the children?
3. What are some of the differences between the ways in which children with autism interact in the classroom as compared to children without autism?
4. How do you have to adapt your teaching methods to address the needs of children with autism in comparison to the methods you use with children who don't have autism?
5. Please describe the way in which you feel the student with autism perceives the classroom, others and the greater world around him or her?
6. How would you envision an ideal environment for a child with autism?
7. How do you think the child with autism experiences the world?
8. If we were to privilege the ways of knowing of the child with autism, what would he or she have to teach others?
9. What did you learn about the world from working with this child/these children?
10. Is there anything else you would like to add about your experiences or observations?