

**UNDERSTANDING CONCEPTUALIZATIONS OF
STUDENTS WITH “SIGNIFICANT INTELLECTUAL DISABILITIES”:
AN ANALYSIS USING DISCOURSE THEORY**

By

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Abstract

Notwithstanding the prominent focus on inclusion in the discourse of special education, students with significant intellectual disabilities in North America continue to receive a part of their education in segregated contexts (G. L. Porter, 2008; Schwartz, Mactavish & Lutfiyya, 2006; P. Smith, 2010). This situation creates an interesting and perplexing anomaly that I attempt to reconcile through an examination of the discursive conceptualizations of these students in Canadian introductory special education textbooks.

My study is framed within (a) the academic field of disability studies, which re-imagines disability using new perspectives (Linton, 1998; Oliver, 1996), and (b) new philosophical concepts of “personhood”, which critique traditional definitions of personhood based on intellectual ability (Carlson, 2010; Carlson & Kittay, 2009; Nussbaum, 2006). Situated within social constructionism and discourse theory (Laclau & Mouffe, 2001), this analysis examines how students with significant intellectual disabilities are depicted in these textbooks.

The language used in portraying these students suggests a discourse of individual pathology, medicalization and professionalization, distancing students with significant intellectual disabilities from other students because of their perceived lack of abilities, needs and behaviours. This discourse relies heavily on traditional understandings of people with significant intellectual disabilities as lacking in value. There is little discursive evidence to suggest that these students are presented in ways that challenge either historical or modern conceptualizations.

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Dedication

This work is dedicated to my family: my partner, Debbie, my children, Ryan and Rebecca, and my parents, Sharon and Sid.

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List of Abbreviations

AAIDD – American Association on Intellectual and Developmental Disabilities

AAMR – American Association on Mental Retardation

APA – American Psychiatric Association

IDEA - Individuals with Disabilities Education Act

LRE – least restrictive environment

PMD – profound multiple disabilities

PMLD - profound and multiple learning difficulties

SLD – severe learning difficulties

TASH - Association for Persons with Severe Handicaps

WSD – Winnipeg School Division

Chapter 1: Introduction

“But the worst fear was that her handicap involved her intellectual faculties. We, her parents, were intellectuals. I was committed to a life of the mind. Nothing mattered to me as much as to be able to reason, to reflect, to understand. This was air I breathed. How was I to raise a daughter that would have no part of this? If my life took meaning from thought, what kind of meaning would her life have?”

We didn’t yet realize how much she would teach us, but we already knew that we had learned something. That which we believed we valued, what we – I – thought was at the center of humanity, the capacity for thought, for reason, was not it, not at all” (Kittay, 1999, p. 150).

In 1959, Margaret Mead discussed the concept of “wholeness” in the context of teaching students with “mental retardation”. In describing the effects of a religious education on a young girl with Down syndrome, Mead (1959) said,

she became a human being in a way that she had not been one before... for the first time she met a situation where people were willing to teach her the *whole* instead of saying, “you are defective and you can only learn a part” ... (p. 260).

In considering Mead’s meaning of wholeness, J. D. Smith (1998) notes that she “emphasized that what makes for a culture of full participation is genuine opportunities for most people to learn how to fully participate” (p. 197).

An Apparent Anomaly

I argue that although the education of students with significant intellectual disabilities¹ has come a long way since these children were considered unable to learn, this education has yet to fully embrace the notion of wholeness to which Mead and J. D. Smith refer. Continuing to emphasize the “special” nature of these students and their education, and failing to conceptualize them as whole human beings compels us to perpetuate an apparent anomaly. In North America today, current laws and policies promote the education of such students based on the idea of “inclusion”. Students with disabilities, including those with significant intellectual disabilities, must be educated “appropriately” according to the law, and in an “inclusive” way, according to policy (Burge, Ouellette-Kuntz, Hutchinson, & Box, 2008; Horn, 2009; G. L. Porter, 2008; P. Smith, 2007, 2010).

Yet, research into every-day practices in the United States (P. Smith, 2007, 2010), Canada generally (G. L. Porter, 2008), and in Manitoba specifically (Schwartz, Mactavish & Lutfiyya, 2006), suggests that students with significant intellectual disabilities continue to receive at least some of their education in congregated and segregated settings. When I refer to segregation, I have two meanings in mind: physical segregation, by encouraging the use of separate “streams”, “clusters” and/or “programs”; but also a kind of “intellectual segregation”. This intellectual segregation

¹ When I use the term “significant intellectual disabilities”, I am referring to those individuals who, in another era, were labelled as severely and/or profoundly mentally retarded. Today, these individuals *may* be conceptualized as: lacking the capacity for rational thought; being unable to learn; being unable to communicate; being unable to form relationships; being unaware of and/or unresponsive to the world around them.

might be manifested in ways of educating these students so as to encourage content that may be neither focused nor applicable and may, in fact, simply lack relevance.

Believing it is both possible and worthwhile to educate students with significant intellectual disabilities may be problematic because of current and prominent discourses. These discourses circulate in a number of academic disciplines and, more broadly, throughout Western society, challenging the notion that such individuals have moral worth and are entitled to human dignity (Carlson & Kittay, 2009). Bogdan and Taylor (1994) stress that “to be called retarded is to have one’s moral worth and human value called into question. It is to be certified as ‘not one of us’” (p. 14). I argue that an exploration of the discourse of significant intellectual disability in the context of humanness is fundamental to gaining a better perspective of how we might make sense of and meaningful improvements to the education of these students.

The Many Meanings of Inclusion

Although the history educating children with significant disabilities was characterized by exclusion, institutionalization and segregation, the field of special education eventually moved toward the philosophy of educating increasing numbers of “exceptional” students in classes within general education (Winzer, 2008). This process has undergone several shifts in terminology and meaning, moving from integration in the 1950s and 1960s, to mainstreaming in the 1970s and 1980s, and finally to inclusion in the 1990s (Andrews & Lupart, 2000; Winzer). The rationale for inclusion is “to change the system so that exclusion and marginalization are avoided” (Winzer, p. 43). This

stands in contrast to integration and mainstreaming, which “sought to change individuals to fit the existing system” (Winzer, p. 43). Notwithstanding that inclusion is recognized in law and policy as best practice today (G. L. Porter, 2008, P. Smith, 2007, 2010), neither its meaning nor its implementation is entirely clear.

In attempting to provide a “snapshot” of Canada’s inclusive education policies, Winzer (2008) describes the current situation in each of Canada’s provinces, finding it difficult to “make any broad statements about inclusive schooling across the whole of Canada” (pp. 48-49). Falling outside federal jurisdiction, education is a provincial matter and thus inclusionary practices vary to suit the “philosophies and resources” of each province (p. 49). Nonetheless, Andrews and Lupart (2000) laud what they perceive as “a commitment in Canadian society as a whole to value diversity and to strive for inclusion as the ideal” (p. 29). They include reference to our *Charter of Rights and Freedoms* as a cornerstone to establishing education as a legal right, rather than as a charity. Winzer (2008) discusses inclusion as an effort to “restructure schools, bring about basic changes in the fundamental operating mode of special education, improve educational practice, and operationalize a closer merger between general and special education” (p. 42).

Research and dialogue about educating students with disabilities have involved discussions of the meaning of inclusion. Much effort has gone into defining the term. Debates centre on whether or not schools, classrooms and educational programs are actually inclusive. Although G. L. Porter (2004) has called inclusion a “Canadian value” (n.p.) and Horn (2009) says that in Canada inclusive education is a “birthright and a

valued tool” (p. 99), Winzer (2008) acknowledges that “a single, universal, or generally accepted version of inclusion simply does not exist” (p. 43).

In the wider North American context, P. Smith (2007) says “there is no clear consensus about what, in fact, inclusion is. Frankly, definitions are all over the place, representing diverse perspectives and ideologies” (p. 301). Artiles (2003) reaches this conclusion as well when he argues that “unclear goals and multiple definitions of inclusion seem to permeate the [inclusive education] movement’s discourse and research practices” (p. 169). P. Smith (2010) makes an interesting point about how inclusion has come to be understood as a place, rather than a concept or practice. “Special education is where things occur, not what is done there” (p. 39).

Notwithstanding this uncertainty, a number of authors have attempted to provide general definitions of inclusion in a Canadian context. G. L. Porter (2008) says that “all students, including those with disabilities and other special needs, are educated in regular classrooms with their age peers in their community schools” (p. 63). In terms of textbook definitions, for Andrews and Lupart (2000), inclusive education means that “all children have the right to be educated in their community schools, and that classroom teachers have the ultimate authority and responsibility for educating them” (p. 14). Friend, Hutchinson and Bursuck (1998) say that inclusion is the “term to describe a professional belief that students with disabilities should be integrated into general education classrooms whether or not they can meet traditional curricular standards and should be full members of those classes” (p. 454). Hutchinson (2010) defines inclusion

more broadly to mean “the social value and policy that persons with disabilities are entitled to full participation in all aspects of Canadian society, including education” (p. 377). She also notes that inclusive schooling means “the value system that holds that all students are entitled to equitable access to learning, achievement, and the pursuit of excellence in all aspects of their education; incorporates basic values that promote participation, friendship, and interaction” (p. 377). Finally, Winzer (2008) describes it as “a system of equity for students with exceptionalities that expresses a commitment to educate each child to the maximum extent through placement, instruction, and support in the most heterogeneous and appropriate environment” (p. 43).

In the United States, Giangreco (1997) provides a comprehensive definition of inclusion, stressing it “is an educational equity and quality issue for *all* students because, when done well, it has the potential to benefit students with a full range of characteristics” (p. 194). His definition is as follows:

Inclusive education means:

1. *All* students are welcomed in general education classes in their local schools.

"Inclusion for some" is a contradiction in terms.

2. Students are educated in classes where the number of those with and without disabilities is proportional to the local population.

3. Students are educated with peers in the same age groupings available to those without disability labels.

4. Students with varying characteristics and abilities participate in shared educational experiences while pursuing individually appropriate learning outcomes with necessary supports and accommodations.
5. Shared educational experiences take place in settings predominantly frequented by people without disabilities (e.g., general education classroom, community work sites).
6. Educational experiences are designed to enhance individually determined valued life outcomes for students and therefore seek an individualised balance between the academic/functional and social/personal aspects of schooling.
7. Inclusive education exists when each of the previously listed characteristics occurs on an ongoing daily basis (p. 194).

Inclusion for Whom?

After examining inclusion in the United States, P. Smith (2010) says that “progress – if you can call it that – in advancing the social justice and human rights project of including students with intellectual disabilities in general education classrooms can only be described as slow” (p. 22). He suggests that “almost 90% of students with intellectual disabilities still spend substantive time outside of classrooms in which all students, regardless of disability label, might be included. Almost all students with intellectual disabilities, in other words, are not fully included” (P. Smith, 2007, p. 299). Although P. Smith (2010) has found that many students attend local

schools, “nearly all of them are in highly segregated classrooms within those schools” (p. 22). Notwithstanding the existing laws and policies in Canada, G. L. Porter (2008) suggests that exceptions to inclusion are “much too common” (p. 62), and specifically notes the ongoing devaluation of people with “cognitive disabilities” (p. 64). This devaluation has been called the “hidden hegemony” of intelligence (Horn, 2009, p. 98).

In the course of my own work as a graduate student, I had the opportunity to do some research in the area of educating students with intellectual disabilities in Manitoba’s public school system. It became clear to me that a traditional discourse of special education was alive and well. The words of one participant, in particular, dismayed me. This teacher, who was a special educator at an elementary school, held the view that the students in that program would ultimately spend their adult lives in group homes and work in sheltered workshops. Given Manitoba’s official position on appropriate education, I was caught off guard by the lack of expectations and limited future this professional envisioned for these young students.

A related example that has intrigued me is the Supreme Court of Canada’s conceptualization of the education of students with significant intellectual disabilities. In the case of *Eaton v. Brant County Board of Education* (1997), an Ontario school board decided to move twelve year old Emily Eaton from a general classroom in her neighbourhood school into a segregated class, arguing that placement in the regular classroom was no longer in her best interest. The court described Emily as

a 12-year-old girl with cerebral palsy. Emily is unable to speak, or to use sign language meaningfully. She has no established alternative communication system. She has some visual impairment. Although she can bear her own weight and can walk a short distance with the aid of a walker, she mostly uses a wheelchair (p. 13).

Her parents opposed the move and a legal battle ensued. Justice Sopinka, writing for the majority of the court, endorsed segregated education when he wrote:

While integration should be recognized as the norm of general application because of the benefits it generally provides, a presumption in favour of integrated schooling would work to the disadvantage of pupils who require special education in order to achieve equality. Schools focussed on the needs of...special education for students with learning disabilities indicate the positive aspects of segregated education placement. Integration can be either a benefit or a burden depending on whether the individual can profit from the advantages that integration provides (p. 36).

This idea that inclusion might not be for every pupil is echoed in the work of B. Simmons and Bayliss (2007). They suggest that, in the U.K., there is support for the argument that “inclusive education may only go so far and that full-time mainstream placements for some children are unrealistic” (p. 19). Yet the authors make the point that “the extent to which special schools actually meet the needs of children with profound and multiple learning difficulties (PMLD) is rarely questioned in the literature

and a culture of ‘faith in special schools’ appears to be prevalent” (p. 19). P. Smith (2010) makes a similar point. “Some argue that current special education practice – including segregated settings, or the so-called differential placement – does little to positively effect the achievement and long-term outcomes of students with disabilities” (p. 70).

Included in What?

If the basic idea of inclusion is to welcome students with varying abilities into a “general” or “regular” classroom, I think it is important to acknowledge that there may be pitfalls to general education, which may not serve all students well either. B. Clark (1996) makes the point that school organization is basically flawed and these flaws act as barriers to “meet the needs of atypical learners” (p. 61). She goes even further by suggesting that “these organizational problems prevent any student from reaching optimum levels of education” (p. 61). In her article on gifted children in the regular classroom, Sapon-Shevin (1996) argues that “while the literature is full of description of ‘what gifted children need’...there is no evidence that this is not what *all* children require” (p. 71). She goes on to point out that “ironically, some of the same activities that are described as being especially appropriate for gifted children are *also* those described as being appropriate for children who are ‘educationally handicapped’, ‘at risk’, and ‘underachieving’” (p. 71).

Over a decade later, Halle and Dymond (2008-09) return to this same issue. “We must continue to question whether a general education classroom is the best or only

context that adds value to a child's education. This question is pertinent to both children with and without disabilities" (p. 197). My point in raising this issue is not to challenge the rights of students with significant intellectual disabilities to a quality education. Rather it is to highlight the nuances of a discussion on inclusion that can appear to be presented as simply "right" or "wrong".

Challenging the "Truth" by Exploring a Myth

These examples have given me pause and have encouraged me to think about why our society is reluctant to embrace the belief that every student is entitled to an inclusive education. While trying to pinpoint exactly what it is about students with significant intellectual disabilities that encourages their exclusion, I realized I was asking the wrong question. I ought to have been asking, what is it about how our society conceptualizes these students that allows us to accept their exclusion as a "natural" exception to inclusivity? What discourses are circulating in our society that might categorize students with significant intellectual disabilities as unworthy of a meaningful education?

A number of writers have begun to challenge the notion that intellectual disability is a real, objective category. They have deconstructed this terminology and introduced the idea that intellectual disability is socially constructed. Gergen (1985) says that social constructionism is concerned with "the process by which people come to describe, explain, or otherwise account for the world...in which they live" (p. 266).

Vehmas (2004b) explores the concept of disability more broadly, and uses “mental retardation” as a specific example of how one might re-examine taken-for-granted definitions and approaches.

The concept of mental retardation, for example, exists in the minds of those who use it as a term to describe the cognitive states of other people. It is assumed to be a term expressing an objective, existing state of reality whereas, in fact, it is a socially invented category that primarily reflects the state of mind of those people who use the concept, not of those who allegedly have it. This view does not deny that there are differences, either physical or mental, among people, but it suggests that the nature and significance of these differences depend on how we view and interpret them (p. 210).

Other writers have also argued that concepts like mental retardation and intellectual disability are constructed. Over twenty years ago in their historical review of the concept of mental retardation, Manion and Bersani (1987) found that “the definitions of mental retardation have varied in direct correlation with the current social values and economic demands of the defining society” (p. 236). In their extensive and ground-breaking work on the issues facing individuals with intellectual disabilities, Bogdan and Taylor (1994) further emphasize that

mental retardation is a social construct and a metaphor that exists in the minds of those who apply the label, and not in those to whom the label is

applied. The answer to the question, “Who is mentally retarded?”, depends on the classification procedures used to define people as such (p. 48).

More recently, Rapley (2004) has put forth the argument that although we understand intellectual disability to be “an historically continuous, clinico-medical, thing-in-the-world that can be ‘diagnosed’ or even ‘differentially diagnosed’ by type” (p. 31) it is a socially constructed term. This term might equally be thought of as “an idea, or a historically contingent *way of talking* about people who appear to be in need of assistance and who are not very good at IQ tests” (Rapley, p. 42). Kliewer, Biklen & Kasahendrickson (2006) present a similar argument and reject the traditional understanding of intellectual disability as an “objective manifestation of impaired capacity to know and think that can be measured and grouped according to severity” (p. 187). Instead, the authors “do not believe a person *has* an intellectual disability; rather, the person is *defined* by others as *having* the condition” (p. 188).

Danforth (1997), Danforth and Rhodes (1997) and Danforth and Navarro (1998) have moved the conversation about the social construction of intellectual disability into the field of special education with a focus on language and how it is used. They rely on postmodern thought, particularly Derrida’s notion of deconstruction (Danforth & Rhodes), as the theoretical basis of this critique. Danforth and Navarro (1998) note the “casual” way in which the term mental retardation is used in special education and suggest that although the meaning of the term is subject to debate, it is “generally accepted as real” (p. 32). However, these authors argue that “if Western civilization

suddenly lost the vocabulary of mental retardation, including terms such as intelligence, normal, disability, and so on, the constructed reality of mental retardation would no longer continue in its present form” (Danforth & Navarro, p. 32)

Seeking New Approaches

In light of the difficulties of seeing inclusion as encompassing *all* students, and the opportunities social constructionism brings to challenge traditional understandings of students with significant intellectual disabilities, I feel the need to address the apparent anomaly in special education in a unique way. I am not a formally trained educator, which means that I have not been exposed to the field’s professional induction (Skrtic, 1995a) and can readily take up Skrtic’s (1995b) challenge to “deconstruct and reconstruct” the field’s “knowledge, practices and discourses”(p. 43).

Special Education and Disability Studies

Linton (1998), a renowned American disability studies scholar, says that the emerging field of disability studies is “a location and means to think critically about disability” (p. 1). Its goal is to “focus an organized critique on the constricted, inadequate, and inaccurate conceptualizations of disability that have dominated academic inquiry” (Linton, p. 2). Disability studies, in which I hold a graduate degree, challenges the idea that disability is “primarily a medical category” and frames it instead as “having primarily social and political significance” (Linton, p. 2).

Linton (1998) makes the point that many professions owe their existence to the word special and all that it has come to mean in educating a particular kind of student.

She says that “a huge infrastructure rests on the idea that *special children* and *special education* are valid and useful structuring ideas” (p. 15). Notwithstanding the definition of special in the *Oxford English Dictionary* as “of such a kind as to exceed or excel in some way that which is usual or common; exceptional in character, quality, or degree”, Linton argues that “labelling the education and its recipients special may have been a deliberate attempt to confer legitimacy on the educational practice” (p. 15). In fact, she emphasizes that the word special “can be understood only as a euphemistic formulation, obscuring the reality that neither the children nor the education are considered desirable...” (p. 15).

Academics and teachers may question the relevance of considering a disability studies perspective within the field of education. Indeed Gabel (2005) suggests that “in spite of the growing influence of disability studies over the last three decades, educational researchers, by and large, have come late” to this movement (p. 1). In his examination of special education in the context of students with intellectual disabilities, Danforth (1997) offers one rationale. He describes the field as “devoted to the practical improvement of the lives of a specific group of children commonly viewed as social or educational failures” (p. 99). He goes on to explain how the processes of diagnostics and labelling define both special education and the students being served. A purportedly objective and value-neutral set of tests diagnoses a student who then becomes eligible for certain services. However, what this process actually does is turn a child from a “normal” student into a “debilitated learner” (p. 101). Thus “the diagnosis makes up

merely one moment of the powerful drama by which a person's social identity is constructed in stigmatized form" (p. 101).

Danforth and Gabel (2006) elaborate more fully on why some scholars and practitioners in education have become interested in incorporating a disability studies perspective in their work. First, they suggest that some education professionals are disenchanted with the "objectification of disabled and labelled students and the scientized reification of deficit constructs and identities" (p. 3).

Second, Danforth and Gabel (2006) argue that "critical education research traditions" focusing on class, race and gender have ignored those students who are most vulnerable, noting specifically "those with significant cognitive impairment" (p. 3), thus creating a space for further inquiry from a disability studies perspective.

Finally, the authors recognize the issues faced by teachers and those in related professions who "witness first-hand the many ways that disability has become synonymous with second-class citizenship, exclusion, derision, and a lesser form of educational provision" (Danforth & Gabel, 2006, p. 4). Engaging in a disability studies perspective helps move the conversation away from traditional views of special educations and students with disabilities and in the direction of more meaningful and lasting change. It also shifts the focus from more traditional research areas, such as inclusion and attitudes, and invites newer approaches.

Philosophy and Disability Studies

Philosophy has traditionally “had so little to say on the subject” of people with cognitive disabilities, including people with intellectual disabilities, “except, of course, when philosophers busy themselves with finding reasons why people with cognitive disabilities do not meet their standards for entities entitled to something called human dignity” (Bérubé, 2009, p. 352). And yet exploring intellectual disability through philosophy is crucial because “the philosophical questions that emerge in connection with intellectual disability are matters that not only are worthy of scholarly interest but speak to the deepest problems of exclusion, oppression, and dehumanization” (Carlson, 2010, p. 3). Bérubé critiques a philosophical tradition that is deeply rooted in Western thought and stretches back to the great classical philosophers. As Stainton (2001) argues, “a core paradigm in the negative construction of intellectual disability in Western society is that human value is directly associated with human reason” (p. 452).

However, this predominant discourse is not the only one circulating today. The inclusion of disability into philosophical conversations has begun to encourage a new way of thinking. Kristiansen, Vehmas and Shakespeare (2009) have recently introduced philosophy to disability studies and disability studies to philosophy. These authors recognize that philosophers “have tended to treat disability in a stereotypical manner” (p. 1) and offer their work as presenting “alternative and complementary viewpoints to current understandings of what disability is all about” (p. 2).

An alternate discourse of cognitive disability, including intellectual disability, has begun to challenge philosophers like Singer and McMahan (Bérubé, 2009; Carlson, 2009; Kittay, 2009). Carlson and Kittay (2009) encourage philosophers to recognize that cognitive disability is “a feature of the human condition” that they should “take seriously”. They further suggest that such an approach will allow for a reconsideration of “a number of fundamental philosophical presumptions and received views” such as “the centrality of rational thought to our conception of humanity and moral standing, the putative universality of philosophical discourse, and the scope and nature of moral equality” (p. 310).

Although I am not a philosopher, I cannot help but wonder how the fundamental philosophical presumptions that Carlson and Kittay (2009) mention affect the education of students with significant intellectual disabilities at its most basic level. I strongly suggest that in order to critically examine the issue of meaningful education for these students, it is essential to focus on how students with significant intellectual disabilities are “ascribed meaning discursively” and the “social consequences” of this ascription (Jørgensen & Phillips, 2002, p. 145).

Statement of Purpose

In articulating the premise of this work, I must emphasize the central importance of language. Like all language, the words that society uses, and more specifically educators use, to talk about students with significant intellectual disabilities are hand me downs (Duranti, 1997). There are strong ideas about who these students are, what

they can do, what they cannot do and how they are defined. The purpose of this work is to reveal the discourses circulating within the domain of introductory special education textbooks about students with significant intellectual disabilities.

This work will centre on a number of interrelated research questions:

- What are the discourses, or fixed meanings (Laclau & Mouffe, 2001) that circulate in introductory textbooks used by students studying special education that conceptualize students with significant intellectual disabilities? Have these meanings become so “neutralized” as to make them seem “natural” and relatively uncontested (Laclau, 1990; Jørgensen & Phillips, 2002)?
- Discourses are only partially fixed at any historical moment in time (Laclau & Mouffe, 2001). Are there any conflicts that contest a dominant discourse? If so, what are the consequences of one discourse “winning” over another or others (Jørgensen & Phillips, 2002)?

In this study, I begin with a review of the relevant literature in Chapter 2. This serves two broad purposes. The first purpose is to provide a backdrop of prominent issues in this work, such as the meaning and history of intellectual disability, how it has been understood, what it has meant historically to teach children with intellectual disabilities, and the kind of research conducted about these students. The second purpose is to introduce key concepts that I will refer back to in my analysis. After my literature review, I present the methodological approaches I rely on in my analysis, as

well as a detailed account of my methods. Chapters 4 and 5 contain a presentation of the data on which I rely. These data are comprised of material from four Canadian introductory special education textbooks which focuses on students with significant intellectual disabilities. This is followed by a detailed analysis of those data. In the final chapter, I discuss the implications of my work on students with significant intellectual disabilities, the education they receive, and the educators who teach them.

In the next chapter, I take a closer look at the idea of significant intellectual disability. I then explore how the notion of intelligence has become entwined with human value. My review moves to a discussion of new philosophical conceptualizations of what it means to be human. I then concentrate on the field of special education. My review of the literature closes with an exploration of the kind of research that has been conducted in the field of special education, paying close attention to any gaps in related work which my research might address.

Chapter 2: Literature Review - Intellectual Disability, Personhood and Special Education

“...the field of special education needs a way of bringing its anomalies to the surface, to prompt the suspicion that something is amiss with the accepted knowledge tradition, thus setting the stage for its deconstruction” (Skrtic, 1995b, p. 43).

In this chapter, I take up Skrtic’s (1995b) challenge to question the knowledge tradition within the field of special education. By attending to the anomaly surrounding the education of students with significant intellectual disabilities, I will examine the foundational principles which inexorably link notions of personhood with intelligence, rationality, and the ability to reason.

I begin this literature review by looking at how the precursors of the term intellectual disability have been described historically and how this language is defined today. This examination allows me to reflect on the ramifications of these definitions, and the effect they have on the lives of the people so labelled. I then review the traditional ways in which personhood and humanness have been constructed by philosophers over time. My emphasis shows a clear link between intelligence, and human value and worth. In the third part of the chapter, I focus on new conceptualizations of people with significant intellectual disabilities in the literature of philosophy and the social sciences, illustrating that more than one discourse of people with significant intellectual disabilities is circulating in society today.

I then move from broad social conceptualizations of significant intellectual disability to an examination of traditional theory and practice in special education, in

which I frame my work. I focus on students with significant intellectual disabilities. I look historically at how children with significant intellectual disabilities were understood in educational contexts as students. I then provide a critique of some of the policies within special education that have impacted upon educating these students.

In the final section of this chapter, I consider the literature concerning the education of students with significant intellectual disabilities. This section includes a categorization of the research in this area by topic, and a presentation of that research. I make particular note of any studies that parallel this work. My goal is to demonstrate a gap in the literature which my study addresses.

The Many Meanings of Significant Intellectual Disability

The focus of this work is on something I call “significant intellectual disability”. Carlson (2010) notes that intellectual disability is a “hierarchical category” and as such there are “graded subcategories from mild to severe” (p. 118). In philosophical contexts, the nature of this continuum is ignored in favour of two “prototypes” the “mildly retarded person and the severely retarded marginal person or non-person” (p. 118). Ferguson (200) refers to the latter group of people as having the “social status...of being judged somehow irredeemably lost or excluded from society” (p. 28). It is upon these individuals that I focus my attention.

I have already introduced the theoretical viewpoint that intellectual disability is a social construction. Although I consider social constructionism in Chapter 3 as a foundation of my epistemological stance, I want to make space here for a discussion

about what it means to use language to name and classify things and people. I also want to show how those names, classifications and meanings have changed over time.

What's in a Name?

I begin with Mercer's (1973) comments on naming to illustrate my intentions and provide a rationalization for my work.

What things are called and where the line is drawn between one class of things and another is socially arbitrated and then validated through common usage. Most definitions we use to interpret the world are learned from others and are sufficiently imbedded in the cultural heritage to make it difficult to extract and objectify them for analysis. This difficulty arises because traditional ways of classifying reality and cataloguing behavior are structured by our language and thought systems. Thus, it can be an arduous, even painful task to identify the fundamental elements of a traditional frame of reference and explore its basic assumptions. However, this intellectual task is essential if we are to recognize the extent to which accepted postures influence our perceptions and may conceal fruitful, alternative ways of structuring reality" (pp. 1-2).

In considering the historical relevance of naming, Stockholder (1994) notes that society never totally extinguishes old understandings with new terminology. Therefore, even when new terminology is developed to avoid the stigma of older terms, it does not take long for these new, "seemingly unsoiled" words to take on older, negative

meanings (Danforth, 2002, p. 51). The naming and categorizing of something is a “powerful process” (American Association on Mental Retardation, 2002, p. 5). It encourages the separation of a smaller group of people from larger society while providing a justification for doing so (Sarason & Doris, 1979). However, rather than reflecting something “inherent” in the categorized group, this act really reflects the values of culture in which we live (Manion & Bersani, 1987; Sarason & Doris). The outcome for the stigmatized group is the maintenance of “social devaluation and political oppression” of those “trapped” within the professionalized terminology (Danforth, 2002, p. 52).

An Historical Account

Now that I have shown the impact of naming, I will present a brief historical account of the different ways in which the idea of significant intellectual disability has evolved, using the terminology and definitions of the relevant time period. I very purposefully present a detailed accounting as I keep Stakeholder’s (1994) words in mind: “The older forms of reasoning...are present in new discussions, sometimes disguised, sometimes integrated into modern reasoning where they still haunt us” (p. 161). I also agree with Carlson (2010) when she argues for the importance of addressing intellectual disability as historical.

In traditional approaches that explicitly address intellectual disability, then, it is taken to be an unproblematic, self-evident, and undesirable *kind* of individual, about whom ethical and bioethical questions can be posed without reference to

any historical, political, or social factors that might affect the nature or status of this group of individuals (p. 11).

Although my focus is on significant intellectual disability, there may be occasions when the literature does not distinguish between types or degrees of intellectual disability. In these cases, I will discuss intellectual disability more broadly.

The Medieval period and the Enlightenment. Manion and Bersani (1987) begin their historical account by suggesting that intellectual disability was not distinguished as a separate “anomaly” until “the authoritative reign of the Church was broken” at the end of the medieval period (p. 233). Scheerenberger (1983) suggests that Pinel’s *A Treatise on Insanity* (1801) summarizes how intellectual disability was understood in the 17th and 18th centuries. The text defines “ideotsim” [sic] as “a defective perception and recognizance of objects, is a partial or total abolition of the intellectual and active faculties” (Scheerenberger, p. 40). This definition goes on to state that “the greatest number of ideots are either destitute of speech or are confined to the utterance of some inarticulate sounds. Their looks are without animation; their senses stupefied; and their motions heavy and mechanical” (Scheerenberger, p. 40).

The 19th century. The beginning of the 19th century marked the age of progress and, in keeping with the times, “considerable progress was made with respect to understanding mental retardation” (Scheerenberger, 1983, p. 52). One of the first definitions of intellectual disability from this period, still known as idiocy, came from the *Dictionnaire de Medicine* (1837). “Idiocy is an absence of mental and affective faculties

and an almost complete nullity of the cerebral functions...It is useless to attempt to combat *idiotism*" (Scheerenberger, p. 70).

In 1846 Seguin defined an idiot as "an individual who knows nothing, thinks of nothing, wills nothing, and each idiot approaches more or less the summum of incapacity" (Scheerenberger, p. 55). Seguin also divided the term idiocy into four sub-categories with the term idiocy referring, more specifically, to individuals with moderate, severe and profound intellectual disability (Scheerenberger). He provided a commentary on idiocy, which he described as follows:

It incapacitates mostly the functions which give rise to the reflex, instinctive, and conscious phenomena of life; consequently, the idiot moves, feels, understands, wills, but imperfectly; does nothing, thinks of nothing, cares for nothing (extreme cases), he is a minor legally irresponsible; isolated, without associations; a soul shut up in imperfect organs, an innocent (Seguin, 1866, pp. 39-40).

Seguin was not the only professional to classify idiocy in the 19th century. In 1887, Ireland distinguished between idiocy and imbecility. The former, "mental deficiency, or extreme stupidity" (Scheerenberger, p. 59) was more severe than the latter. Down also had a classification system for the term idiot, and included "congenital (idiots); accidental (idiots and feeble-minded); and developmental (feeble-minded)" (Scheerenberger, p. 56).

The first definition of intellectual disability that was endorsed by the American Association on Mental Deficiency in 1877 read as follows:

Idiocy and imbecility are conditions in which there is a want of natural or harmonious development of the mental, active, and moral powers of the individual affected, usually associated with some visible defect or infirmity of the physical organization and functional anomalies, expressed in various forms and degrees of disordered vital action, in defect or absence of one or more of the special sense, in irregular or uncertain volition, in dullness, or absence of sensibility and perception (Scheerenberger, 1983, p. 110).

The 20th century. By the beginning of the 20th century, the definition of intellectual disability contained three components: early onset, a decrease in intellectual functioning and an inability to adapt to society's requirements and demands (Scheerenberger 1983). The American Association on Mental Deficiency (1910) continued to use the term idiot to identify "those so deeply defective that their mental development does not exceed that of a normal child of about 2 years" (Scheerenberger, 1983, p. 139).

A number of different definitions evolved during the first half of the 20th century. For example, Tredgold's (1908) description of "mental deficiency" emphasized a state of mental defect from birth, or from an early age, due to incomplete cerebral development, in consequence of which the person affected is unable to

perform his duties as a member of society in the position of life to which he is born (p. 2).

His description was slightly revised in a later edition (Tredgold, 1937).

Mental deficiency is a state of incomplete mental development of such a kind and degree that the individual is incapable of adapting himself to the normal environment of his fellows in such a way to maintain existence independently of supervision, control, or external support (p. 4).

Doll (1941) came up with a more complex definition, focusing on “social incompetence” and emphasizing a condition that was “essentially incurable through treatment and irremediable through training” (p. 215). His conceptualization also included six criteria: “(1) social incompetence, (2) due to mental sub normality, (3) which has been developmentally arrested, (4) which obtains at maturity, (5) is of constitutional origin, and (6) is essentially incurable” (AAMR, 2002, p. 20).

In the second half of the 20th century, mental retardation became the term adopted by the American Association on Mental Retardation (AAMR). Variations of retardation began to appear in different guises, beginning with emphasis on IQ scores. For example, Hebert’s (1959) definition measured severity by levels, with Level I being the most significant, characterized as more than 5 standard deviations below the mean IQ. Mental retardation was noted as “subaverage general intellectual functioning” in association with an impairment of adaptive behaviour (AAMR, 2002, p. 21). In Herbert’s

1961 version and Grossman's 1973 description, significant intellectual disability was referred to as "severe" or "profound" mental retardation (AAMR, p. 21).

Under the guise of scientific authority, IQ numbers continued to represent a "single innate entity" called "intelligence" (Parmenter, 2001, p. 273). Thus professionals had an assessment tool which, by virtue of its quantitative nature, was assumed to be an accurate measure. However, J. D. Smith and Polloway (2008) emphasize the dangers of relying on IQ numbers to define and label people in their discussion of the 1973 change of definition from one to two deviations below the mean. "Burton Blatt and his colleagues noted the irony that with this change in the definition of mental retardation, millions of people were 'cured' of the condition overnight (Blatt, Bogdan, Biklen, & Taylor, 1977)" (p. 234).

The most recent definition of intellectual disability, as provided by the American Association on Intellectual and Developmental Disabilities (AAIDD), is a "disability characterized by significant limitations both in intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills. This disability originates before the age of 18" (AAIDD, 2010). However, Schalock et al. (2007) note that this definition "cannot stand alone" (p. 118). For this reason, five assumptions accompany the definition. They are:

1. Limitations in present functioning must be considered within the context of community environments typical of the individual's age peers and culture.

2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioural factors.
3. Within an individual, limitations often coexist with strengths.
4. An important purpose of describing limitations is to develop a profile of needed supports.
5. With appropriate personalized supports over a sustained period, the life functioning of the person with intellectual disability generally will improve (p. 118).

It was not until 1992 that the AAMR dropped classification by IQ score (AAMR, p. 22). Now “commonly used measures/indices of intelligence need to be interpreted within a broader context than a single IQ score” (AAIDD, 2010, p. 31). Notwithstanding these changes, P. Smith (2010) confirms that the traditional reliance on IQ scores has been accepted in the field of special education. “Intellectual disabilities are assumed to represent people having an IQ of 70 or below and concurrent deficits in what is known as adaptive behaviour” (p. 8).

A fairly recent addition to the AAMR/AAIDD conceptualization of intellectual disability is a focus on an individual’s need for supports and the duration and intensities of those supports (AAMR, 2002; AAIDD, 2010). Specifically, support intensities have been classified as intermittent, limited, extensive and pervasive (AAMR). It is most likely that people with significant intellectual disabilities will require either extensive or

pervasive support. The former is defined as “regular involvement (e.g., daily) in at least some environments (e.g., school work, home) and not time-limited in nature (e.g., long-term support and long-term home living support)” (AAMR, p. 152). The latter supports are “characterized by their constancy, high intensity, provision across environments, potentially life-sustaining nature. Pervasive supports typically involve more staff members and intrusiveness than do extensive or time-limited supports” (AAMR, p. 152). Newer discussions of support intensities reject the scale approach in favour of a broader understanding of support as “an enduring characteristic of the person rather than simply a point-in-time description of the need for a particular type of support” (AAIDD, p. 107). Language now focuses on “the provision of ongoing, extraordinary (when compared with their peers with no intellectual disability) pattern and intensity of supports” (AAIDD, p. 113). Thus the purpose of supports is linked to enhancing functioning and outcomes (AAIDD).

The AAIDD is not the only professional organization to provide definitions of intellectual disability. The American Psychiatric Association (APA) continues to identify intellectual disability as mental retardation in its diagnostic manual (APA, 2000). “The essential feature of Mental Retardation is significantly subaverage general intellectual functioning (Criterion A) that is accompanied by significant limitations in adaptive functioning in at least two...skill areas” (APA, p. 41). The APA describes individuals with severe mental retardation as follows:

The group with Severe Mental Retardation constitutes 3%-4% of individuals with Mental Retardation. During the early childhood years, they acquire little or no communicative speech. During the school-age period, they may learn to talk and can be trained in elementary self-care skills. They profit to only a limited extent from instruction in pre-academic subjects, such as familiarity with the alphabet and simple counting, but can master skills such as learning sight reading of some "survival" words. In their adult years, they may be able to perform simple tasks in closely supervised settings. Most adapt well to life in the community, in group homes or with their families, unless they have an associated handicap that requires specialized nursing or other care (APA, p. 43).

The Association goes on to define profound mental retardation:

The group with Profound Mental Retardation constitutes approximately 1%-2% of people with Mental Retardation. Most individuals with this diagnosis have an identified neurological condition that accounts for their Mental Retardation. During the early childhood years, they display considerable impairments in sensorimotor functioning. Optimal development may occur in a highly structured environment with constant aid and supervision and an individualized relationship with a caregiver. Motor development and self-care and communication skills may improve if appropriate training is provided. Some can perform simple tasks in closely supervised and sheltered settings (APA, p. 43).

Conceptualizations of idiocy, mental deficiency, mental retardation, and intellectual disability have changed over the years. Historically, there have been a number of common themes running through the various terminologies. Intellectual disability, from the outset, was seen as something that could not be cured or even ameliorated. The people so classified were commonly considered to be defective, deviant and limited in their abilities. These individuals have been described as being unable or incapable of living up to the societal norms expected of them. In fact, several definitions allude to the idea of forever being a child. Although more recent definitions currently being promoted by the AAIDD are focusing on an individual's need for support with the ultimate goal of enhancing outcomes, the cornerstone of many of the definitions I have reviewed, in my opinion, is a lack of intelligence.

I want to now turn my attention to an exploration of personhood. In so doing, I intend to illustrate how the concept of personhood has become inexorably entwined with notions of intelligence and rationality.

Philosophical Understandings of Personhood

The idea of a "person" has two very different meanings. One meaning may refer to the biological individual *homo sapien* while the other may refer, in philosophical and ethical contexts, to an individual who enjoys "something comparable, in relevant respects, to the type of mental life that characterizes normal adult human beings" (Tooley, 2001, "Basic Moral Principles", para. 1). Tooley goes on to say that

conceptualizing personhood is important “for the formulation of many *basic* moral principles” (para. 1).

Farah and Heberlein (2007) argue that “many of our most foundational concepts, on which we construct our understanding of the world, lack clear definitions”, the word “person” being no exception (p. 37). They further suggest that attempts to “specify criteria for personhood has occupied philosophers for centuries” (p. 37). On the other hand, Tooley (2001) describes in some detail a particular list of criteria that he claims “is almost universally accepted among philosophers” (“What Makes Something a Person, para. 1). This idea of a set of criteria to which Farah and Heberlein and Tooley refer is what Sullivan (2003) calls “empirical functionalism” or “the view that human personhood may be defined by a set of functions or abilities” (p. 17).

I agree with Spaemann (2006) when he says that this view of personhood has become evaluative. “Suddenly the term ‘person’ has come to play a key role in demolishing the idea that human beings, qua human beings, have some kind of rights before other human beings” (p. 2). Holub (2008) builds upon Spaemann’s thinking and, in the process, explains why the word “personhood” is of particular importance.

One human life is considered priceless and worth living, while another’s is perceived as without value and not worth living; one human is bestowed with dignity, while the other is devoid of it; one human has rights, and especially a right to life, while another has no rights at all (p. 268).

Although Holub is not writing specifically about people with significant intellectual disabilities, my arguments in this section focus specifically on his point.

Definitions of Personhood

Boethius has been credited for advancing the first definition of personhood in the 6th century (Farah & Heberlein, 2007). “Wherefore if Person belongs to substances alone, and these rational, and if every nature is a substance, existing not in universals but in individuals, we have found the definition of Person, viz.: ‘The individual substance of a rational creature.’” (Boethius, trans. 2007, p. 29).

In the 17th and 18th centuries, philosophers continued to consider the meaning of a person. In his work, Locke (trans. 1975) considers “what a person stands for” (p. 335). He takes the idea of rationality and expands upon it.

A thinking intelligent Being, that has reason and reflection, and can consider it self as it self, the same thinking thing in different times and places; which it does only by that consciousness, which is inseparable from thinking, and as it seems to me essential to it (p. 335).

Kant (trans. 2005) says that “rational beings... are called *persons*, because their very nature restricts all choice (and is an object of respect)” (p. 87). He continues by explaining that a person is not something to be used as a means. Rather, people are “things whose existence is an end in itself - an end, moreover, for which no other can be substituted” (p. 87).

More modern formulations of personhood have tended to be based on a list of attributes that persons have. Fletcher's (1972) "profile of man" contains 20 criteria, which he divides into positive (what human beings are) and negative (what human beings are not) human criteria. His positive human criteria are: (a) minimal intelligence, (b) self-awareness, (c) self-control, (d) a sense of time, (e) a sense of futurity, (f) a sense of the past, (g) capacity to relate to others, (h) concern for others, (i) communication, (j) control of existence, (k) curiosity, (l) change and changeability, (m) balance of rationality and feeling, (n) idiosyncrasy, and (o) neo-cortical function (pp. 1-3). His negative human criteria are set out as follows: (a) man is not non- or anti-artificial, (b) man is not essentially parental, (c) man is not essentially sexual, (d) man is not a bundle of rights, and (e) man is not a worshipper (pp. 3-4).

In Fletcher's (1974) re-assessment of his profile, he reviews several key criteria that were prominent in the literature of the time. He looks first at Tooley (1972), who argues that "an organism possesses a serious right to life only if it possesses the concept of a self as a continuing subject of experiences and other mental states, and believes that it is itself such a continuing entity" (p. 44). He also notes McCormick's (1974) suggestion that the ability to form relationships is the key to personhood. Yet for Fletcher (1974), "neocortical function is the key to humanness, the essential trait, the human *sine qua non*" (p. 6).

Dennett (1976) suggests six themes each identifying a condition of personhood. The first theme is rationality. The second is that "persons are beings to which states of

consciousness are attributed, or to which psychological or mental or *intentional predicates*, are ascribed” (p. 177). Third, personhood depends on the “attitude taken” or “stance adopted” (p. 177). It is how others treat a particular individual that demonstrates his or her personhood. In conjunction with this, the individual who is labelled as a person must be capable of reciprocating. Fifth, to be a person one needs to be able to verbally communicate. Finally, persons are conscious “in some special way” (p. 178). Dennett suggests this may be conceptualized as self-consciousness.

Tooley (2001) has also created a list.

Consider, for example, a being that possesses consciousness, has preferences, has conscious desires, has feelings, can experience pleasure and pain, has thoughts, is self-conscious, is capable of rational thought, has a sense of time, can remember its own past actions and mental states, can envisage a future for itself, has non-momentary interests, involving a unification of desires over time, is capable of rational deliberation, can take moral considerations into account in choosing between possible actions, has traits of character that undergo change in a reasonably non-chaotic fashion, can interact socially with others and can communicate with others. Few would disagree that such an entity is a person (“What Makes Something a Person?”, para. 1).

Evnine (2008) discusses four conditions of personhood. The first of these is that a person must be material. Second, Evnine requires that persons “necessarily possess concepts and have beliefs...in having beliefs a creature must also have those other kinds

of mental states, such as desires and intentions...” (p. 11). Third, a person is an agent. This requires an individual to perform intentional acts and to also engage in long-term plans and deliberate about those plans and actions. Finally, Evnine suggests that a person must have the ability “to have beliefs about beliefs, both one’s own and other people’s” a concept he calls “second-ordinality” (p. 15).

A number of authors have presented brief overviews of how personhood has been variously defined in the literature. For example, Nelson (2002) discusses “ordinary criteria for personhood that has been advanced in the philosophical literature” in the context of her sister, Carla (p. 32).

She was incapable of rational reflection, as required by Immanuel Kant’s and John Rawls’s theories. She probably was not self-aware, as Michael Tooley requires. It was not clear to what extent we could ascribe intentional predicates to her—the criterion advanced by P.F. Strawson. She was not able to treat others as persons, as Rawls and Thomas Nagel demand. She could not communicate with us verbally, as Daniel Dennett says she must. She was not capable of forming second-order desires, as required by Harry Frankfurt. She could not organize her experiences, acts, or relationships into an autobiographical narrative, as Schechtman believes is necessary (pp. 32-33).

In their article, Farah and Heberlein (2007) reference Feinberg’s (1980) criteria of commonsense personhood. “Persons are those beings who are conscious, have a concept and awareness of themselves, are capable of experiencing emotions, can

reason and acquire understanding, can plan ahead, can act on their plans, and can feel pleasure and pain” (p. 38). Farah and Heberlein quote Englehardt (1986) and Rorty (1988). The former says, “what distinguishes persons is their capacity to be self-conscious, rational, and concerned with worthiness of blame or praise” (p. 38). The latter argues that a person is

(a) capable of being directed by its conception of its own identity and what is important to that identity, and (b) capable of interacting with others, in a common world. A person is that interactive member of a community, reflexively sensitive to the contexts of her activity, a critically reflective inventor of the story of her life (p. 38).

The one idea that links all of these criteria of personhood to one another is the central theme of intelligence. It is to this trend that I now turn.

Linking Intelligence to Value and Personhood

Wilde (1891) wrote, “whatever, in fact, is modern in our life we owe to the Greeks” (p. 119). This statement is especially relevant to the ideal of the human intellect and its association with human value as developed and emphasized in the classical works of Plato and Aristotle.

In Plato’s *Timaeus* (trans. 1965), he discusses a scale of beings based on intelligence. He provides a very vivid description of living beings, where a scale of intelligence is clearly revealed. At the top of the scale is man. Plato writes:

a man who has given his heart to learning and true wisdom and exercised that part of himself is surely bound, if he attains to truth, to have immortal and divine thoughts, and cannot fail to achieve immortality as fully as is permitted to human nature (p. 121).

Below man is woman, created out of “the men of the first generation who lived cowardly or immoral lives” (p. 122). Thereafter are the animals.

Birds were produced by a process of transformation, growing feathers instead of hair, from harmless, empty-headed men...Land animals came from men who had no use for philosophy and never considered the nature of the heavens because they had ceased to use the circles in the head...And the reason why some have four feet and others many was that the stupider they were the more supports god gave them, to tie them more closely to the earth. And the stupidest of the land animals, whose whole bodies lay stretched on the earth, the god turned into reptiles...But the most unintelligent and ignorant of all turned into the fourth kind of creature that lives in water...they live in the depths as a punishment for the depth of their stupidity. These are the principles on which living creatures change and have always changed into each other, the transformation depending on the loss or gain of understanding or folly (pp. 123-124).

In Aristotle’s *Nicomachean Ethics*, the philosopher stresses the importance of living a contemplative life, and called it “the best and most pleasant life for man”

(Stainton, 2001, p. 457). Pakaluk (2005) suggests that in Book 6, Aristotle implicitly argues “for the view that wisdom, a profound understanding of things (*sophia*), is the best and most fundamental human virtue” (p. 207). Therefore, thinking and reflecting on “those matters of which we have a profound understanding – is the best activity available to us” (Pakaluk, 2005, p. 207). In Book 10, *Pleasure and Happiness: Further Discussion*, Aristotle (trans., 1999) writes of the “activity of study”.

For this activity is supreme, since understanding is the supreme element in us, and the objects of understanding are the supreme objects of knowledge...It is agreed that the activity in accord with wisdom is the most pleasant of the activities in accord with virtue...But the activity of understanding it seems, is superior in excellence because it is the activity of study, aims at no end apart from itself, and has its own proper pleasure... Hence a human being’s complete happiness will be this activity... For a human being the life in accord with understanding will be supremely best and most pleasant, if understanding, more than anything else, is the human being. This life, then, will also be happiest (pp. 163-165).

The foundational discussions of the Greek philosophers were incorporated into the writings of later philosophers such as St. Augustine, St. Thomas Aquinas, Locke, Kant, and Mill (Stainton, 2001; Vehmas, 2004a; Vorhaus, 2005). For example, St. Thomas, in his work *Summa Contra Gentiles* (translated by Bourke, 1975), writes,

On the same basis, there is also found an order among men themselves. Indeed, those who excel in understanding naturally gain control, whereas those who have defective understanding, but a strong body, seem to be naturally fitted for service, as Aristotle says in his *Politics*. The view of Solomon is also in accord with this, for he says: “The fool shall serve the wise” (Prov. 11:29)...for the dominion of fools is weak unless strengthened by the counsel of the wise...And since he who gives counsel rules the man who takes counsel, and in a sense governs him, it is said in Proverbs (17:2): “a wise servant shall rule over foolish sons”...So, it is evident that divine providence imposes order on all things; thus what the Apostle says is certainly true: “the things which are of God are well ordered” (Rom. 13:1)” (pp. 273-274).

Braddock and Parrish (2001) note that Western thought continued in this tradition with the work of Locke. In his work *An Essay Concerning Human Understanding* he writes of “idiots” (edited, 1975). In Chapter XI (Of Discerning, and other Operations of the Mind) in Book II, Of Ideas, Locke discusses those who cannot think.

Those who cannot distinguish, compare, and abstract, could hardly be able to understand, and make use of language, or judge, or reason to any tolerable degree: but only a little, and imperfectly, about things present, and very familiar to their senses. And indeed, any of the forementioned Faculties, if wanting, or out of order, produce suitable defects in Men’s Understandings and knowledge...the defect in *Naturals* seems to proceed from want of quickness,

activity, and motion, in the intellectual faculties, whereby they are deprived of Reason...In short, herein seems to be the difference between Idiots and mad Men...Idiots make very few or no Propositions, and reason scarce at all" (pp. 160-161).

Parmenter (2001) suggests that Locke's work confirms the belief that people with intellectual disabilities "do not attain the same level of personhood as those of higher intelligence" (p. 270).

Vehmas (2004a) writes that "in moral philosophy (at least in the works of such classics as Plato, Aristotle, Kant and Mill), rationality and practical reason are attributed to adult human beings whose intelligence is 'normal'" (p. 34). Not only were people with intellectual disabilities devalued in this context, but, it has been argued, they were also characterized as lacking certain human qualities. Meininger (2001) agrees and notes

the German philosopher and pedagogue Franz Schönberger argues that persons with intellectual disabilities, seen in the light of the work of great philosophers as Plato, Aristotle, Kant and Hegel, appear as nonhumans, at best as children, that is: as human creatures who are on their way to being real humans (p. 241).

Parmenter (2001) and Stainton (2001) (both also citing Goodey, 1992) argue that the theme of linking intelligence to value and personhood continues today. If Evnine (2008) is correct in his assertion that "the concept of person has its home in a network of social, legal, cultural, and moral institutions and practices" (p. 3), then the insistence

on defining personhood by certain standards or characteristics that are linked with intelligence has a tremendous impact upon the lives of those excluded by definition.

As an example, it is worth considering the premise of Rawls's (1972) theory of justice, based on social contract theory in the tradition of Locke, Rousseau and Kant (p. 11). This theory discusses the principles of justice upon which society is based. Rawls describes these principles as those that "free and rational persons concerned to further their own interests would accept..." (p. 11). Rawls' whole premise is based on the participation of the rational man who is able to reflect rationally, make rational decisions and contribute in a way that is mutually advantageous to the group. The ramifications of social contract theory for those people considered to be outside of its parameters are discussed by Nussbaum (2006). "The fact that they are not included in the group of choosers means that they are not included (except derivatively or at a later stage) in the group for whom principles are chosen" (Nussbaum, 2006, p. 16). Rawls himself acknowledges this, albeit in a footnote, as Haldane (2008) notes.

... since the fundamental problem of justice concerns the relations among those who are full and active participants in society, and directly or indirectly associated together over the course of a whole life, it is reasonable to assume that everyone has physical needs and psychological capacities within some normal range. Thus the problem of special care and how to treat the mentally defective are aside. If we can work out a viable theory for the normal range, we can attempt to handle these other cases later (p. 272).

The exclusion of those considered to lack rationality from the contracting process implies they are simply an “afterthought” (Nussbaum, 2004, p. 311). So ingrained are these theories, that it is difficult to conceive of laws, policies and social practices that reflect otherwise.

Significant Intellectual Disability – Explicit Exceptions to Personhood

My review of conceptualizations of personhood would be incomplete without considering the ways in which some philosophers explicitly exclude individuals with significant intellectual disabilities from membership into personhood. As Carlson (2010) says of her philosophical reflections into intellectual disability, “the intellectually disabled are not persons” (p. 2). She goes on to provide a rationale of why intellectual disability is considered in philosophical contexts. “Many who bring the intellectually disabled into the philosophical fold mark this group out according to its departure from the normal and highlight its profound otherness, its radical alterity” (p. 4).

Sibley (1995) examines the role of otherness in the context of exclusion and notes the effect of characterizing the other as animal.

The relegation of some groups to nature, where they are ‘naturally’ wild, savage, uncivilized, is also expressed in the representation of people as animals, either as animals generically distinct from humans or as particular species which are associated with residues or the borders of human existence – animals as abject (p. 27).

A similar point is made by L. T. Smith (1999) when she considers early European accounts of indigenous people.

“How often do we read in the newspaper about the death or murder of a Native man, and in the same paper about the victimisation of a female Native, as though we were a species of sub-human life?” asks a First Nation Canadian woman, Lee Maracle. “A female horse, a female Native, but everyone else gets to be called a man or a woman” (p. 9).

In her work, Carlson (2010) discusses the animalization of people with intellectual disabilities specifically. Historically, she notes that “it is clear that from its inception, the category of idiocy relied heavily on defining these individuals in terms of their animal nature” (p. 132). Even more importantly, Carlson argues that “the face of the beast that masks the human face of intellectual disability has not disappeared” (p. 132). She says that this beast is evident in the “unexpected place” of “philosophical discussions of justice, rights, respect, dignity, and moral status” (p. 132).

Among his 20 criteria for personhood, Fletcher (1972) mentions intelligence at the outset. He stresses that “any individual of the species homo sapiens who falls below the I.Q. 40-mark in a standard Stanford-Binet test, amplified if you like by other tests, is questionably a person; below the 20-mark, not a person” (p. 1). Clinkenbeard (1989) points out the “pitfalls” of this kind of approach when considering people with intellectual disabilities. “...the criteria will serve, mainly in a negative way, to determine that some mentally handicapped individuals are 'non-human'. In so doing, they function

to reinforce the prevailing social attitude about mental handicap” (p. 91). The effects of characterizing someone as a “non-human” is, to Clinkenbeard, “morally dangerous” because it places some people “‘beyond humanhood’ and thus beyond moral consideration” (p. 91).

These explicit exclusions are not limited to Fletcher’s writings in the 1970s. Evnine (2008) does not believe that all human beings are “obviously” persons and makes particular note of young children and “the severely mentally impaired” (p. 4). He says

...although children and the severely mentally impaired are undoubtedly human beings, they are nonetheless lacking with respect to the standards and norms associated with that kind. They are...incomplete, not-yet-fully realized, or functionally impaired human beings. Hence, their failure to be fully persons might be explained precisely by their failure to be fully realized human beings” (pp. 4-5).

As science progresses and new dilemmas continue to emerge, philosophical discussions about who counts as a person flourish in bioethical contexts. Koch (2004) views this as “a debate over the understanding or construction of the notion of *personhood*” (p. 697). He describes two competing paradigms in the field of bioethics. Proponents of one paradigm argue for a traditional definition for personhood for those “with severely restricting physical and cognitive attributes” (p. 697). Proponents of the

other paradigm favour a wider understanding, and emphasize the position of valuing “persons of difference” (p. 697).

Prominent Princeton philosopher Singer uses individuals with significant intellectual disabilities, whom he refers to as having “profound mental retardation” (2009, p. 569), as an example of how speciesism undermines the value of intelligent non-human animals. In her introduction to Singer’s work, Kuhse (2002), writes that according to Singer, “what is important is not whether a life is human or inhuman; rather what is of central importance...is what interests and capacities a being has” (p. 3). Singer promotes abandoning “the idea of the equal value of all humans” preferring to replace it “with a more graduated view in which moral status depends on some aspects of cognitive ability, and that graduated view is applied both to humans and nonhumans” (Singer, 2009, p. 575). He believes that “some human beings, such as newborn infants and the severely brain-damaged, are not persons in the moral sense” (Kuhse, 2002, p. 4). In the case of infants born with disabilities (“paralyzed from the waist down, incontinent, and mentally retarded”) Singer (2002) advocates the “replaceability principle” which allows parents to “kill the defective infant and then go ahead with another pregnancy”, in hopes of having a “normal” child (p. 120).

In his writing on ethical killing, McMahan is another contemporary philosopher who considers which members of society ought to be afforded moral status and which members are disposable. He uses people with significant intellectual disabilities, labelled by him as “congenitally severely cognitively impaired” (2002, p. 204), “severely

retarded” (2002, p. 205), and “radically cognitively limited” (2009, p. 582), as exemplars to make his arguments. McMahan describes these individuals as “human beings who are capable of consciousness but whose cognitive capacities and congenital cognitive potential are no higher than those of the most highly psychologically developed nonhuman animals” (pp. 582-583). He conceptualizes a person to be “any entity with a mental life of a certain order of complexity and sophistication...to be person, one must have the capacity for self-consciousness” (2002, p. 6). Of the “severely retarded”, McMahan says, “it is difficult to identify *any* intrinsic difference between the severely retarded and animals with comparable psychological capacities that is relevant to the morality of killing them” (p. 206).

McMahan (2002) makes an interesting point when he discusses people with significant intellectual disabilities: “I have claimed... that they have an enhanced moral standing – or merit a wider array of protections – by virtue of their being specially related to certain people” (p. 232). Although McMahan finds a parallel between people with significant intellectual disabilities and pets, I use this quote to introduce the idea, more fully considered in the next section, that relationships are one avenue by which personhood for these individuals can be broadened and re-conceptualized in a particularly valorizing way.

Byrne (2000) sums up the arguments that deny personhood to people with significant disabilities as follows:

The self-conscious, rational creature must live in a world which is more than an array of present stimuli. It must have some comprehension of this world as having a past and an array of possible futures. It is able to discern and comprehend its existence through this past and into those futures. Such general, non-specific knowledge is a product of intelligence (p. 5).

The description of this “creature” often fails to include the “severely mentally handicapped” (Byrne, p. 5). In order to move away from speciesism, philosophers have created an “empirically discernable” measure of moral status which defines personhood in a way that

places a question mark, to say the least, over those human beings whose intellectual development is disordered or retarded and who may, in consequence, not acquire that sufficient grasp of language, self and the world which allows them to function as fully self-conscious, autonomous and rational creatures (Byrne, p. 5).

Rethinking Personhood and Humanness

Societal recognition of an individual as human or a person is crucial. “It is to humans that we extend the mantles of equality, dignity, justice, responsibility, and moral fellowship” (Carlson & Kittay, 2009, pp. 307-308). Yet if, as philosophers have decreed, the “mark of humanity” is the “ability to reason” (Carlson & Kittay, p. 307), can we re-evaluate the privileged place of intelligence, rationality and the ability to reason? The discussion I have presented on how personhood has traditionally been defined

appears to be uniform and largely unquestioned. However, there have been a few philosophers and social scientists who have challenged this view.

MacIntyre (1999) asks, “what difference to moral philosophy would it make, if we were to treat the facts of vulnerability and affliction and the related facts of dependence as central to the human condition?” (p. 4). He explains why we must reevaluate our philosophical and moral foundations. MacIntyre insists we must recognize that the “habits of mind” as described above “are after all *our* habits, part of a mindset that many of us have acquired, not only from our engagement in the enquiries of moral philosophy, but from the wider culture which provides the background of those enquiries” (p. 4). He then goes on to suggest that we might begin

with a certain suspicion of ourselves. For whatever the philosophical idiom in which we frame our initial enquiries, whatever philosophical resources upon which we find ourselves able to draw, we will be liable to think in terms that may prevent us from understanding just how much of a change in standpoint is needed (p. 4).

In presenting new ways in which personhood is being re-considered in philosophy and the social sciences, I want to stress MacIntyre’s thesis of how rationality might relate to designations of personhood.

The virtues that we need, if we are to develop from our initial animal condition into that of independent rational agents, and the virtues that we need, if we are to confront and respond to vulnerability and disability both in ourselves and in

others, belong to one and the same set of virtues, the distinctive virtues of dependent rational animals, whose dependence, rationality and animality have to be understood in relationship to each other (p. 5).

With MacIntyre's (1999) words to serve as a reminder of why a new mindset is important, I will turn my attention to ways in which conceptualizations of personhood have changed focus. I will look at two new emphases: (a) the capabilities approach and (b) relationships.

The Capabilities Approach

In their critique of liberal theory, Silvers and Francis (2009) note that "broad tolerance of substantially different ideas of the good is abridged by an austere process for arriving at these notions" (p. 477). The result of such abridgement is the exclusion of "uncommon people" from conversations about the good and the formulation of the principles of justice (Silvers & Francis). The work of Nussbaum (2006, 2009) begins to address this concern. Although she does not take issue with liberal theory generally, one of Nussbaum's (2006) main criticisms of Rawls's social contract theory is his lack of consideration of people with disabilities in his formulation of justice theory. "Thus, in effect, people with mental impairments are not among those for whom and in reciprocity with whom society's basic institutions are structured" (p. 98).

Nussbaum (2006) suggests that society benefits from supporting people with intellectual disabilities because such support respects their dignity, develops their "human potential", and understands "humanity and its diversity that comes from

associating with mentally disabled people on terms of mutual respect and reciprocity” (p. 129). The dangers of failing to conceptualize people with significant intellectual disabilities within liberal theory and social contract theory are clear.

Where there is no role for certain kinds of uncommon people in formulating justice, there may be no protection through justice for them. Instead, conceptions of their goods may be misshapen to fit within a framework of justice constructed for others (Sillers & Francis, 2009, p. 478).

In response to traditional contract theory and its failure to consider people with significant intellectual disabilities, Nussbaum (2006) introduces what she calls the “capabilities approach”. She uses this theory “to provide the philosophical underpinning for an account of core human entitlements that should be respected and implemented by the governments of all nations, as a bare minimum of what respect for human dignity requires” (p. 70). Her thinking is called the capabilities approach because it focuses on human capabilities or “what people are actually able to do and to be” based upon the idea of “life that is worthy of the dignity of the human being” (p. 70). There is an obligation, therefore, to pursue these capabilities for everyone in society. Nussbaum’s approach begins from the premise of dignity for every person, and not just for those who are deemed worthy by virtue of their rationality, intelligence or the advantage they can bring. She also re-envisioned the central notion of reciprocity and mutual advantage in social contract theory and replaces it with cooperation resulting from a “wide range of motives”, including “the love of justice itself, and prominently including a moralized

compassion for those who have less than they need to lead decent and dignified lives” (pp. 156-157).

Nussbaum (2006) lists ten capabilities “as central requirements of a life with dignity” which are “held to be part of a minimum account of social justice” (p. 75). These central human capabilities are: a) life; b) bodily health (including adequate shelter); c) bodily integrity (including being able to move freely from place to place and being secure against violence); d) senses, imagination and thought; e) emotions (being able to have relationships and attachments); f) practical reason (“engage in critical reflection about the planning of one’s life”); g) affiliation (engage in social interaction and be treated as “a dignified being whose worth is equal to others”); h) other species (live in relation to the world); i) play; and j) control over one’s environment (political and material) (pp. 76-78).

Nussbaum’s (2006) list of capabilities stands in stark contrast to Wolfensberger’s (1998) consideration of the wounds suffered by people who are devalued in their society. As this review suggests, our society highly values attributes such as intelligence, competence and independence. As a consequence of these valuations, we devalue a perceived lack of intelligence, incompetence and dependence (Wolfensberger, 1998). It has been argued that the act of devaluing, or attributing “low or negative value” to something or to someone is universal and has particularly affected those who are seen as impaired in some way (Wolfensberger, p. 3).

A consequence of such devaluation is a number of experiences or “wounds” that devalued people suffer (Wolfensberger, 1998, p. 12) These wounds or “hurtful things” may be inflicted “consciously and with specific intent... unconsciously... and sometimes... are simply the result of life conditions and circumstances which are the way they are for the devalued party because of that party’s devalued status and life conditions” (Wolfensberger, p. 12). The list of wounds includes: a) being relegated to a low social status, b) being cast into devalued social roles, c) being juxtaposed against images that carry negative messages, d) being at risk of being made into scapegoats, e) being put at a distance from society, either physically or socially, f) losing control over their lives, g) experiencing discontinuity with relationships, places and things, h) a lack of opportunity to form and maintain genuine relationships with others, i) deindividualization, j) poverty, k) impoverishment in “world experiences”, l) being cut off from spiritual opportunities, m) having wasted lives, and n) being at risk of brutalization and violation (Wolfensberger, pp. 12-21).

The first thought that occurred to me as I considered each capability was how much our society has to reconsider people with significant intellectual disabilities so that they can achieve these capabilities. While reading Nussbaum’s theory, I reflected on how the lives of people with significant intellectual disabilities would be affected if a capabilities approach was adopted.

At the most basic level of “life”, significant changes could occur. Current trends in medicine and bioethics encourage genetic screening, selective abortions, arguments

of medical futility, and withholding and withdrawing life-sustaining end-of-life care. These trends tend to discount the lives of people living with significant disabilities (Hansen, Janz & Sobsey, 2008; Koch, 2004) but might be re-examined if the capabilities approach was a focus.

In educational contexts, Nussbaum (2006) envisions being able to imagine and think “in a truly human way’, a way informed and cultivated by an adequate education” (p. 76). This is a marked contrast to the ways in which many students with significant intellectual disabilities are educated today.

Nussbaum also emphasizes the importance of relationships and emotional development, which are often elusive for people with intellectual disabilities (Lord & Hutchison, 2007). Even this brief consideration of several capabilities shows how important certain basic standards are for everyone in society. It also serves as reminder of the “respect we owe to people with mental impairments as fully equal citizens who are members of the human community and who have the ability to lead a good human life” (Nussbaum, 2006, p. 190).

Relationships, Humanness and Personhood

Carlson (2010) emphasizes how crucial it is to recognize people with significant intellectual disabilities as entitled to personhood.

When we recognize persons with intellectual disabilities as members of our social, *human* world who are directly and indirectly affected by our institutional practices, and recognize that the treatment (e.g., institutionalization) of certain

individuals is often justified by extension to other members of that same group, the difficulty of distinguishing between non-human animals and the most severe cases of intellectual disability in human beings disappears (p. 152).

Within this new tradition, a number of philosophers and social scientists have moved beyond identifying people based on their perceived rationality, intelligence, and ability to reason (Bérubé, 2009; Bogdan & Taylor, 1998; Byrne, 2000; Carlson, 2010; Goode, 1984, 1992; Kittay, 1999, 2005, 2009; Lindemann, 2009; MacIntyre, 1999; and Nelson, 2002). Instead they look to and focus on “an affinity between *fellow human beings*” (Carlson, 2010, p. 154).

Byrne (2000) urges us to leave our reliance on the ability to reason as a measure of personhood behind us. Instead, he proposes that we accept that there is a “fundamental moral equality” between human beings (p. 71). This is accomplished through relationships between fellow human beings.

I am established in *my* eyes as a being who has moral standing by virtue of *others* treating my interests, concerns as things which affect their wills...They will not treat me as an object to be shoved about or manipulated as their desires dictate. Positively, they will act to help the satisfaction of my own interests... It is important for my establishment as a being of worth in the eyes of others that my value for them is quite other than a use value...Acting toward other human beings so as to establish in them a sense that they are things of unconditional worth enables them to grow up as beings with self-respect (pp. 71-72).

I also return to the work of MacIntyre (1999) to re-affirm the idea that identity as a person comes from the ability to have relationships with others. In discussing individuals who are “physically and mentally incapacitated”, the author warns those who believe that “we can only say that at most they can be passive objects of benevolence designed to limit their suffering” (p. 138), by suggesting such a view is a mistake. MacIntyre insists that what people with significant intellectual disabilities give us “is the possibility of learning something essential, what it is for someone else to be wholly entrusted to our care, so that we are answerable for their well-being” (pp. 138-139). One aspect of caring in this way is taking on the role of speaking for those who cannot speak for themselves. MacIntyre suggests that “no one will be able to speak adequately for me who does not already know me” (p. 139), which implies that to speak for someone, there must be a connection “rooted in previously existing relationships of friendship” (p. 139).

In attempting to understand why some people do not “stigmatize, stereotype, and reject” people with significant disabilities, Bogdan and Taylor (1998) conducted a study in which they examined how humanness is socially constructed by nondisabled people who are in “caring and accepting relationships” with people who have significant and/or multiple disabilities (p. 242). I consider their conceptualization of humanness to be similar in nature to what others have called personhood. The authors summarize their work by saying, “although the disabled people in these relationships sometimes drool, soil themselves, or do not talk or walk – traits that most would consider highly

undesirable – they are accepted by the non-disabled people as valued and loved human beings” (pp. 242-243).

Bogdan and Taylor (1998) were particularly interested in the “mental constructions” that non-disabled people developed in connection with their “disabled partner” (p. 247). The authors noted four dimensions in which non-disabled people described the “humanness” of their disabled partner. The first dimension is described as attributing thinking to the disabled partner. Bogdan and Taylor confirm that “the ability to think – to reason, understand and remember – is a characteristic that is commonly thought of as defining humanness” (p. 247). The authors then go on to describe the disabled people involved in their study as

unable to talk and have been diagnosed as severely or profoundly retarded. A few accomplish minimal communication...In the conventions of psychological testing, many have extremely low IQs (below 20), so low in some cases that they are considered untestable. Many give few or no obvious signs of experiencing the stimuli presented to them. Most people would say they lack the ability to think (p. 247).

Notwithstanding what “most people would say”, the non-disabled people saw their partners as “more intelligent than they appear” (p. 248). One way in which this is accomplished is by standing in the shoes of their disabled partner or “taking the role of the other” (p. 249).

The second dimension involves seeing the disabled partner as a “distinct, unique” individual who has “particular and specific characteristics that set them apart from others” (Bogdan & Taylor, 1998, p. 251). Using this mindset, the nondisabled partners attribute a personality, likes and dislikes, feeling and motives, and life histories to their disabled partner. They are also able to “actively create” this individuality through managing appearances (p. 253).

In the third dimension, non-disabled partners view the relationship with their disabled partner as reciprocal, meaning that the disabled person gives something back, even though this may be an “abstract” benefit (Bogdan & Taylor, 1998, p. 254). Reciprocity is a major element of social contract theory, so this dimension is particularly significant as a means of re-thinking what it means to reciprocate. Elements of this reciprocity include deriving pleasure from the relationship, feeling that the relationship has made the non-disabled partner a better person, and being able to contribute to the “disabled person’s well-being and personal growth” (p. 255).

Lutfiyya (1991) prefers the term “mutual” over reciprocal. Previous work on relationships tended to insist that reciprocity, conceptualized as a fairly equal exchange of goods over time, was an essential part of friendship. However, Lutfiyya found that, although there was an unequal exchange of goods in relationships between people with and without disabilities, those in the relationship still defined it as a “real friendship”. They reported their friendship to be mutual and meaningful. Mutuality was therefore understood as “the giving and receiving of emotional support, practical assistance,

inspiration, rule-breaking and dispensations of certain societal norms, and the sheer enjoyment of being together” (p. 238).

Bogdan and Taylor’s (1998) final dimension involves identifying a social place for their disabled partner in their family unit and in the larger social circle. “When severely disabled people are integrated into primary groups and have their humanness declared there, they have a vehicle for inclusion in the social web that defines community membership” (p. 256). Ultimately, people with significant disabilities come to be identified as “people like us” (p. 247), instead of being identified as the “other”.

Conceptualizing the humanness of people with significant intellectual disabilities through strong relationships is a theme that is echoed in the writings of others. For example, Kittay (2005, 2009), who has a daughter with a significant intellectual disability and Bérubé (2009) who has a son with Down syndrome, write eloquently of the value of their children.

In addition to her writings about her daughter, Kittay (1999) has looked at the issue of people with significant intellectual disabilities in the context of care and dependency. This examination has led her to discuss and extend upon Ruddick’s (1989) three “requirements of maternal work”: a) preserving the child’s life, b) socializing the child for acceptance and c) fostering the child’s development (p. 163).

In preserving the child’s life, Kittay (1999) stresses both the fragility of some children with disabilities, including her own daughter, and the need to ensure medical

professionals see the value of treating the disabled child. Here, the importance of the relationship between mother and child is vital.

When Kittay (1999) writes of socializing the child, she refers not only to socializing the child in her environment, but also to socializing the environment to her child. Ensuring that her daughter is well-dressed and well-presented is “our family’s way of telling the world that this person is loved and cared for, and hoping the message that she is worth being cared for will be absorbed by others” (p. 166). It also parallels the findings by Bogdan and Taylor (1998) that describe how the non-disabled partners encourage the identity of the disabled partner by managing his or her appearance.

Fostering development also means something different for parents of a child with a significant disability. Kittay (1999) realizes that it can be dangerous for her to rely too heavily on the notion of development and independence for her daughter because she will always be dependent on others for care. She fears that “the stress on independence reinstates Sesha as less than fully human” (p. 173). Instead, Kittay chooses to focus on developing “whatever capacities are there to be developed”, which means enhancing her daughter’s capacities to “experience joy” (p. 173).

Another related way of defining personhood for people whose humanness may be cast into doubt is to consider what Nelson (2002; Lindemann, 2009) calls “holding in personhood”. This is something loved ones do by “constructing or maintaining a personal identity” when the person cannot do this on his or her own behalf (2002, p. 30). In recounting her own experience with her disabled baby sister, Nelson (2002)

explores how her family constructed Carla: “We made a place for her among us, treating her according to how we saw her, and in so treating her, making her even more that person we saw” (p. 32). Nelson (2002) explains this action as a kind of “social practice”, where “the value of our narrative activity lay in the goodness of acknowledging a loved one’s personhood with our own” (p. 32). Because identity creation lies, not only with the individual but also externally through others, a person with a significant intellectual disability can be “held” in their identity by those close to him or her (Lindemann, 2009). Like Bogdan and Taylor (1998) and Kittay (1999, 2009), Lindemann (2009) uses the power of relationships to develop and maintain identity, thus reinforcing personhood for those who might otherwise be seen as not fully human.

A related idea is Wolfensberger’s (1998) concept of valued social roles, which he uses as a means of combating the devaluation and wounds I discussed earlier. He suggests that social roles are important because they help to define people and locate them within the larger world. Thus, the creation and establishment of valued social roles is vital because such roles lead to social acceptance and respect (Wolfensberger, 1998). One significant aspect to holding a highly valued role is that role’s ability to overshadow less desirable characteristics. Highly valued roles also affect the perceptions and reactions of others. This effect may even be of greater consequence than the actual role itself.

There are many types of roles that people hold. Wolfensberger (1998) discusses eight common role domains—relationships; residence; occupation; education;

recreation and leisure; civic identity; and participation, values, and culture. Holding valued social roles has been difficult for many people with significant intellectual disabilities. Social roles such as those of valued family member, neighbour, employee, student, organization member, board member, voter, volunteer, parishioner, arts patron, and music or book lover are all valued ways in which to identify people with significant intellectual disabilities. Notwithstanding the simplicity in recognizing these roles, such individuals are more likely to be perceived as holding negatively valued roles such as special education student, welfare recipient, and charity case.

Conceptualizing people with significant intellectual disabilities as human and reinforcing their personhood is not limited to parents or family members. Goode (1984, 1992) worked with Bobby, a 50 year old man with Down syndrome who had spent the majority of his life at a board and care facility. Goode rejected initial representations of Bobby that appeared in his clinical records because “nowhere was Bobby discussed in terms of his having any sort of competence and human value; instead an exclusively fault-finding perspective was employed” (1992, p. 200). Once Goode got to know Bobby, he saw a very different person “a man with an unusual countenance, different ways of thinking and evaluating, trying to explore and master his everyday world” (1992, p. 211). Goode suggests that looking at Bobby in a “humanistic” way focuses on how Bobby is like him and puts less emphasis on how Bobby may be different.

Focusing on Students with Significant Intellectual Disabilities

I now turn my attention to students with significant intellectual disabilities in educational contexts. In this section I explain why I chose to focus on students, consider some theoretical implications for considering special education, examine the goals of general and special education, and take an historical look at special education, including past and present trends.

Why Students?

Questions of personhood and moral value in the context of people with significant intellectual disabilities are often raised today in bioethical contexts (Byrne, 2000; Carlson, 2010; Singer, 2002). Fertile areas of discussion often centre on the beginnings and endings of life. For example, the value of the lives of infants with significant intellectual disabilities is debated. Byrne (2000) suggest that arguments about personhood and cognitive disability “pose a particularly severe threat to disabled infants” (p. 74). More chillingly, he points to “the avowed practice of some paediatricians, who in effect take steps to ensure that certain infants in their care will die on the very grounds of the nature and extent of predicted cognitive (and other) disability” (p. 74). Wilkinson (2006) agrees and notes that “in my experience of neonatal and paediatric intensive care, the single most important factor in discussions on withdrawal of treatment is the presence (or predicted presence) of severe intellectual disability” (p. 454).

These philosophical and bioethical dialogues lead to the question of what happens to the infants who do not die. If decisions are made to treat and/or nurture these children, they eventually reach the age when education becomes the cornerstone of children's lives. Their non-disabled peers enrol in school. When they too enrol, as is their right, what kind of an education awaits them? How pervasive are philosophical discussions linking personhood and moral worth to intelligence and rationality? It is these questions that my work addresses.

Hierarchy of Presuppositions

In his critique of special education, Skrtic (1995a) sets out the scientific community's "hierarchy of presuppositions" (p. 13). At the most abstract level of the hierarchy is the metaphysical paradigm, or meta-theory, which is "a set of implicit basic beliefs or presuppositions that unrandomize complexity and provide scientists with a general picture of the world and how it works" (Skrtic, p. 12). The next level of the hierarchy is theories, which are based on the presuppositions, and used "to explain and act upon actual phenomena" (p. 12). Guiding assumptions follow, and are "derived from the logic of the theories" (p. 12). The next hierarchical level is models that "define and subsume an associated set of research practices and tools" (p. 12). I will use this hierarchy to illustrate how the foundational beliefs about personhood and intelligence, the meta-theories, affect the theories, assumptions, models, practices and tools involved in the thinking about and supporting the education of students with significant intellectual disabilities.

The theory that arises as a result of the meta-theory is that people with significant intellectual disabilities are less than human because they are perceived as lacking awareness, self-consciousness, the ability to think rationally, the ability to reason and the ability to reciprocate. Being less than human means that members of society are not inclined to offer them the same “equality, dignity, justice, responsibility, and moral fellowship” (Carlson & Kittay, 2009, p. 307) to which other non-disabled members are entitled.

In conjunction with this theory, several assumptions are made about these individuals. It is assumed that they are morally unworthy (Stainton, 2001) and incompetent (Angrosino, 1998). In term of education, such statements further assume that students with significant intellectual disabilities are simply unable to learn and unable to benefit from learning. These assumptions form a rationale for the development of special spaces, controlled by specialists with special knowledge, to provide a special way of educating students for whom a real education is simply not feasible or worthwhile.

As a result of the assumptions, a number of inter-related models of disability are in play. The most significant of these, in terms of its impact, is the individual model of disability (Oliver, 1996). Oliver suggests that this model is “underpinned” by the “personal tragedy theory of disability” and also includes the medicalization of disability (p. 31). Related to this model is the charity conceptualization of disability (Derksen, 1980), which disempowers people with disabilities and focuses on people with

disabilities as objects of pity (Wolfensberger, 1998). The hallmark of the individual model locates the “problem” of disability within the person (Oliver). Gabel (2005) notes that typical understandings of disability within educational contexts tend to pathologize disability as an individual deficit within the student. Such understandings have moved into the structure of how special education works, but do little to either affirm or emphasize notions of equality, justice or citizenship.

Moving from models to practices, the effects of our foundational beliefs become even clearer. The major practice resulting from the belief that people with significant intellectual disabilities are less worthy is the establishment of a segregated system to “educate” these students. Tomlinson (1995) suggests that special education was actually “more of a solution to problems of social order than a way of ‘doing good’ for children with special educational needs” (p. 129). Although inclusion is largely mandated in 21st century North America at least, rationalizations still exist that prevent these students from receiving an education that is meaningful and productive for them. This is evidenced by the existence of special programming, even if it is located within a “regular” school. Other practices that maintain the parallel system include the need for professionalized testing to establish and confirm “diagnoses”. Such testing is required in order for funds to be allocated. In Manitoba, the Appropriate Educational Programming Regulation requires “specialized assessment” by “qualified practitioners”, further demonstrating the ingrained belief in the individual model of disability and all that it implies (Public Schools Act, 2005).

The Purposes of Education

Before I examine special education in an historical context, I believe it is important to step back for a moment and consider why we educate the children in our society. This examination will help me to compare the ultimate goals of educating students with and without intellectual disabilities.

The United States. In her report on public education for the American Center on Education Policy, Kober (2007) discusses the “public missions” that public schools are expected to fulfill. These include: (a) providing universal access to free education, (b) guaranteeing equal opportunities for all students, (c) unifying a population that is diverse, (d) preparing students for citizenship, (e) preparing students to be economically self-sufficient, and (f) improving social conditions (p. 7). The report also recognizes other, more individual purposes of education, such as enriching people’s lives

by developing their capacities to think critically, appreciate culture, and maintain a sense of curiosity about the world. Education exposes children to new ways of thinking [and] can spur young people to go on to higher education and pursue learning all their lives (Kober, p. 13).

Canada. Stewart (2005) offers reflections on the purposes of public education in Canada. He examines the missions and goals of seven provincial and two territorial education ministries and comes up with four themes: (a) “the good or well-being of the individual”, (b) “the public good or good of society”, (c) “vocational preparation”, and (d) “the economic good” (p. 5). He argues that the primary goal of schooling is

education, which allows students to look at the world in new ways and achieve a deeper understanding of themselves and their place in that world. The reason for schooling is ultimately “the development of the mind or intellect” from which other goals of social good and vocational preparation follow (Stewart, p. 6). Emphasizing a different perspective, Coulter and Wiens (2005) declare that education is about preparing students to participate in our democratic society.

In Manitoba, the government has declared its mission as ensuring that the province’s children experience success through “relevant, engaging and high quality education” which, in turn, will prepare them for “lifelong learning and citizenship in a democratic, socially just and sustainable society.” This statement unites Stewart’s (2005) focus on intellectual development with Coulter and Wiens’ (2005) emphasis on democratic participation.

Although it can be argued that all of the goals and mission statements suggested here are vital reasons why children are educated in our society, I am interested in understanding how these goals are reflected in the actual education of students with significant intellectual disabilities. Some might argue that many students are not meeting these educational purposes. However in the context of this work, I cannot help but wonder how these objectives of learning and citizenship mesh with underlying assumptions about intellectual disability including incompetence and segregation. The origin of these assumptions will be explored as I delve into an historical account of education and people with intellectual disabilities.

A Brief Historical Account of Special Education for Students with Intellectual Disabilities

It is difficult to undertake the task of deconstructing special education without understanding the historical foundations and underlying philosophies of the field. For this reason, I briefly review the history of educating people with significant intellectual disabilities and the history of special education itself. I focus on North America, with an emphasis on Canada wherever possible. I pay particular attention to the original goals and practices of special education as well as to the curriculum for students with significant intellectual disabilities. By doing so, I can determine the extent to which these old ideas have crept into the modern education of these students. In providing this review, I want to stress that the history of special education includes the education of children with various types of disabilities. Wherever possible, I have tried to limit this discussion to intellectual disability. However, historical accounts of the education of children with significant intellectual disabilities are not always specifically noted in the literature.

The Origin and Goals of Special Education for Individuals with Intellectual Disabilities in North America

The mid-19th century marked the origin of institutions in the United States for “deviant groups” with the purpose of making “the deviant less deviant” (Wolfensberger, 1975, p. 24). This goal was to be achieved by education. “The goal was a combination of diminishing the intellectual impairment and increasing adaptive and compensatory skills of pupils so they would be able to function at least minimally in society”

(Wolfensberger, p. 24). Institutions were originally conceptualized as schools, and meant to educate children with intellectual disabilities and then return them back to the community. This approach to education was a functional one and was predicated upon the developmental model where it was believed that such children did have some capacity to be improved.

Toward the end of the century, the views of educating children with intellectual disabilities began to change. Wolfensberger (1975) argues that the thinking shifted from the developmental model to a pity and charity model due to the perceived failure of the early institutions as schools. Hence the notion grew that “instead of schooling, loving care and protection should be bestowed upon” these individuals. Soon the word “school” in institutional names was replaced with the word “asylum” (p. 28) and the educational purpose was lost.

Special education classes in public day schools were originally developed in North America in the 1890s for “backwards boys and girls” (H. G. Simmons, 1982, p. 90). These classes were established to meet a number of objectives, and included: (a) removing “feeble-minded” children from the “regular school system” to avoid disrupting the education of other students, (b) allowing these feeble-minded children to receive an education that would promote them to be somewhat self-supporting, (c) affording some protection for these children from harassment by other students, and (d) weeding out those who were considered incapable of being educated for institutional placement (H. G. Simmons, 1982, p. 90). Sarason and Doris (1979) point to the belief that having

“mentally defective” students in regular classrooms took away from the time teachers had to spend on the other students.

The period of time that Wolfensberger (1975) describes as being driven by pity and charity was short-lived. It was replaced by the image of people with intellectual disabilities as a menace (Trent, 1994), resulting in a “long period of brutalization” (Wolfensberger, p. 31). Trent argues that there was “increasing insistence in the first and second decades of the new century that mental defectives, in their amorality and fecundity, were not only linked with social vices but indeed were the most prominent and persistent cause of those vices” (p. 141). The response to this new view of people with intellectual disabilities was control (Trent). The effect of this “indictment” (Wolfensberger) was chilling:

In any society that places high value on intelligence and achievement, there is probably a pre-disposition to brutalize and dehumanize the inadequate deviant person. When the deviant person is seen as not only inadequate but also as a menace, latent dehumanization becomes overt (p. 37).

As new perceptions about people with intellectual disabilities changed, public support for educating students with intellectual disabilities waned and the final objective noted by H. G. Simmons (1982) became a paramount consideration. For example, the school program at the institution in Orillia, Ontario almost closed because public opinion was critical of the cost and futility of educating “idiots” (Winzer, 1993, p. 132). Helen MacMurchy, Ontario’s Inspector of the Feeble-Minded and Inspector of

Auxiliary Classes, mandated the first special education classes in 1910 and considered their purpose to be a “clearing-house” (H. G. Simmons, p. 90). “For MacMurchy, special classes were not an end in themselves, for their purpose was not primarily educational. Rather they were to be the first step in a policy of identifying those mentally retarded children who needed permanent, institutional care” (H. G. Simmons, p. 91).

Wolfensberger (1975) also notes that the early educational goals for people with intellectual disabilities were later replaced by the view that their education was “worthless” (p. 53). Moreover, special education “in the community, far from being seen primarily as a constructive and viable alternative, was seized upon as a means of identifying the retarded for subsequent institutionalization” (Wolfensberger, p. 53).

The eugenics movement of the 1920s and 1930s spawned “a critical period of public scorn toward those diagnosed as mentally retarded, with widespread calls for mandatory sterilization and segregation” (Andrews & Lupart, 2000, p. 32). In fact, P. Smith (2010) argues that “special education is founded in the eugenics movement of the early modernist period” (p. 46). He goes on to suggest that Social Darwinism, which differentiated between “those who are Normal” and “those who are Different”, continues to hold “remarkable currency in an increasingly rightist American culture and dominates present educational thinking” (p. 46).

The proliferation of special education created an increased demand for teachers. In order to find these educators, school boards looked to institutions to staff their programs (Winzer, 1993). Winzer declares that “nowhere were the links between

residential schools and day classes stronger than in the early curricula presented in segregated classes” (p. 333). This situation had the significant consequence of transferring “training activities” from institutional settings to educational settings (Winzer, p. 333). For example, students with intellectual disabilities in special classes made rugs, scrubbing brushes, baskets, and lace (Winzer). However, education was not the only purpose of these classes. Educators could also diagnose, identify and treat children with intellectual disabilities, ultimately weeding out those who were thought to require “more restrictive environments” (Winzer, p. 333).

The origin of special education and its curricular history raise several important points. First, the education of children with intellectual disabilities began and has continued in settings separate and apart from the education of students without intellectual disabilities. Second, children with intellectual disabilities were not expected to learn the same kinds of things as students in the regular public school system. The curriculum for these students originated within a functional and developmental mindset. Third, the kinds of activities described by Winzer (1993) emphasize the low expectations placed on the ability of these students to learn other kinds of things, including academic subjects. Finally, the educational foundations of teaching these children arose, not from any educational philosophy, but from an institutional philosophy, which, from the late 1800s, emphasized the care and social control of people with intellectual disabilities (H. G. Simmons, 1982). The issue of curriculum in special education has been summed up succinctly by Danforth, Taff and Ferguson

(2006). "Curriculum comes into play only when teaching is attempted, and teaching is attempted only when learning is thought possible" (p. 1).

The Movement towards Community-Based Education in Canada

Eventually the political and social rationale for special classes changed. Educators believed that these classes served their students better than regular classes due to smaller class sizes, the specialized knowledge of the teachers, unique programming, and better resources and equipment (Andrews & Lupart, 2000).

In Canada, it was not until the 1950s and 1960s that the movement against institutionalization for children with intellectual disabilities began, led largely by parent advocacy (Andrews & Lupart, 2000). At first, advocacy groups established special classes or schools, outside of the public education system, in an attempt to "provide more personalized attention and educationally relevant experiences" (Andrews & Lupart, p. 33). These efforts led to the creation of special classes within the public education system in the late 1960s and into the 1970s (Andrews & Lupart).

The 1970s were influenced by the principle of "normalization". This concept was originally formulated by Bank-Mikkelsen of Denmark (Bjarnason, 2004) and was introduced through the Danish *Mental Retardation Act* in 1959 (Ericsson, 1985). Bank-Mikkelsen said,

normalization does not mean that we are trying to make the mentally retarded so-called normal, but we are aiming at giving the mentally retarded normal or ordinary rights. You could just as well talk of principles of equalization. Some

basic principles of normalization are to arrange for the retarded a living as close (to) the normal life as possible” (Bjarnason, p. 34).

Nirje, a Swedish pioneer of normalization, believed that a “normal life” for people with intellectual disabilities included:

1) a normal rhythm of the day, 2) a normal rhythm of the week, 3) a normal rhythm of the year, 4) an opportunity to experience the normal developmental phases of the life cycle, 5) that ones [*sic*] own choices, wishes and demands be respected, 6) that one lives in a bisexual world, 7) that one has a normal economic standard and 8) that the standards of physical facilities available to the mentally retarded are the same as those apply for non-handicapped citizens (Ericsson, 1985, p. 4).

In educational contexts, normalization meant integrating students with intellectual disabilities into regular schools, with an emphasis on placing students in the least restrictive environment possible (Andrews and Lupart, 2000).

Mainstreaming was the key word used in special education in Canada in the 1980s and emphasized education for students in the regular classroom (Andrews & Lupart, 2000). In a practical way, however, continued “categorical services” for students with intellectual disabilities meant that the dual system of regular and special education continued (Andrews and Lupart, p. 36).

In the 1990s, the notion of inclusion gained prominence, largely because “the social-cultural realities of mainstreaming and integration are that one group is viewed as the ‘mainstream’ and one group is not; hence one group has to ‘push in’” (Winzer, 2008, p. 43). Winzer argues that the inclusion philosophy encourages changes to the system whereas integration and mainstreaming focus on forcing students to fit the system. Andrews and Lupart (2000) suggest that inclusion will only work when there is a paradigm shift and recognition that a dual system of education must be replaced with a single, unified system. These authors argue that “artificial designations such as categories, IQs, and grade levels must be replaced with the student-centred focus of determining individual learning strengths and needs, and with differentiation of instruction and resources to tap the learning potential of all students” (p. 37).

In terms of curriculum development, Browder et al. (2003) reviewed the curriculum trends for students with severe disabilities in the United States. This review reveals how students with significant intellectual disabilities have been conceptualized from the 1970s to the 21st century. The original curricular philosophy, dating from 1975, was based on the developmental model, which meant an adaptation of an infant/preschool curriculum for students ranging in age from 6 to 21.

From 1975 to the late 1980s, there was a shift to a functional curriculum, which used “major domains of life” such as vocational, leisure, home and community (Browder, et al., 2003, p. 166). Brown et al. (1979) describe the focus of this curriculum

as “chronological-age-appropriate functional skills in natural environments” (p. 83). The authors define functional skills as

the variety of skills that are frequently demanded in natural domestic, vocational, and community environments. Functional skills are not limited to performances which affect the actual survival or physical well-being of an individual; they also include the variety of skills which influence a student’s ability to perform as independently and as productively as possible in home, school, and community (p. 83).

Natural environments are seen as “the variety of least restrictive environments in which a severely handicapped student is being prepared to function” (Brown, et al., p. 84). Finally, the material to be used in educating these students ought to be material that does not “highlight the deficiencies in their repertoires” (p. 86).

From the mid 1980s to the 1990s, the philosophical foundation was social inclusion, which focused on social skills and “opportunities to interact” (Browder, et al., 2003, p. 166). The 1990s had a self-determination focus, with instruction in choice-making and goal-setting (p. 166). Now, the emphasis is on access to the general curriculum and learning “selected skills derived from the general curriculum” (p. 166).

Notwithstanding this philosophy, some authors have argued that today, “the course of study for students with disabilities is often governed in practice by a system of presumptive labels that determine what they will be taught, by whom, and in what type of educational setting” (Danforth, Taff & Ferguson, 2006, p. 1).

I have noted that current trends are moving toward including students with significant intellectual disabilities in general curriculum education. However, I want to point out that this does not mean that the general curriculum itself is beyond critique. McPhail and Freeman (2005) discuss the orientation of the post-World War II curriculum in the United States, with its focus on “literacy, math, science, and social studies” (p. 258). The expectation is that students will “progress methodically with the ‘rationally designed curriculum instruments’ by subject-area experts within the standard disciplines” (p. 259). This views “positions curriculum as a neutral field of development and inquiry without respect for differences in ethnicity, gender, and ability” (p. 259). Consequently, children’s cognitive and social development is expected to be fostered by means of these systematically developed curriculum materials” (p. 259). Unfortunately, as the authors note, these materials are not neutral and those who cannot meet the curricular expectations are labelled as “‘abnormal’, ‘exceptional’ or ‘at risk learners’” (p. 259).

Special Education in Manitoba

In Manitoba, children who were considered to be “mentally defective” were simply not allowed to go to public schools before 1967 (Lutfiyya & Van Wallegghem, 2001). As a result, children with intellectual disabilities stayed at home, lived in institutions, or attended a private school or class initiated by parents or parent advocacy (Lutfiyya & Van Wallegghem). By 1970 “most school divisions across the province were operating special schools or at least a number of special classes” (Lutfiyya & Van Wallegghem, p. 82). Notwithstanding these small advances, there were, as Schaefer

(1999) relates, no educational options for children with significant intellectual disabilities like her daughter, Catherine.

First I called every school for the handicapped in the city. As soon as I launched into a description of Cath's defects, I was regretfully told that "she wouldn't fit into our program..." The closest I got to success was when the principal of a school for the multiply handicapped evidently decided I was being unduly modest about Cath's mental capabilities. He sent a psychologist to test her IQ, but the poor woman was embarrassed when she saw Cath. She wrote some perfunctory notes on a form and left before she had finished her coffee. I didn't hear from the school again (p. 142).

Over the next three decades, Lutfiyya and Van Wallegghem (2001) suggest that the development of special education in Manitoba followed North American trends and moved forward due to the work of parent advocates and some allied educators. As a result, "there has never been a grand plan or direction in special education" in Manitoba (Lutfiyya & Van Wallegghem, p. 83).

An illustration of the curriculum for students with significant intellectual disabilities in Manitoba today can be found in the programs offered by the Winnipeg School Division (WSD). I choose this example because the WSD is the largest division in Manitoba, serving over 32,000 students across 77 schools (Winnipeg School Division, 2009-2010, p. 72). The division's "Adaptive Skills Programs" are designed for students "between the ages of 4 and 21 who have multiple disabilities or are medically fragile

and/or have a significant cognitive disability paired with one or more of the following disabilities: communication, physical, behavioural, functional” (Winnipeg School Division, 2008, p. 40). The goals of these programs are

to provide either Manitoba Education, Citizenship and Youth curriculum with adaptations or a modified or an individualized curriculum as is appropriate to the student’s potential in the following skill areas: academics, self management, social/emotional, communication, pre-employment, leisure/recreation, community awareness and motor (physical) (p. 40).

It is worth noting that these programs are only available at 6 elementary schools, one junior high school and five high schools within the division.

The Professionalization of Special Education

As more and more students were diverted into special classes, the profession of special education grew. In his critique of the professions, Skrtic (1995a) explains that professional authority is based on two claims: a “practical claim” that professionals have “exclusive access to knowledge” in their field, and a “political claim” that they will use their knowledge to the benefit of society (p. 3). As professionals, special educators bring with them a certain authority to which students, parents, and society in general respond.

Skrtic (1995c) also notes that the field of special education and its practices are the “product of a functionalist view of education” (p. 66). By this he means that special education is based on the belief that there is a “single social reality” which is recognized

as objective and “inherently correct” (p. 67). For example, this reality might conceptualize students with significant intellectual disabilities as in fact fundamentally defective, based on the objective measures of instruments which are designed to test intelligence. Referring to the hierarchy of presuppositions, Skrtic argues that “the guiding assumptions” behind the “models, practices, and tools” of special education “are premised on theories of human pathology and organizational rationality” (p. 75).

Skrtic’s (1995a & b) theoretical work has been confirmed by Jones’ (2005) practical research with educators who teach students with profound and multiple learning difficulties (PMLD). She notes that her participants’ views of these students “reflect the historical definitions and classifications of PMLD closely” (p. 383). She goes on to suggest that this view is understandable given that these teachers “are trained professionals and operate in a professional world” (p. 383).

What this perspective fails to recognize, I strongly argue, is that there may be other ways in which to conceptualize these students and their education. Such a re-conceptualization may move beyond characterizing students in terms of pathology, may reconsider the allegedly value-neutral assessment tools used to categorize students, and may critically examine the foundations upon which current practice is based.

In order to more fully consider why students with significant intellectual disabilities continue to face at least some segregation in their educational experience, I will now turn to an examination of two key issues in North America that have guided services for people with intellectual disabilities, including students. These are the North

American policy “palimpsest” (H. G. Simmons, 1982) and the least restrictive environment (LRE) continuum. This examination will allow me to reflect on the place these issues have in special education today.

Educational Policies and Special Education

Pedlar, Haworth, Hutchison, Taylor and Dunn (1999) suggest that “studies and commentaries on Canadian social policy and human service systems have pointed to ways in which existing legislation and policies tend to disempower rather than empower individuals who receive social support” (p. 13). Government policy is relevant to this discussion because it is a “creed – a statement of beliefs, hopes and ideas. Policy shapes the process that moves ideas into action” (Lord & Hutchison, 2007, p. 201). It is to these policies that I now turn.

Policy palimpsest. H. G. Simmons (1982) argues that in the United States and Canada in the nineteenth century, mental retardation policy did not evolve in a linear fashion, but rather was “composed of a number of disparate strands all developing at quite different rates” (pp. 42-43). He uses the metaphor of a palimpsest. The *Oxford English Dictionary* defines a palimpsest as “a parchment or other writing surface on which the original text has been effaced or partially erased, and then overwritten by another; a manuscript in which later writing has been superimposed on earlier (effaced) writing.” H. G. Simmons says that “a series of mental retardation policies were superimposed on one another, with newer policies obscuring, blurring or relegating older policies to minor importance, although never entirely replacing them” (p. 43).

In terms of educating students with significant intellectual disabilities, the policy palimpsest continues to exert influence. It has meant that older, segregated educational policies continue to exist alongside newer, more inclusive policies. Unless and until the palimpsest is exposed and rejected, outdated practices will never be completely expunged from the education system. Coupled with Skrtic's (1995a) hierarchy, this lack of policy direction helps explain why segregated services and barriers to full inclusion persist. Andrews and Lupart (2000) explain the issue.

Most school systems continue to use some form of the special education approach to serve students with exceptional learning needs. Unfortunately, fundamental flaws inherent in the special education approach negate – or run counter to – building a unified system of inclusive education (p. 38).

P. Smith (2010) has called for the elimination of special education altogether and can see “no real benefit to students with intellectual disabilities and their families of the kinds of special education policies in the United States” (p. 223). He goes on to suggest there has been some real progress in spite of special education. P. Smith concludes by saying that “until, or unless, *all* educators take responsibility for *all* students... people with intellectual disabilities will be left by the wayside” (p. 224).

The continuum and the least restrictive environment. Another reason why these barriers are on-going within special education is the companion policies of the continuum of services and the least restrictive environment. Winzer (2008) describes the provision of educational services as “a cascade, or continuum of services – an

ordered sequence of placements that vary according to their degree of restrictiveness” (pp. 23-24). In describing the continuum, she places the general classroom at the top of an inverted pyramid. This is the least restrictive environment. Other environments move from less to more restrictive and include “general class and support personnel”, “general class and resource room”, “part-time special class”, “full-time special class”, “special day school”, “residential school”, “homebound instruction” and finally, “hospital instruction” (p. 24).

Winzer (2008) goes on to say that “the continuum manifests the concept of the least restrictive environment (LRE) – the most appropriate placement in which a student can receive instruction and services” (p. 24). The American educational law, the Individuals with Disabilities Education Act (IDEA), “obliges states to educate children with disabilities in the ‘least restrictive environment’ appropriate to their needs” (Nussbaum, 2006, p. 205). In Canada, the Supreme Court of Canada holds a similar view. In Manitoba, educating students with disabilities is also identified in terms of “appropriateness”. S. J. Taylor (1988) notes that “the phrase ‘least restrictive environment’ is almost always qualified with words such as ‘appropriate,’ ‘necessary,’ ‘feasible,’ and ‘possible’” (p. 47). Recent research (Schwartz, Mactavish & Lutfiyya, 2006) has confirmed the establishment of a continuum of educational services in Manitoba.

Winzer (2008) sets out the rationale for policies based on appropriateness and a continuum of services.

The continuum reflects the intensity of a child's needs and the type and severity of his or her disability. With a full continuum of services, educators base placement decisions on potential student outcomes, determining in which setting the child will succeed and be prepared to become a productive and active citizen. Whether this means receiving educational services in the general classroom; moving out of the classroom for remedial help for short periods of time; or working in a resource room, self-contained class, or even a separate setting must be determined on a child-by-child basis (p. 24).

I am troubled by policies which are driven by language such as appropriateness, which appears to me to be value-laden and over-reliant on the continuum "escape hatch". I am far more persuaded by S. J. Taylor's (1988, 2001) critique of the continuum. I highlight a number of his points here in order to demonstrate the underlying societal values and presumptions behind offering services and supports to students with intellectual disabilities in this way. First, S. J. Taylor says that "the LRE principle legitimates restrictive environments" (1988, p. 45). Because the concept of "least restrictive" is open to interpretation, some may believe that segregated classes are least restrictive.

In his second point, S. J. Taylor (1988) suggests that "the LRE principle confuses segregation and integration on the one hand with intensity of services on the other" (p. 46). He goes on to point out that "some of the most segregated settings have provided the least effective services" (1988, p. 46). Just because a student with a significant

intellectual disability receives services in a segregated class or stream does not mean that those classes are effective or intense.

Third, S. J. Taylor (1988) says that “the LRE principle is based on a ‘readiness model’” (p. 46). The theory is that students with significant intellectual disabilities “must earn the right to move to the least restrictive environment”, placing the onus on the student to “‘get ready’ or ‘be prepared’ to...go to school in integrated settings” (p. 46).

Fourth, the LRE principle “supports the primacy of professional decision making” masking the point that “integration is ultimately a moral and philosophical issue, not a professional one” (S. J. Taylor, 1988, p. 47). This is also evidenced by Winzer’s (2008) comments on the continuum quoted above.

S. J. Taylor’s (1988) fifth point emphasizes that the LRE principle “sanctions infringement on people’s rights” (1988, p. 47). Therefore, referencing Turnbull (1981), S. J. Taylor says that “the question implied by LRE is not *whether* people with developmental disabilities should be restricted, but *to what extent*” (p. 47).

As his final point, S. J. Taylor (1988) argues that “the LRE principle directs attention to physical settings rather than to the services and supports people need to be integrated in the community” (1988, p. 48). He goes on to say that “by its name, the principle of the least restrictive environment emphasizes facilities and environments designed specifically for people with developmental disabilities” (p. 48). As we enter the second decade of the 21st century, S. J. Taylor’s warnings have yet to be heeded; the

continuum is still the dominant policy in special education contexts, and the policy palimpsest (H. G. Simmons, 1982) in the field of special education continues.

The Research Literature: Educating Students with Significant Disabilities

Before discussing my own study, I first need to examine how the research literature has engaged with the issue of educating students with significant intellectual disabilities. I am specifically looking for existing research which has used a philosophical or foundational basis for considering how these students have been educated, are being educated, or might be educated.

Overview

My search efforts began with searches of the electronic databases Academic Search Premier, Proquest, ERIC, and Sage Journals. I then searched the University of Manitoba Bison catalogue under the keyword “special education” and examined the following journals: *Australasian Journal of Special Education*; *British Journal of Special Education*; *Disability & Society*; *Exceptional Children*; *Exceptionality*; *Focus on Exceptional Children*; *International Journal of Disability, Development & Education*; *International Journal of Special Education*; *Journal of Special Education*; *Remedial and Special Education*; *Research & Practice for Persons with Severe Disabilities*; *Teacher Education and Special Education*; and *Teaching Exceptional Children*. I also searched the *Journal of Research in Special Education Needs* and the *Journal of Philosophy of Education*.

In all of my searches, I used the keywords “severe disability”, “profound disability”, “intellectual disability”, and “special education”. I chose the terms “severe” and “profound” based on terminology within the literature I was reviewing. I limited my search to the past fifteen years (1995-2010). I chose these dates because a) significant progress in conceptualizing inclusion for students with disabilities and other educational needs has occurred in recent years (Andrews & Lupart, 2000; Winzer, 2008), b) new understandings about educating students with disabilities has emerged in the context of disability studies (Gabel, 2005), c) the traditional idea of intellectual disability has been re-considered (Danforth, 2000; Rapley, 2004), and steps have been undertaken to re-conceptualize these individuals (Schalock, et al., 2007). I also limited the articles I included to students in grades one through twelve, omitting studies that considered preschool and kindergarten-aged children.

My searches revealed a total of 96 published articles². Papers containing discussions of students with significant intellectual disabilities have been written in the contexts of (a) segregated, special schools, (b) integrated, inclusive schools, and sometimes (c) a combination of both. Articles were published between 1997 and 2009. Perspectives and research from Australia, Finland, Ireland, the Netherlands, the United Kingdom, and the United States were represented, although the vast majority were American. This is likely due to the large number of articles from the American journal, *Research & Practice for Persons with Severe Disabilities*. Most of the papers were

² I made the decision to examine and include all of the 96 articles I found that matched the parameters of my search, notwithstanding that some do not expressly indicate whether the students who are the focus of the work actually have significant intellectual disabilities. My research leads me to believe this is assumed by the authors where not expressly stated.

empirical studies. There were also commentaries, editorials to special issues, and literature reviews.

A Note on Terminology

Before I provide some detail on this body of work, I must reflect on the issue of terminology. In my own work, I refer to students with significant intellectual disabilities. The use of the word “significant” is my own creation and is not typically represented in the literature. More common terms used include students with: (a) severe and/or profound disability, (b) severe and/or profound and/or multiple learning difficulties or disabilities, (c) severe and/or profound mental retardation, (d), severe and/or profound intellectual disability, (e) severe or significant cognitive disabilities, (f) extensive support needs, (g) complex multiple disabilities, and (h) developmental disabilities.

Extensive use of the term “severe disabilities” can be accounted for due to the large number of articles from *Research & Practice for Persons with Severe Disabilities*, which uses this term consistently and virtually exclusively. The Association for Persons with Severe Handicaps (TASH) (1991), the organization responsible for its publication, defines the concept “persons with severe disabilities” as

individuals who require extensive ongoing support in more than one major life activity in order to participate in integrated community settings and to enjoy a quality of life that is available to citizens with fewer or no disabilities. Support may be required for life activities such as mobility, communication, self-care, and

learning as necessary for independent living, employment, and self-sufficiency (p. 19).

Although the organization has developed this definition, it does not appear specifically in the literature I canvassed. Perhaps writers for the TASH journal assume that the definition is widely known. I also assume, although it is not expressly stated, that severe disability implies an intellectual disability.

I found it to be particularly perplexing that many authors discussed students with significant and complex disabilities without actually defining the students to whom they were referring. Two articles provided a fairly comprehensive description of students with “profound multiple disabilities” (PMD) (P. D. Smith, Gast, Logan & Jacobs, 2001) and “profound and multiple learning difficulties (PMLD) (Jones, 2005). Students labelled as having PMD are described as having “impairments” that are

“serious and dramatic, and they may include significant or total sensory impairment in addition to very severe cognitive impairments, severe physical disabilities, chronic health impairments, and sometimes terminal illness” (Ferguson, Willis, & Meyer, 1996, p. 100). Historically, these students have been referred to as children with multiple disabilities and are an important subgroup of students referred to in special education literature as having “severe disabilities” (Orellove & Sobsey, 1996; Reid, Phillips, & Green, 1991). For many of these students, identification of a single voluntary response (e.g., eye gaze;

small movement of hand, arm, or head) is extremely difficult (P. D. Smith, Gast, Logan & Jacobs, pp. 135-136).

Jones (2005) reviews historical and current definitions of students considered to have PMLD. She begins with the 1980 World Health Organization criteria of an IQ below 20, and a range of impairments. Over time, criteria changed as did emphases. “For some, definitions of profound and multiple learning disability are dominated by physical, medical and intellectual characteristics with pupils presenting two or more of a list of impairments and deformities...” (p. 377). Other definitions “are based on the intensity and extremity of individual need” (p. 377). Jones also cites Lacey and Ouvrey’s (1998, p. ix) suggestion that “profound and multiple learning disabilities indicate two of the most important facets of the difficulties faced by these people; that is, they have more than one disability and that one of these is profound intellectual impairment” (p. 377).

Given that my own work focuses on language use, I was surprised at the number of authors, including those where definitions of students were provided, who treat this kind of terminology as unproblematic. However, the authors of two papers did specifically comment on the difficulties of the language used to describe these students.

B. Simmons and Bayliss (2007) discuss the term “profound and multiple learning difficulties” (PMLD). They argue that it is

common to see “children with PMLD” within a medical discursive practice which is located in concepts of “cognitive and sensory impairment”. The language of such descriptions is “loaded” in that the core constructs the descriptions use are

based on developmental models (such as “mental age”) which are contestable (pp. 19-20).

The authors go on to summarize some of the “traditional terminology” (p. 20).

Individuals carrying the PMLD label are viewed as having “the severest of cognitive impairments resulting in an extremely ‘young mental age’, often compared to that of an infant at the preverbal stages of development” (p. 20). In addition to having an IQ that is under 20, these individuals are also considered to have other types of disabilities, such as physical and /or sensory impairments (B. Simmons & Bayliss).

In discussing students with “severe learning difficulties” (SLD) and PMLD, Ockelford, Welch and Zimmerman (2002) indicate that the first issue they had to deal with in their study about music education was “the fact that there are no established definitions of the terms ‘SLD’ and ‘PMLD’ that are readily available and commonly understood across the sector” (p. 180). They developed their own working definition of these students, which they noted was “accepted without comment” by their participants (p. 180):

Pupils with PMLD have profound global developmental delay, such that cognitive, sensory, physical, emotional and social development are in the very early stages of development (as in the first year of ‘typical’ development). Pupils with SLD have severe global developmental delay, such that cognitive, sensory, physical, emotional and social development are in the early stages (as in the first 12 to 30 months of ‘typical’ development) (p. 180).

This lack of interest in exploring and critiquing the language used to describe and define these students demonstrates a relevant gap in this literature.

Themes

In order to make sense of this body of work, I reviewed each article and categorized it into one of ten themes. These themes are: (a) assessing students, (b) student behaviour, (c) participation in the general curriculum, (d) reports on specific educational programs, (e) educators including paraprofessionals and pre-service teachers, (f) inclusive policy, (g) parent perspectives, (h) non-disabled peer perspectives, (i) research focusing on rehabilitation and/or therapy, and (j) miscellaneous issues. I explore each of these themes in turn with the purpose of demonstrating the kinds of issues with which this body of research is concerned. My research illustrates that the literature has thus far neglected to examine, explore and analyze the various discourses of “students with significant intellectual disabilities” that currently circulate in the profession of special education.

Assessment. Nine papers address issues of assessment. In 2000, McNicholas looked at the practices of educator assessments of students with profound and multiple learning difficulties. Dowrick (2002) examined “desirable educational outcomes” for students who have been “marginalized by existing educational arrangements” (p. 189). Work by Hessels-Schlatter (2002) sought to determine the reliability and validity of the Analogical Reasoning Learning Test, which is a test to measure the cognitive capabilities of those with “moderate or severe mental retardation” (p. 342). The purpose of

Browder et al.'s (2004) study was to "examine the alignment of the content on alternate assessments to academic standards and functional life domains" to determine the extent to which alternate assessments were "aligned" with state standards (p. 213). Tadema, Vlaskamp and Ruijsenaars (2005) reported on the development of an instrument to assess the abilities of students with multiple and profound learning difficulties while Kontu and Pirttimaa (2008) were interested in the tools educators use to assess students described as "severely intellectually disabled" (p. 75). In 2008, Towles-Reeves, Kleinert and Anderman considered principals' perceptions of alternate assessments based on alternate achievement standards in light of students with the most significant cognitive disabilities. Towles-Reeves also reviewed the literature on alternate assessments with colleagues Kleinert and Muhomba (Towles-Reeves, Kleinert & Muhomba, 2009).

Behaviour. Issues of behaviour were addressed in fifteen articles and covered several areas of interest. Richards and Richards (1997) reviewed biobehavioural state research for students with profound disabilities, including cognitive, sensory and physical disabilities. Snell (2005) provided a commentary on the effectiveness of assessment-based positive behaviour support interventions in reducing behaviour considered to be problematic. An evaluation of the impact of using weighted vests to keep young students in their seats was considered by Cox, Gast, Luscre and Ayres (2009).

The authors of several works discussed patterns of behaviour states among students with severe intellectual disabilities in order to discern classroom engagement (Arthur, 2004; Arthur-Kelly, Bochner, Center & Mok, 2007; Foreman, Arthur-Kelly & Pascoe, 2007; Foreman, Arthur-Kelly, Pascoe & King, 2004). Another series of articles were included in a special issue of school-wide positive behaviour supports, with particular emphasis on the inclusion of students with severe disabilities (Brown & Michaels, 2006; Carr, 2006; Crimmins and Farrell, 2006; Freeman et al., 2006; Hawken & O'Neill, 2006; Sailor et al., 2006; Snell, 2006 & Vaughn, 2006).

Curriculum. A significant discussion in the literature on curriculum centres on how to include students with significant intellectual disabilities in the general education curriculum. In 2003, Browder et al. set out to “evaluate the curricular philosophies that states use in their alternate assessment guidelines, through a content analysis of their performance indicators” (p. 166). A U.K. study discussed how the development of a distinctive curriculum for older students with severe and profound and multiple learning difficulties presented both opportunities and challenges. Areas of concern included balancing a functional curriculum against a wider curricular base and entitlements to general curriculum access versus the need for individualization (Lawson, Waite & Robertson, 2005). In contrast, work by Dymond, Renzaglia, Gilson & Slagor (2007) investigated methods of providing students with significant cognitive disabilities “meaningful access to the general curriculum in inclusive academic classrooms” (p. 3). Work by Agran, Cavin, Wehmeyer and Palmer (2006) examined the effects of using the Self-Determined Learning Model of Instruction to promote access to the general

curriculum for students with moderate to severe disabilities. In another study, Lee, Soukup, Little and Wehmeyer (2009) considered the role of both teacher and student variables as factoring into access to the general curriculum for students with intellectual and developmental disabilities. Some of these variables included “student academic/competing response, teacher instruction/management behaviour, and teacher focus” (p. 40).

In 2006, *Research & Practice for Persons with Severe Disabilities* produced a special issue on access to the general curriculum for students with severe disabilities, with an introduction by Spooner, Dymond, Smith and Kennedy. The authors indicated that the purpose of the issue was “to describe several evidence-based practices that have the most visible support in the literature and discuss some of their strengths and limitations” (p. 277). Wehmeyer (2006) stresses the importance, not only of gaining access, but also being provided the accommodation and modifications so that students with severe disabilities can truly benefit from the general curriculum. Both Wehmeyer and A. Smith (2006) noted the importance of accessing the general education curriculum, where opportunities to progress are far better than in segregated settings. Also in the special issue is an article by Browder, Spooner, Wakeman, Trela and Baker (2006) on linking instruction for students with significant cognitive disabilities with state content standards, and Downing’s (2006) commentary surveying work on higher standards and access to the core curriculum for students with severe disabilities.

A more recent issue of *Research & Practice for Persons with Severe Disabilities* also featured a number of articles on students accessing the general curriculum, with an introduction by Halle and Dymond (2009). Copeland and Cosbey (2008-09) explored instructional approaches in order to provide students with extensive support needs access to the general curriculum. Ryndak, Moore, Orlando and Delano (2008-09) explained that access to the general curriculum means access to general education contexts, instruction on general education content, high expectations and accountability. Confirmation that there is both theoretical and empirical support for using the general education curriculum for students with extensive support needs came from Jackson, Ryndak and Wehmeyer's (2008-09) piece. Finally, Sailor (2008-09) critiqued the use of the medical model and the idea of "special" in educational contexts for students requiring extensive supports. He considered these issues to be stumbling blocks in inclusion and access to the general curriculum.

Educational Programs. The literature not only covers access to the general education curriculum but also considers specific education programs and tools that promote a more meaningful education for students with significant intellectual disabilities. Examples of research into educational programs of a more general nature can be found in the work of Cushing, Carter, Clark, Wallis and Kennedy (2009), Downing and Peckham-Hardin (2007), Ohtake (2003), P. D. Smith, Gast, Logan and Jacobs (2001), Snell (2008-09) and Stephenson, Bo, Chavez, Fayle and Gavel (2007). Cushing's work focused on the development and testing of a tool called the Program Quality Measurement Tool, which evaluates programming for students with severe disabilities.

Using a qualitative approach, Downing and colleagues sought the opinions of key stakeholders to gain a better understanding of what a good educational program looks like for students with moderate to severe disabilities. Ohtake explored the importance of practicing the skills from a student's individualized education program (IEP) in general education subject classes and building classroom membership by contributing to classmate learning. A process for customizing instruction for students with profound multiple disabilities was explored by P. D. Smith, Gast, Logan and Jacobs. Snell stressed the need for instructional methods to teach academic and social skills to students with severe disabilities. Finally, Stephenson and colleagues looked at the application of the New South Wales model of pedagogy for students with severe intellectual disabilities.

Discussions about programming also covered different subjects. In the area of English literature, Aird (2000) discussed the development of a "whole school framework" (p. 171) for teaching literacy to students with severe, profound and multiple learning difficulties. Browder, Mims, Spooner, Ahlgrim-Dezell and Lee (2008) examined the use of shared reading to promote literacy for pupils with multiple disabilities. Park used Dickens to explore interactive drama games in re-telling stories (1998) and the use of objects of reference and interactive story-telling (2001). What I found quite interesting was Park's (1998) inclusion of a quote on teaching students with significant intellectual disabilities. "Ware (1994) suggests that in choosing activities for people with profound and multiple learning difficulties, our aim should be: 'to enable the child to participate in those experiences which are uniquely human' (p. 72), one of which is storytelling" (p. 114). In a related issue, Mueller, Singer and Carranza's (2006)

national survey looked at the practices of special educators teaching students with moderate and severe disabilities who are also English language learners.

The authors of several articles also addressed science and math. Courtade, Spooner and Browder (2007) looked at teaching science to students with significant cognitive disabilities. Similarly, Dymond et al. (2006) used participatory action research to redesign a high school science course, keeping in mind principles of universal design for learning. In a more specific study, J. Porter (2005) examined how young students with severe and profound learning difficulties became aware of small quantities.

In the areas of art and music, Ockelford, Welch and Zimmerman (2002) stressed the need for clearer guidance on how to frame music education for students with severe, multiple and profound learning difficulties. In an Australian paper, Waugh and Riddoch (2007) examined the role of classical music on students who are painting.

In the context of physical activity, van der Putten, Reynders, Vlaskamp, and Nakken (2004) analyzed the goals of the functionally-focused Mobility Opportunities via Education curriculum.

Finally, there were two papers that I considered to cover miscellaneous program issues. Hewett (2007) considered the role of touch and physical contact when working with students with severe learning difficulties and autism. Stephenson (2004) focused her work on a number of controversial practices in educating students with high support needs. She looked to the literature in defining controversial practices as including “claims that it can cure a disability; that it requires specially trained practitioners; that

there are no published experimental studies supporting its use; that it requires very intense treatment; and that it has been the subject of legal action” (p. 58). This piece struck me as tangentially relevant to my own work. The author found that “controversial and unsupported practices appear to be so widely used in the education of students with high support needs” in Australia (p. 60). This causes me to wonder whether such controversial practices would be as widely embraced for students considered to be non-disabled.

Educators. A significant body of the literature is concerned with educators. When I use the term educators, I am including (a) pre-service educators, (b) paraprofessionals, (c) administrators, and (d) teachers of all levels in both segregated and inclusive settings.

Carter and Hughes (2006) were interested in the perceptions of special educators, paraprofessionals and administrators in their examination of the barriers to, benefits of, goals and supports for including students with severe disabilities in general education classes. N. M. Clark, Cushing and Kennedy (2004) demonstrated the effects of an onsite technical assistance model on inclusive teaching practices.

In more focused studies, Bishop and Jones (2003) explored changing attitudes and perceptions by pre-service teachers teaching science to young children with severe and profound learning difficulties. An action planning tool designed as an alternative to over-reliance on paraprofessionals was discussed by Giangreco, Smith and Pinckney

(2006). Salisbury (2006) looked at the perspectives of principals involved in developing inclusive elementary schools.

With a focus on teachers, several articles considered perceptions and attitudes. For example, Cook (2001) looked at whether the severity of the disability affected teachers' attitudes toward students with disabilities. Relatively few Finnish teachers felt that inclusive settings were best for students with severe and profound intellectual disabilities (Jahnukainen & Korhonen, 2003). J. Ware, Julian and McGee (2005) concentrated on the turnover rate of teachers who teach students with severe and profound learning disabilities.

In 2005, Jones explored perceptions of teachers who teach students with profound and multiple learning difficulties. This study is perhaps the most significant in terms of the work I intend to pursue because the author was investigating how teachers viewed their students. Jones begins by suggesting that "there is little research reflecting the views of teachers of pupils with PMLD. The little there is reflects the negative way such teachers and pupils appear to be perceived in schools" (p. 375). She goes on to stress the importance of "contextualizing" teacher perceptions by reflecting upon "how society has presented its understandings of this group of learners" (p. 376). She does this by looking at definitions and classifications, rather than by analyzing discourse. However, the importance of this work lies in its rejection of traditional ways of focusing on student deficit and instead emphasizing social influences and understandings. Her findings are telling. In reflecting on the foundational knowledge, Jones says that "the

teachers in the present study seem to reflect the historical definitions and classifications of PMLD closely” (p. 383). Even more significantly, Jones notes that

the discussions of teachers in this study reflect the professional literature. They are trained professionals and operate in a professional world. They are a product of the society in which they were prepared and now work. Interestingly, the teachers did not represent a more contemporary view of disability...This could reflect a mismatch between developing policy and practice in the field... (p. 383)

Several studies were concerned with preparation for teaching these learners. Delano, Keefe and Perner (2008-09) looked at current issues in preparing teachers to work with pupils who have extensive support needs. Jones and West (2009) also reflected on the education of teachers who teach students with severe and profound disabilities. More specifically, Poppes, Vlaskamp, de Geeter and Nakken (2002) focused on whether specialized training leads to improvement in IEP goal quality. In a somewhat related issue, Lohrmann and Bambara (2006) explored the kinds of supports teachers felt they needed to better accommodate students with developmental disabilities and challenging behaviours.

Teachers’ perceptions of alternate assessments were discussed by Flowers, Ahlgrim-Delzell, Browder and Spooner (2005). In England, Goss (2003) looked at the gender mix of educators at special schools for students with severe, profound and multiple disabilities.

Inclusive policy. The next area of inquiry is consideration of inclusive policy.

Fisher and Mayer (2002) compared the behaviour and competencies of students with severe disabilities in both inclusive and self-contained programming. A. Smith (2008-09) provided a commentary on the difficulties of implementing inclusive education for all students. B. Simmons and Bayliss (2007) studied the education of students with profound and multiple learning difficulties in a special school and found it lacking in providing an appropriate educational experience. Finally, Stough (2003), in Costa Rica, explored inclusion of students with severe disabilities.

Parents. Three articles considered the education of students with significant intellectual disabilities from a parent perspective. Fonteine, Zijlstra and Vlaskamp (2008) looked at the information being transferred between teachers and parents in log books. Kraemer and Blacher (2001) were concerned with transition experiences for students with severe mental retardation in the context of families. Roach (2006) sought to understand those variables that influence parent perceptions of the Wisconsin Alternate Assessment.

Peers. Studies also focused on the non-disabled peers of students with significant intellectual disabilities. The work of Hall and McGregor (2000), Carter and Hughes (2005) and Naraian (2008) all considered relationships between non-disabled and disabled students.

Carter, Cushing, Clark and Kennedy (2005), Carter and Kennedy (2006), Carter, Sisco, Melegoglu and Kurkowsli (2007) and Weiner (2005) looked at the issue of peer

support. The focus of work by Carter, Cushing, Clark and Kennedy, and Carter and Kennedy was peer support interventions. Carter Sisco, Melegoglu and Kurkowsli also considered peer support as an alternative to support provided by adults. Weiner examined the issue of the development of conversational skills using peers as mediators.

Shevlin and O'Moore (2000) and Shevlin (2003) pursued the issue of contact between non-disabled students and students with severe and profound intellectual disabilities by examining the effects of structured contact (Shevlin & O'Moore) and the effectiveness of a video program preparing mainstream students for interaction with their disabled peers (Shevlin).

Rehabilitation/Therapy. I have called this section rehabilitation/therapy as the major themes are concerned with ameliorating communication skills and movement skills, which I consider to be rehabilitative in nature. One literature review was conducted in the area of increasing communication skills (P. Pinto, Simpson and Bakken, 2009) and another in the area of augmented and alternative communication (Snell, Chen and Hoover, 2006) for students with severe disabilities.

Barber (2008) considered using Intensive Interaction to help students with severe and profound intellectual disabilities and autism develop communication skills. Also in the area of communication, Dyches (1998), Lancioni et al. (2006) and Mechling (2006) all examined the effects of micro-switch use by pupils with severe disabilities to help them interact.

Van der Putten, Vlaskamp, Reynders and Nakken (2005a, 2005b) studied movement. One work (2005a) analyzed the Top Down Motor Milestone Test which is used to plan and evaluate “movement-oriented interventions” (p. 635). Their other piece (2005b) looked at the effect of functional movement activities on student independence in the context of children with profound intellectual disabilities and multiple disabilities.

Miscellaneous. The final theme deals with two issues that I was not able to categorize in any of the other nine themes. Wehmeyer (2005) wrote a piece on self-determination and students with severe cognitive and multiple disabilities. He conceptualized a new definition of self-determination to address the contention that these students cannot become self-determined. Zijlstra and Vlaskamp (2005) looked at the impact of medical conditions on the support received by students with profound intellectual and multiple disabilities.

Gaps in the Literature

The result of my review of the literature on students with significant intellectual disabilities revealed several gaps. I was only able to find one published Canadian study which considered these students (Bensted and Bachor, 2001). In their work, five students in elementary school were paired with five peers who had severe disabilities. However, the focus of the work was on the non-disabled students and little attention was given to the students with disabilities.

Another gap is the lack of critical analysis about who these students are. In some articles, students were labelled without an explanation of that label. In other studies the label was defined, albeit using clinical and professional terminology. Only Jones (2005) provided any significant analysis of the societal effects of teacher views. There was also a noticeable absence of any real challenge to the taken-for-granted assumptions that students with significant intellectual disabilities exist as a category of learners or people. Even in the many examples where important work has been done in advancing and broadening notions of inclusion and concentrating on gaining meaningful access to the general curriculum, conversations about how these students have been constructed has not been a major focus.

With the exception of Browder et al.'s (2003) consideration of curricular philosophies, I could find no other studies which discussed students with significant intellectual disabilities in any philosophical context. In addition, only one article mentioned humanness when Park (1998) quoted Ware (1994).

I would be remiss if I did not draw attention to Nussbaum's (2004, 2006) discussions of the education of students with "unusual mental impairments" in the United States (2006, p. 199). However, I find her defence of the least restrictive environment to be highly problematic and I do not share her optimism in the context of educating students with significant intellectual disabilities. She says:

when a child seems to profit more from special education than from mainstreaming, the state is required to support such a special placement... there

may be cases in which a child's cognitive level is so out of step with those of other children of his or her age that more progress can be made through special education (2006, p. 206).

Nussbaum's statement only serves to reinforce the call for continuing special education, and contradicts a significant amount of the research I have presented. I would like to challenge Nussbaum's thinking in the area of education using new philosophical discourses, as she does, to better understand students with significant intellectual disabilities. I believe that using the philosophical framework on personhood, combined with the theoretical framework of discourse theory will shed light on how students with significant intellectual disabilities are conceptualized in the special education discourse.

In Chapter 3, I outline my epistemological standpoint and explain the methodology of discourse theory in some detail. After locating myself within my study, I outline my research design, focusing on how I collected and analyzed my data.

Chapter 3: Epistemology, Methodology and Methods

“Having a language is like having access to a very large canvas and to hundreds or even thousands of colors. But the canvas and the colors come from the past. They are hand-me-downs. As we learn to use them, we find out that those around us have strong ideas about what can be drawn, in which proportions, in what combinations, and for what purposes” (Duranti, 1997, p. 334).

I will begin this chapter with a brief discussion about the philosophical underpinnings of qualitative research because I cannot properly reference discourse analysis and discourse theory, which are located within the qualitative paradigm, without giving this paradigm some context. I have decided against contrasting qualitative research with the traditional positivist research paradigm as I believe, like Creswell (2007), that “today qualitative research is legitimate in its own right and does not need to be compared to achieve respectability” (p. 16).

Qualitative inquiry is “built on a profound concern with understanding what other human beings are doing or saying” (Schwandt, 2000, p. 200). Crotty (1998) suggests that this kind of research typically begins with a “real-life issue that needs to be addressed” (p. 13). This issue then leads to a consideration of the goals of the research, the strategies that might be used, and the means or methods that are required to achieve the goals (Crotty). Qualitative inquiry is well established in the field of education and, increasingly, within special education. However, Pugach (2001) suggests that it is important for scholars in the field to take a “broader and deeper view of qualitative research” (p. 442). It is my intention that this work adds to what Pugach refers to as “an

impressive record of the use of qualitative research to document various aspects of disability-related concerns” in special education contexts (p. 447).

Locating My Work: Ontology and Epistemology

In articulating my own philosophical assumptions, I begin with ontology and the nature of reality. I believe it is important to step away from the notion that there is a single reality that is ultimately knowable. Rather, I think that the world is experienced via multiple and subjective realities, each one different yet valid. I reject “the very idea of any foundational, mind-independent, and permanently fixed reality that could be grasped or even sensibly thought of without the mediation of human structuring” (Shusterman, 1991, p. 103). The world is made intelligible “only when meaning-making beings make sense of it” (Crotty, 1998, p. 10).

Although I have begun by stating my ontological position, I am mindful of Andersen’s (2003) discussion of a theoretical shift from “the primacy of ontology to the primacy of epistemology” and his insistence that it “makes a fundamental difference whether one begins by answering the question of ontology or by answering the question of epistemology” (p. xi). The questions about which I am most interested are epistemologically situated and involve a concern with “how the world comes into being as a direct result of the specific perspectives held by individuals, organizations, or systems. It also asks how this causes the world – in the broadest sense – to emerge in specific ways” (p. xiii). My interest stems from the position, also articulated by Skrtic (1995b), that “regardless of the field of social science one focuses on, the most

noticeable thing is change, and changes often touch upon and challenge fundamental values, raising questions about the constituent character of what we see” (Andersen, p. ix).

In her discussion of epistemology from a feminist perspective, Code (1995) notes that “the dominant epistemologies of modernity, which developed out of the intellectual achievements of the Enlightenment with a later infusion of positivist-empiricist principles, are defined around highly rarefied ideals of objectivity and value-neutrality” (p. 15). She considers problematic the view that “knowledge is just knowledge, it does not matter whose it is, who has made it, who knows it” (p. 13). Code argues that “a long tradition of distinguishing between knowledge and ‘mere opinion’ rests, in part, upon granting knowledge a status – and hence a generality, a universal scope – that enables it to transcend the specific experiences of particular knowers” (pp. 13-14).

I make a conscious effort not to privilege one kind of knowledge or set of knowledges over others. I do this by recognizing that there are always at least two ways of understanding any issue or experience. I may not personally agree with all view points, but I try to treat them as equally valid in the eyes of those espousing the claims. Although this work does not use data from participants, I have worked with participants in other research. I have treated these participants as collaborators in the course of generating and disseminating knowledge. I recognize that my research can never be free of either my own values and beliefs or the values and beliefs embedded within the

social and cultural environment in which I conduct my research. In this context, my intention is to openly articulate the “values that shape the narrative” (Creswell, 2007, p. 17).

Social Constructionism

I wish to move now from the general to the specific in locating my epistemological position within social constructionism. Andersen (2003) argues that “the social sciences currently exist in light of constructivism” (p. ix). Guba and Lincoln (2005) and Patton (2002) suggest that this philosophy is built upon the premise of “ontological relativity” wherein “all tenable statements about existence depend on a worldview, and no worldview is uniquely determined by empirical or sense data about the world” (Patton, p. 97). Gergen (1985) says that this form of inquiry is concerned with “the process by which people come to describe, explain, or otherwise account for the world...in which they live” (p. 266). He contrasts this endogenic perspective with the exogenic perspective found amongst logical empiricist thinkers (Gergen).

I see parallels of Gergen’s (1985) discussion with Crotty’s (1998) careful consideration of social constructionism. Crotty defines social constructionism as

the view that all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context (p. 42).

He says that it “emphasizes the hold our culture has on us: it shapes the way in which we see things...and gives us a quite definite view of the world” (p. 58).

Berger and Luckmann’s (1966) work on the “sociology of knowledge” has opened the door to examining a socially constructed world. The sociology of knowledge is introduced as being “*concerned with the analysis of the social construction of reality*” (p. 3) or how knowledge comes to be “socially established *as reality*” (p. 3). The authors pose the following questions, which help illustrate the direction in which their work goes and with which my own work is concerned. “How is it possible that subjective meanings *become* objective facticities?...an adequate understanding of the ‘*reality sui generis*’ of society requires an inquiry into the manner in which this reality is constructed” (p. 18).

In explaining how this construction takes place, Berger and Luckmann (1966) describe two people from “entirely different social worlds” (p. 56) who begin to interact on an island. Over the course of these interactions, the pair begins to construct a “background of routine” (p. 57). When the couple has children, these routines pass to the next generation as institutionalized and objective practice. “The institutions that have now been crystallized...are experienced as existing over and beyond the individuals who ‘happen to’ embody them...the institutions are now experienced as possessing a reality of their own” (p. 58). The social world becomes “real” (p. 59) and yet “it is important to keep in mind that the objectivity of the institutional world, however massive it may appear to the individual, is a humanly produced, constructed objectivity”

(p. 60). This world must also be legitimated as the original meanings of the institutions are known only to the originators of those institutions and not to any subsequent generations. Berger and Luckmann contend that “the edifice of legitimations is built upon language and uses language as its principal instrumentality” (p. 64).

Hacking (1999) presents an interesting critique of social constructionism. He encourages social constructionists to be clear about what it is they claim is socially constructed. His work allows me to articulate how I will use the term in this work. He begins by suggesting that social construction talk has become “common coin”, largely because it is “liberating” (p. 2). Its “primary use” has been to raise consciousness, particularly about “local claims”, the social construction of something specific (p. 6). In critiquing the status quo, social constructionists argue that

(1) X need not have existed, or need not be at all as it is. X, or X as it is at present, is not determined by the nature of things; it is not inevitable. Very often they go further, and urge that: (2) X is quite bad as it is. (3) We would be much better off if X were done away with, or at least radically transformed (Hacking, p. 6).

Hacking also notes a precondition for social constructionism. “In the present state of affairs, X is taken for granted; X appears to be inevitable” (p. 12).

Hacking (1999) describes three categories or “distinguishable types” (p. 21) which can be socially constructed: objects, ideas and “elevator words”. Examples of objects are people, conditions, practices, actions, behaviour, experiences, relations and the like (pp 21-22). Ideas include “ideas, conceptions, beliefs, attitudes to, theories” (p.

22). Elevator words are “words that are often made to work at a different level than words for ideas or objects” such as “facts, truth, reality, and knowledge” (p. 22).

As my own work centres on the idea of students with significant intellectual disabilities as a categorization, rather than on any specific students themselves, I want to provide more detail on Hacking’s (1999) use of the word “idea”. It denotes “some general way to make the distinction needed...for a host of...items said to be socially constructed” (p. 10). Although ideas are “out there in the public” and can be “proposed, criticized, entertained, rejected” they do not exist “in a vacuum” (p. 10). Rather, they “inhabit a social setting” which Hacking calls a “matrix”. For Hacking, “when we read of the social construction of X , it is very commonly the idea of X (in its matrix) that is meant” (p. 11).

In the context of this work, the conceptualization of students with significant intellectual disabilities is the idea. The matrix is special education which includes institutions (schools, classes and programs, both segregated and integrated), professionals (teachers, educational assistants, doctors, psychologists and other experts, administrators), laws and policies and proceedings. Special education also has a “material infrastructure” (Hacking, p. 10) of tests, plans, meetings, devices and the like. When I talk of the social construction of X , I am concerned with the social construction of the idea of students with significant intellectual disabilities within the matrix of Canadian introductory special education textbooks.

Hacking (1999) also introduces the concept of interactions. He says that “ways of classifying human beings interact with the human beings who are classified” (p. 31). In addition, these classifications exist within the matrix, “in institutions, practices, material interactions with things and other people” (p. 31). In my own example, students with significant intellectual disabilities are more than a “kind of person” (p. 31). Hacking would argue that they are a sort of quasi-legal entity used by schools, teachers, administrators, related professionals, advocates, policy-makers and even courts. These students, even if they themselves are unaware of their classification, can still acquire the characteristics of the group “precisely because they are so classified” (Hacking, p. 32).

In his example of the “feeble mind” taken from Rapley’s (2004) work, Hacking (1999) talks about the construction of the “retarded child”. He mentions all of the labels that have evolved over time, which I have discussed in Chapter 2, noting that “each classification has been associated with a regimen of treatment, schooling, exclusion, or inclusion” (p. 111). He further acknowledges that the precondition of inevitability, which is necessary for exploring this topic using social constructionism, is present.

At the time that each classification was in use, it seemed somewhat inevitable, a perfectly natural way to classify children with various sorts of deficit. Yet when we see the parade of ungainly labels, we quickly realize that these classifications are highly contingent. Each reflects the medical and social attitude of a particular epoch. They could have been otherwise (p. 111).

In Hacking's view, mental retardation is "an idea waiting for a social construction thesis to happen upon it" (p. 111).

My purpose in reviewing social constructionism as the foundation of my epistemology is to focus on how the idea "students with significant intellectual disabilities" is conceptualized in certain professional discourses found in the field of special education.

The Importance of Language

Language and its relationship to knowledge and understanding is an essential component to and rationale for research within the broad tradition of discourse analysis. For example, Gergen (1985) acknowledges the importance of language and talks about "the performative use of language in human affairs" (p. 270). Gubrium and Holstein (2000) argue that words are "the constitutive building blocks of the social world" (p. 489). Potter and Wetherell (1987) and Burr (2003) also argue in favour of the study of language in examinations of self, culture and society. If, as Fairclough (2003) argues, "language is an irreducible part of social life", then social research must always take language into account (p. 2).

In the context of special education, Liasidou (2008) explains how significant the study of language is.

In so far as the language of special needs remains unchallenged, little can be done in terms of developing transformative change. The very term of special educational needs is a discursive artefact that represents some students as

different and deficient. Therefore, it is of crucial importance to acknowledge the necessity to question the representations and subject positions conveyed through language (p. 486).

Now that I have placed my research in its paradigmatic context, I must locate myself within this research.

On Reflexivity

Throughout this work, I have undertaken to place myself within the research, recognizing that “how we write is a reflection of our own interpretation based on the cultural, social, gender, class, and personal politics that we bring to research” (Creswell, 2007, p. 179). In making this statement, I want to unequivocally reiterate my earlier point that this research cannot be either neutral or free of my own values. I do not believe it is possible for me, or any other researcher, to stand outside of myself and stand outside of the society in which I live, work and interact.

I am interested in the issues facing people with significant intellectual disabilities because of my journey through the field of disability studies. Although my interest predates my graduate work, I have been dismayed at the extent to which many academics and scholars within disability studies privilege certain types of disabilities. This has created a hierarchy of disability that often disregards the issues faced by those who are most vulnerable and cannot gain doctorate degrees and speak and write of their experiences. Many cannot articulate their position to society’s exacting standards or satisfaction – standards with which I take issue.

I do not identify as a person with a disability, nor am I the parent of a child who has a disability. Although I am not a philosopher, I identify with Carlson's (2010) position on this issue, which I quote at length here.

One of the first questions I am often asked by other philosophers when I tell them about my interest in intellectual disability is, "Oh, do you have a disabled family member?" This question might not have struck me as particularly odd had it not been asked so consistently. I became increasingly irritated by the assumption that seemed embedded in the question...the only reason I would have an interest in this topic is because someone in my family has an intellectual disability. As I have delved deeper into the margins of philosophy, this relatively benign question has come to represent far more troubling beliefs that I have encountered. First, the intellectually disabled are not persons. They are owed respect and justice only by virtue of their relationship to non-disabled family members who *are* persons. Second, this realm of inquiry is justifiably marginal since concerns about intellectual disability are remote, and third, those who *do* have close personal ties to persons with intellectual disabilities are unable to achieve the distance required for objective and reasonable moral considerations (p. 2).

I come to this research with a varied background and with a series of life experiences. I am a Canadian woman with a law degree, which prompts me to reflect on the concepts equality and rights and how they relate to people with intellectual

disabilities and to the *Charter of Rights and Freedoms*. I have a graduate degree in disability studies, which I believe provides me with a critical social perspective.

I have volunteered at an institution providing services to people with intellectual disabilities. This experience has shaped my belief that institutions are not places in which vulnerable people should be placed. Although the residents I met had complex and challenging issues, I cannot conceive that they would be unable to flourish in community homes with the support they require.

I have worked with advocacy groups, been involved in community-based projects and conducted research arising from large grants. Work with the former has convinced me that there is still a lot of work to be done. Work in the latter has led me to discourse analysis and reaffirms my belief in the power of language and the need to critically examine what we do and why we do it.

Perhaps one of the most influential pieces I read as a graduate student is Bogdan and Taylor's (1998) chapter on the social construction of humanness. It started me thinking about what it means to be human and how people's humanity gets stripped away. Bogdan and Taylor's work encouraged me to become more interested in those characteristics on which humanness turn. In my search to discover more about humanness, I found Kittay's (1999, 2005) writing about her daughter, Sesha, and her philosophical discussions about personhood. These thought-provoking and moving works, together with Stainton's (2001) article on the significant link between intelligence and human value form the base of my own inquiry.

Although I am associated with the faculty of education, I am not a teacher. This association was prompted by my choice of advisor, who has an extensive and fairly exclusive knowledge base on the issues facing people with intellectual disabilities. I do, however, believe that segregating students based on their identification as disabled, being unable to learn, or as otherwise problematic to the educational system is a deeply flawed approach. I am reluctant to say I believe in inclusion because I remain unconvinced that the concept has been articulated clearly enough. My concern, which has been raised by P. Smith (2010), is that it is too easy to conceptualize inclusion as a place and to declare its success by the mere presence of a diversity of students in the same classroom. It is for this reason that I endeavour to take a different path in trying to understand how society conceptualizes students with significant intellectual disabilities.

I came to discourse analysis almost by accident. While occupying a position as a research assistant during my graduate program, I was asked to provide an analysis of media representations of disability and end of life. In order to make sense of this task, I turned to discourse analysis and the work of Fairclough (1992, 1995, 2003). I was fortunate to have published two analyses using discourse analysis (Schwartz & Lutfiyya, 2009; Schwartz, 2010) with a third paper having been submitted at the invitation of the editor (Schwartz & Lutfiyya, in press). When I first began to research discourse analysis, I was dismayed that I was unable to really understand what authors meant when they claimed that discourse was language in use. During the course of my graduate studies, however, I have not only become convinced of the importance of studying language, I

now understand the force of showing how language is used to create identity and meaning.

In researching and writing this work on language, I struggled with my own language use. The most pressing issue for me was what to call the individuals who are at the centre of this inquiry. As my literature review and analysis reveal, there have been many twists and turns in terminology use over the years and I am very mindful of the warnings issued by both Stockholder (1994) and Danforth (2002). I am concerned that my own choice of the word “significant” has become inappropriate. Yet I cannot escape from the fact that we use words to identify people and things. In order to talk about something or someone, a choice must be made. I have used “significant” to express the idea that the students to which I am referring have an intellectual disability that is more complex and affects their lives in more encompassing ways than other kinds of intellectual disabilities. It is my hope that the word “significant” carries with it less stigma and fewer negative connotations than the terminology that has been used more traditionally. However, I am aware that any attempts to label can have both harmful and unintended consequences.

I now move to an in-depth examination of discourse analysis, discussing the struggle to define it, its origins and location within qualitative research, and methodological considerations guiding the approach.

Using Discourse Analysis as a Methodological Approach

Locating discourse analysis within the varied terminology of qualitative research such as “assumptions”, “epistemologies”, “paradigms”, “world views” and “theoretical approaches” is highly problematic. There seems to be little consensus among theorists, not only about definitional issues, but more fundamentally, on how to order the various concepts. Thus the process of articulating the foundation of my own research is made more difficult. After my perusal of how noted authors in the field of qualitative research sort out epistemological, theoretical and methodological questions, Patton (2002)’s reason for choosing foundational questions over categories becomes clear: “distinctions between paradigmatic, strategic, and theoretical dimensions within any particular approach are both arguable and somewhat arbitrary” (p. 80).

Location

I rely on the work of Crotty (1998), Wetherell (2001) and Jørgensen and Phillips (2002) which places discourse analysis as a methodology that falls under the epistemological umbrella or framework of constructionism. Jørgensen and Phillips, in particular, rely on several “key assumptions” that Burr (2003) describes as “things you would absolutely have to believe in order to be a social constructionist” (p. 2). These are worth reviewing briefly here. First, Burr argues that social constructionists must critically confront the “taken-for-granted ways of understanding the world” (p. 2). Next, she emphasizes the importance of recognizing that the ways in which people make sense of and understand their world are historically and culturally situated. Third, Burr suggests that our understanding of the world comes, not from essential truths, but from the

“daily interactions between people in the course of social life” (p. 4). Finally, she says that different ways of constructing the world mean that different “patterns of social action” are either permitted or denied, depending upon the construction (p. 5).

There is not much emphasis on the epistemological location of discourse analysis in the literature. Perhaps this is due to the fact that the field is fairly new. It may also be because discourse analysis is being used broadly, across so many fields, and in so many different ways. For example, Tonkiss (2004) suggests that, although it began in linguistics and social psychology, this “method” can now be found in areas as diverse as sociology, media studies, cultural studies, management studies, education, and history. This breadth invites thought and theory development from different viewpoints and orientations, thereby muddying the theoretical waters. Now that I have situated the field, I turn to an examination of the origin of discourse analysis.

Origins

Although a relatively new area of study, Potter and Wetherell (1987) have provided a very comprehensive review of the origins of discourse analysis. They maintain that discourse analysis developed out of three foundational pillars: a) Austin’s (1962) work on speech act theory, b) ethnomethodology as developed by Garfinkel (1967) and considered in Wieder’s (1974) work, and c) semiology as developed by Saussure (1974) and discussed in the writings of Barthes (1972).

In response to the existing philosophical approach to language as “essentially an abstract corpus” Austin’s (1962) work contends that language is, instead, a “*human*

practice” (Potter & Wetherell, 1987, p. 18). This position, known as the general theory of speech acts, highlights the notion that because people do things with language, a social view of language is required.

Ethnomethodology is the study of how people construct social reality, with a focus on how this is accomplished in “everyday life” (Holstein & Gubrium, 2005, p. 484). The field is “keenly attuned to naturally occurring talk and social interaction” and can be studied through, among other avenues, conversation analysis (Holstein & Gubrium, p. 487). It is relevant in this historical context as it considers the use of language in everyday situations, especially in the context of how people actively produce the events that happen to them (Potter & Wetherell, 1987).

Semiology is the “science of signs” and was developed by Saussure (1974). Its purpose is to study “significations apart from their content” (Barthes, 2006, p. 110) and its basic claim is that an “underlying system involving rules of acceptable sequences and combinations can generate and make sense of cultural phenomena” (Potter & Wetherell, 1987, p. 24). Significantly for discourse analysis, Barthes (1972) plays with the ideas in semiology to demonstrate that “taken-for-granted meanings are not natural, inherent properties of these things but essentially arbitrary, culturally constructed conventions” (Potter & Wetherell, p. 27).

In contrast to Potter and Wetherell’s (1987) historical review, van Dijk (2008) considers the origins of discourse analysis to have arisen from the critical theory of the Frankfurt School before World War II, and from the work of the critical linguists of the

late 1970s. Powers (2001) describes the foundations of discourse analysis as critical social theory, postmodernism and antifoundationalism, whereas Flick (2006) sees such origins in conversation analysis and discursive psychology. In terms of written discourse analysis, Kaplan and Grabe (2002) suggest it indirectly derives from hermeneutics.

The Meanings of Discourse

Discourse is a word that is not easily defined as it has different meanings depending upon the author of the definition and the scholarly tradition or discipline with which he or she is associated. Definitional issues arise because this “fashionable term” is used “indiscriminately, often without being defined” (Jørgensen & Phillips, 2002, p. 1). This has resulted in a vague concept, “either meaning almost nothing, or being used with more precise, but rather different, meanings in different contexts” (Jørgensen & Phillips, p. 1). What follows is a brief discussion of some different definitions found in the literature in the context of discourse analysis.

Schiffrin, Tannen and Hamilton (2001) suggest that there are three main definitional categories of discourse: a) that which is beyond the sentence, b) language use, and c) wider social practices including nonlinguistic instances. Tonkiss (2004) describes discourse as “a single utterance or speech act” or “a systematic ordering of language involving certain rules, terminology and conventions” (p. 373). Young and Fitzgerald (2006) consider discourse to encompass the things that people read and hear.

Blommaert (2005) describes discourse as “language-in-action” (p. 2). Similarly, Gee (2005), Jaworski and Coupland (2006), and Wetherell, Taylor and Yates (2001) all

define it as “language in use”. However, Gee distinguishes between small “d” discourse as described above, and “D” discourse, which includes not only language, but the “other stuff” (ways of being, feeling, interacting) that allows people to make meaning.

Wetherell and colleagues contend that discourse is language in use plus the “study of human meaning-making” (p. 3). Jaworski and Coupland expand their understanding to include language that both reflects and shapes social order as well as shaping individuals and their interactions in society.

Discourse can also be considered more broadly as “a particular way of talking about and understanding the world or an aspect of the world” (Jørgensen & Phillips, 2002, p. 1). Powers (2001) says that discourse is “a group of ideas or patterned way of thinking which can be identified in textual and verbal communications and can be located in wider social structures” (p. 1). Burr (2003) provides a very functional definition by stating that discourse “refers to a set of meanings, metaphors, representations, images, stories, statements and so on that in some way together produce a particular version of events” (p. 64). Foucault’s (1972) conceptualization is also defined broadly.

We shall call discourse a group of statements in so far as they belong to the same discursive formation...it is made up of a limited number of statements for which a group of conditions of existence can be defined. Discourse in this sense is not an ideal, timeless form...it is, from beginning to end historical - a fragment

of history, a unity and discontinuity in history itself, posing the problem of its own limits, its divisions, its transformations... (p. 117).

More concretely, Foucauldian discourse can be seen, not only as ideas, ideologies, or symbols, but also as “working attitudes, modes of address, terms of reference, and courses of action suffused into social practice” (Gubrium & Holstein, 2000, pp. 493-494).

Discourse Analysis

What then is discourse analysis? Again, there are a number of ways of conceptualizing this term, largely depending upon the discipline within which the researcher works. Because discourse analysis has developed in many different areas, “panoply of theoretical perspectives” has evolved (Potter & Wetherell, 1987, p. 6). In their seminal work on discourse and social psychology, Potter and Wetherell give an indication of the diverse areas in which discourse analysis has been used.

The label “discourse analysis” has been used as a generic term for virtually all research concerned with language in its social and cognitive context...as a description for studies focusing on linguistic units above the level of the sentence...as the correct term for research concerned with cohesion and connectedness across sentences or turns of talk...and to cover developments stemming from structuralism and semiotics (p. 6).

To further bring home their point, these authors have even suggested that it is possible to peruse two books on discourse analysis without finding any overlap in the material that each covers (Potter & Wetherell).

To provide some contemporary examples, some scholars consider it primarily as a linguistic analysis which has the ability to “expose misrepresentation, discrimination, or particular positions of power in all kinds of public discourse” (Young & Fitzgerald, 2006, p. 8).

Others look at discourse analysis more widely. Johnstone (2008) explains that discourse analysis focuses on “what happens when people draw on the knowledge they have about language...to do things in the world” (p. 3). It has also been described as “a series of interdisciplinary approaches that can be used to explore many different social domains in many different types of studies” (Jørgensen & Phillips, 2002, p. 1) as well as an examination of how language is “recruited” to enact activities and create identities (Gee, 2005, p. 1).

There are also those theorists who describe discourse analysis mainly in term of power. Blommaert (2005) uses this approach in looking at “an analysis of power effects, of the outcome of power, of what power does to people, groups, and societies, and how this impact comes about” (pp. 1-2). Similarly, van Dijk (2008) concentrates on the issue of power in what he terms “critical discourse studies”, although his focus lies specifically in “*the study of the discursive reproduction of power abuse*” (p. 6).

Finally, Fairclough (2003) analyzes discourse with a special emphasis on its critical nature. The aim of his research is to enact “contemporary social change” (p. 4). He provides a real sense of the meaning behind this type of work.

Critical social research begins from questions such as these: how do existing societies provide people with the possibilities and resources for rich and fulfilling lives, how on the other hand do they deny people these possibilities and resources? What is it about existing societies that produces poverty, deprivation, misery, and insecurity in people's lives? What possibilities are there for social change which would reduce these problems and enhance the quality of the lives of human beings? The aim of critical social research is better understanding of how societies work and produce both beneficial and detrimental effects, and how the detrimental effects can be mitigated if not eliminated (Fairclough, 2003, pp. 202-203).

Jørgensen and Phillips (2002) suggest that all discourse analytical approaches agree on four major points: a) language does not reflect a pre-existing reality, b) language is structured in discourses or patterns where meanings can change, c) discursive patterns are "maintained and transformed in discursive practices", and d) this maintenance and transformation is explored through "analysis of the specific contexts in which language is in action" (p. 12).

Discourse analysis has been used to examine an enormous variety of research questions, as a quick perusal of the handbook edited by Schiffrin, Tannen and Hamilton (2001) suggests. On the subject of linguistics alone, chapters include discussions on (a) cohesion and texture (Martin, 2001), (b) semantics (Norricks, 2001), (c) relevance theory (Blakemore, 2001) and (d) typology (Myhill, 2001), to name a few. Influential research in

the field has also focused on such significant issues as (a) the media (Bell, 1991, Fowler, 1991, and Fairclough, 1995), (b) racism (Reisigl & Wodack, 2001 and van Dijk, 1991, 1993), (c) the role of power (van Dijk, 2008), and (d) social change (Fairclough, 1992, 2003).

Discourse analysis in special education research. There are a number of examples where discourse analysis has been used in the context of special education. Forman and McCormick (1995) applied discourse analysis to study remedial and special education in the context of adult learners. Liasidou (2008) used critical discourse analysis to consider inclusive education policies in Cyprus. Through Foucauldian discourse analysis, Morgan (2005) sought to understand “how power within the British special education system affects the discourse of ‘choice’ for parents who seek an alternative educational placement than mainstream for their child with SEN” (p. 330). Rogers (2003) used Fairclough’s critical discourse analysis in her study of the special education referral process, while Stamou and Padelidiadu (2009) used the same methodology to explore how teacher candidates in Greece represent disability. Finally, Vehkakoski (2008) was inspired by both discourse analysis and conversation analysis in her piece on “how professionals negotiate for school entrance positions for preschool-aged hard-of-hearing children with cochlear implants considered as special needs children” (p. 496).

Discourse analysis and people with intellectual disabilities. Discourse analysis has also been used by some researchers in the areas of identity construction and the

experiences of individuals with intellectual disabilities. Danforth and Navarro (1998) focused on “speech acts” in their examination of the social construction on mental retardation, whereas Rapley (2004) used discursive psychology to argue that intellectual disability is socially constructed. Jingree and Finlay (2008) devised a “discourse analytic study examining staff talk on empowering service-users” (p. 708) in the context of supporting people with learning disabilities. Scior (2003) employed discourse analysis in her consideration of how women with learning disabilities position themselves in terms of their identities within the categories of gender and disability. Similarly, Brownlow (2010) used discourse analysis to study how individuals with autism negotiate their identity.

Discourse Theory

As my review has thus far illustrated, there are many ways to use discourse analysis as a methodology of social inquiry. I have chosen to use Laclau and Mouffe’s (2001) discourse theory in this work. I want to begin by explaining what discourse theory is and why I believe it is an appropriate methodology in which to frame this study. There are two issues I have had to negotiate in relying on discourse theory. First, it is “rather inaccessible” and presupposes “extensive knowledge of the theories on which [the authors] draw” (Jørgensen & Phillips, 2002, p. 24). Second, Laclau and Mouffe are theorists and “do not do much detailed analysis of empirical material themselves” (Jørgensen & Phillips p. 49). The first issue has been addressed by several authors who have interpreted the original theory and provide me with companion pieces to further explain the original theory. Jørgensen and Phillips have clearly

identified ways in which Laclau and Mouffe’s conceptualizations can be used as analytical tools in a concrete way. They have also considered complementary instruments from other discourse analysis theories to augment the tools Laclau and Mouffe originally propose. For these reasons, I will rely on the original text and the work of these other authors who have used discourse theory in their own research.

Origins, Goals and Purposes

Discourse theory is a political theory which has been explicated in Laclau and Mouffe’s (2001) book *Hegemony and Socialist Strategy*. It was written as a critique of traditional Marxist thought and in response to what the authors see as a “theoretical crisis” arising from “the very wealth and plurality of contemporary social struggles” (p. 2). Jørgensen and Phillips (2002) suggest that the theory has been constructed by “combining and modifying...Marxism and structuralism” (p. 25). Andersen (2003) argues that Laclau and Mouffe’s work is “one of the most comprehensive rewritings of Foucault’s discourse analysis” and that it “defines a new critical project, constructed around a discourse-analytical reconstruction of the concept of hegemony” (p. 49). The theory has also been called “a novel fusion of recent developments in Marxist, post-structuralist, post-analytical and psychoanalytic theory” (Howarth & Stavrakakis, 2000, p. 1).

Discourse theory is political in the broadest sense of the word. It is concerned with “the manner in which we constantly constitute the social in ways that exclude other ways” (Jørgensen & Phillips, 2002, p. 36). Its purpose is to allow for an

investigation of “the way in which social practices articulate and contest the discourses that constitute social reality” (Howarth & Stavrakakis, 2000, p. 3). Although much of the work using discourse theory has been in the arena of politics and political analysis (Howarth, Norval & Stavrakakis, 2000; Sutherland, 2005), the theory has also been applied more broadly in cultural analysis (Carpentier & Spinoy, 2008) and in the area of race and sexuality (A. M. Smith, 1994).

Howarth and Stavrakakis (2000) explain that discourse theory assumes that “all objects are meaningful, and that their meaning is conferred by historically specific systems of rules” (p. 2). A particular situation, event or identity takes on a different meaning and/or significance depending upon whose perspective is being highlighted or which discourse is being attended to. “Each of these discourses is a social and political construction that establishes a system of relations between different objects and practices, while providing (subject) positions with which social agents can identify” (Howarth & Stavrakakis, p. 3). Laclau & Mouffe (2001) suggest the following example.

An earth quake or the falling of a brick is an event that certainly exists, in the sense that it occurs here and now, independently of my will. But whether their specificity as objects is constructed in terms of “natural phenomena” or “expressions of the wrath of God”, depends upon the structuring of a discursive field (p. 108).

The premise underlying the theory is that “discursive totality never exists in the form of a simply *given and delimited* positivity” (Laclau and Mouffe, 2001p. 110). In

other words, the meaning of any social phenomenon can never be finally determined or “fixed”. The effect of this premise is that there are “constant social struggles about definitions of society and identity, with resulting social effects” (Jørgensen & Phillips, 2002, p. 24). Meaning is therefore created by successful attempts, at least temporarily, at fixing it in a certain way.

The goal of discourse analysis within discourse theory is to

map out the processes in which we struggle about the way in which the meaning of signs is to be fixed, and the process by which some fixations of meaning become so conventionalized that we think of them as natural (Jørgensen & Phillips, 2002, pp. 25- 26).

I believe it is appropriate to extend the use of discourse theory to my own work because I see “the concepts and logics” of this particular theoretical framework to be “sufficiently ‘open’ and flexible enough to be adapted, deformed and transformed in the process of application” (Howarth & Stavrakakis, 2000, p. 5). If, as Laclau and Mouffe (2001) argue, there is nothing inherent in an individual or a group of individuals that objectively defines them as such, the creation of these identities occurs through discourse. The professional discourse within the field of special education constitutes the categorization of students with significant intellectual disabilities in a particular way that prohibits their constitution in other ways. An analysis of this professional discourse through textbooks reveals which identities have become fixed within this discourse and whether there is a struggle over these identities. Such an analysis is critical because

“meanings, interpretations and practices are always inexorably linked” (Howarth & Stavrakakis, p. 6).

The Meanings of Discourse and Discourse Analysis

In my overview of discourse analysis earlier in this chapter, I gave some examples of how discourse has been variously defined. Now I will outline how Laclau and Mouffe (2001) present the concept. They say that discourse is “the structured totality resulting from the articulatory practice” (p. 105) and a “system of differential entities” (p. 111). Howarth and Stavrakakis (2000) speak of “systems of meaningful practices that form the identities of subjects and objects” (pp. 3-4). Jørgensen and Phillips (2003) define discourse as “the fixation of meaning within a particular domain” (p. 26).

There are several further points that are worth noting. Within discourse theory, discourses are political, meaning that “they always involve the exercise of power” (Howarth & Stavrakakis, 2000, p. 4). The result is that of all the potential possibilities of meaning and identity, the construction of a discourse necessarily excludes certain possibilities (Howarth & Stavrakakis; Jørgensen & Phillips, 2003). Not only is the concept of discourse political, it is also contingent and historical (Howarth & Stavrakakis).

According to Howarth & Stavrakakis (2000), discourse analysis “refers to the practice of analyzing empirical raw material and information in discursive forms” (p. 4). Data can be both linguistic and non-linguistic because Laclau and Mouffe (2001) suggest that discourse is not simply language but has a “material character” (p. 108). As

Jørgensen and Phillips (2003) illustrate, the characterization of children as a distinct group is accomplished both linguistically and also materially by virtue of their participation in certain social institutions such as schools. The data in discourse theory, which can take the form of reports, policies, speeches and historical events for example, are seen as “sets of signifying practices that constitute a ‘discourse’ and its ‘reality’” (Howarth & Stavrakakis, p. 4).

Key Terms in Discourse Theory

Laclau and Mouffe (2001) provide the following description of how their theory is conceptualized.

We will call *articulation* any practice establishing a relation among elements such that their identity is modified as a result of the articulatory practice. The structured totality resulting from the articulatory practice, we will call *discourse*. The differential positions, insofar as they appear articulated within a discourse, we will call *moments*. By contrast, we will call *element* any difference that is not discursively articulated (p. 105).

It is important to bear in mind that all social practices are articulations (Laclau & Mouffe, 2001). Using this introduction, I will now consider some of the terminology Laclau and Mouffe use in their theory and illustrate how these concepts are used in discourse analysis.

Laclau and Mouffe (2001) suggest that discourses are “constituted” in an attempt to “dominate the field of discursivity, to arrest the flow of differences, to

construct a centre” (p. 112). They use the term “field of discursivity” to denote a “reservoir” for meanings that a sign has in other discourses “but which are excluded by the specific discourse in order to create a unity of meaning” (Jørgensen & Phillips, 2002, p. 27). This constitution of discourse is done in a particular way using signs. Laclau and Mouffe call all signs within a discourse “moments”. The meaning that each sign has is determined by “its relation to other signs” (Jørgensen & Phillips, p. 26). Some signs within a discourse are privileged over other signs. These “privileged discursive points” are referred to as “nodal points” (Laclau & Mouffe, p. 112). They order the other signs, which “acquire meaning” from their “relationship with the nodal point” (Jørgensen & Phillips, p. 26). It is at this juncture that other meanings of a sign are excluded in that discourse. “Elements” are signs that do not yet have a fixed meaning. Instead, an element has “multiple, potential meanings (ie. they are *polysemic*)” (Jørgensen & Phillips, p. 27). The term “floating signifiers” is used to denote any elements that are open to multiple meanings and over which a struggle to fix meaning develops (Laclau, 1990, p. 28). Using Laclau and Mouffe’s terminology, a discourse “attempts to transform elements into moments by reducing their polysemy to a fully fixed meaning” (Jørgensen & Phillips, p. 28).

Key Concepts in Discourse Theory

There are several more concepts in discourse theory that are worth examining at this point as they will form a critical aspect of my work. Laclau and Mouffe (2001) discuss objectivity, but they define it differently than the objectivity known in positivist research. I have already noted that meanings within discourses are only partially or

temporarily fixed and can never be finally fixed. Analyzing the struggle to fix meaning is an important agenda within discourse theory. However, there may be times within certain discourses that it seems as if something is objectively true. Laclau (1990) notes that this happens when the contingent nature of meaning is forgotten within a discourse.

Insofar as an act of institution has been successful, a “forgetting of the origins” tends to occur; the system of possible alternatives tends to vanish and the traces of the original contingency to fade. In this way, the instituted tends to assume the form of mere objective presence. This is the moment of sedimentation (p. 34).

There may be times when discourses collide. This collision results in “social antagonism” (Jørgensen & Phillips, 2002, p. 47). For example, two different identities may “mutually exclude each other” (Jørgensen & Phillips, p. 47). In order to resolve the conflict between the competing and antagonistic discourses, a “hegemonic intervention” occurs (Jørgensen & Phillips, p. 48). “The major aim of hegemonic projects is to construct and stabilise the *nodal points* that form the basis of concrete social orders by articulating as many available elements – floating signifiers – as possible” (Howarth & Stavrakakis, 2000, p. 15). In a more practical sense, “one discourse is undermined from the discursive field from which another discourse overpowers it” (Jørgensen & Phillips, p. 48). The purpose of the intervention is to ensure that one particular discourse dominates, thereby restoring the myth of objectivity.

Identity, Group Formation and Representation

I have stated that I am interested in examining the conceptualization of students with significant intellectual disabilities within the domain of special education. This focus necessitates a consideration of identity, group formation and representation within discourse theory. Howarth & Stavrakakis (2000) argue that “questions surrounding the way social agents ‘live out’ their identities and act...are of central importance” within discourse theory (p. 12). Laclau and Mouffe (2001) suggest that a person’s identity is determined by discourses. “Whenever we use the category of ‘subjects’ in this text, we will do so in the sense of ‘subject positions’ within a discursive structure” (p. 115). Different discourses position a single individual in more than one way and these different positions may conflict with one another. Laclau and Mouffe (2001) refer to this as overdetermination. Jørgensen & Phillips (2002) make an interesting point when they note that subject positions that are not conflicting with other positions “are the outcome of hegemonic processes whereby alternative possibilities have been excluded and a particular discourse has been naturalized” (p. 41).

To deconstruct a subject position, one must identify “nodal points of identity” (Jørgensen & Phillips, 2002, p. 42). Other signifiers within the discourse give the nodal point its meaning. Signifiers are linked together in a “chain of equivalence” where “signs are sorted and linked together” (Jørgensen & Phillips, p. 43). Jørgensen and Phillips use the word “man” as an illustration of a nodal point. The word “man” is empty until it is given meaning. A discourse offers “different content to fill” this nodal point (p. 42). The authors use words like “strength”, “reason” and “football” as examples of other

signifiers that create the chain to identify “man” in a particular way. Other words could also be used in a different discourse, creating a different meaning. Not only does the discourse give meaning, it also “provides behavioural instructions to people who identify with man...which they have to follow in order to be regarded as a (real) man...” (Jørgensen & Phillips, p. 43).

There are two other points I want to emphasize about identity. First, identity is organized relationally (Jørgensen & Phillips, 2002). An individual is always contrasted against something he or she is not. Second an identity is always “contingent – that is, possible but not necessary” (Jørgensen & Phillips, p. 43). This again highlights the denial of any objectively determined and fixed nature of an individual and the potential for social antagonism to disrupt perceived objectivity of identity.

The focus of my research is on the conceptualization of students with significant intellectual disabilities. As a result, it is important to also explore the formation of group identities from a discourse theory perspective. If, as Jørgensen and Phillips (2002) contend, “there are no objective conditions that determine into which groups the social space is divided” (p. 44), such groups are determined discursively. The process of identifying group positions is similar to that identifying individual subject positions. “People are constituted as groups through a process by which some possibilities of identification are put forward as relevant and others are ignored” (Jørgensen & Phillips, p. 44). Again, chains of equivalence are used to create this identity.

Laclau and Mouffe (2001) introduce two companion terms when they explain group identification. These terms are the “logic of equivalence” and the “logic of difference”. “A project employing the logic of equivalence seeks to divide social space by condensing meanings around two antagonistic poles” (Howarth & Stavrakakis, 2000, p. 11). According to Laclau and Mouffe, “the differences cancel out one another insofar as they are used to express something identical underlying them all” (p. 127). On the other hand, “a project employing a logic of difference attempts to weaken and displace a sharp antagonistic polarity” (Howarth & Stavrakakis, p. 11).

The terms are not mutually exclusive and it is evident that each creates a different discursive struggle. For example, the dominant non-disabled group might use the logic of equivalence to group together all of those who fall outside of the boundaries of the norm, a group that might be termed “the disabled”. However, in order to argue for greater employment for people with disabilities, people with physical disabilities might use the logic of difference to weaken the connection between themselves and people with intellectual disabilities and mental health issues, in an effort to highlight their own competence against the perceived incompetence of the disabled in the wider discourse.

Jørgensen & Phillips (2002) also discuss the related issue of representation. A group has no existence until it is “constituted in discourse” (p. 45). To be constituted in discourse means that “someone talks about, or on behalf of, the group” (p. 45). Representation serves to emphasize that people with intellectual disabilities, for

example, as an articulated homogeneous group, become so when an individual or group talks about them in ways that define and identify them. They are not a group existing outside of the discourse in any real or objective sense.

Now that I have outlined discourse theory and terms necessary to explain it, I will describe the methods I have used to conduct this research.

My Study

In this study, I sought to answer a number of questions. What are the professional discourses circulating in introductory special education textbooks that conceptualize students with significant intellectual disabilities? Has the language used in relation to these students become so neutralized as to make the meaning seem natural and relatively uncontested? Do any discourses reflect traditional philosophical understandings of personhood? Are there any conflicts that contest a dominant discourse? If so, what are the consequences of one discourse “winning” over another or others?

Source of Discourse – A Rationale

In order to deconstruct this discourse, I needed to determine what kind of discourse to analyze. I had a number of options available to me. I could have examined professional discourses found in the empirical literature, in different kinds of textbooks, or in discourses of educators and/or other professionals in related fields. I could have also looked at non-professional discourses. My initial goal was to explore a variety of discourses conceptualizing students with significant intellectual disabilities. For the

purposes of this study, however, I decided limit my focus to data collected from sections of Canadian introductory textbooks on special education, which focus specifically on students with significant intellectual disabilities.

My choice to study a professional discourse was influenced, in part, by Carlson's (2010) remarks about the role of power in the history of mental retardation. Power dynamics were and, I argue, continue, to be at play "between object of power and expert, between classified individual and those in positions of power (parents, advocates, institutional figures, physicians, psychiatrists), between groups of the intellectual disabled themselves, between the experts and reformists vying for authority and professional legitimacy..." (p. 99). Apple and Christian-Smith (1991) emphasize the importance of power in educational contexts when they say that "what counts as legitimate knowledge is the result of complex power relations and struggles among identifiable class, race, gender/sex, and religious groups" (p. 2).

Sleeter and Grant (1991) suggest that textbooks have played "a paramount role in Western education for over the past five hundred years" (p. 80). In their discussion of textbooks, Apple and Christian-Smith (1991) argue that texts "are not simply 'delivery systems' of 'facts'" (p. 1). Instead, they are "at once the results of political, economic, and cultural activities, battles and compromises" (pp. 1-2). Moreover, they signify "particular constructions of reality, particular ways of selecting and organizing that vast universe of possible knowledge" (p. 3). As Rice (2005) notes,

Textbooks are purveyors of what is implicitly understood to be legitimate material for a particular area of study (Apple, 1988). They signify constructions of reality and ways of selecting, organizing and prioritizing knowledge. Textbooks provide selected access to ideas, information and practices that are interpreted by students as natural, fixed and inevitable. Much of the information that textbooks convey to students involves cultural and professional values. Symbolic representations in textbooks are often used to confer legitimacy on particular groups, while the silencing or omission of other perspectives may have the opposite effects for those groups (Sleeter & Grant, 1991). Textbooks are one mechanism by which ideological positions in a field of study can be conveyed (p. 407).

Textbooks dedicated to teaching issues in special education to prospective teachers can be a significant source of information and influence. In her critical analysis of textbooks, Brantlinger (2006) uses Foucault's analyses of power and governmentality to present similar arguments illustrating the power of the text in the field of special education. "As distributors of disciplinary routines, textbooks' coverage fits into hierarchical schemas that anonymously descend from the authorities who originally research and delineate deviance to school personnel who eventually practice according to the strategies laid out in texts" (p. 66). Moreover, the "conditions and procedures" that are described in these books are presented to the education student and other readers as "accurate, permanent, and objectively derived policy and practice" (p. 66).

Textbooks have been used as data in the context of discourse analysis in a number of recent studies. Liu (2005a) looked at “how language textbooks introduce the child reader to the cultural values and beliefs constructed by the government and cultural elites” (p. 16). The author also examined the “pro-science and technology discourse that is constructed in Chinese language textbooks” (Liu, 2005b, p. 306). Both studies used a critical discourse analysis approach.

McDonald (2002) explored “the textual relationship among three genres of medical discourse – research article, textbook and doctor–patient interview; and the way in which they relate to their institutional sites of production” (p. 449).

Ninnes (2000) was concerned with describing and evaluating the ways in which junior high science texts “have attempted to overcome ethnocentric, racist and culturally imperialistic approaches to knowledge representation through the incorporation of representations of diverse knowledges” (p. 605). He used Foucault’s archaeology and an analysis of “ideological and grammatical textual features” (p. 605). In a related work, Ninnes (2001) tackled the issue of the “extent to which junior secondary science texts assist or hinder science teachers who wish to develop inclusive learning environments in their classrooms” (p. 83). D. Pinto (2004) focused on authoritative discourse when he examined Fascist civics text books. Finally, Thomson and Otsuji (2003) used critical discourse analysis to analyze Business Japanese textbooks in relation to gender.

Textbooks in special education have been analyzed in three articles (Brantlinger, 2003; Rice, 2005; R. M. Smith, 2006) and a textbook chapter (Brantlinger, 2006). In an unpublished paper, Brantlinger (2003) looked at how textbooks structure special education. Rice analyzed “discussions of inclusive education in best-selling introductory special education textbooks” to better understand what pre-service teachers were being taught about inclusion. R. M. Smith examined classroom management textbooks with the goal of looking at “what the texts communicated about the students who would ultimately be served and how the authors’ attitudes reflected their cultural traditions about disability” (p. 94).

Brantlinger (2006) critically re-visited the idea of textbooks in the context of special education, focusing on the “big glossies”, as she calls them. She did so because they “have an impact on preservice teachers’ thinking about education, and hence on the eventual nature of practice” (p. 46). She argues that such textbooks become an almost automatic addition to post secondary education. They are convenient tools for professors and expected by students, who are not only used to them but also become “suspicious of alternatives” (p. 48). Unfortunately, as Brantlinger suspects, “busy faculty often select textbooks without carefully reading them” (p. 51). Textbook selections can also be passed on in syllabi from faculty to graduate students teaching courses, further cementing “textbook-oriented traditions in professional teacher education practice” (pp.46-47).

Data Sources

Introductory textbooks provide both pre-service educators and educators seeking more knowledge about special education, with a first glimpse into teaching students who are considered to have exceptionalities. Textbook material may be the first time in which prospective teachers have been introduced to these students. This introduction may be even more noteworthy in the case of students with significant intellectual disabilities, who make up a very small percentage of exceptional students, and will likely not be in every class every year. Teachers may initially come to know such students only through introductory textbook material.

I originally intended to draw on seven introductory textbooks currently used in undergraduate degree introductory courses and post-baccalaureate degree courses in special education (Appendix 1). I chose these particular texts based on advice I received from instructors and professors in the special and inclusive education area within the Faculty of Education at the University of Manitoba. The texts are all in use in the education faculties at both the University of Winnipeg and the University of Manitoba.

I wanted to use material that was Canadian, given that my research is Canadian. I felt it was important that the books recognize the unique Canadian perspective. Unlike the United States, Canada has a Charter of Rights and Freedoms, which has been discussed in educational contexts. We also have a system in which education falls within the jurisdiction of each province and territory. This reality means that we do not have

any unified federal education laws. The textbooks I have chosen are either Canadian or are American and have been adapted for use in Canadian contexts.

In the preliminary stages of this work, I examined all of the texts in some detail. I found that only four of them specifically addressed students with significant intellectual disabilities (Appendix 2). The other three books did not reference these students as a specific group so there was insufficient discourse with which to engage. For this reason, only the former works have been included in my study. My analysis in Chapters 4 and 5 demonstrates that using data from these four textbooks was sufficient in allowing me to reach data saturation, which Bogdan and Biklen (2003) define as “the point of data collection where the information you get becomes redundant” (p. 62).

In conducting my analysis, I began by locating those sections of the textbooks which discussed students with significant intellectual disabilities. In so doing, I did not analyze those parts which discussed intellectual disability generally or which talked about students with “mild” intellectual disabilities. Some texts discussed students with “moderate” intellectual disabilities within the context of students with “mild” intellectual disabilities. I did not explore these areas. However, some texts discussed students with “moderate” intellectual disabilities along with students with “severe” and/or “profound” intellectual disabilities. In these cases, I examined the discussions as long as there was an indication that students with “severe” and/or “profound” intellectual disabilities were being considered. In using the words “mild”, “moderate”, “severe” and “profound”, I am consciously using language that appears in the texts and

professional discourse as a way to distinguish between degrees of intellectual disability. This is not necessarily terminology I use.

The textbooks typically contain the main text, tables and boxes. The latter often feature stories of a particular student. Data for this study came from the main text and from tables where information was provided that related to students with significant intellectual disabilities. Only one textbook (Hutchinson, 2010) contained a box with a story about an individual with “severe physical and intellectual disabilities” (p. 122). I chose not to include data from this box as it related to adult community living. The individual who is the subject of the story appears to be an adult and the information did not focus on education.

Methods

In choosing my methods, I rely on how Jørgensen and Phillips (2002) suggest Laclau and Mouffe’s (2001) concepts can be transformed into the tools of discourse theory. Although there are tools, I must emphasize that how these tools ought to be used is an issue that Laclau and Mouffe do not discuss, and one which I had to resolve myself. I began by looking for the points “around which identity is organized” (Jørgensen & Phillips, p. 46). “When collective (and individual) identity is investigated by discourse analysis, the starting point is to identify which subject positions – individual or collective – the discursive structures indicate as relevant” (Jørgensen & Phillips, p. 46). Laclau and Mouffe use two related terms to talk about these points: (a) master signifiers, which organize identity, and (b) nodal points, which organize discourse.

The identification of the master signifiers was a fairly straightforward process. The literature review in Chapter 2 provided me with insight into the issues facing people with significant intellectual disabilities. My familiarity with these issues, through this work and through work I have been doing over the past eight years, allowed me to focus in on language that is frequently used and has been the subject of discussion in other research. However, pinning down the nodal points was more difficult, largely because of the different language used across texts. I had a sense of the areas I wanted to explore, but finding the exact nodal points proved more elusive. On the positive side, this search really highlighted for me how empty and devoid of meaning nodal points are. They have no contextual meaning until the signifiers surrounding them are examined more fully. It is only then that the full implication of the nodal points was revealed.

Once the master signifiers and nodal points were identified, the next step in the analysis was to investigate how they “are combined with other signs” (Jørgensen & Phillips, 2002, p. 50). As I have mentioned, master signifiers and nodal points are essentially empty of meaning until they are actually combined with other signs via chains of equivalence. Thinking back to Jørgensen and Phillips’ example of the word “man”, the word itself relies on other words used in conjunction with it to infuse it with meaning. “By investigating the chains of meaning that discourses bring together in this way, one can gradually identify discourses” (Jørgensen & Phillips, p. 50). Ultimately, my goal was to investigate how the discourse(s) “constitute knowledge and reality, identities and social relations; where discourses function unobtrusively side by side, and where there are open antagonisms; and which hegemonic interventions are striving to

override conflicts – in which ways and with which consequences” (Jørgensen and Phillips, 2002, p. 51).

Pulling out signifiers was the most challenging aspect of this research. Discourse theory does not provide any assistance in actually going through this process. As I read and re-read the data and made attempts to organizing what I was reading, I began to intuitively note the signifiers. When I thought more closely about how I might rationalize my choice of signifiers, I realized that intuition was not the best way to describe the process. What I was actually doing was relying on my literature review and my experience researching and studying the issues facing people with intellectual disabilities. This knowledge provided a solid foundation for extracting signifiers from the textbooks. Certain words have meaning within academic and social discourses in the fields of intellectual disability, disability studies, humanness, and special education. These terms set off alarm bells in my head as being discussion points at best and problematic at worst.

Another way that I established signifiers was by noting their frequency. As this is neither a quantitative study nor a content analysis, I did not count the number of times certain words appeared. By using the term word frequency, I am referring to the repetition of some signifiers both within a textbook and across textbooks. This will become clear in the next two chapters when I present my data in table form.

I made every attempt to include all signifiers or descriptors of master signifiers and nodal points. This is a key element in discourse analysis because one of the issues I

needed to determine was the extent of hegemony within the discourse and whether alternative or competing discourses emerged. When I was convinced that I had extracted all of the descriptors of each master signifier and nodal point, I moved to the next one.

I had to make some choices when delimiting the discourse. I was tempted to look at intellectual disability more broadly as presented in the textbooks. However, I had to remind myself that my goal was to examine the conceptualization of students with significant intellectual disabilities. These students are distinguished in the textbooks I used. Discourses about intellectual disability in general contexts are not necessarily the same as those about individuals with more significant disabilities. This is particularly noticeable in the textbooks when considering the extent to which categories of intellectual disability are stressed. To examine intellectual disability more broadly would mean changing the focus of my work and going beyond my research question.

An equally pressing issue that I faced was whether to consider the discourse of inclusion. Although the purpose of my research is to examine how students with significant intellectual disabilities are understood, the idea of inclusion is inexorably tied to many discussions within special education contexts. I stated at the beginning of this paper that what led me to design this study was a perceived anomaly between the language of inclusion and the practice of some policies promoting segregation. Each textbook contains a chapter on inclusion, which I could have used in my analysis. However, the problem of considering inclusion was my concern that inclusion may be

understood in different ways, depending upon which label a student may be assigned. This problem was resolved when I realized that inclusion was a nodal point in all of the texts in direct discussions about students with significant intellectual disabilities.

I read over the sections relevant to my research numerous times, keeping in mind the specific language being used. I identified words and phrases that I thought might be master signifiers or nodal points. These words originally included mental retardation, intellectual disability, developmental disability, severe and multiple disabilities, students, educators and education. I then looked for other signs in the discourse that gave meaning to the master signifiers and nodal points. I created lists of signifiers that were relevant to each potential master signifier and nodal point. My next step was to take these lists of signifiers and categorize them. I also examined the nodal points across texts.

When I reached this point, I realized that my methods were straying from discourse analysis and moving toward a more key theme analysis, which was not the intent of this work. I then went back to the original data, with the goal of re-examining the master signifiers and nodal points. This exercise allowed me to locate the master signifiers and nodal points more accurately as being words used in each text's discourse. I then focused on the signifiers that gave meaning to them. This process enabled me to see that different texts had different master signifiers and nodal points, although many signifiers were similar.

As I began to write up my analysis, I presented information on each textbook separately. I had to rework this organizational method as the result was too repetitious. I also decided to reorganize my data into two distinct areas: master signifiers and nodal points. This re-categorization allowed me to focus on how students with significant intellectual disabilities are conceptualized within the textbooks. It then permitted an examination of what it means to educate these students.

A Note on Credibility and Trustworthiness

S. Taylor (2001) argues that discourse analysis “is a process of exploration and interpretation, and simultaneously, one of evaluation” (p. 318). As such, it falls outside of positivist and postpositivist research and lies beyond the criteria of reliability, validity and replicability. I assume that, like all knowledge, the knowledge that I have produced in this work is situated, contingent and partial (S. Taylor). I further operate on the assumption that “truth is inevitably influenced and altered by any processes through which a researcher attempts to investigate and represent it” (S. Taylor, p. 319). In the spirit of this assumption, I have included a section in this chapter which locates me within this research, using the technique of reflexivity.

Creswell (2007) suggests a list of “characteristics of a ‘good’ qualitative study” (p. 45), and I will review those which are applicable to my work. First, the researcher must frame the study “with the assumptions and characteristics of the qualitative approach to research” (p. 45). I have discussed this in great detail at the outset of this chapter.

Second, Creswell (2007) insists that the researcher use a recognized approach to research. Again, I have spent considerable time outlining discourse analysis and discourse theory, demonstrating my methodology and methods to be consistent with these approaches.

Third, it is suggested that the researcher begin with a “single focus” (Creswell, 2007, p. 45). My focus has clearly been stated as examining conceptualizations of students with significant intellectual disabilities within discourses found in introductory special education textbooks.

Creswell (2007) then discusses the inclusion of detailed methods and a “rigorous” approach to data collection, analysis and writing (p. 46). Although my data collection for this study did not involve interviews, focus groups or observations in the field, I have justified why I have used these data and I have presented an analysis in Chapters 4 and 5 that uses “multiple levels” and “abstract dimensions” (p. 46). This allows me to move from theory to practice and to discuss the implications of the discourses present in textbooks in Chapter 6. These implications refer back to my discussions in Chapter 2 about how individuals with significant intellectual disabilities have been portrayed over time and in philosophical and sociological contexts.

Another technique I have used to demonstrate credibility and trustworthiness is triangulation (Creswell, 2007; S. Taylor, 2001). I have interpreted triangulation in my study to refer to several specific processes. I have used four textbooks as sources of data, rather than a single text. The use of multiple master signifiers and nodal points

within each text allows for an analysis from different angles. This technique helps to shed light on the hegemony of the discourse and to illustrate any conflicting discourses. My exploration of both students and their education adds additional depth to the analysis.

In addition to all of these measures, my approach to discourse analysis using discourse theory is to show, rather than to tell. By this I mean that the words themselves as they appear in the textbooks show the power of the language. The master signifiers, nodal points, and the signifiers have been identified within the text to paint a picture of how students with significant intellectual disabilities and their education are conceptualized. This method of analysis will add to the rigor of the work.

I am extremely conscious of the fact that my decisions of which words to include and how to analyze them are highly subjective. My choices may not necessarily reflect choices that other researchers might make. However, I do feel that I have sufficient background in and knowledge of the issues facing people with intellectual disabilities, alternate conceptualizations of significant intellectual disability, and discourse analysis to make this work relevant and meaningful.

Chapter 4: Master Signifiers: Data and Analysis

“Many professionals still agree that the most useful classification system is that proposed by the AAMR, which considers the condition along a continuum, or scale, of severity. The AAMR’s categories – mild, moderate, severe, and profound retardation – describe an individual’s functioning clearly and carry no negative stereotyping and little stigma”(Winzer, 2008, p. 172).

“Literacy, language, comprehension, and communication are inseparably linked to power and ideology. This link is very apparent in special education, where the label traditionally has become the person” (Peters, 2005, p. 158).

I have begun this chapter with the quotation by Winzer (2008) because it highlights the very reason why I have undertaken this work. In declaring that certain categories “carry no negative stereotyping and little stigma” (p. 172), Winzer fails to recognize how powerful language is. The use of language, whether consciously or unconsciously, creates conceptualizations of individuals and things that become so entrenched as to become truths. My premise, consistent with Peters’ (2005) thinking in the quote below Winzer’s, is that far from being benign, such language ensures that certain students are destined for a particular type of education and a particular kind of life.

The purpose of this chapter is to review the data from this textbook analysis on identity and to show how the language used in the selected textbooks creates a particular meaning in the context of students with significant intellectual disabilities. My analysis will illustrate how these students are conceptualized in the discourse.

I am treating the four Canadian introductory special education textbooks that I analyzed in this research as one discourse, which I call the discourse of students with

significant intellectual disabilities. Using this organizational approach, I can describe the discourses specifically and look more broadly at how the different texts compare with each other, noting similarities and differences.

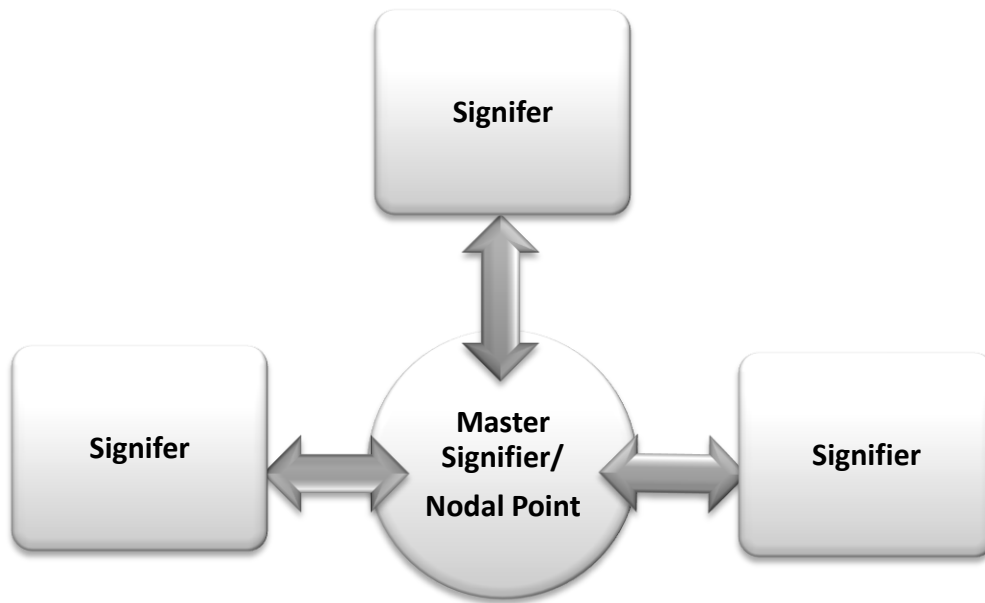
I have divided my data and analysis into two major sections: (a) master signifiers, which create student identity, and (b) nodal points, which help to identify the educational discourse. This chapter focuses exclusively on master signifiers. In Chapter 5, I examine the nodal points. In my discussions of the master signifiers and nodal points, I highlight the signifiers that are associated with each. My intent is to explore how the master signifiers and nodal points are crystallized and given meaning. To help illustrate the master signifiers, nodal points and signifiers, I have created a number of tables. Within this work, I have also used italics to indicate the signifiers found in the various textbooks.

During the course of Chapters 4 and 5, I refer to what the authors have written in the textbooks. I do want to clarify, however, that the authors rely upon the language we as a society use. The textbook discourse is one product of the larger discourse about people with significant intellectual disabilities that circulates throughout our society. This discourse must also be seen as historically and culturally situated; as Duranti (1997) has noted, the language we use today is language that comes from the past as hand-me-downs.

Data

As I explained in the previous chapter, within discourse theory “master signifier” is the term used to note the creation of identity within a discourse. Master signifiers do not, in themselves, carry any particular meaning. They are empty signs. Their meaning is only created by virtue of other signs in the discourse, referred to as “signifiers”. These signifiers are vital to discourse theory because they infuse master signifiers with a specific significance. Figure 1 illustrates how the terminology of discourse theory works.

Figure 1. A demonstration of the relationship between master signifiers/nodal points and their respective signifiers.



Figures 2 and 3 illustrate the relationship between the master signifier and signifiers and show how the choice of signifiers actively changes the identity of the individual being described.

Figure 2. An illustration of how discourse theory works using negative signifier language from Bogdan & Taylor (1998, p. 242)

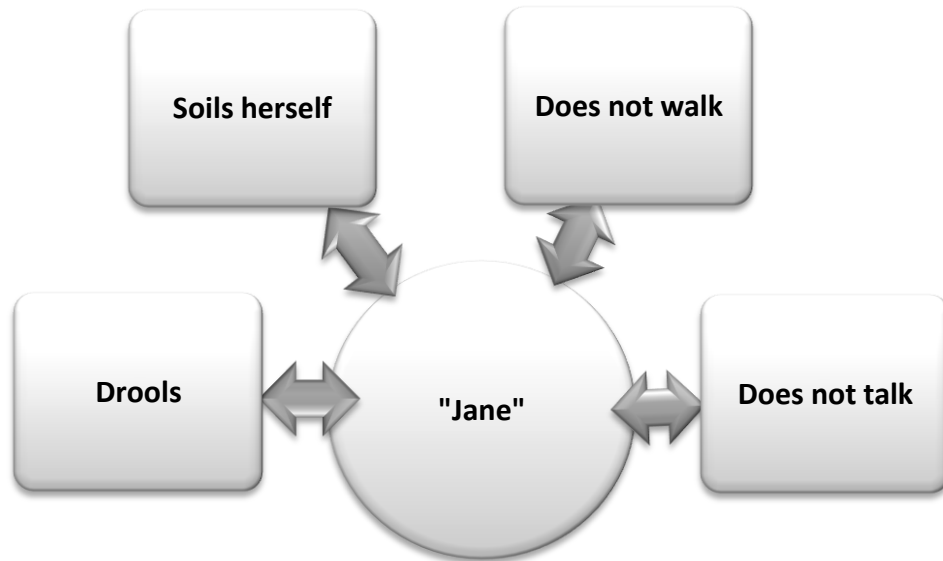


Figure 3. An illustration of how discourse theory works using positive signifier language from Bogdan & Taylor (1998, p. 242)

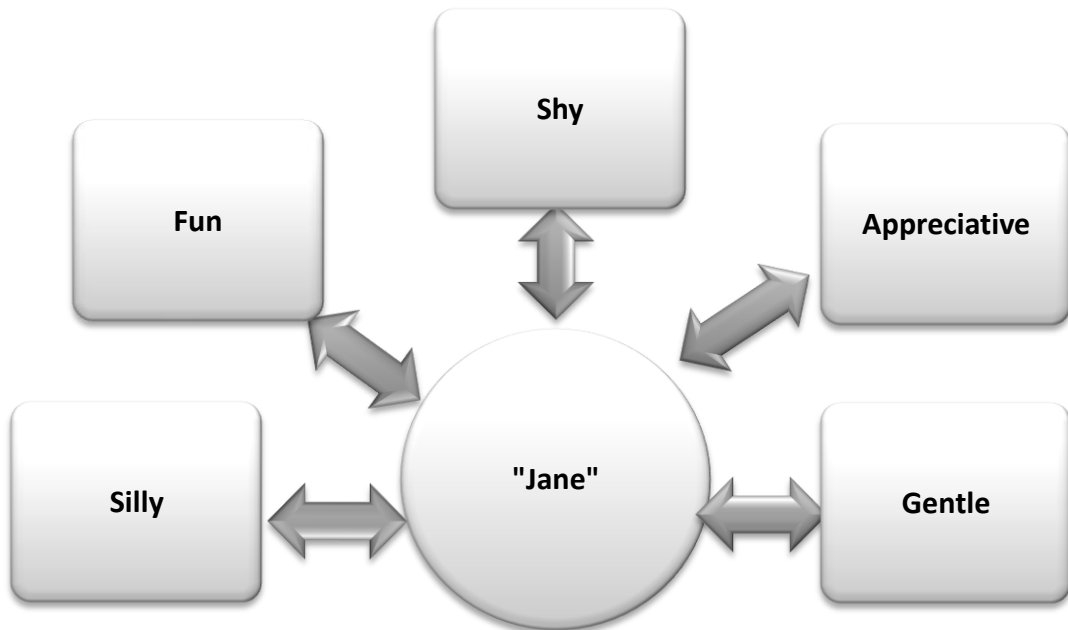
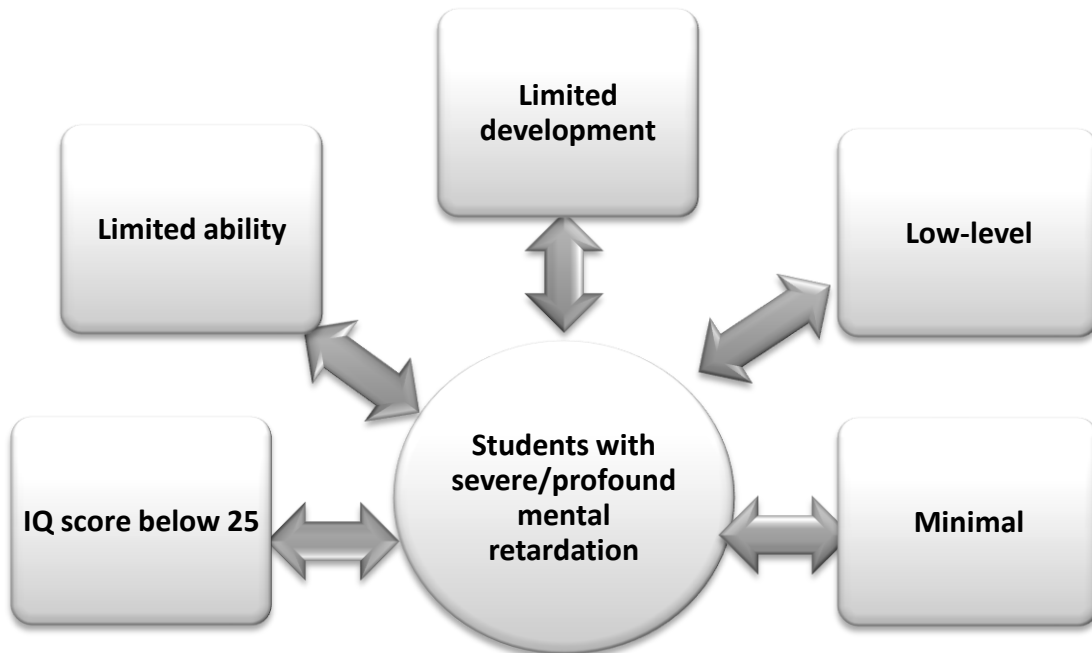


Figure 4 provides an example from one of the textbooks, using students with severe/profound mental retardation as the master signifier. The signifiers surrounding the master signifier give it meaning within the textbook discourse.

Figure 4. An illustration of how discourse theory works using signifiers from one of the textbooks.



Students with significant intellectual disabilities are identified using different language in each of the textbooks. Andrews and Lupart (2000) call them children/youth with *mental retardation (severe and/or profound)* and children with *severe disabilities*. Friend et al. (1998) refer to these students as *developmentally disabled* and as having *multiple disabilities*. Hutchinson (2010) makes reference to students with *severe intellectual disabilities*. Winzer (2008) discusses students with *severe and profound intellectual disabilities*. I have also included these “labels” themselves as master

signifiers. In addition to these labelling terms, there are several other master signifiers in the texts. The textbooks create identity using the terms *needs* and *supports*. Hutchinson (2010) and Winzer (2008) also consider the *psychological characteristics* and *behaviours* of these students. Table 1 sets out the master signifiers across the texts.

Table 1

Master Signifiers across Texts

Andrews & Lupart (2000)	Friend, Bursuck & Hutchinson (1998)	Hutchinson (2010)	Winzer (2008)
Students with severe/profound mental retardation	Students with moderate to severe developmental disabilities ³	Students with severe intellectual disabilities	Students with intellectual disabilities (severe/profound) ⁴
Students with severe disabilities			
Severe/profound mental retardation & severe disabilities	Moderate to severe developmental disabilities	Severe intellectual disabilities	Intellectual disabilities (severe/profound)
Needs	Supports	Assistance	Needs
Behaviour		Psychological characteristics	Behaviours

I have created Tables 2 through 5 to indicate which signifiers are present in each textbook. This provides a glimpse into the meanings of each master signifier. The analysis section will consider the signifiers in greater detail.

³ Friend et al. (1998) also contains information on students with multiple disabilities. However, there are no specific signifiers for this term and, given the limited discussion, I have treated the two labels as one.

⁴ Winzer (2008) also contains a chapter on students with severe and multiple disabilities. I chose not to include that data chapter for two reasons. First, the data within the chapter on children with intellectual disabilities were ample. Second, the language was similar within each chapter.

Table 2

Andrews & Lupart (2000) Master Signifiers and Accompanying Signifiers

Students with severe/profound mental retardation	Students with severe disabilities	Severe/profound mental retardation/ Severe disabilities	Needs	Behaviour
IQ score below 25	Extreme deficiencies	Dysfunctional severity	Lifelong care	Acceptable
IQ score between 25 and 40	Difficulty/greater difficulty	Severe	Close supervision	Appropriate
Limited ability	Lack	Profound	Support	
Limited development	Limited	Heterogeneous	Extensive	
Minimal	Impaired	Classification system	Pervasive	
Low-level	Severe	Subgroups	Services	
	Challenging characteristics	Intellectual & adaptive behaviour	Interventions	
	Warm	Problems	Educational interventions	
	Caring	Diagnosed	Intensities of services	
	Determined	Standardized intelligence tests	Ongoing	
	Likeable	Sociological perspectives/ Phenomenon		
	Humorous	Multicultural pluralistic assessment		
	Poor language	Extreme deficiencies		
	Poor skills	Difficulty		
		Condition		

Table 3

Friend, Bursuck & Hutchinson (1998) Master Signifiers and Accompanying Signifiers

Students with moderate to severe developmental disabilities ⁵	Moderate to severe developmental disabilities/Multiple disabilities	Supports
Significantly limited	Significant	Considerable
Exceptionally slow	Below average	Ongoing
Difficulty maintaining	Deficits	Intensive
Difficulty generalizing	Severe	Services
Challenge	Impairments	Extraordinary
Noticeable characteristics	Pervasive	
	Limited	
	Intelligence tests	
	Adaptive behaviour scales	
	Delay	

⁵ Although Friend et al. has a section which deals with students labelled as multiply disabled, there are no specific signifiers for this master signifier. However, identity is established with other master signifiers.

Table 4

Hutchinson (2010) Master Signifiers and Accompanying Signifiers

Students with severe intellectual disabilities	Severe intellectual disabilities	Assistance	Psychological characteristics (behaviour)
Range of abilities	Severe	Support	Frustration
Difficulties	Limitation	Require assistance	Impulsivity
Acquire	Significant	Entire lives	Challenging
Strengths	Condition	Personal care	Loyal
Weaknesses	Mental retardation		Caring
Delayed	Causes		Withdraw
Not develop	Disorder		Repetitive behaviours
Loyal	Syndrome		Bizarre
Caring	Abnormalities		
	Category		
	Profound		
	Genetic screening		
	Amniocentesis		
	Incidence		
	Medical advances		
	Diagnosed		

Table 5

Winzer (2008) Master Signifiers and Accompanying Signifiers

Students with intellectual disabilities (severe/profound)	Intellectual disabilities (severe/profound)	Needs	Behaviours
Severe	Classification system	Pervasive	Maladaptive
Profound	Categories	Lifetime	Serious
Basic	Continuum	Hinder	Aggression
Non-ambulatory	Scale/spectrum	Constancy	Self-stimulating
Non-responsive	Severity/severe	High intensity	Self-injurious
Poor	Profound	Intensive	
Inadequate	Condition	Life-sustaining	
Impairments	Low incidence	Life care	
Incontinence	Retarded	Supervision	
Seizures	Delays		
Cerebral palsy	Absolute/relative profoundly retarded		
No adaptive behaviour	Seriously impaired		
Medically fragile	Clear cut signs		
Sensori-motor stage	Untestable		
Extremely limited	Developmental scales/tools/measures		
Primitive levels			

Babbling

Jabbering

Serious problems

Overt/obvious problems

Low percentage of social interactions

Typical students

In addition to the tables by textbooks, I am also providing a series of tables (6 through 9) of signifiers across texts, to provide a sense of whether the discourses are uniform or diverse.

Table 6
Signifiers for Students across Texts

Students with severe/profound mental retardation Students with severe disabilities (Andrews & Lupart, 2000)	Students with moderate to severe developmental disabilities (Friend et al., 1998)	Students with severe intellectual disabilities (Hutchinson, 2010)	Students with intellectual disabilities (severe/profound) (Winzer, 2008)
IQ score below 25	Significantly limited	Range of abilities	Severe
IQ score between 25 and 40	Exceptionally slow	Strengths	Profound
Limited ability	Difficulty maintaining	Weaknesses	Basic
Limited development	Difficulty generalizing	Delayed	Non-ambulatory

Extreme deficiencies	Challenge	Not develop	Non-responsive
Difficulty/greater difficulty	Noticeable characteristics	Loyal	Poor
Lack		Caring	Inadequate
Limited		Difficulties	Impairments
Impaired		Acquire	Incontinence
Severe			Seizures
Challenging characteristics			Cerebral palsy
Warm			No adaptive behaviour
Caring			Medically fragile
Determined			Sensori-motor stage
Likeable			Extremely limited
Humorous			Primitive levels
Minimal			Babbling
Low-level			Jabbering
Poor language			Serious problems
Poor skills			Overt/obvious problems
			Low percentage of social interactions
			Typical students

Table 7

Signifiers for Labels across Texts

Severe/profound mental retardation Severe disabilities (Andrews & Lupart, 2000)	Moderate to severe developmental disabilities (Friend et al., 1998)	Severe intellectual disabilities (Hutchinson, 2010)	Intellectual disabilities (severe/profound) (Winzer, 2008)
Dysfunctional severity	Significant	Severe	Classification system
Severe	Below average	Limitation	Categories
Profound	Deficits	Significant	Continuum
Heterogeneous	Severe	Condition	Scale/spectrum
Classification system	Impairments	Mental retardation	Severity/severe
Subgroups	Pervasive	Causes	Profound
Intellectual & adaptive behaviours	Limited	Disorder	Condition
Problems	Intelligence tests	Syndrome	Low incidence
Diagnosed	Adaptive behaviour scales	Abnormalities	Retarded
Standardized intelligence tests	Delay	Category	Delays
Sociological perspectives/phenomenon		Profound	Absolute/relative profoundly retarded
Multicultural pluralistic assessment		Genetic screening	Seriously impaired
Extreme deficiencies		Amniocentesis	Clear cut signs
Difficulty		Incidence	Untestable
Condition		Medical advances	Developmental scales/tools/measures
		Diagnosed	

Table 8

Signifiers for Needs/Supports across Texts

Needs (Andrews & Lupart, 2000)	Supports (Friend et al., 1998)	Assistance (Hutchinson, 2010)	Needs (Winzer, 2008)
Lifelong care	Considerable	Require assistance	Pervasive
Close supervision	Ongoing	Entire lives	Lifetime
Supports	Intensive	Support	Hinder
Extensive	Services	Personal care	Constancy
Pervasive	Extraordinary		High intensity
Services			Intensive
Interventions			Life-sustaining
Educational interventions			Life care
Intensities of services			Supervision
Ongoing			

Table 9

Signifiers for Behaviour across Texts

Behaviour (Andrews & Lupart, 2000)	Psychological characteristics (Hutchinson, 2010)	Behaviours (Winzer, 2008)
Acceptable	Frustration	Maladaptive
Appropriate	Impulsivity	Serious
	Challenging	Aggression
	Loyal	Self-stimulating
	Caring	Self-injurious
	Withdraw	
	Repetitive behaviours	
	Bizarre	

Analysis

As I noted in the previous section, I have organized the data into thematic groupings in an attempt to best present both the data and the paper itself. I want to stress that I have used my discretion and judgment in placing particular signifiers within the context of certain master signifiers. Some signifiers may be associated with more than one master signifier. Actual thematic word groupings are less important to an understanding of the discourse as a whole. What is more significant is the highly repetitive nature of some of the language, which actually serves to reinforce the ways in which these students are conceptualized. This repetition is neatly exposed in the tables.

Students and their Designated Labels

I want to begin my analysis of identity with the first set of master signifiers involving the students and the labels they acquire as a result of their intellectual disability. I will start with quotations from each of the four textbooks which introduce these students to the reader. In the first paragraph under the heading, “Children with Severe Disabilities”, Andrews and Lupart (2000) note that these students “have extreme deficiencies in cognitive functioning. They tend to display poor language skills; have difficulty developing self-help skills; lack social and vocational abilities; and have limited physical mobility due to impaired physical and motor development” (p. 172).

According to Friend, et al. (1998), “students with moderate to severe developmental disabilities are significantly limited in their cognitive abilities and adaptive skills and have ongoing needs for intensive supports during their school years and into adult life” (p. 109).

Hutchinson (2010) says:

the category of severe intellectual disabilities now includes students considered at times in the past to have moderate, severe, or profound disabilities. They span a wide range of abilities, from those who can acquire academic skills to those who will require assistance with self-care for their entire lives (p. 123).

Finally, here is what Winzer (2008) writes:

Individuals who are severely retarded may show poor speech, inadequate social skills, poor motor development or non-ambulation, incontinence, sensory impairments, seizures, and cerebral palsy. The population of persons who are profoundly retarded can be divided functionally into two groups. “Relative” profoundly retarded persons have less organic damage and are capable of some degree of ambulation, communication, and self-help skills. “Absolute” profoundly retarded individuals are some of the most seriously impaired of all people with disabilities. The nature and degree of their disabilities are so great that, without various forms of intensive training and therapy, they exhibit virtually no adaptive behaviour (p. 187).

I wonder about the effects of such language on pre-service and other educators whose introduction to students with significant intellectual disabilities is the reading of opening paragraphs in these textbooks. Language affects both the educators who read the material and the children who may eventually become their students.

My discussion of students and their labels will involve an examination of six themes: (a) deficit perspectives, (b) medicalized language, (c) classification, (d) tests, (e) distancing, and (f) alternative discourses.

Deficit. The words in Tables 6 and 7 demonstrate that the texts all depict students with significant intellectual disabilities and the label of intellectual disability from a deficit perspective. This perspective is emphasized by words such as *limited*, *minimal*, *low level*, *difficulty (difficulties)*, *impaired (impairments)*, *dysfunction*,

weaknesses, inadequate, delayed, not developed, deficiencies, damage, and problems, both *serious* and *overt*. Use of this wording repetitively within texts and homogeneously across texts suggests that there is a consensus within the discourse that these children are lacking in qualities that are required of students.

I find the use of the words *difficulties* and *problems* interesting. The focus in the texts is on the difficulties facing the students. Winzer (2008) mentions the *overt and obvious problems* displayed by children with moderate to profound intellectual disabilities. It is assumed that these difficulties and problems arise due to the student's disability. There is no recognition that other perspectives of disability may be equally valid. Oliver (1996) explains the differences between the individual model of disability and social model of disability, which are relevant to this analysis. The individual model "locates the 'problem' of disability within the individual" and sees "problems" as coming from the disability (p. 32). Oliver goes on to say that "these two points are underpinned by what might be called 'the personal tragedy theory of disability' which suggests that disability is some terrible chance event which occurs at random to unfortunate individuals" (p. 32). On the other hand and in contrast, the social model locates the "problem of disability...squarely within society" (p. 32). The language of the texts tends to "blame" difficulties and problems in learning and development on the deficient student, while ignoring any discussion about how school environments and policies, and the attitudes of others may impact on and/or contribute to these difficulties and problems.

As with other signifiers creating the identities of these students, the use of several words speak to predictions of what students with significant intellectual disabilities are able to accomplish. For example, the term *skills* is used to emphasize what students with severe and profound mental retardation and severe disabilities cannot do, as well as what they do not have and are unlikely to develop. At best, Andrews and Lupart (2000) suggest these students will only attain *minimal* or *low level* skills. Winzer (2008) discusses the *low percentage of social interactions* these students engage in. Similar language includes mention of *difficulties maintaining* and *difficulties generalizing*, as well as abilities that *may not develop*. All of this language again reinforces the deficit perspective.

Predicting minimal accomplishments speaks directly to expectations. These textbooks suggest to pre-service and other educators that students labelled as having significant intellectual disabilities simply cannot be expected to achieve much during the course of their education. The language also focuses on what the students *lack* and the *difficulties* they have. This list of negative words may encourage the belief that these students are destined to fail.

Medicalized language. The language of deficit is further underscored in the textbooks by some particularly medicalized language, beginning with idea that intellectual disability is a *condition* which can be *diagnosed*. In our society, we diagnose diseases as a step towards curing them, in order to remain in a state of well-being. We ask professionals, usually physicians, to identify problems or conditions in our bodies

and minds so we can be treated, cured and become healthy and whole again. When we are ill, we may become dysfunctional, dependent and burdensome. When we are well, we are fully functioning, independent, and productive. We have value. The incorporation of the words *condition* and *diagnosis* in this educational discourse implies that educators ought to equate disabilities with ill health or sickness, rather than simply equating disability with difference. The use of these words in the field of special education confirms the point made by Peters (2005) when she argues that “the language used within this discipline communicates a medicalization of disability that is all-powerful, with oppressive consequences” (p. 158).

In Winzer (2008), a major focus of the discussions concern health issues such as *incontinence*, *seizures*, medical fragility, *cerebral palsy*, and being *non-ambulatory*. This kind of language brings to mind some of the original critiques of how disability has traditionally been conceptualized (Linton, 1998, Oliver, 1996). Oliver (1996) discusses characteristics of what he calls the “individual model” of disability (p. 34). He notes, for example, the “personal tragedy theory”, disability as a “personal problem”, and a focus on “medicalisation” and “professional dominance” (p. 34). Barnes and Mercer (2003) expand on the idea of personal tragedy. “This encompasses an individual and largely medicalized approach: first, disability is regarded as a problem at the individual (body-mind) level; second, it is equated with individual functional limitations or other ‘defects’; and third, medical knowledge and practice determines treatment options” (p. 2). The characterization of students with significant intellectual disabilities in this way confirms Linton’s (1998) argument that considerations of disability have been “constricted,

inadequate, and inaccurate conceptualizations” with its study resting in “the specialized applied fields (rehabilitation, special education, health...)” (p. 2).

In Hutchinson, in addition to language such as *disorder*, *syndrome*, and *abnormalities* there is an interesting discussion about the “incidence of severe intellectual disabilities” (p. 123). This section contains signifiers such as *genetic screening* and *amniocentesis* in the context of *medical advances*. Hutchinson (2010) explains that these medical developments are ethical issues which question “the value we place on members of our society with intellectual disabilities” (p. 123). Such a statement does not, however, explain why the author chose to include issues of genetics in a textbook on education.

From a disability perspective, the concept of genetic testing presents many thorny philosophical issues. The medical community has encouraged the belief that genetic testing can treat or cure disability, which Shakespeare (1999) calls the “narrative of optimism” (p. 675). However, very little of what can be accomplished today in the field of genetics involves the ability to treat or cure intellectual disability. In practice, preventing disability means preventing children with disabilities from being born. “We seem to be using this technology to respond to difference in the way in which we have done for centuries – by choosing to eliminate rather than embrace and care” (Fitzgerald, 1998, p. 1). Hubbard (1997) argues that the question “about a humane society’s responsibility to satisfy the requirements of people with special needs and to offer them the opportunity to participate as full-fledged members in the culture” becomes

obscured in these medical discussions (p. 200). The social implication of eradication is a lack of impetus to spend time, effort and money on support and services for people with intellectual disabilities.

This word choice also echoes one of Wolfensberger's (1998) "major common negative social roles into which members of societally devalued groups are apt to be cast" (p. 14), specifically the role of the "sick, ill or diseased organism" (p. 16). He explains what this role means:

People who are the objects of devaluation often get cast into the role of a sick, ill or diseased organism, in which case the devalued characteristic or condition is said to be a "disease" or "illness"... the "disease" is said to require treatment by various forms of "therapy" which are to be given to the "patient" in settings, and by personnel, that either are medical, or at least medically imaged (Wolfensberger, p. 16).

Parallels are easily seen in the context of these textbooks, particularly in discussions of the various professionals who are included in a student's life to help with rehabilitative measures. This will become more evident in my discussion of nodal points, which follows in Chapter 5.

Classification. Andrews and Lupart (2000), Hutchinson (2010) and Winzer (2008) all use the terminology of *classification* and categorization. This brings up issues related to medicalization. Beginning with Linnaeus in the 18th century, scientists moved ahead in their quest to classify the natural world. This idea of classification moved beyond

nature and into the realm of humans, with the effect of establishing “a long historical association” between nature and “the other” (Sibley, 1995, p. 26). “Fitting species and human groups into taxonomic schemes was a major concern of nineteenth century European science” (Sibley, p. 26), with science serving to confirm, not only the “global dominance of white societies” (Sibley, p. 26) but also the inferiority of people with intellectual disabilities (Davis, 1997; McPhail & Freeman, 2005).

My overview of the history of intellectual disability in Chapter 2 is replete with examples of the development and use of various classification systems. Classifying was a way of trying to better understand intellectual disability through a scientific lens. Davis (1997) makes a similar point when he discusses the history of the word “average” and notes its movement from statistics and astronomy to use in the context of human populations and human beings. The examination of intellectual disability through scientific explanation continued into the 19th century, with a new stress on “biology and heredity in human affairs” (Gelb, 1987, p. 248). The impact of this emphasis meant that “concerns that were initially focused on morality” were channelled into “the area of biological fitness” (Gelb, p. 248).

McPhail and Freeman (2005) discuss classification in the context of colonialism and the education of children with disabilities. They argue that during the Enlightenment period, science justified classifying indigenous people as primitive using the civilized/primitive dichotomy. At the same time, “natural and social scientists views on the ‘normal’ development of the child colonized the life-world of children with

different minds and bodies, marking them as ‘abnormal’” (p. 255). The authors go on to suggest that these classifications were made “separate from the sociocultural and historical circumstances of indigenous and disabled people’s lives” (p. 255). These textbooks continue to rely upon these notions of *classification*, carrying the language and its colonizing effects into the present.

The need to classify and categorize has also been critiqued by Jenkins (1998). He calls the labels used to discuss intellectual disability “classificatory categories of Western medicine and psychology, defined according to locally specific criteria” (p. 4). He goes on to suggest that such categories are not “‘natural’ or ‘real’ in any sense” but rather are “very powerful” constructs. As analytical tools, Jenkins argues that these categorizations “are unstable, context-dependent, and likely to be unhelpful” for “comparative analysis” (p. 12).

Carlson (2010) discusses the history of intellectual disability and the implications of its evolution into a “distinct condition worthy of separate consideration” (p. 24). Perhaps the most significant outcomes of the creation of the study of intellectual disability were its medicalization, professionalization and the creation and proliferation of state institutions to house those “afflicted”. As Carlson argues, “for the first time, causes, definitions, descriptions, and treatments of idiocy were being discussed and practiced within an organized structure” (p. 25). Moreover, in the context of education, “schools for the feebleminded created a new space for the study of intellectual disability in its various incarnations” (p. 25). Interestingly, this conceptualization of intellectual

disability continues to be advanced in these textbooks with language such as *classification system, subgroups* and levels of severity.

One of the most well known classification names for intellectual disability is mental retardation. Andrews and Lupart (2000) and Winzer (2008) use the word *retardation* in some form to describe either the disability or the student. Andrews and Lupart (2000) use the term to describe intellectual disability. Winzer (2008) uses the term intellectual disability but often lapses into *mental retardation* throughout her chapter. Although this language is no longer socially acceptable to people with intellectual disabilities, in fairness to Andrews & Lupart, the AAIDD did not change its name or official terminology to intellectual and developmental disabilities until 2007. However, it is disconcerting to continue to read references to mental retardation in 2010. The use of outdated language reinforces Brantlinger's (2006) warnings that professors may not read textbooks carefully before assigning them, or texts may be chosen by default when new professors rely on older syllabi.

Tests. There are references in Andrews and Lupart (2000), Friend and colleagues (1998) and Winzer (2008) to *intelligence tests, low IQ scores* and other *tools, scales* and *measures*. Describing and categorizing students by scores suggests that these children are being compared unfavourably to scores achieved by students falling within a normal or above average ranges. This creation of identity using IQ score reiterates the point made by J. D. Smith and Polloway (2008) that a pen stroke made by a professional can

have an impact on an identity with negative, far-reaching and often irreversible consequences.

It is now clear that, notwithstanding his role in developing the IQ test, Binet's concept of intelligence was as a "pliant structure that could be developed through good health and educational instruction and in a good environment" (Trent, 1994, p. 157). It was not developed "to buttress any theory of intellect" or to "define anything innate or permanent" (Gould, 1981, p. 185). Even more importantly, Gould argues that one of Binet's "cardinal principles" for using this test was that "low scores shall not be used to mark children as innately incapable" (p. 185). Unfortunately, when mental retardation is equated with low IQ scores, pre-service and other educators may be left with the impression that IQ scores play a significant role in creating the identity of these students. As P. Smith (1999) notes, "persons with mental retardation and other developmental disabilities are described using surveying tools such as intelligence quotients and adaptive behaviour measures, reflecting the authorization of statistics and numbers in modern Western culture...serving the needs of some while devaluing others" (p. 124). In addition, the label of having a low or poor IQ score carries with it the assumption that these students are unable to learn or unworthy of being taught.

Distancing. The other important discursive work that these signifiers do is to distance students with significant intellectual disabilities from other students. The best example is the use of the logic of difference in discourse theory (Laclau & Mouffe, 2001) through the terms *noticeable characteristics* and *clear cut signs*, particularly when

contrasted to *typical students*. Everyone, including students, has some type or types of characteristics. However, the characteristics presented in these textbooks about students with significant intellectual disabilities are almost all negative. This construction brings to mind Goffman's (1963) discussion of stigma. He notes the Greek origin of the term as referring to "bodily signs designed to expose something unusual and bad about the moral status of the signifier" (p. 1). Goffman then talks about stigma today and notes that it applies "more to the disgrace itself than to the bodily evidence of it" (pp. 1-2). Noting the social distinction between those who have an "undesired differentness" and those who are "normals" and do not "depart negatively from the particular expectations at issue", Goffman suggests that the person with the stigma is "not quite human" (p. 5). It is this assumption that opens the door to discrimination and a reduction of "life chances" (Goffman, p. 5). I argue that by emphasizing the *noticeable characteristics* of this particular group of students, they are being stigmatized as "other" and clearly separated from students Goffman would call "normals" by the logic of difference.

The word *typical* is synonymous with the term *normal*. These kinds of words are of particular significance in this discourse. Davis (1997) discusses how the term normal has been constructed, noting that "we live in a world of norms... there is probably no area of contemporary life in which some idea of a norm, mean, or average has not been calculated" (p. 9). Although Davis does not discuss intellectual disability in his work, much of what he says about disability generally can be extrapolated to people with intellectual disabilities. He argues that "the concept of the norm, unlike that of an ideal,

implies that the majority of the population must or should somehow be part of the norm” (p. 13). I suggest that reference in this example to typical or normal students excludes students with significant intellectual disabilities by definition. These students fall below the average or normal ranges in their levels of intelligence, ability to learn, unusual behaviours and other noted characteristics.

Not only are students with significant intellectual disabilities described as being of less worth, their shortcomings are characterized by the use of what I call “extreme language”, which acts to position these students as far from the typical student body as possible. Word choices such as *extreme*, *severe*, *exceptionally*, *not developed*, and *profound* indicate the worst of a kind or type and help to convince the reader that these students have been relegated to the distant margins of educational space. In what I consider to be the most damaging use of characterizing language, Winzer (2008) feels it necessary to include these statements: “Among persons who are profoundly retarded, expressive speech and language skills are extremely limited. Mutism is common among these individuals, as are primitive levels of speech such as babbling and jabbering” (p. 190). Use of the words *primitive*, *babbling*, and *jabbering* carry clear connotations of animalistic, non-human or not fully developed human behaviours.

Winzer’s (2008) language invokes two other negative social roles that Wolfensberger (1998) discusses: the role of the “other” (p. 14) and the role of the “subhuman or non-human” (p. 14). The other is someone “so different that one does not know how to classify the person” (Wolfensberger, p. 14). Wolfensberger describes

one of the ways in which the subhuman or non-human role may be used. “Devalued people may be cast into the role of subhuman animals, and be perceived as having primitive, animalistic feelings and behaviours” (pp. 14-15). I argue that this is the effect of Winzer’s language use.

Alternative discourses. There is another, albeit smaller, group of signifiers in this discourse, which describe students with significant intellectual disabilities in a more positive light. Andrews and Lupart (2000) use the words *warm, caring, determined, likeable, and humorous*. In Hutchinson’s (2010) book, this language includes: *range of abilities, acquire academic skills, strengths, loyal, and caring*. These words might constitute a rupture in the otherwise deficit-focused discourse I have already discussed. What concerns me as I read these words in their contexts, however, are the phrases that surround them. In Andrews and Lupart, for example, the text reads, “At the same time, like many other children, they can also be warm, caring, determined, likeable, and humorous” (Andrews & Lupart, p. 172). Similarly, Hutchinson writes of these students, “often they do not know how to make friends, even though they may be loyal and caring” (p. 123). Even Hutchinson’s consideration of the *wide range of abilities* is written in the following manner: “They span a wide range of abilities, from those who can acquire academic skills to those who will require assistance with self-care for their entire lives” (p. 123). The negative portrayal in the latter part of the sentence takes away from the potential discussed at the beginning. This positioning of an alternate view of students with significant intellectual disabilities prompts me to wonder what it is about children with severe disabilities that requires the authors to remind their readers

that these children are, indeed, like children who are not severely disabled. Rather than reinforce their sameness, these phrases actually work to set students with severe disabilities further apart from “normal” learners or learners without “exceptionalities”.

Andrews and Lupart (2000) also mention *sociological perspectives* in their discussion of mental retardation, which brings a different set of signifiers into the discourse. Considering something to be sociological shifts the emphasis from the medicalized terminology I have already discussed. However, this alternative way of viewing mental retardation is not explored further in this part of the text. The discussion returns to the medicalized and scientific terminology in the next paragraph, by stating that “educators use this classification system to distinguish among subgroups of students with mental retardation” (Andrews & Lupart, 2000, p. 126). The brief mention of other perspectives in this section reads as if it were added out of context. Rather than rupturing the hegemony of the discourse, the presentation of the sociological phenomenon reads as an afterthought.

Needs and supports

The next master signifiers that I discuss are needs and supports. Our society expects its citizens to be independent and valuable contributors. Toombs (2004) discusses these “prevailing cultural attitudes” of “health, independence, physical appearance” and the “strong cultural message that we should be able to stand on our own two feet, look after ourselves. Dependence on others is perceived as weakness” (p. 193). This commentary leads to my discussion of the next set of master signifiers.

Students with significant intellectual disabilities are conceptualized as being in need.

They need *care, supervision, interventions, and services*.

Not only do they need to be taken care of, but their needs are characterized as *pervasive, extensive, ongoing, intensive, extraordinary, and considerable*. To be pervasive is to permeate, to saturate, to fill. This leads the reader to draw the conclusion that requirements to be supported fills people up to the extent that they become so saturated with need, they cannot be anyone else and cannot do anything else. Their need comes to define them in their entirety.

A specific discussion of needs, care and dependence has arisen from theorizing within disability studies. This conversation centres on personal care and the phenomenon of the “leaky body” (Devaney, in press), particularly the leaky disabled body. Siebers (2006) calls this the “new realism of the body” and quotes Wade’s (1994) “powerful but not untypical example”:

To put it bluntly -- because this need is as blunt as it gets -- we must have our asses cleaned after we shit and pee. Or we have others' fingers inserted in our rectums to assist shitting. Or we have tubes of plastic inserted inside us to assist peeing or we have re-routed anuses and pissers so we do it all into bags attached to our bodies... (p. 179).

Wade’s words bring to mind Kristeva’s (1982) idea of abjection, or “the in-between, the ambiguous, the composite” (p. 4). Kristeva says that the cause of abjection is “what disturbs identity, system, order. What does not respect borders, positions,

rules” (p. 4). In considering the distancing of those with significant intellectual disabilities from those who identify as “normal”, Sibley (1995) suggests that “the urge to make separations, between clean and dirty, ordered and disordered, ‘us’ and ‘them’, to expel the abject, is encouraged in Western cultures” (p. 8). I argue that whenever we are faced with Kristeva’s rupture of the expected rules, abjection occurs. In the context of these textbooks, we are reminded of the abject whenever we are forced to consider that someone’s *needs* and *dependence* can mean a lifetime of personal care.

Nussbaum (2006) discusses the reality for people who are dependent in her critique of social contract theory. She points out that the theory is premised on the notions of freedom, equality and independence. “The parties to the social contract are imagined as *independent*, that is, individuals who are not...asymmetrically dependent upon any other individuals” (p. 32). People who have needs and must rely on others are often considered to be of less value, and therefore their needs “do not shape the parties’ choice of basic political principles, or even their conception of the primary goods of a human life” (Nussbaum, p. 33).

The preoccupation with independence and negative portrayals of dependence in these textbooks is also in direct contrast to McIntyre’s (1999) re-conceptualization of dependence. In Chapter 2 I discussed McIntyre’s approach and wish to re-emphasize here that we are all dependent on others both for specific purposes and at particular times. Independence is a myth in our society which is used to devalue some members of society and place distance between “us” and “them”.

There are several other aspects of the *needs* master signifier to which I want to draw attention. The first is the suggestion that individuals with significant intellectual disabilities need *close supervision* in *supervised settings*. This language is used in the context of students in their adult life. The word *supervision* invokes the idea that adults with intellectual disabilities who have these needs are regarded as and treated like children who cannot be trusted to be left alone. This is another example of a negative social role that Wolfensberger (1998) discusses: the child role. He says that one form of the child role is the “eternal child who never matures into adult status and competence, and whose behaviours, interests, capabilities, etc., will always remain at a childish level” (p. 16). In this context, although students are children, these students are imagined as remaining child-like throughout their adult lives.

Further to the idea of supervision in adulthood, Andrews and Lupart (2000) indicate that some people with significant intellectual disabilities “may be able to acquire low-level vocational skills and work, under close supervision, in sheltered workshops” (p. 125). Mention of these segregated workshops provides educators with a clear picture of what adult life will be like for their students. If these students are destined to spend their time in this highly restrictive kind of setting where they waste their days doing virtually nothing (Murphy & Rogan, 1995), the duty to educate them is replaced with a duty to care for them. Furthermore, this focus on *care* represents a re-birth of a period of time in the history of people with intellectual disabilities, when the focus of institutional purpose shifted from education to care (Wolfensberger, 1975).

The final element to the *needs* master signifier is the unending nature of what people with significant intellectual disabilities require. In the words of the texts, their needs are *ongoing*, will last their *entire lives*, mean a *lifetime of support* and require *lifelong care*. In his consideration of “chronicity” as “an official judgment that a person is unfixable and beyond help”, Ferguson (2002, pp. 28-29) recalls the terminology describing the individuals so designated over time. He says, “the terms have always varied from disability to disability, from era to era, and from colloquial insults to professional jargon: incurable, incorrigible...unteachable, ineducable...unmanageable, untestable” (p. 29). Ferguson goes on to argue that today these terms may be “gentler and framed around metaphors of dependence and support” but “the status remains” (p. 29).

I argue that when the discourse centres on *needs*, it really means dependence and care, which are always cast in a negative light. The word *needs* also suggests that individuals who require such assistance are outsiders, living on the margins in our society, not really counting as participating members, never having been considered as counting. By virtue of their needs, these people are, as Ferguson (2002) says, “unsalvageable” (p. 29).

Behaviour

The final master signifiers that create the identity of students with significant intellectual disabilities are *behaviour* and *psychological characteristics*. Use of this language in the textbooks may suggest to pre-service and other educators that students

with significant intellectual disabilities tend to have behaviours that society deems to be inappropriate and it is therefore incumbent upon them to teach behaviours that are acceptable. Signifiers which suggest this view include *maladaptive*, *serious*, *bizarre*, *acceptable*, *appropriate*, and *challenging*. However, it is important for readers to recognize that these words are value-based and not neutral terminology. In our society, judgments are continuously made about what is *acceptable* and *appropriate* for whom and where. We also judge which behaviours are *maladaptive* and *bizarre*.

In her work on disabled “bodyspace” in health care, Hansen (2009) considers the colonization of the bodies of people with disabilities. She says,

in the possible belief that the appropriation of certain levels of able-bodiedness can turn people with disabilities into something approaching the norm, normalizing or corrective measures are often presented as a “civilizing” influence ostensibly for the betterment of the individuals toward whom it is directed. Here “civilizing” stands for being able to fit in... (p. 29).

Borrowing from this argument and expanding upon it, I maintain that the language in the Andrews and Lupart (2000), Hutchinson (2010) and Winzer (2008) textbooks is promoting a version of *appropriate* behaviours while denigrating other conduct as inappropriate. This is an effort to colonize and civilize people with significant intellectual disabilities. The need to colonize behaviour, as L. T. Smith (1999) notes, stems from the colonizer’s understanding of “primitive peoples” as being unable to “use our minds or intellects” (p. 25). L. T. Smith’s analysis of the colonization of indigenous

peoples closely parallels the way in which professionals understand and characterize people with significant intellectual disabilities.

We could not invent things, we could not create institutions or history, we could not imagine, we could not produce anything of value, we did not know how to use land and other resources from the natural world, we did not practice the ‘arts’ of civilization. By lacking such virtues we disqualified ourselves, not just from civilization but from humanity itself. In other words we were not “fully human”; some of us were not even considered partially human (p. 25).

I want to conclude this section on behaviours with two quotations from the textbooks, which will highlight how the signifiers are used to colonize behaviour and distance these students from their peers. Winzer (2008) writes:

Maladaptive behaviour is found across the spectrum of the population of intellectual disabilities but is more common in persons who are severely and profoundly retarded... the frequency of maladaptive behaviours is extremely variable. Serious maladaptive behaviour can be divided into three types – aggression toward other people and objects, self-stimulating behaviour, and self-injurious behaviour” (p. 194).

Hutchinson (2010) discusses the characteristics of students with “severe intellectual disabilities” as often including “frustration and impulsivity... often they do not know how to make friends... They may withdraw or develop repetitive behaviours that seem bizarre to their peers” (p. 123). This statement suggests that non-disabled

students would label certain behaviour they see being exhibited as bizarre. It projects the colonizing discourse on students who may not feel the same way and may not have the tools or ability to consider and express their own interpretations (Naraian, 2005).

Creating Identity in Discourse Theory

Discourse theory specifically addresses the creation of individual or group identity through discourse. One way in which to create an identity is to measure the individual or group against what that person or group is not. By emphasizing the general lack of abilities and deficiencies of these students, the discourse shows that children and youth with significant intellectual disabilities are not the same as “typical” students. The group of students that I identify as students with significant intellectual disabilities has come into existence in this textbook discourse as a group that is separated from other children by virtue of their depiction as “other”.

Another way in which identity is created in discourse theory is through the logic of difference and logic of equivalence. The logic of difference operates through the use of signifiers that emphasize this group of students’ perceived lack of abilities. Signifiers such as *lack*, *limited*, *minimal*, *delayed*, *slow* and *low* all designate these students as being separate from students who have the ability to do all of the things that are expected of them in school. The logic of equivalence works in a different way. Although the Andrews and Lupart (2000) text, for example, notes the *heterogeneous condition* of mental retardation, it treats students with significant intellectual disabilities as

fundamentally the same by lumping them together as students who are fundamentally unable and defective.

My analysis of this discourse suggests that the identity of students with significant intellectual disabilities has an element of truth about it. Laclau (1990) refers to this phenomenon as “sedimentation” (p. 34). This term refers to a situation where we forget that there is a contingency or alternative way of thinking about something in the discourse. Sedimentation makes it appear as though the content of the discourse is objectively true. The terms “significant intellectual disability” or “students with significant intellectual disabilities” may have other potential meanings. For example, these students may be seen as deserving of and benefiting from an inclusive education, as having competencies, and as having a promising future. However, these potential meanings have been absorbed by a “hegemonic intervention” (Jørgensen & Phillips, 2002, p. 48), which stabilizes the conceptualization of students with significant intellectual disabilities as undeserving, unable to benefit, a burden to other students, and a problem for teachers to deal with. This hegemony has the effect of overpowering and discounting competing meanings, creating a unified discourse and identity.

I want to close this chapter by quoting from McPhail and Freeman (2005) who discuss children with intellectual disabilities and how they are conceptualized.

Children whose cognitive and social development fall within a range of expectancy for stage and sequence developmental patterns are referred to as “normal” learners, while those children whose sociocognitive patterns deviate

significantly from the “normal” curricular expectations are described as “abnormal,” “exceptional,” or “at-risk” learners. This nomenclature is predominant in classrooms in spite of the combined work of postmodern philosophers, educational theoreticians, and cultural psychologists, who have challenged researchers to rethink and reexamine the foundational assumptions based on dualistic conceptualizations underpinning the “normalizing” theoretical framework of child development” (p. 259).

In addition to setting out a challenge for researchers, I believe the same challenge ought to be set out for educators. Every time they think about and talk about students with significant intellectual disabilities, the words they choose matter. Educators can play a huge role in changing the discourse of deficit and modeling that new discourse to the benefit of students, their families, and other professionals. Educators must care about and pay close attention to language because the words they use deeply and profoundly affect all of their students. No student deserves to be a part of a discourse that focuses on marginalization and devaluation. All students benefit from understanding that differences between people are simply a natural part of who we are as human beings. The words educators use and the discourses they rely upon can mean the difference between a life of isolation and a life of full participation.

In the following chapter, I turn my attention from master signifiers in the textbooks to an exploration of nodal points. This provides an understanding of how the

education of students with significant intellectual disabilities is conceptualized within the discourse.

Chapter 5: Nodal Points: Data and Analysis

“As a teacher, you can expect that some but probably not all students with multiple disabilities will participate in regular education activities in your school” (Friend et al., 1998, p. 114).

“There are three major goals in the education of students with intellectual disabilities: productivity, independence, and participation... Depending on the extent and severity of the disability, the major goals may or may not always be achievable; success may be only fractional for children at the low end of the continuum” (Winzer, 2008, p. 200).

My initial goal in this research was to explore how **students** with significant intellectual disabilities are conceptualized in the introductory special education textbook discourse through an examination of master signifiers. However, I decided that my research would be more textured if I extended my project to investigate how the **education** of these students is understood within the discourse. Using the same textbooks, I present nodal points, together with their signifiers, which I believe create an awareness of the education students with significant intellectual disabilities receive.

Data

Each textbook discusses the education of students with significant intellectual disabilities to some extent. My purpose is to explore several components of this education discourse which I believe raises questions that are central to this research. These questions are: (a) how is teaching understood, (b) who teaches, (c) what are the goals of educating these students, and (e) what does inclusion mean. The nodal points within each issue that arise in the data are set out in Table 10.

Table 10

Nodal Points across Texts

Andrews & Lupart (2000)	Friend, Bursuck & Hutchinson (1998)	Hutchinson (2010)	Winzer (2008)
Educational programs	Instruction	Teaching	Education
Educators	Teachers	Teachers ⁶	Professionals
Implications/Guidelines	Instructional approaches	Goals	Goals
Inclusionary practices	Inclusive programs	Inclusion	Inclusive placements

Tables 11 through 14 set out the nodal points, together with their signifiers, in each textbook.

Table 11

Andrews & Lupart (2000) Nodal Points and Accompanying Signifiers

Educational programs	Educators	Implications/guidelines	Inclusionary practices
Educational intervention	Teacher aides	Social integration	Community schools
Service	Wide variety of professionals	Skill development	
Educational programs	Educators	Function more independently	
	Range of disciplines	Adaptive skills	
		Academic skills	
		Participation	
		Achievement	

⁶ Hutchinson (2010) refers to the reader as “you”, implying the nodal point *teachers*.

	Contribution
	Satisfaction
	Choice-making activities Socially acceptable behaviour Select
	Vocational competencies

Table 12

Friend et al. (1998) Nodal Points and Accompanying Signifiers

Instruction	Teachers	Instructional approaches	Inclusive programs
Educational experience	Special educator	Live independently	Inclusion
Services	Paraprofessionals	Skills/real-life skills	Classroom community
Instruction	Consultant	Succeed/successful	Regular classroom setting
Learning activities	Multi-disciplinary team	Confidence	General school conditions
Appropriate		In context	Adaptations
		Social interactions	Value
		Learning to function	Respect
	Choosing	Some but probably not all	
	Appropriate social skills	Regular education activities	

	Perform job-specific skills	Part of the day
	Expectations	Resource room
		Some core classes

Table 13

Hutchinson (2010) Nodal Points and Accompanying Signifiers

Teaching	Teachers	Goals	Inclusion
Teaching	In-school team	Life skills	Climate
		Independent living	Some degree
		Community living skills	Accommodations
		Functional academic skills	Valued
		Physical development	Fairness
		Personal care	Regular schools
		Communication skills	Enable
		Social interaction skills	Engage
		Career development	
		Work experience	

Table 14

Winzer (2008) Nodal Points and Accompanying Signifiers

Education	Professionals	Goals	Inclusive Placements
Educational intervention	Doctors	Productivity	Current trend
Appropriate educational services	Speech therapists	Independence	General classroom
Training	Social workers	Self-help skills	Separate settings
Services	Psychologists	Community living skills	Problematic
Service delivery models	Personnel	Fractional success	Controversial
	Professionals	Increase awareness	Neighbourhood schools
		Basic communication skills	Placement
		Language acquisition	Conflicting ideologies
		Eliminate undesirable behaviour	Redefine
		Different	Social acceptance
			Social competence
			Social outcomes
			Regular classrooms
			Disappointing
			Marginal position

The next set of tables (15 through 18) illustrates the signifiers across the textbooks.

Table 15

Signifiers for Education and Teaching across Texts

Educational Programs (Andrews & Lupart, 2000)	Instruction (Friend et al., 1998)	Teaching (Hutchinson, 2010)	Education (Winzer, 2008)
Educational interventions Service	Educational experience Services	Teaching	Educational intervention Educational services
Educational programs	Instruction Learning activities Appropriate		Appropriate Training Services Service delivery models

Table 16

Signifiers for Educators across Texts

Educators (Andrews & Lupart, 2000)	Teachers (Friend et al., 1998)	Teachers (Hutchinson, 2010)	Professionals (Winzer, 2008)
Teacher aides	Special educator	In-school team	Professionals
Wide variety of professionals Educators	Paraprofessionals Consultant		Doctors Speech therapists
Range of disciplines	Multi-disciplinary team		Social workers Psychologists Personnel

Table 17

Signifiers for Goals/Guidelines across Texts

Implications/guidelines (Andrews & Lupart, 2000)	Instructional approaches (Friend et al., 1998)	Goals (Hutchinson, 2010)	Goals (Winzer, 2008)
Social integration	Live independently	Life skills	Productivity
Skill development	Skills/real-life skills	Independent living	Independence
Adaptive skills	Succeed/successful	Community living skills	Self-help skills
Academic skills	Confidence	Functional academic skills	Community living skills
Participation	In context	Physical development	Fractional success
Achievement	Social interactions	Personal care	Increase awareness
Contribution	Learning to function	Communication skills	Basic communication skills
Satisfaction	Choosing	Social interaction skills	Language acquisition
Choice-making activities	Appropriate social skills	Career development	Eliminate undesirable behaviour
Select	Perform job-specific skills	Work experience	
Vocational competencies Socially acceptable behaviour Function more independently	Expectations		

Table 18

Signifiers for Inclusion across Texts

Inclusionary practices (Andrews & Lupart, 2000)	Inclusive programs (Friend et al., 1998)	Inclusion (Hutchinson, 2010)	Inclusive placements (Winzer, 2008)
Community schools	Inclusion	Climate	Trends
	Classroom community	Some degree	General/regular classrooms
	Regular classroom setting	Accommodations	Separate settings
	General school conditions	Valued	Problematic
	Adaptations	Fairness	Controversial
	Value	Regular schools	Neighbourhood schools
	Respect	Enable	Placement
	Some but probably not all	Engage	Conflicting ideologies
	Regular education activities		Redefine
	Part of the day		Social acceptance
	Resource room		Social competence
	Some core classes		Social outcomes
			Disappointing
			Marginal position

Analysis

Now that I have identified the nodal points and their signifiers, both within and across texts, I turn my attention to their analysis.

Education and Teaching

In the texts, I first examined the nodal point I call education and teaching. Some of the signifiers used are *educational interventions, services, experiences, instruction, activities, and training*. A common signifier describing this education is the word *appropriate*. I will examine the words *services* and *appropriate* in more depth as they are prominent signifiers within the discourse.

Services. Three of the four textbooks use the word *services* in the context of educating students with significant intellectual disabilities. Non-exceptional students take classes, they may be enrolled in programs, and they engage with subjects. They do not receive services. The use of the word *services* therefore distinguishes the kind of education for students with exceptionalities from the kind of education for students who are considered typical.

Giangreco (2000) discusses the issue of the provision of services for students with low incidence disabilities in schools. He notes the disadvantages of providing “related services”, specifically pointing to the fact that they are often provided in ways that “do not adequately support students with disabilities in general education classes” (p. 231). More importantly, Giangreco notes the irony of such services in educational contexts. “Students are placed in special education schools or classes so they can

receive related services rather than being provided services that support them in less restrictive general education programs and placements” (p. 231). In these textbooks, *services* are considered to be the education provided to students with significant intellectual disabilities. Emphasis on the word *services* separates the language used to discuss the education of students without intellectual disabilities, which connotes academic subjects. The signifier *services* infers something other than traditional curricular pursuits.

Appropriate. I also want to briefly return to the signifier *appropriate*. The *Oxford English Dictionary* defines this adjective as “specially fitted or suitable, proper”. The term has been used in many contexts within these textbooks to modify the word education, in an effort to convey the kind of education students with significant intellectual disabilities ought to be receiving. *Appropriate* also plays a leading role in the language of special education in Manitoba and Canada. Provincially, the regulation providing for educating students with exceptionalities is called the *Appropriate Educational Programming Regulation*, although the term is not defined within the legislation. The Supreme Court of Canada also used *appropriate* to deny an inclusive education to the plaintiff in the *Eaton* case.

Often the argument is made that “regular” educational programs are not *appropriate* for students with significant intellectual disabilities because it is assumed they cannot learn or benefit from such content. Indeed, the Andrews & Lupart (2000) textbook affirms this argument in its index/glossary in defining *appropriate education* as

“a variety of services, including educational, remedial, and rehabilitative measures, that are appropriate to the needs of each student with disabilities” (p. 545). I suggest that it is highly problematic to refer to appropriateness as the kind of education best suited to students with significant intellectual disabilities. Without a common understanding of the term, assumptions about what students can learn and what they can benefit from easily translate into value judgments, rather than sound educational practice.

Educators

The nodal points *teachers, educators, and professionals* open the door to exploring the question of who teaches children with significant intellectual disabilities. The signifiers reveal that those include *special educators, paraprofessionals, teacher aides, a wide variety of professionals from a range of disciplines, consultants, and multi-disciplinary teams*. Some of the professionals are not educators at all but are *doctors, speech therapists, social workers, and psychologists*. I want to raise three issues in the context of who teaches these students: (a) the role of general versus special educators, (b) the role of paraprofessionals, and (c) professionalization.

Special educators. If inclusion means that all students, regardless of labels, are part of a general classroom community, the classroom teacher is responsible for the education of all of the students. Yet the role of the classroom teacher can be seen as being undermined due to the necessity of relying on special educators, who are assumed to have unique knowledge that general educators do not. There is potential for pre-service and other teachers to be convinced that as general educators, they will

simply not know enough to teach students with exceptionalities. Friend et al. (1998) emphasize the importance of special educators when they offer this advice to their readers: “If you are unsure about a student’s needs, rely on the same professional you would use in working with any other students. If you encounter difficulty, you can access the technical support that special education professionals offer” (p. 108). Studies have shown that general educators may feel unprepared to teach students with disabilities (Kosko & Wilkins, 2009). Burge and colleagues (2008) surveyed the public perception of inclusion and students with intellectual disabilities. Almost 70% of respondents indicated that a major obstacle to inclusion was that teachers were not prepared to teach these students. Without meaning to suggest that general educators be unsupported in their work, perhaps pre-service education needs to focus on ensuring that general educators believe themselves to be competent to teach all students who may be in their classrooms.

Paraprofessionals. Textbooks by Andrews and Lupart (2000) and Friend et al. (1998) both mention the role of *teacher aides* and *paraprofessionals* in discussing the education of students with significant intellectual disabilities. Friend et al. suggest that “students with disabilities, especially severe or complex ones, are often accompanied by a paraprofessional, teaching assistant, or personal assistant who might be able to offer insight about responding to the student” (p. 108). However, Giangreco (2003) points out that “little evidence suggests that students do as well or better in school, academically or socially, when they are taught by paraprofessionals” (p. 50). Moreover, he argues that “sometimes relying on paraprofessionals may feel effective because it relieves,

distributes, or shifts responsibility for educating a student with specialized needs, but educators should not confuse this outcome with effectiveness for students” (p. 50). It is teacher engagement with students that increases successful inclusion. When paraprofessional involvement reduces engagement, students and their education suffer (Giangreco).

The question of teacher engagement is compounded by the assumptions of general educators that paraprofessionals have better training to teach students with disabilities. However, this is not necessarily the case.

The literature suggests that many paraprofessionals continue to be undertrained or untrained. In other words, students with disabilities—usually the students with the greatest learning challenges in the classroom—often receive their primary or exclusive instruction and support from the least qualified staff members (Giangreco, 2003, p. 51).

In addition, the reality is that “once paraprofessionals receive virtually any amount of training—at best, usually equivalent to a single college-level course—many teachers feel even more justified in relinquishing instructional responsibilities to them” thereby reducing teacher engagement even further (Giangreco, p. 51). The textbook discourse presumes that paraprofessionals will be a part of the education of students with significant intellectual disabilities, notwithstanding critiques to the contrary.

Professionalization. All textbooks focus on the role and involvement of *multidisciplinary teams* in educating exceptional students. Using an example from a

more rehabilitative perspective, Winzer (2008) says that “these children often require a range of other services from professionals such as doctors, speech therapists, social workers, and psychologists” (p. 202).

Ferguson (2002) discusses the history of people with significant intellectual disabilities and notes the trend in the 18th and 19th centuries toward “the broad distinction between the supposedly salvageable and the unsalvageable” (p. 29). He describes a cyclical process where a “burst of professional optimism” arose in attempting to “cure or dramatically improve” those previously considered to be unsalvageable (p. 29). This process “produced a ‘cult of expertise’ whereby professional specialization and differentiated service systems were more scientifically entrenched and socially legitimized than ever” (p. 29).

The language of professionalization and specialization is reiterated in this textbook discourse, notwithstanding Ferguson’s argument that failures of professionals have tended to be explained by placing the blame on the “severity of the disability” (p. 29). He further warns of the tendency for professionals to “define all problems so as to require professionals for their solution” (p. 37). Careful use of language is a starting point to retreating from professional dominance in educating these students.

Giagreco (2000) also critiques professionalization. Although he notes that “obviously, educational and related services are offered with positive intentions and are meant to help students with disabilities”, he also cautions that “our common professional approaches to ‘helping’ can inadvertently have the opposite effects than

those that were intended” (p. 231). Language which highlights professionalization strengthens education’s traditional reliance on special education professionals in educating students with disabilities. Moreover, terminology that stresses medical and rehabilitative professions ignores the more progressive view that disability is more than a pathological condition in need of treatment.

Goals and Guidelines

The next nodal points for discussion are *goals*, *approaches* and *guidelines*. These points focus on what students with significant intellectual disabilities learn within the foundational principles of a *community-based, functional* curriculum. Three of the four textbooks (Andrews & Lupart, 2000; Friend et al., 1998; Hutchinson, 2010) expressly describe this curriculum. The idea of a functional curriculum for these students is an interesting one because it emphasizes that students with significant intellectual disabilities ought to be taught material that falls outside of the “regular” curriculum taught to other students.

The kind of education envisioned for students with significant intellectual disabilities is described by Hutchinson (2010) as one in which “the goals for a student are based on life skills... and relate what is learned in school to what occurs in the community” (p. 124). Friend et al. (1998) concur when they say that this curriculum is based on “real-life skills” that these students “need to succeed” (p. 110), and is “significantly different from that of other students in your class” (p. 108). This kind of curriculum is contrasted with participation “in regular education activities” (Friend et al.,

p. 114). These two principles lead me to examine what this discourse says about the kind of education students with significant intellectual disabilities are expected to receive.

I have organized the signifiers in the textbooks into five themes: (a) independence, (b) skills, (c) behaviour, (d) success, and (e) choice. I will review each of the signifiers within these themes in turn.

Independence. The idea of gaining at least some independence has historically been a primary goal in educating students with intellectual disabilities, as I have discussed in Chapter 2. One of the key goals for educating students with significant intellectual disabilities within the textbook discourse is to *function more independently, live independently, learn to function, and have independence*. It is instructive to note how this idea of trying to develop these individuals has carried through from some of the earliest educators, such as Seguin in the 19th century, to the present.

The discourse suggests the importance of encouraging students to develop as many skills as possible, and leads the reader to believe skill development will decrease their dependence on others. In the process, this will allow them to be more productive. In fact, Winzer (2008) calls productivity one of three “major goals in the education of students with intellectual disabilities” (p. 200). By way of example, developing vocational competencies is a way to “help them obtain and perform meaningful work” (Andrews & Lupart, 2000, p. 173). Friend et al. (1998) suggest that “because these students are limited in the amount of information they can learn, it is crucial to

emphasize skills that will help them live independently as adults” (p. 110). In focusing on independence, this discourse reinforces the identity of students with significant intellectual disabilities as dependent beings, a topic I have already explored in Chapter 4.

Skills. A survey of the textbooks illustrates that *skills* play a central role in the functional, community-based curriculum. The education of students with significant intellectual disabilities is fully focused on *skill development*, including *adaptive skills*, *functional academic skills*, *real-life skills*, *communication skills*, and *self-help skills*. My examination of the examples used in the texts allows me an effective way to show what these students are expected to learn.

In the context of instructional guidelines, Andrews and Lupart (2000) suggest that teachers “provide choice-making activities for students to help them function more independently” (p. 173). Students are also encouraged to develop their ability to “select recreational and leisure activities” (p. 173). Friend et al. (1998) also note the importance of “choosing appropriate recreational activities” (p. 110). Other examples these authors provide include *practicing buttoning and unbuttoning coats and sweaters*, *making a sandwich*, *learning to wait in line*, *tying shoes*, *punctuality*, *following multiple-step directions*, *choosing between two items during math*, *going to a bank*, *learning about the public library*, *exploring job possibilities*, and *learning how to ride the bus* (pp. 110-111). Punctuality is a theme repeated in Hutchinson (2010) along with *learning how to speak to customers*, and learning banking skills (p. 124). Winzer’s (2008) emphasis is

even more basic, focusing on *language acquisition, self-feeding, ambulation, dressing skills, and toilet training* (p. 202). This language comes across as sounding very professionalized and can be contrasted with words such as “talking”, “eating”, “walking”, and the like. For students who are “severely or profoundly disabled” Winzer says that

learning is possible and individuals can acquire basic living and self-help skills; they may learn to regulate toilet habits, eat with a spoon or fork, throw a ball at a target, understand simple verbal directions, and participate in simple play and games (p. 192).

Teaching children with significant intellectual disabilities how to make choices is a really fascinating example in this discourse as it speaks directly to the expectations educators have of these students in a learning context. Andrews and Lupart (2000) and Friend et al. (1998) suggest that educators ought to teach students how to make choices. Not only is the inability to make choices assumed, the matters about which students ought to be choosing are somewhat perplexing. The examples used demonstrate that there is little evidence in this discourse to indicate that these students are able to make more significant choices and decisions. Moreover, the promotion of simple choices would seem to run contrary to the focus on independence and functionality. It is difficult to learn independence when decision-making is absent and choosing is practiced in such a limited way. A focus on choosing between several items

also reinforces the notion that there are no academic expectations within this curriculum.

The signifiers within this group of nodal points also speak to the issue of competence. Angrosino (1998) argues that “to the average citizen, ‘mental disability’ equals ‘mental incompetence’” (p. 25). The discourse in these textbooks affirms his statement. There is no indication that students with significant intellectual disabilities are capable of learning anything beyond that which the texts envision. There is nothing in the textbooks to suggest that it is worthwhile to teach these students any academic subjects, contrary to recent findings by Browder and colleagues (2006) which I detailed in Chapter 2. This strengthens the notion that students with significant intellectual disabilities are considered to lack competence.

Basic development, skills, and functioning would seem to be the ceiling imposed on the abilities of these students. To me, this is most clearly evidenced in discussions about *community living skills* (Hutchinson, 2010; Winzer, 2008). I am hard-pressed to imagine what these skills might be. The implication is that these students are living somewhere other than a community and need to be taught how to adapt from living elsewhere to living in the community. However, these students likely already live in the community. What other students might we envision as requiring the acquisition of such a skill set? The prescribed need to learn how to live in the community further distances these students from their peers, as it distances adults with intellectual disabilities from other community members.

There is another theme running through the examples of skills: a continued focus on the behaviour of students with significant intellectual disabilities. Andrews and Lupart (2000) suggest that teachers ought to increase “appropriate behaviours” in students with mental retardation (p. 127). Friend et al. (1998) note the importance of keeping one’s voice “appropriately low” and encourage teaching students how to approach “adults and peers without hugging them” (p. 111). Winzer (2008) stresses that “undesirable behaviour” must be eliminated (p. 202). I have already considered behaviour as inexorably linked to the identity of these students. These goals simply reinforce the idea that educators ought to be judging the appropriateness of behaviour and colonizing what is acceptable and unacceptable.

The discourse also encompasses other, more amorphous goals. These include *participation, achievement, contribution, satisfaction, success, confidence, and career development*. They are worthy goals for all students. The issue lies in how this language is conceptualized and implemented by educators. The expectations educators have for students with significant intellectual disabilities play a huge role assessing whether goals such as *success, achievement, satisfaction, and confidence* have been achieved. For example, they may be measured by more limited understandings of what these students are capable of. On the other hand, they may also be measured by ignoring traditional or preconceived notions of what these children are thought to be capable of. Encouraging educators to have high expectations for all students would go a long way to fulfilling the goals above in the widest sense possible. The discourse, however, does not necessarily point educators in that direction.

Looking back to the purposes of educating students offers a way of comparing goals for students generally and goals for students with significant intellectual disabilities. In Canada, some general purposes for educating children include: (a) allowing students to look at the world in new ways, (b) encouraging students to achieve a deeper understanding of themselves and their place in that world (Stewart, 2005), and (c) preparing students to participate in our democratic society (Coulter and Wiens, 2005). At its most basic, education means developing competencies. It is difficult for me to find any connections between these three purposes and the goals for educating for students with significant intellectual disabilities as they have been communicated in these textbooks. I am unconvinced that children with significant intellectual disabilities will have been encouraged and prepared in the ways envisaged by Stewart or Coulter and Wiens. I say this, not because I am convinced they are incapable, but rather because there is such a large gap between how education is conceptualized for *typical* students and how it is understood for students with significant intellectual disabilities in these textbooks.

Inclusion

The education of students with disabilities today is intertwined with the notion of inclusion. For this reason, it is difficult to get a sense of how children with significant intellectual disabilities are conceptualized as students without at least considering how inclusive education is understood within the textbooks. It is to this final nodal point that I now turn.

Wehmeyer (2006) discusses the three generations of inclusive practices that have thus far evolved. He says that in the first generation

inclusion was additive in nature. That is, resources and students were "added" to the general education classroom. The second generation of inclusive practices was more generative in nature, in that instead of focusing on moving students from separate settings to regular classroom settings, the second-generation practices focused on improving practice in the general education classroom (p. 323).

The third generation of inclusive practices

builds on the first two generations of practices. The most salient characteristic of this third generation of inclusive practices is that the focal point for our effort switch from advocacy and supports with regard primarily to "where" a student receives his or her educational program to a focus on "what" the student is taught (p. 323).

Placement in the "regular" classroom is assumed to be a given.

Beyond identification of place (*community schools*), Andrews and Lupart (2000) do not go into any detail about inclusion or inclusive practices in their discussion of students with severe and/or profound mental retardation or students with severe disabilities. An analysis of the language used in the other texts, however, gives a glimpse into how inclusion is understood for students with significant intellectual disabilities.

The textbook signifiers for inclusion certainly focus on the question of “where”. They include the words *community schools*, *regular classroom setting*, *regular schools*, *general classrooms*, *community settings*, and *neighbourhood schools*. Focusing on place is less problematic than focusing on curricular content, although it significantly limits both the meaning and purpose of inclusion in broader contexts. However, these signifiers alone do not tell the whole story. For example, Friend et al. (1998) describe where the education of students with multiple disabilities takes place:

As a teacher, you can expect that some but probably not all students with multiple disabilities will participate in regular education activities in your school...In elementary school, a student with multiple disabilities might attend your class for part of the day and also receive some services in a resource room...In a secondary school, a student with multiple disabilities might attend some core classes with peers and spend part of the school day learning to function in the broader community and to perform job-specific skills (p. 114).

Mention of spending part of the day in a *resource room*, as opposed to general classroom brings to mind the continuum of services I described in Chapter 2. In particular, I point to S. J. Taylor’s (1988, 2001) critique of the continuum and the distasteful idea that we somehow expect people with intellectual disabilities to earn the right to live and participate in the community. By reinforcing the idea that students with significant intellectual disabilities need to spend part of their day away from their school peers, the textbook discourse promotes a continuum of educational services for these

students. This promotion, together with the idea of learning *community living skills* invites pre-service and other educators to believe that the principle of inclusion can only reach so far.

I want to quote extensively from Winzer's (2008) understanding of inclusion because it envisions what I imagine Wehmeyer (2006) might refer to as a pre-inclusive generation.

Within the school system, the current trend is to include students with intellectual disabilities in the general classroom, especially those with mild but also an increasing number of children with moderate and severe intellectual disabilities... The provision of appropriate educational services remains problematic for many secondary-school-aged students with disabilities... Research has not yet provided a compelling body of data on the outcomes of inclusive placements for students with intellectual disabilities... Inclusion assumes that students with disabilities will be better accepted, have more friends, and feel better about themselves. There is little empirical data for this assumption... Often these children occupy a marginal position in the social network of the class (p. 199).

Winzer goes on to write:

While almost all students with mild intellectual disabilities and many with moderate disabilities will be educated in general classrooms, the placement of students who are severely and profoundly disabled is more controversial. For

these youngsters, there are conflicting ideologies that revolve around the issue of inclusive schooling (p. 202).

Based on my reading of literature as summarized in Chapter 2, best practice certainly seems to suggest that students with significant disabilities should not only be included in the general classroom, but also in the general curriculum. Pre-service and other educators would certainly not get that impression from reading this textbook discourse. Students with significant intellectual disabilities are not expected to be in the general classroom all of the time and the most basic philosophy of inclusion itself is challenged.

Discussions about place and space bring to mind the significance of the study of human geography, particularly Sibley's (1995) work on exclusionary geographies. He begins with the premise that "the human landscape can be read as a landscape of exclusion" because "power is expressed in the monopolization of space and the relegation of weaker groups in society to less desirable environments" (p. ix). Sibley's unique perspective focuses on what he calls the "more opaque instances of exclusion" (p. ix). By this he means those practices which fall under the radar or are "taken for granted as part of the routine of daily life" (p. ix). By examining exclusion through this lens, Sibley is able to discuss how such practices conceal the ways in which control are exercised.

Moving back to the context of the language of the texts, shining the spotlight on educational spaces is noteworthy because there is no discussion of where to educate

students considered “normal”. However, it becomes a major issue for those groups who are considered to be, in Sibley’s words “weaker groups”. The “fact” in our society that some students are understood to require at least some parts of their education somewhere other than community schools and classrooms speaks to the taken-for-granted view that students with significant intellectual disabilities are still assumed to rightly occupy excluded spaces.

In her textbook, Hutchinson (2010) writes about setting a “climate of inclusion in which differences are seen as normal, expected, and valued” (p. 125). Although these words affirm inclusive principles, other language in the textbook, which I have already reviewed, ignores this advice by discussing students with significant intellectual disabilities as something other than normal, expected or valued.

I have already looked at the signifiers conceptualizing the functional and community-based curriculum, but I want to revisit these principles in light of this discussion about inclusion. A functional curriculum is vastly different than an academic curriculum. Whereas students with significant intellectual disabilities are thought to benefit from learning the kinds of skills I highlighted earlier, other students are not. The two groups of students, those labelled as having disabilities and those not, participate in very different kinds of learning. Unless students with significant intellectual disabilities take part in the general curriculum, they cannot be included. Similarly, a community-based program means that students in that program will spend at least some of their class time in the community transferring the skills they have learned at school into skills

they will use in everyday life. As with the functional curriculum, this approach separates students with significant intellectual disabilities from other students who learn the general curriculum material in school. What students with significant intellectual disabilities learn (functional curricular material) and where they learn it (separate classes and/or in the community) promote exclusion, rather than inclusion.

Discourse Theory and Educating Students with Significant Intellectual Disabilities

Returning to discourse theory, this analysis has shown that it appears that there are certain truths about the education of students with significant intellectual disabilities, as there was with their identity. However, this part of the discourse has some elements which I consider to be at least somewhat “socially antagonistic” (Jørgensen & Phillips, 2002, p. 47). By this, I mean that there is some collision in the discourse, creating a more divisive meaning and leading away from the appearance of a unified truth.

The different signifiers giving meaning to the nodal point *inclusion* illustrate this point. While the discourse in the Andrews and Lupart (2000), Friend et al. (1998), and Hutchinson (2010) textbooks look favourably upon the idea of inclusion (at least for some students) the Winzer (2008) text does not. Friend et al. write about *adaptations*, *value*, and *respect*. Hutchinson uses words such as *accommodations*, *valued*, *enable* and *engage*. These signifiers point to some positive aspects of inclusion. Winzer, however, focuses on the problematic nature of inclusion. It is called *controversial* and the author writes of *conflicting ideologies* and the *marginal positions* occupied by these students.

Notwithstanding the antagonism in my example, I argue that there is no real “hegemonic intervention” needed to resolve the conflict within these discourses (Jørgensen & Phillips, 2002, p. 48). Across the textbook discourses, students with significant intellectual disabilities are still not conceptualized as being able to be fully included. The hegemonic view of the kind of education these students are entitled to is never really threatened by the inclusion discourse, which still promotes a limited view of both curricular content and physical place.

In Chapter 6, I turn my attention to the implications of this work. I address: (a) how the textbook discourse conceptualizes and creates identity for students with significant intellectual disabilities in light of traditional and more recent philosophical discourses on personhood and humanness; (b) how the discourse on the education envisioned for these students compares with the kind of education Nussbaum (2006) discusses in the capabilities approach; and (c) how the message of inclusion is deciphered in the context of the realities of teaching these students.

Chapter 6: Implications

“Whether or not people with severe disabilities will be treated as human beings or persons is not a matter of their physical or mental condition. It is a matter of definition. We can show them that they are human by proving that we are capable of showing humanity to them” (Bogdan & Taylor, 1998, p. 257).

The purpose of this concluding chapter is to step back and consider this work in the following two contexts. I examine the identity of students with significant intellectual disabilities within the textbook discourse and consider its relationship to discourses of personhood and humanness. Using the tool of immanent critique (Kiel, 1995; Skrtic, 1995b), I also look at the education of these students within the textbook discourse to assess the relationship between what we **say** about inclusion for these students and what we **do** about their inclusion.

The Identity of Students with Significant Intellectual Disability

I spent considerable time in Chapter 2 discussing the idea of personhood and humanness in the context of people with significant intellectual disabilities. I did this because in a number of social and academic discourses, these people have been either impliedly or expressly excluded from membership within the human community. I reiterate the reasons why Carlson and Kittay (2009) believe individuals with cognitive disabilities must be recognized as humans: “It is to humans that we extend the mantles of equality, dignity, justice, responsibility, and moral fellowship” (pp. 307-308). The authors then ask the following question:

Reason, in philosophical accounts, is generally taken to be the ground for human dignity, hence the special accord and moral status we attribute to humans. But people with cognitive disability are individuals who have, at best, a diminished capacity for rational deliberation. Yet they are human. How should we think about these individuals? In what way do they present challenges to some of philosophy's most cherished conceptions of personhood, agency, responsibility, equality, citizenship, the scope of justice, and human connection? (p. 308).

The introductory special education textbook discourse indirectly addresses this question by constructing a particular identity for students with significant intellectual disabilities. These students are conceptualized from a deficit perspective because of the way their differences are interpreted (Vehmas, 2004(b)). Their identities thus become inexorably entwined with their "condition". As a result, the language used to describe a condition becomes the language used to talk about the student. The deficits attributed to these children lie within a framework of intellectual ability and the capacity to learn the curricular elements routinely taught in school. The words of disability and defect used in the textbook discourse are closely tied to the inability to reason. Such language use makes it difficult to easily identify students with significant intellectual disabilities as worthy of the mantles Carlson & Kittay (2009) identify as being extended to humans.

Kittay (1999) addresses the issue of preserving the human identity of her daughter as they interact with medical professionals. I argue that this preservation of human identity is necessary with other professionals as well, including educators.

The physician who remarked that he didn't "really enjoy a really handicapped child who comes in drooling" still has to understand that regardless of the level of impairment, this child, as every other child, is "some mother's child." It is by virtue of the toil and love of some mothering person(s) that this child stands before him. If the physician or other professional is so limited that he cannot see beyond the disabling trait, might he be open to the child's humanity and need through the loving care lavished on this child? (p. 164).

I look at this question in a different light in the context of this work. If a pre-service or current educator could be taught to see beyond the disabling trait, or to see the disabling trait in a different light, might he or she stand alongside a child's family and contribute to promoting the child's humanity to others by fostering it?

After examining Kittay's daughter as a baby, a neurologist's commented: "One rotten apple doesn't spoil the barrel" (pp. 149-150). In writing about her own son Justin, L. Ware (2002) contemplates Kittay's story and asks,

I wondered how much time had to pass before you could hear others use this simple phrase without recoiling? Wondered what power this physician assumed as he erased Sessa's personhood? How much time had to pass before you could name what she taught others about humanity? (p. 147).

My work on textbook discourse shows the dangers of taking Winzer's (2008) stance that labelling and language "carry no negative stereotyping and little stigma" (p. 172). The identity created within this discourse not only stigmatizes students with significant intellectual disabilities, it has the potential to jeopardize their education and rob them of their very humanity, placing their position as equal members of our society at serious risk.

In their research on the social construction of humanness, Bogdan and Taylor (1998) discuss how their participants felt about the use of professional labels.

None of these people use phrases like *profoundly retarded* or *developmentally disabled* to refer to their friend or loved one. Some feel that clinical designations are too impersonal and do not tell much about the character and personality of the person labelled. A few indicate that they believe that clinical labels define the person in terms of deficits rather than positive characteristics, and they prefer not to see their companions from this vantage point. The label can strip the person of his or her unique personality (p. 251).

They then look at the language used by the nondisabled partners to talk about their disabled loved one. "By using a rich repertoire of adjectives and defining the partner in specific personal terms, these nondisabled people maintain the humanness of their severely disabled partners" (p. 251).

Positive language within the textbooks could create more human portrayals of students with significant intellectual disabilities by focusing less on what the children

cannot do and more on the fact that they are children first. What they are unable to do is presented as fact. Yet we just might have to give these students the benefit of the doubt when we really start to think about who they are and what they may be able to accomplish if they were viewed in a new light and if our expectations about them were altered.

Education and Capabilities

Earlier in this work, I discussed theories of social justice and the exclusion of people with significant intellectual disabilities in the formulation of these basic principles. I suggest that the discourses which create the identity of these students and conceptualize their education provide an excellent example their status as “outliers” (Silvers & Francis, 2009, p. 476).

The analysis of the textbook discourse clearly sets out the kind of education envisioned for students with significant intellectual disabilities: a functional curriculum which is community-based. Examples in the texts of the kinds of activities these students might do serve to reinforce fairly low expectations. The textbook discourse is strikingly familiar to Wolfensberger’s (1975) discussion of the historical goals of education for individuals with intellectual disabilities. This education consisted of “the transformation of poorly socialized, perhaps speechless and uncontrolled children into children who could stand and walk normally, have some speech, eat in an orderly manner, and engage in some kind of meaningful work” (Wolfensberger, p. 25).

These students are clearly presented as being unable to either take part or actively reciprocate and contribute as members of society. This presentation is accomplished through (a) the creation of their identity as deficient, as well as through (b) the conceptualization of their education, which does not prepare these students to participate as social contract theory envisions. The assumptions arising out of the textbook discourse reinforce the idea that social justice does not apply to people with significant intellectual disabilities as they are not able to meet their basic contractual obligations. This outcome serves to highlight Nussbaum's point that contract theory was never meant to consider those people who fall outside the boundaries of the "normal".

The textbook discourse can be contrasted with the idea of education in Nussbaum's (2006) capabilities approach. Her thinking begins with the concept of the "dignity of the human being" (Nussbaum, p. 74) and is reinforced by the understanding that capabilities are basic to social justice and, as such, are the entitlement of "all citizens" (p. 74).

Learning falls within Nussbaum's (2006) fourth capability: senses, imagination and thought. She says that people should be able to use the senses, to imagine, think, and reason – and to do these things in a "truly human" way, a way informed and cultivated by an adequate education, including, but by no means limited to, literacy and basic mathematical and scientific training. Being able to use imagination and thought in connection with

experiencing and producing works and events of one's own choice, religious, literary, musical, and so forth (p. 76).

This quote details some of the ways in which educators can re-imagine what it means to learn and to take part in knowledge acquisition. Nussbaum's conceptualization of education is not bound by the strict parameters of either the general curriculum or the functional curriculum.

Two authors describe new ways of thinking about people with intellectual disabilities and their ability to learn. Bérubé (2009) has a son named Jamie, who is the subject of some of his writing. Although Jamie's intellectual disability would not be considered to be significant, Bérubé's remarks speak to the narrow expectations of what people with intellectual disabilities are capable of learning. Responding to claims by Singer (1994) that people with Down syndrome cannot be expected to "play the guitar, to develop an appreciation of science fiction, to learn a foreign language, to chat with us about the latest Woody Allen movie, or to be a respectable athlete, basketballer or tennis player" (p. 213), Bérubé responds:

...when Jamie was only three, I might have been persuaded by this; I once believed and wrote that Jamie would not be able to distinguish early Beatles from late Beatles or John's songs from Paul's, and now he knows more about the Beatles' oeuvre than most people who don't study the Beatles for a living... His interest in *Star Wars* and *Galaxy Quest* has given him an appreciation of science fiction, just as his fascination with Harry Potter has led him to ask questions

about innocence and guilt. He is learning a foreign language... Lastly, I confess that neither of us has the least interest in chatting about the latest Woody Allen movie; but it might interest Singer to learn that Jamie and I have had a running conversation over the past five years about the film *Babe*, which introduced Jamie not only to the question of whether it is right to eat animals but also to the fact that there are various theories out there as to why humans eat some animals and not others (p. 353).

Kittay's (1999, 2005, 2009) daughter, Shesha, does have a significant intellectual disability. Notwithstanding this label, Kittay (2009) describes her daughter in terms that would be unrecognizable in the textbook discourse.

She is enormously responsive, forming deep personal relationships with her family and her long-standing caregivers and friendly relations with her therapists and teachers, more distant relatives, and our friends. I have written quite a bit about her love of music, especially but not exclusively classical symphonic music, with the master of this form, Beethoven, being on the top of her list. So much for the assertion that persons with severe mental retardation cannot experience aesthetic pleasures! (p. 616).

If pre-service and other teachers "know" students with significant intellectual disabilities only through the material in these texts, they cannot be expected to imagine the value in exposing these children to learning opportunities in the broadest sense of the word. Narrow ways of thinking utterly fail these students and makes it difficult, if

not impossible, to realize the educational goals for all students: equality, participation and citizenship.

Inclusion and Immanent Critique

Immanent critique is “the critical evaluation of practical norms and social practices internal to some society or culture, together with the conviction that this requires assessing the rationality or worth of those conventional norms and practices” (Sabia, 2010, p. 685). Kiel (1995) traces the origins of immanent critique to Hegel as his method of “critically revealing the disjuncture between appearance and reality” thereby exposing “how the claims of humans do not correspond to their life conditions” (p. 139). This allows people to think about the disconnection between the values and principles they say they believe in, and the actual way in which these values and principles are practiced. In educational contexts, Kiel (1995) and Skrtic (1995b) both use this technique to evaluate special education practices. I will use immanent critique as the basis to discuss the implications of the textbook discourse on inclusion.

Currently, there is an international statement from the United Nations Education, Scientific and Cultural Organization (UNESCO) (1994) which reaffirms the “commitment to Education for All, recognizing the necessity and urgency of providing education for children, youth and adults with special educational needs within the regular education system” (viii). The United States and the United Kingdom have laws promoting inclusion. Canada has several national laws and policies promoting human rights and providing protection from discrimination on the basis of disability. Provinces

have educational laws and policies that are premised on inclusive education. However, in reality, there is a disjuncture between these statements, laws and policies and actual educational practices.

As the textbook discourse clearly shows, inclusion is often discussed as a place. Students with significant intellectual disabilities may be included more broadly in a community school or more narrowly in a general education class. There seems to be less discord within the broader understanding of inclusion. However, when it comes to promoting inclusion for students with significant intellectual disabilities in general or regular classrooms on a full-time basis, particularly at the high school level, the textbook discourse is less certain. There was even less discussion within this discourse about whether or how to include students in the general curriculum.

My analysis of inclusion in the textbook discourse is in keeping with the work of P. Smith (2007, 2010) and G. L. Porter (2008), which I discussed in Chapter 2. This work also brings to mind the comment made by B. Simmons and Bayliss (2007) that “inclusive education may only go so far” (p. 19). Pre-service and other educators may draw the conclusion that inclusion is not meant to apply to all students, putting the education and equality of these individuals in jeopardy.

The rhetoric of inclusion operates on the level of principles and ideals, as a right for all. However, in practice, the discourse centres on separate classes, functional curricula and part-time inclusion. It is important that pre-service and current educators are taught to use tools like discourse analysis, immanent critique and other critical

methods to see where and how values depart from practice. This textbook discourse shows that inclusion may be an important value, but only for some students in some circumstances. Giangreco (1997) rightly points out the obvious: “‘inclusion for some’ is a contradiction in terms” (p. 194).

Educators must somehow make attempts to reconcile theory and practice. If inclusion, as defined by place, curricular content or both, is a worthwhile goal, time and effort must be spent finding ways to fully implement it for all students, no matter how daunting that may seem at first. Inclusion, by definition, brings together, rather than separates. Therefore the language of inclusive education must do the work of including and not defeat it.

The community-based, functional curriculum promotes exclusion by its very nature, unless such a curriculum is adopted for all students. Students with significant intellectual disabilities simply cannot be in the general classroom and be in the community at the same time. In her work on Harry, a young student with significant disabilities, Naraian (2008) describes his education.

The special education teacher’s strong concern for Harry to develop functional skills would necessarily draw him further and further away from his peers as he traveled between classrooms to collect recyclable cans or watered the plants in the building. Such a restrictive conception of functionality not only obscured the importance of embedding Harry in a community, it forced educators to conjure

up futuristic scenarios for him that were at best unsupported or at worst stereotypical (D. L. Ferguson, 1987) (p. 116).

If students with significant intellectual disabilities would be better served learning the general curriculum, as adapted or modified, they should learn it in same place as their peers. In terms of curricular content, if students with significant disabilities are excluded because there is an assumption that they cannot learn the general material, or that the material is inapplicable to them, talk of inclusion is simply empty rhetoric. I refer again to Naraian's (2008) work with Harry.

Aligning individual student goals with educational outcomes for all students has received increasing attention in the literature in the last decade... Neither Ms. Hilton [his teacher] nor the special education teacher appeared to be familiar with these developments. Consequently, Harry's participation was itself prescribed by the limited kinds of activities designed for, and expected of, him (p. 116).

If these students are worthy of curricular inclusion, it should not matter whether the benefit to them is readily apparent to educators. It should be understood that as students, they will benefit. Surely not all students benefit equally from physics, geometry or literary criticism. But all students who are cognitively able learn this material. I believe the words of Arnold (1974) are relevant to this discussion.

Some of you may possibly remember a phrase of mine which has been the object of a good deal of comment, an observation to the effect that in our culture, the

aim being *to know ourselves and the world*, we have, as the means to this end, *to know the best which has been thought and said in the world* (p. 56).

This kind of education is what Nussbaum's (2006) capabilities approach envisions.

Perhaps it is worth challenging educators to rationalize why this ought not to be the case for students with significant intellectual disabilities.

One of the ways to begin the process of reconciliation is to change the language we use to conceptualize students with significant intellectual disabilities. We cannot argue that they belong while creating an identity of difference and deficit. In order to truly believe that these students will benefit from an inclusive education, we must see them as human beings deserving of human dignity and all that such dignity implies. This change involves some significant alterations to how society views humanness and personhood and their relationship to rationality, self-awareness, dependence, and need.

In the alternative, if educators do not believe that inclusion is possible for students with significant intellectual disabilities, there is little to be gained from its promotion. As I read Winzer (2008), I tried to come to grips with the idea that inclusion is controversial and involves conflicting ideologies. Then I began to think of the other textbooks. The authors seem to encourage inclusion, but the reader is left with no doubt that inclusion does not mean inclusion for all. Does the language supporting inclusion in the other textbooks benefit students with significant intellectual disabilities when inclusion does not actually apply to them? Perhaps Winzer's approach is simply clearer in its presentation of how inclusion works in practice. If the consensus emerges

that inclusion as a place or as curricular content is not feasible for these students, perhaps other language is required to articulate why this conclusion has been reached. Is it because students with significant intellectual disabilities will not benefit from learning? Is it because they will never be smart enough? Is it because educators cannot envision a benefit? Is it because educators simply do not know what inclusion actually means and how it might be implemented? Such clarity would at least provide a basis upon which to consider the issues or to justify the practices.

Further Research

This work has some limitations that I wish to address. This work considers a very small percentage of students who are entangled in the process of special education. They represent only a tiny proportion of students labelled as having an intellectual disability. This work also presents a discourse of four textbooks. Within these texts, mention of students with significant intellectual disabilities is sparse. In addition, textbooks are but one discourse circulating about people with significant intellectual disabilities. There are many others, in addition to the philosophical and family discourses I have reviewed. The analysis of identity creation can also be tackled from other methodological perspectives, although I have used only discourse theory here. I have also considered this topic in a Canadian context, which is the one I am most familiar with. The identity and inclusion of students with exceptionalities are international issues.

Notwithstanding these limitations, this work has potential to be a springboard to further research. For example, I have become interested in the creation of identity for other marginalized students. This interest has led me to wonder whether there are other students for whom inclusion is only illusory. It would also be fruitful to explore other discourses, beyond textbooks, to find out how people with significant intellectual disabilities are understood. Discourses of families, educators, support providers, friends, social workers, doctors, courts, the empirical literature, media, and policy would add considerable depth to the textbook discourse.

A Personal Conclusion

This work has been a long personal journey, which did not begin with the writing of this dissertation and will not end when it is finished. However, throughout the process, I have been continually drawn to the idea of the power of language, what we can do with our words, and what a tremendous impact words can have. We do not simply use words to communicate. We use words to create meaning, build our identities, structure our lives, and construct our societies. Words create boundaries which include some and exclude others. Words allow some to dominate and keep others oppressed. The key to language is that its influence is not always recognized. Labelling students is not a benign process. It creates their identity. It can condemn them to a life lacking in value and dignity. It can profoundly alter their lives. Language always matters and its power can never be underestimated.

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**Appendix 1 – Introductory Special Education Textbooks Used in Education Faculties in
Manitoba⁷**

Andrews, J. & Lupart, J. (2000). *The inclusive classroom: Educating exceptional children* (2nd ed.). Scarborough, ON: Nelson Thomson Learning.

Friend, M., Bursuck, W., & Hutchinson, N. (1998). *Including exceptional students: A practical guide for classroom teachers* (Canadian ed.). Scarborough, ON: Allyn & Bacon.

Hutchinson, Nancy L. (2010). *Inclusion of exceptional learners in Canadian schools: A practical handbook for teachers* (2nd ed.) Toronto, ON: Pearson Education.

Jordan, A. (2007). *Introduction to inclusive education*. Mississauga, ON: John Wiley and Sons Canada Ltd.

Peterson, J. M. & Hittie, M. M. (2003). *Inclusive teaching: Creating effective schools for all learners*. Boston, MA: Pearson Education.

Smith, T., Polloway, E. A., Patton, J. R., Dowdy, C. A., Heath, N., McIntyre, L. J., & Francis, G. C. (2006). *Teaching Students with special needs in inclusive settings* (3rd Canadian ed.). Toronto, ON: Pearson

Winzer, Margret (2008). *Children with exceptionalities in Canadian classrooms* (8th ed.). Toronto, ON: Pearson Education Canada

⁷ In Manitoba, all students in the Bachelor of Education program must take an introductory course in inclusive special education. One of the following textbooks would be used by students taking that course. All education graduates have the same level of training in inclusive special education. Educators also have an opportunity to take a post-baccalaureate certificate in education. This is considered to be a form of professional development. One set of courses offered focuses on inclusive special education. Introductory courses at this level may use of the textbooks identified below. All of these textbooks are available at the University of Manitoba library for any person who wishes to read or consult them.

Appendix 2 – Introductory Special Education Textbooks Used in this Research

Textbook 1:

Andrews, J. & Lupart, J. (2000). *The inclusive classroom: Educating exceptional children* (2nd ed.). Scarborough, ON: Nelson Thomson Learning.

Textbook 2:

Friend, M., Bursuck, W., & Hutchinson, N. (1998). *Including exceptional students: A practical guide for classroom teachers* (Canadian ed.). Scarborough, ON: Allyn & Bacon.

Textbook 3:

Hutchinson, Nancy L. (2010). *Inclusion of exceptional learners in Canadian schools: A practical handbook for teachers* (2nd ed.) Toronto, ON: Pearson Education.

Textbook 4:

Winzer, Margret (2008). *Children with exceptionalities in Canadian classrooms* (8th ed.). Toronto, ON: Pearson Education Canada