

**Exploring Health and Social Service Navigational Barriers  
Experienced by Children with Intellectual Disabilities: A discourse  
analysis.**

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## **Preface**

Anna Don received approval from the University of Ottawa Research Ethics Board to conduct this study. Further, Anna Don was granted permission by the Special Olympics Ontario, and the Developmental Service Centre agency to distribute the invitation letter of this study within these agencies. I, Anna Don, developed the research proposal, reviewed the literature, conducted the methods of data collection and analysis, interpreted these findings within a discussion, and wrote this thesis under the supervision of my supervisor, Dr. Patrick O'Byrne.

## Abstract

Children with intellectual disabilities (ID) experience a higher prevalence of dental disease, obesity, challenging behaviours, and mental health disorders compared to children without ID; and health and social service navigational barriers associated with unresolved health needs. The research literature has identified the types and implications of service navigational barriers experienced by children with ID and their carers<sup>1</sup>, and the demographics of people vulnerable to them; however, the literature has not identified how ID is currently understood within social policy and by carers of children with ID. Using a Foucauldian discourse analysis, I explored how ID is understood and the subsequent materializations on service navigation trajectories for children with ID. I collected four governmental agency documents and conducted six interviews with eight carers of children with ID, between the ages of six to 14, residing in a rural Ontario area. I interpreted the dataset themes using Powers' framework. I found three major findings: (1) ID is understood as an impaired identity, an experience of disabling barriers, and heterarchical difference; (2) children with ID participate in a standardized assessment-diagnostic-treatment process; (3) the hegemony of service providers to make decisions for children with ID contributes to tensions with carers, and unresolved needs of children with ID. Nurses should enhance collaboration with children with ID and their carers to deliver client-centred care.

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<sup>1</sup> A carer is a term used within disability literature and legislation, primarily in the UK and Australia, to refer to a person who provides ongoing care (general, intimate, and/or emotional) within a care relationship to a member of their family or household who has an "disability,... is older,... has a mental illness,... or an ongoing medical condition". A carer is not a "person providing care under a contract of service... employment,... doing voluntary work,... or as part of ... education or training" 1. The Parliament of Victoria. Carers Recognition Act 2012. Victoria, Australia.2012.P3-4. 2. Strategy and Projects Team, Care and Transformation, Community Care. Carers Action Plan 2018-2020 - Supporting carers today In: Department of Health and Social Care, editor. London: GOV.UK; June 2018. Carers Canada defined carers similarly to the above definitions and notes that carers also refer to caregivers

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# Chapter 1

## Introduction

The United Nations (3) human rights treaty, the “Convention on the Rights of Persons with Disabilities”, states that persons with disabilities have the right to receive comprehensive healthcare equal to person without disabilities, and deserve specialized services related to their unique needs (Article 25, p18). According to the World Health Organization (4), however, health services are often fragmented and inadequate to respond to and provide care for children with intellectual disabilities (ID). Researchers of extant literature have found that navigational barriers to health and social services for children with ID contribute to this problem, and have highlighted this as an area requiring research to achieve the objectives of the “Convention on the Human Rights of Persons with Disabilities” (5-8).

To facilitate a review of the health inequities and service barriers affecting children with ID, I used a Foucauldian discourse analysis approach. Discourse is defined as the knowledge and truth within a society that structures reality and meaning and influences behaviour (9). A Foucauldian discourse analysis examines how a group or issue has come to be understood by examining the discourses that form them and how power is exercised through them (10). A tenet of discourse analysis of social policy is that the perceptions of an identifiable group influence the policies that affect the members of such groups (11). Accordingly, I focused this study to understand the discourses surrounding ID, and to explore how these affect and are influenced by social context and navigation trajectories of health and social services. Thus, in this thesis, I aimed to understand the tacit rational behind how people with ID are viewed, socially prioritized and treated, and the systems of service distribution. Children with ID were the focus in a deliberate effort to improve health promotion and illness prevention measures for this vulnerable group.

As a guide, in Chapter 1 I present the research problem and corresponding research questions, followed by the epistemic position and the paradigmatic lens that structured the study. In Chapter 2 I present a literature review of the historical perception and treatment of persons with ID, current literature outlining service navigation for children with ID, and a critique of the literature to identify knowledge gaps and justification for the thesis. In Chapter 3 I present the theoretical framework incorporating the work of Deleuze and Guattari (rhizome); Foucault (power/knowledge, discourse, and biopower), and the construct of citizenship by critical disability theorists (the construction of citizenship). In Chapter 4 I detail the methodology used to conduct the research, including the criteria of rigour that were followed. I present my thesis findings in Chapter 5, followed by discussion in Chapter 6, and my conclusions in Chapter 7.

### **Research Problem**

The social perception of ID and the subsequent treatment of persons with ID in society has changed throughout history (12). For example, ID has been believed to be a punishment from God, and a person with ID has been considered as being without a mind, being trainable or untrainable, curable or incurable, an idiot, a moron, an imbecile, and/or retarded (12). Consequently, people with ID have been previously institutionalized and removed from society, used as court jesters, put in “freak shows”, sterilized and euthanized, and provided only custodial care and minimal education (12). These persons, effectively, have been marginalized.

In Ontario, beginning in the 1970s, people with ID began returning to the community to live and receive health and social services through the general public health system (10). This occurred due to deinstitutionalization, with the last institutions in Ontario closing in 2009 (13). In the literature, this shift to integrated services for persons with ID corresponded with the needs of children with ID being unmet due to service navigation barriers (5, 7, 8). Children with ID have been identified in various studies as experiencing more health problems, compared to children without ID (7, 14-20). Shooshtari et al. (21), for example, found in Manitoba that children with

developmental disabilities (the umbrella term for cognitive and physical disabilities, which includes ID) were more likely to have respiratory illness, diabetes, and be hospitalized for injuries, and were also “eight times more likely to die before the age of 17” (p598), compared to children without developmental disabilities.

According to Tonge, children with ID are five times more likely than children without ID to experience mental health disorders, such as attention deficit hyperactivity disorder, depression, anxiety, and autism (18)(p94). Although not classified within the DSM-V as a mental health disorder, challenging behaviours are often presented as mental health disorders in research about ID (20). Aggression, destruction, disruption, and harm to self and others are the most common of these challenging behaviours for persons with ID (14, 17). Whitaker and Read (20) reported that, in most of the prevalence studies about mental health disorders among persons with ID that also classified challenging behaviours as a mental health disorder, challenging behaviours accounted for greater than 50% of the identified mental health disorders experienced by persons with ID.

An alternate view to a diagnostic-centric approach is that challenging behaviours are a form of communication (22, 23). In studies by Baker, Valenzuela, and Wieseler (24) and Martin (22), the function of *coprophagia* and *scatolia* in persons with ID was explored. In the first of these studies, Baker et al. (23) assessed if a lack of food diversity contributed to participants' challenging behaviours. Where Baker et al. (23) determined that such relationship possibly existed, they introduced spicy foods and found complete cessation of the challenging behaviour at six months following the intervention; notably, this outcome continued to the end of the study at two years. In Martin's (20) study, similar results emerged: they found that the frequency of *scatolia* incidents decreased from 25 per month pre-intervention, to four per month three months post-intervention. These findings – and subsequent recommendations by the World Health Organization (4) – thus suggest that assessment of the function or antecedent of challenging behaviour, followed by behavioural support planning, may decrease the occurrence of these behaviours.

Irrespective of the proposed etiology of challenging behaviour, the issue in the current literature with such indiscriminate categorization is that it confounds prevalence findings, as specific behaviours and/or diagnoses are included inconsistently. Whether included or not, however, challenging behaviours negatively affect the physical, social, mental health, quality of life, and familial outcomes of people with ID, and thus warrant consideration (17, 25).

Another health issue is that children with ID have a higher prevalence of dental disease, missing teeth, and inaccessibility to dental services compared to children without ID (7, 16). In a study of Special Olympic athletes with ID at the New York City Metro Tournament, Fernandez et al. (26) found that children with ID, aged 6 to 19 years, had a higher prevalence of dental decay and untreated cavities compared to national data of children without ID.

Children with ID have also been found to experience higher rates of obesity than children without ID. De, Small, and Baur (15) found that, in Australia, 40% of children with ID, aged 2 to 18, were overweight or obese, compared to 23% of matched aged general population. In a study of Special athletes with ID in the United States, Foley et al. (27) found a higher prevalence of obesity among participants aged 12 to 19, with ID, compared to national data of the general population; they did not, however, identify any significant difference in obesity prevalence between children with ID, ages of 8 to 11, and the general population. The apparent correlation between increasing age and prevalence of obesity informed the recommendation for early health promotional initiatives to prevent over weight and obesity in this population (27).

Researchers have consistently found in the literature that, compared to children without ID, those with ID are more likely both to experience health issues and to face challenges accessing health and social services (6, 27-29). From a growing body of literature, researchers have identified considerable navigational barriers in these systems, which may prevent the aforementioned health vulnerabilities of children with ID from being addressed (5, 29-31).

Freeman and Rodriguez (32) defined patient navigation as a strategy of “movement of an individual patient through an often complex healthcare continuum” (p3541). Navigation can be

related to access (33), which has been defined as a concrete or absolute attainment of, or participation in, activities or processes that benefit participants (34). A distinction should be made between access to services and the process of navigation, which may not result in attainment of sought-after services (34). Nind and Seale (34) articulated the divide between ideal service access for people with ID and their lived experiences of access. The emergent theme of “experienced access” described fragmented, discontinuous, and inequitable services requiring gatekeeper admission; participants also expressed feelings of powerlessness, and stories of successful attainment were illustrated as irregular breakthroughs.

Navigation thus describes the *process* of access, and the point of conflict experienced when striving to gain entry to services, rather than the product of the concept of access, which is related to service attainment (34). Examples of navigational barriers specific to children with ID within the current health and social service systems have been identified as disjointed service silos, challenges obtaining required medical diagnoses, extensive waitlists, complex eligibility criteria, cumbersome eligibility forms, lack of information, and gaps in health promotion and illness prevention campaigns applicable and accessible for this population (5, 29-31).

### **Socio-Political Context of Developmental Service Navigational Barriers**

At the commencement of this study, the Legislative Assembly of Ontario’s Select Committee on Developmental Services had just released their final report and recommendations following the compilation of feedback they received from Ontario governmental agencies, stakeholders, families, and people with ID (35). This committee assembled to “... to develop a comprehensive developmental services strategy to address the needs of children, youth, and adults in Ontario with an intellectual disability or who are dually diagnosed with an intellectual disability and a mental illness, and to coordinate the delivery of developmental programs and services across many provincial ministries...” (35)(p2).

The Ombudsman of Ontario had also released a case update on the report “Between a Rock and a Hard Place” detailing the “persist[ent]” issue of parents being wrongly advised that their children with ID could not access “care unless they surrendered them to the custody of children’s aids societies” (36)(“Between a Rock”, para 1).

The provincial Liberal government announced three important financial budgets specific to developmental services: \$810 million between 2014-2017 toward developmental services for all ages and across sectors (37), \$533 million for autism funding in 2016 (38), and a pre-election budget for 2018-2022 of 1.8 billion for developmental services for adults with ID (39). At the time of completion of this study in 2019, the Conservative party was the elected provincial leader. The Minister of the newly amalgamated Ministry of Children, Community and Social Services announced a change to the Ontario autism program and a budget of \$300 million that was met with protests and ultimately was increased to an estimated \$600 million, including the addition of occupational, physio, and speech therapies to be provincially funded for children with autism (40). Concurrently, social media groups of parents, allies, and persons with disabilities and the Ontario Disability Coalition responded to the autism funding allocation with letter writing campaigns and media releases that identified a “disability divide” caused by government funding that “discriminat[es] between disabilities” (41). These advocacy groups called for the governmental agency to support all children with disabilities by “fund[ing] the need not the label” in a “person-centred” service system (42).

Over the past decade, researchers have repetitively identified within the literature health inequities to which children with ID are vulnerable, furthered by the mounting issue of navigational barriers (4). Current research has indicated service barriers for this population and identified those who are *most* vulnerable to experience such barriers (28, 43, 44). In this study, I examined the functions, assumptions, and justifications of service system trajectories for children with ID to gain understanding of the persistent barriers present within these service systems.

## **Nursing Connection**

In 1978, Ontario institutions for people with ID began to close and persons with ID began accessing primarily mainstream and some specialized health care services from nurses and other health and social service providers. The last Ontario institutions for people with ID closed in 2009 (13). The Canadian Nursing Association (CNA)(45) directs nursing education to “incorporate new developments in society”(p9) so that nurses can be prepared with the knowledge and skills to provide competent, patient-centred care. The CNA (45) requires practicing nurses to engage in “life-long learning” to respond to emerging patient needs within their practice settings (p12). From the dearth of Canadian and US nursing research about providing care to people with ID, nurse researchers have identified, however, that nursing students receive inadequate, if any, education, training, or clinical exposure regarding people with ID (46-48). In Breau, Aston, and MacLeod’s study (49), practicing nurses also reported that their hospital work settings did not provide education to support nurses to provide respondent and holistic care for children with ID and their families. Temple and Mordoch (46) found that nursing students, lacking adequate education about people with ID, often understood people with ID according to a medical model which may appoint service providers as experts to prioritize impairment focused, rather than patient-centred, care. Further, Aston et al. (50) found that pediatric nurses often differentiated, and thus stigmatized, children with ID as “not the same” as the general pediatric patient population (p232). Breau et al. (47) noted that education is associated with health care providers’ attitudes and that “attitudes may affect the provision of care to people with ID” (p3). It is important to thus explore how children with ID are understood within service contexts and how these understandings may affect how care is prioritized and how service providers and users interact.

## **Research Objectives**

1. To explore contemporary understandings of ID by carers of children with ID and governmental agencies.
2. To explore the current social discourses about ID.

3. To explore how power is exercised within service user-provider relationships to inform nursing practice.

### **Research Questions**

1. How is ID currently understood by carers of children with ID and governmental agencies?
2. What are the social discourses surrounding how children with ID are understood?
3. What are the materializations of how children with ID are currently understood?
4. (a) How is power exercised within service-user and service-provider relationships?  
(b) How can nursing practice be informed from understanding how power is exercised within service user-provider relationships?

### **Ontology and Epistemology**

How researchers understand how knowledge is developed represents their epistemic perspective, whether by objectively considering knowledge development to be independent of internal and external influences and separate from the researcher-research participant dyad, or by perceiving it as subjectively constructed and influenced by the social, political, historical, economic, etc. world where researchers and participants interact to co-produce data (51). This epistemology relates to the researcher's ontological perspective regarding what truths exist, whether from a realist perspective positing (i.e., that there is only one truth awaiting discovery), or a relativist perspective (i.e., believing in multiple relative and variable truths) (52). The views and beliefs of truth and what is considered knowledge of epistemologies and ontologies are articulated within paradigms. A paradigm encompasses a unified worldview or belief system about specific ways of doing and knowing within a discipline (51). The postulates of the critical theory paradigm articulated through a poststructuralist approach situate my ontological and epistemic stance guiding the methodological approach and measures of rigour of this thesis.

#### **Ontological perspective: Truth from an antifoundational lens.**

*“The little human organism, which begins with no sense of a distinction between itself and the world, gets separated off from its surroundings and is obliged to formulate its demands in terms of the differences already available in language, however alienating these might be... the real is that organic being outside signification, which we can't know, because it has no signifiers in the world of names the subject inhabits” (53)(p58)*

Saussure (53, 54) theorized that underneath the signifier, or what the word or discourse represents, there is a thing, i.e., the signified, that is devoid of meaning outside of its context (53). The options for language, understanding, and social currency in a culture do not emanate from a pre-existing, universal, objective origin of truth, but are the product of the contributions of history, society, culture, politics, etc. (53-55). This position is one of anti-foundationalism and critical of logocentrism, where meaning is presumed to precede the language used to articulate it (53, 54). The paradigm of poststructuralism articulates this position, rejecting the merit or possibility of determining concrete structure, truth, and absolutes (56). The outcome of this process is the production of one of an infinite number of possible interpretations (57-60). Determining rigour from this view of constructive truth involves demonstrated thoroughness in interpretation, reflexivity, and internal coherence of the thesis (57, 58, 60-63). The rigour of this study can be evaluated by the clarity of linkages made between the theoretical framework, methodological decisions, and the data. I included excerpts of quotes of different voices to provide transparency to my study interpretations and the included data and allow for the audience to appraise my interpretations and draw their own. Further, I exercised reflexivity through declaring my speaking position and recognizing that we all stand within a discourse that contributes to how we produce our research (59). My position as a white, middle class, coupled, parent of a child with ID is acknowledged as contributing to this research (61, 64). I further detail the criteria of rigour employed in this study in Chapter 4.

### **Epistemology.**

The objective of critical theory is to expose power imbalances which create “hegemonic subjects” and simultaneously create marginalized groups (65). Applying a poststructural view, new knowledge is acquired by exploring, exposing, and deconstructing the foundational reasoning that provides the root of hegemonies and binary oppositions, referred to by Deleuze and Guattari (66) as arborescent schema. Thus, the formation of truth, objects, subjects, and social *status quo*

operations, which appear illogical to question, would be explored (67). This poststructural approach of critical theory continually deconstructs settled truths of normal and the contexts that have been used to determine who and what is outside the limits of perceived normality. The objective of this deconstruction is to destabilize the understanding of difference as an abnormality, and instead reposition difference as infinite, undefinable, and unanchored by any reference point of truth. This provides a location for radical change in that the value of being normal is shed and an opportunity to disrupt marginalization possible (38, 41, 43). Through the analysis of social discourses, researchers can appreciate 'what can be said' and how subjects 'can be understood' (68). Through new knowledge, space and place for resistance is created (51, 54, 69, 70).

Knowledge is therefore contextually constructed, value laden, and subjective, reflective of the researcher's position (70-72). Foucault believed analysis begins with finitude, where we analyze from within the limits of the time we inhabit (72). The researcher cannot be outside current social understanding to analyze a problem because the researcher works within that order to be able to speak about specific topics that have become visible in that order (72). The researcher may only question, in a nuanced way, how this order has come to be and what social practices arise from it. Interpretations made from this type of inquiry are, therefore, subjective, open and welcoming of incurring interpretations of them. No "speaker's benefit" of pronouncing greater truth over other interpretations is granted to the researcher (72). I do not present my findings of this study as generalizable truths about the study issue but are considered to be one of many possible constructed interpretations (59). I intend that my findings of this study will provide a position from which to disrupt, critique, and engage nuanced discussion regarding the study issue (60).

This epistemic position therefore promotes disruption and illumination of factors that contribute to service navigational challenges experienced by children with ID. Findings are considered one of infinite potential interpretations of the problem and are intended to provoke debate, discussion, and reflection.

## Chapter 2

### Literature Review

In this chapter, I present an overview of how intellectual disability (ID) is understood and a review of the current literature examining how children with ID navigate multiple service systems. First, ID is broadly contextualized through a presentation of epidemiologic data of ID and a summary of how ID has been defined and theorized. Second, I review literature about the process of children with ID accessing services and synthesize it according to the themes that emerged: (1) identification of primary care and service navigation barriers; (2) implications of service navigational barriers for children with ID and their families, and (3) demographics of the children with ID who are most vulnerable to experiencing service navigation barriers. I then evaluate my findings of the literature review to identify what is currently known about how children with ID navigate multiple services and critiqued to identify knowledge gaps to direct this study. The literature review includes articles published between 2000 and 2018 in which researchers have examined how children with ID navigate health and social service systems. The publication date of 2000 was selected because around that time deinstitutionalization initiatives (i.e., the transfer of the residency and care of persons with ID from institutions to the community) were creating systematic changes, which means that information before 2000 might not apply to the current research.

#### **Epidemiology**

The prevalence of ID is estimated to be 1% globally (73-75). Maulika et al. (74) conducted a meta-analysis that found the prevalence of ID was higher in low-income countries, such as Bangladesh and Ethiopia (1.64%), and in lower-middle income countries, such as China, India, and Pakistan (1.59%) than in high-income countries, such as Canada, European countries, and the United States (0.92%). Prevalence studies of ID have been critiqued overall for methodological variabilities that create limitations for comparing and corroborating findings in meta-analyzes (74,

75). In 2016, McKenzie et al. (75) conducted a systematic review to extend the 2011 prevalence findings of the meta-analysis conducted by Maulika et al. (74). McKenzie et al. (75) identified that the studies included in this meta-analysis had varied diagnostic data sources as well as definitions of ID, age ranges, and unclear time trends that represented limitations to determining a global prevalence of ID. Maulika et al. (74) and McKenzie et al. (75) found that studies using household sampling frequently identified persons with ID using psychological assessment and IQ scales that potentially inflated prevalence findings of ID. Alternatively, researchers that conducted studies using administrative data (recordkeeping by educational, health, and social services, of individuals receiving services (76)) frequently identified persons with ID according to standardized diagnostic systems of adaptive skills and functioning and differing case definitions, which may have under represented prevalence findings of ID (74, 75).

The Statistics Canada, 2017 Canadian Survey on Disability indicated that 1.1% of Canadians 15 years of age or older had a developmental disability (77). Although this survey is the largest data source about disabilities in Canada, a limitation is that the prevalence of ID in this survey is unclear; that is, ID is included under the broader title of developmental disability, potentially conflating these terms. Researchers of the survey identified respondents with a developmental disability by asking if they had been told by a medical professional that they had a developmental disability, including “Down syndrome, autism, Asperger syndrome, mental impairment due to lack of oxygen at birth, etc.” (78)(p61). Further, researchers included in the survey participants residing in private dwellings but not residents of collective dwellings, including group homes, temporary lodgings, long-term care homes, hospitals, and correction centres (78). The survey results may thus under represent the actual Canadian prevalence of developmental disabilities because of the survey’s limitations regarding place of dwelling. Indeed, the Ontario Legislative Assembly’s Select Committee on Developmental Services reported that persons with developmental disabilities are negatively impacted by housing issues: long-term care placement prior to being over 65, lengthy hospitalization awaiting residential placements, incarceration, and

homelessness (35). Further, the Canada Survey on Disability showed that persons with disabilities residing in private dwellings were more likely to live in poverty than those without disabilities (77). Persons with disabilities may thus be considered to have housing instability.

The prevalence of ID within Canada has been determined by individual studies of provincial and county data (76). In these studies, researchers have found the prevalence of ID ranges between 0.23% and 1.1% depending on location, age of inclusion, and the definition of ID used (76). Within Ontario, Ouellette-Kuntz and Paquette (79) found the prevalence of people of all ages with ID to be 0.8% to 0.9% in Lanark County, and Bradley and Thompson (80) found a prevalence of 0.72% of adolescents with ID in the Niagara region. Ouellette-Kuntz et al. (76) critiqued the representativeness of the aforementioned Canadian studies, asserting that the findings of these studies were based on administrative data that may have under represented the prevalence of ID because these data rely on (1) “the care-seeking behaviour of the individuals themselves or in the case of individuals with ID, their families or support network members” (76)(p77) and (2) inaccurate or inconsistent use of diagnostic categories across service agencies.

Indeed, Maulika et al. (74) frequently found that school administrative prevalence data of ID was lowered by children with mild ID being identified as having a learning disorder. Balogh et al. (81) also found that persons with ID are “not consistently identified in administrative databases” (p823) as having ID. McKenzie et al. (75) noted that “only when the quantity and quality of services are high will administrative prevalence likely approach the true prevalence” (p112). Although each service region provides a unique service offering to a specific clientele, services for persons with ID globally have been reported as insufficient and ill-suited to meet this population’s needs (7, 82). As such, the accuracy of administrative prevalence of ID data should be interpreted through assessment of the quantity and capacity of services provided. To explain further, Der-Chung et al (83) suggested that administrative data from agencies that have a high capacity to provide services would also have broader eligibility criteria that would in turn allow for more children to be identified with ID and thus captured within administrative data. Der-Chung et al (83) claimed that

agencies with less service capacity have lower administrative data because of narrowed eligibility criteria that disqualifies more children who are not accounted for.

## **Definitions of Intellectual Disability**

### **Historical Glimpse.**

Until the mid-19th century, persons with mental illness and ID were not differentiated from each other (84). John Locke was the first to theorize that a difference existed between the “lunatic”, who was temporarily unable to reason because of illness, and the “idiot”, who would never be able to reason (85). The result was that the “lunatic” was considered curable and the “idiot” was not (86). In North America, in the late-19th century, persons with ID, then labelled “feeble-minded”, began to be institutionalized separately from persons with mental illness (12). In 1876, the first Ontario institution for persons with ID was constructed in Orillia and named “Hospital for Idiots and Imbeciles”; it was soon after renamed the “Hospital for the Feeble-minded” (13).

Historically, persons with ID have been classified and ordered according to their degree of intellectual impairment, and then assigned to standardized educational, residential, and vocational placements according to what has been called their *diagnosed level of severity of impairment*. Notably, this term denotes a person’s degree of impairment. According to the Ontario Ministry of Community and Social Services (MCSS)(13), in the late 19th and early 20th centuries, people with ID were referred to as “morons”, “imbeciles”, or “idiots” according to increasing level of disability. In 1952, the DSM-1 termed persons with ID as “mentally deficient” and classified the severity of deficiency according to IQ scores: mild (IQ 70 - 85), moderate (IQ 50 - 69), severe (IQ <50), and unspecified when unable to assess IQ (87). In 1968, the DSM-2 used the term “mental retardation” to label persons with ID, and added two categories: “borderline mental retardation” (IQ 68-85) and “profound mental retardation” (IQ <20) (88). In 1980, the DSM-3 designated “mental retardation” as an intellectual mental disorder, with five subtypes determined by IQ: mild, moderate, severe, profound, and unspecified. A mild subtype meant a person was “educable”

academically, while a moderate subtype was equated with a person being “trainable” in vocations and requiring moderate supervision and sheltered workshops (89)(p39). The MCSS noted that custodial care was associated with severe and profound subtypes of ID (13). In 1994, the DSM-4 determined the severity of ID impairment according to specifiers of IQ ranges, which were equated with mild, moderate, severe, profound, and severity unspecified (90).

A professor, photographer, reporter, and lawyer conducted independent reports and exposés revealing the deplorable conditions within the custodial care of institutions occurred simultaneously to the changing diagnostic constructions of ID, contributing to the eventual closure of institutions (see Blatt & Kaplan, Rivera, and Williston (91-93)). The last Ontario institution for persons with ID was closed in 2009 (13).

#### **Current definitions of intellectual disability.**

In 2013, within the DSM-5, the American Psychiatric Association (APA) (94) replaced the term “mental retardation” with “intellectual disability” and categorized it as a neurodevelopmental disorder, which comprises a group of developmental disorders that impair “personal, social, academic, or occupational functioning”, and which includes ID, communication disorders, autism spectrum disorder, and ADHD (94). The American Association on Intellectual and Developmental Disabilities (AAIDD) (95) defined developmental disabilities as “severe chronic disabilities that can be cognitive or physical or both” (para 4). The APA specifically defined ID within the DSM-5 as “a disorder with onset during the development period that includes both intellectual and adaptive functioning deficits in conceptual, practical, and social domains” (94)(p30). As per the DSM-5, three criteria are required to establish a diagnosis of ID: (a) intellectual deficit determined by clinical and IQ testing ( $IQ \leq 75$ ); (b) deficits in one or more domains of adaptive functioning; and (c) onset of said deficits in the developmental period (94). The DSM-5 was revised to determine the level of severity of ID impairment according to specifiers (mild, moderate, severe, profound) of impairment within the conceptual, social, and practical domains of adaptive

functioning (94, 96). The APA revised the DSM-5 classification of severity according to adaptive functioning because this measure is believed to better inform the services a person requires (94, 96). Of interest is the consistency between these two approaches to specifying the severity of ID, in that both connote an understanding and reflection of a person that is standardized and which predicts a person's abilities and required interventions.

***Diagnostic criterion A: Intellectual functioning.***

Intellectual functioning pertains to degree of intelligence in understanding, reasoning, learning, problem solving, and/or judgement (94, 97). The AAIDD (95) defined intellectual functioning as one's ability to experientially learn, interpret and respond to one's environment in an effective way to be able to participate in society (98). A person is considered to have an intellectual functioning deficit if their intellectual functioning is below the population mean, as determined by "clinical assessment and individualized, standardized intelligence testing" (94).

***Diagnostic criterion B: Adaptive functioning.***

Adaptive functioning concerns a person's skills and ability to be independent and responsible compared to the general population in the sociocultural context in which they live. The categories of skills and abilities assessed in this diagnostic criterion are social, practical, and conceptual. In the DSM-5, the APA (94) equates the conceptual domain with academics, related to scholastic skill development in areas including literacy, problem solving, and mathematics. The social domain of adaptive functioning examines a person's interactions, including appraisal of situations, effectiveness of communication, and relationship development with others. The practical domain refers to a person's ability to perform "activities of daily living (e.g., personal-care)" and instrumental activities of daily living (e.g., managing personal finances, employment) (98)(p44). A deficit of adaptive functioning is defined as "failure to meet developmental and sociocultural standards for independence and social responsibility" in one or more of the adaptive

functioning domains, requiring a person to receive ongoing supports determined according to their degree of adaptive functioning deficit (94)(p33) and related to an intellectual impairment (94).

***Diagnostic criterion C: Age of onset.***

In the DSM-5, the APA (94) states that intellectual and adaptive impairments present during the developmental period of childhood and adolescence. The AAIDD specifies that ID begins before age 18 (98).

**Identification of Intellectual Disability**

Because population screening has not been found to improve health outcomes but has been found to produce false-positive results, the Canadian Task Force on Preventive Health Care (99) recommends against population screening for developmental delays in children under age five who are asymptomatic and whose parents have no developmental concerns. That is, the Task Force is concerned about over-diagnosis, and the associated harms of creating anxiety for parents, labelling the child, and using specialists, funding, and early intervention services resources that children with signs of developmental delay require (99).

The Task Force (99) does, however, recommend continual developmental surveillance of all children, assessing for risk factors and parental concern for developmental delay. At the time of completion of this thesis, Ontario's Special Needs Strategy was developing an Early Years Check-In tool as part of a developmental surveillance initiative to facilitate parent-clinician discussions related to child development and concerns (100). Case finding through individualized assessment for developmental delay is recommended for children with known risk factors for developmental delay (preterm birth, low birth weight), parental concern, and/or signs of delay (99). Positive case findings require referral to a "trained clinician" (94) whose scope of practice permits assessment of intellectual and adaptive functioning and confirmation of a diagnosis (98).

### **Assessment and diagnosis.**

The assessment and diagnosis of ID most often occurs after age five. A formalized diagnosis of ID is delayed until interventions can be implemented and evaluated for their outcome in the functioning of the child (94). According to the APA, prior to age five, children with suspected ID would be assessed and diagnosed as having a global developmental delay, and are reassessed when assessment of severity and standardized testing becomes possible (94). The APA suggested in the DSM-5 that children over age five are better able to participate in intellectual assessments and standardized testing, which is supposed to improve the accuracy and reliability of an ID diagnosis (94).

Assessment and diagnosis of ID is completed through testing and the gathering of supportive documentation to evaluate the three criteria of ID. Assessment of intellectual and adaptive functioning is completed through standardized testing, ideally in a naturalistic setting (94, 98). The testing scores identify a child's level of intellectual and adaptive functioning compared to the mean score of the same aged population (94, 98). Intellectual and/or adaptive functioning scores of "two or more standard deviations below the mean" (94)(Diagnostic section, para 2), with a margin of measurement error of five constitute a diagnosis of impaired functioning in that area (94, 98). Persons with longstanding knowledge of the child being evaluated may contribute information and/or documents to the assessment of adaptive functioning, particularly when assessment of an individual's adaptive functioning is not possible (94, 98). The clinician appraises the collected data (test scores, informant input, health status, the person's environment) to evaluate a person's adaptive functioning and identify if impairment exists and its severity (94, 98).

The AAIDD and the APA diverge on their positions related to the purpose of assessment for diagnosis. The AAIDD reported the purpose of diagnosing ID is "establishing the presence of a disability in an individual and confirming an individual's eligibility for services, benefits, and legal protections" (98). The AAIDD proposed in the DSM-5 that the purpose of assessment for planning and developing supports uses alternative measures and tools, which produce person-centred

planning and interventions that support the goals, needs, and optimal functioning of the person with ID (98). The APA stated in the DSM-5 that assessment of intellectual function and diagnosis of ID identifies individual strengths and needs and informs “academic and vocational planning” and “level of support required” (94). Herein lies the divergence of approaches: the assessment procedures for the purpose of diagnosis and eligibility are incongruent with the assessment purpose to achieve individualized support planning and development according to the framework for assessment detailed by AAIDD (98). The aforementioned perspectives of interpreting and decision-making based on differing data suggest the importance of evaluating what information is gained from differing assessment procedures and the extent to which standardized data can inform individualized interventions. To explain, it may be fruitful to explore service delivery to children with ID by examining the meaning of diagnostic labels and how individual needs are determined.

### **Theories of Intellectual Disability**

The medical model predominantly informed society’s understanding and treatment of people with ID until the late 1970s. It viewed a person with ID as deviant from able-bodied society and as a problem to be fixed and transformed into a normal citizen through assessment, diagnosis, and intervention (101).

The theory of normalization was introduced by Wolfensberger in 1972 (102) to counter the outcomes of the medical model that created the separation of persons with ID from society through different treatment and segregated living. Wolfensberger’s aim of normalization was to improve society’s perception of people with ID and their life by including them in community living, work, education, and resources comparable to the rest of society (103). Yates and Dyson (103) criticized normalization for requiring persons with ID to assimilate through exhibiting normalized ways of living in society that were accepted and valued, and which required persons with ID to reform aspects of themselves that were different. In this way, within his theory of normalization,

Wolfensberger did not resist the medicalized concept of ID but rather he promoted the normalization of persons with ID.

The social model can be argued to have originated from the theories of normalization and community living that followed deinstitutionalization. Today, the social model is supported by key disability authors (Oliver (104), Hahn (105), Finkelstein (106)) as an empowering model through which to view disability and develop healthcare and service delivery initiatives (107-109). The social model can be used to draw a distinction between impairment and disability (110). Impairment is identified as the incomplete or ineffective physicality and/or functioning of a body part (111). Societies that value certain abilities and are designed to fit these abilities and needs create a hegemony of valued citizens who are accommodated, while also creating a class of citizens who are disabled because their abilities and needs are not accommodated (105, 107, 112, 113). The barriers and hindrances of uncaring attitudes as well as physical and operational designs are considered to be the source of the disabling process (104). Therefore, the objective is to resolve the disabling practices of society through advocacy for full inclusion and participation of people with impairments within society and the workforce (104-106, 113). Disability is considered outside of the person and nonexistent when society compensates for all abilities (105, 106). The social model has been used by researchers and advocates to propose that the removal of social barriers to participation in employment and society removes the sequelae of disability, equalizing citizenship and opportunities for all (113). Thomas (113) critiqued the social model's concept of disability for its lack of applicability to those who may never be employed or independent because of the severity of their impairment (s). The social model has been promoted by many authors who have physical disabilities that are not experienced in the same way as ID (105).

Theorists' and researchers' use of the social model has also been critiqued for constructing impairment as a naturalized, pre-discursive product of nature through "biological foundationalism... that is unquestioned and unproblematized" (111)(p632). Corker (111) proposed

that use of the social model can inadvertently reinforce medical professionals' hegemony through the naive adoption of the term "impairment" (as distinct from "disability") as a value free, objective definition that conceals the historically and politically produced diagnoses and identities that are uniquely managed within the system (114). Tremain (114) further challenged the premise that users of the social model contest the hegemonic outcomes of the medical model, arguing that "truth discourses that purport to describe phenomena contribute to the construction of their objects" (p187) by constructing hierarchical categories of certain diagnoses that correspond to access to specific treatments.

### **Hierarchy of Social Perceptions and Service Allotment between Sub-diagnoses**

The social phenomena of commodification and "splitting" of disability have been associated with compounding navigational and service access barriers for people with ID (65, 115). I will define these concepts before explaining their relationships to ID. Marx defined commodification as the transformation of something/someone being perceived and valued as having inherent worth to that something/someone being understood and valued as a commodity and currency to exchange for goods or services (116). Freud defined splitting as the separations and splits between groups which in this thesis could be between disability sub-diagnoses (65).

In relation to service navigation and access challenges for children with ID, Mallett and Runswick-Cole (115) linked the "commodity fetishism" of autism with disproportionate research, funding, services, and resources. Tasse and Burnhill (96) reported that the working group on developmental disorders for the DSM-5 was disproportionately made up of professionals focussed on autism. Goodley et al. (116) believed the splitting of autism from other neuro-developmental disorders imbues a favourable value for children with autism that creates hierarchies within developmental disabilities. Autism is now socially perceived as an understood and accepted thing that professionals desire to engage with and study. The commodification fetish

created of autism distinguishes through splitting, less recognized diagnoses of disabilities as the “other” which are less understood and accepted and receive fewer resources (65, 113, 115).

### **Health and Social Service Navigation for Children with Intellectual Disability**

I conducted a search of the CINAHL, OvidMedline, and Pub Med databases utilizing the MeSH search terms “developmental disabilities” OR “mental retardation” OR “intellectual disability” OR “learning disability”, “North America”, “community health services” OR “accessibility of health services” OR “referral and consultation” OR “continuity of patient care” , AND “gatekeepers” OR “health service” OR “navigat\*”. From this search, I identified 18 studies relevant to health and social service navigation for children with ID in Canada and the United States from the 228 overall search results. The primary focus of the researchers of these studies was the identification of barriers related to service navigation experienced or perceived by parents of children with either ID or other developmental disabilities in comparison groups. A detailed description of the literature review search strategy and prisma flow diagram are located in Appendix A.

Within this section, I first state the included literature’s limitations. I then present the findings of the reviewed research studies according to what is known about the issue of primary care and service navigational barriers for people with ID, the implications of these barriers on children with ID and their families, and who is most vulnerable to these barriers.

#### **Limitations of current knowledge.**

Similar to the reviewed literature regarding ID epidemiology, in studies on service navigation barriers, researchers frequently categorized children with ID under the broad category of developmental disability, making it difficult to appreciate the unique results of parents of children with ID.

The majority of included studies were conducted in the United States, with few from Canada. Researchers of US studies found that children with ID and their carers experienced challenges with poverty and health insurance that related to the US health service delivery model.

A greater representation of Canadian studies is needed to understand the challenges experienced by children with ID and their carers within the context of a Canadian health service delivery model.

The primary limitation of these aggregated findings is that many of the identified studies do not move beyond description and compilation of barriers, and those identified as most vulnerable to them. There is thus a lack of focus on the antecedent of navigational barriers and how they function. This limitation reveals a gap in the literature and an area for researchers to explore how persons with ID are understood and how this influences service trajectories, and subsequent barriers which have been previously identified but not addressed. For example, there was an implied shared assumption by researchers that parents understood the social value of diagnoses, expectations, and prognoses of different developmental disabilities similarly and comparatively. This assumption, and subsequent study findings, may have reinforced a biased hierarchy of need within developmental disabilities. The perception of government service mandates and/or of primary care providers and service agents were not included within these studies which also left a gap in understanding service navigational challenges from the perspectives of stakeholders that direct the system and deliver the services.

Furthermore, the majority of the researchers' study findings were informed by caregivers' perceptions of their children's need for services and of the adequacy, quality, and barriers of services systems. How parents' understanding of their children's ID influenced their expectations and perceptions of service navigation was unclear however. Researchers of five of the quantitative studies (43, 117-120) used data from the National Survey of Children with Special Health Care Needs (NSCSHCN) that analyzed caregivers' perceptions to determine the needs of children with special health care needs and the adequacy of service systems for them. Baker et al. (121) and Bogenschutz et al. (122) also examined caregivers' perceptions of their children's service needs and of overall barriers within service systems. It was also not clear if the perspectives of caregivers and primary care providers were aligned regarding what services the

children needed. The operating assumption of the researchers of these studies was that caregivers' perception of their children's needs should inform service system improvements.

Alternatively, Betz et al. (30), Doig et al. (31), Liptak et al. (123), and Schleien et al. (124) examined caregivers' perception of barriers to navigating services and the quality and adequacy of services that their children were eligible to receive. Despite agreement between primary care providers and/or service providers and caregivers that the children needed the services, the caregivers identified a lack of service availability and qualified providers. An important limitation of the studies included within this literature review is a gap in understanding if there are common differences between what caregivers perceive their children need and what primary care providers and/or service providers determine is required. Further, it is unclear if there is congruency between the needs that primary care providers or other professionals identify and refer children with ID for service for and the eligibility of service agencies and their capacity to deliver the services.

The researchers of the qualitative studies focused on understanding the perspective of parents/caregivers which provided insight into the experienced barriers, but failed to pursue lines of inquiry regarding how power within these contexts might reveal hegemonic systemic operations. A limitation of the quantitative studies, in which researchers compared experienced barriers and diagnoses (28, 43, 117, 123), was the implied shared operating assumption of the researchers that the available services for compared diagnoses were equivalent and therefore the experiences comparable as well.

### **Barriers within primary care.**

#### ***The medical home.***

In the literature review, I identified studies that indicated that securing a medical home was an important precursor to service navigation and access. A medical home is a concept defined by the American Academy of Pediatrics and the College of Family Physicians of Canada

as accessible, comprehensive, continuous, coordinated, and family centred primary care provided by a continuous primary care provider, working within a team-based approach (125, 126). Indeed, securing a medical home was found to positively influence access to other health and social services and effective care, and mitigate some of the unique challenges experienced by children with ID and their families (21, 118). McGrath et al. found that for children with Down syndrome, a medical home was paramount to receiving genetic counselling services (118), and reduced barriers to services, family support and healthcare service needs, and family financial and employment strain (127).

Researchers in various studies found barriers in access to primary care provider services to be an important and statistically significant issue for persons with developmental disabilities (30, 81, 119, 123, 128). Compared to the overall sample within the NSCSHCN, US children with developmental disabilities were found to obtain a medical home less often. McGrath et al. (118) found that only 30% of a subgroup of children with special healthcare needs, including children with ID, autism, and Down syndrome, had access to a medical home compared to 50% of the overall group of children with special healthcare needs who had a medical home. Phelps et al. (119) similarly found that children with Down syndrome and ID were less likely to receive “comprehensive care within a medical home” (p216) compared to the overall population of children with special health-care needs.

Within Canada, contrasting findings related to access to continuous primary care were found for persons with ID. Balogh et al. (81) conducted a secondary analysis of administrative data from Manitoba to compare hospitalization rates for ambulatory care sensitive conditions<sup>2</sup> between people with ID and those without, across the lifespan. Ambulatory care sensitive conditions are indicators of “access to appropriate primary care” (8)(p182). Balogh et al. (81)

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<sup>2</sup> An ambulatory care sensitive condition is defined by Canadian Institute of Health Information (2018) as “conditions where appropriate ambulatory care may prevent or reduce the need for admission to hospital”. E.g. epileptic convulsions, COPD, asthma, diabetes. <http://indicatorlibrary.cihi.ca/display/HSPIL/Ambulatory+Care+Sensitive+Conditions>

found that people with ID, under age 75, were hospitalized more often for ambulatory care sensitive conditions than people without ID. Other literature supports this finding. Walsh et al. (129) found people with ID in North America more likely to be out-patients and in-patients of hospitals than people without ID. Balogh et al. (8) found that people with ID in Ontario were three times more likely to be admitted for ambulatory care sensitive conditions than people without ID. Specific to the age group of concern for this study, children with ID ages 0 to 9, and 10 to 19 were hospitalized more often than their non-ID counterparts (81). People with ID who resided rurally, moreover, were hospitalized for ambulatory care sensitive conditions more often than those with ID residing within urban centres; however, the rate ratio between people with ID and those without was greater for those from urban residences (81). Epilepsy, schizophrenia, and constipation were identified as ambulatory care sensitive conditions with which people with ID were hospitalized 54, 15, and 8 times more often than people without ID respectively (81). Balogh et al. (81) concluded that these findings indicated a need for improved access to primary care for people with ID, specific to health promotion and appropriate screening. A limitation of this study is that higher prevalence of certain conditions experienced by people with ID were not considered. Furthermore, comparisons of ambulatory care sensitive conditions between those with ID and those without were calculated from a population aged 11 to 74, thus making it impossible to distinguish priority ambulatory care sensitive conditions with correlating age groups.

In a more recent study, Shooshtari et al. (21) found that Manitoban children with developmental disabilities had more ambulatory physician visits not directly related to developmental disability, more injury-related hospitalizations, and higher rates of continuity of care with the same primary care provider than children without developmental disabilities in the matched comparison group. The contrast between the recommendations by Balogh et al. (81) for greater access to primary care and for a medical home for children with special healthcare needs, and Shooshtari et al. (21) findings about greater continuity of healthcare evokes questions related to the effectiveness of consistent and accessible primary care in reducing hospitalizations for

ambulatory care sensitive conditions. A limitation of the study by Shooshtari et al. (21) was that the definition of developmental disability was broad, with no distinction between sub-diagnoses. Further research is needed to explore quality and effectiveness indicators regarding hospitalizations for ambulatory care sensitive conditions to evaluate the impact of a medical home, particularly considering children with developmental disabilities have been found to be 8 times more likely to die before age 17 than children without developmental disabilities (21).

***Parents' perception of quality and competency of primary care providers.***

Two components of the medical home are (1) trust within the family and medical home primary care provider relationship, and (2) the primary care providers' comprehensive, knowledgeable care to meet patient needs (126). In this literature review, I found studies that showed a breakdown in primary care providers' communication with parents/families of children with ID. Pogge et al. (130) reviewed an archival sample of children admitted into a New York State psychiatric unit for behaviour problems who underwent an intellectual assessment to identify ID. Of the total in-patient sample (n=23,629), 2621 children had psychological and IQ testing completed as in-patients (130). Pogge et al. (130) compared the presence of an admission diagnosis of ID and a discharge diagnosis of ID in the charts of children who had undergone intellectual assessment and where the assessment documentation and results were present in the chart. The findings showed that 16% of the children assessed had ID, of whom only 2 were identified as having ID on the admission chart. Of those subsequently further assessed for adaptive functioning, 81% were also found to have IQ scores below 70, indicating adaptive impairment (130). Children diagnosed with an IQ less than 70 were also more likely to be diagnosed with a psychotic condition, compared to those with scores above 70. Pogge et al. (130) found that primary care providers' failure to identify and diagnose children with ID, confounded behavioural assessment and treatment regimes which may not have reflected the needs of children with unidentified dual diagnoses of ID and a mental health condition (130).

Of further concern, of the children who were assessed as in-patients for ID, only 9% of children diagnosed with ID with the Full Scale IQ test and only 30% of those diagnosed with ID from the adaptive functioning test received a charted discharge diagnosis of ID. The significance of this omission, as stated by Pogge et al. (130), is that the “these discharge diagnoses would be one of the main ways that parents or other responsible individuals would learn about these test results” (p. 1708). Phelps et al. (119) found that parents of children with Down syndrome and those with ID alone reported higher dissatisfaction with doctor-to-doctor and doctor-to-school communication than parents of children with special healthcare needs overall. Phelps et al. (119) did not describe the aspects of communication parents were unsatisfied with. The lack of communication of diagnosis may perpetuate navigational and treatment challenges for this population and undermine the trust families place in the knowledge and comprehensiveness of their primary care provider.

In this literature review, I also found that parents/families perceived the knowledge and ability of their children’s primary care providers to address the complex needs of children with ID and/or autism to be lacking (28, 30, 122, 123, 128). Reichard et al. (44) conducted a phenomenological study of children with diverse developmental disabilities, ages 6 to 18, and found that families of children with developmental disabilities reported their primary care providers were available and competent to address general medical needs; however, the families perceived primary care providers, in particular rural primary care providers, to have insufficient knowledge about their child’s developmental disability. The respondents described quality care as primary care providers accommodating their child’s needs, “go[ing] to bat” for them, and participating in educational program development (44)(p463). Reichard et al. (44) recommended that primary care providers receive education related to developmental disabilities and that they provide enhanced information to parents regarding their child’s developmental disability (44).

In a quantitative correlational study conducted in the US, Krauss et al. (28) identified and contrasted barriers to accessing “specialty medical doctors” experienced by children under the

age of 18 with autism, ID, and other special healthcare needs (p329). Both parents of children with autism and parents of children with ID identified difficulty finding “skilled and experienced specialty doctors”(28)(p334). Parents of children with autism were more likely to experience challenges getting referrals and appointments with specialty medical doctors than the other groups (28).

Betz et al. (30) completed a secondary analysis of interviews conducted with Californian parents of children with developmental disabilities to determine their needs and perceived barriers to services for their children. The majority (63%) of the children were diagnosed with ID and the remaining 37% had a diagnosis not otherwise specified. All children were aged 4 to 17. The findings of this study showed consistent parent perceptions of insufficient information and lack of availability of services for their children with developmental disability (30). The participants perceived service providers demonstrated lack of information through inaction: lack of awareness and provision of available services for children with developmental disability, lack of response to parent concerns, and “lack of information” regarding the child’s diagnosis and treatment (30)(p101). Betz et al. (30) identified that many children were not enrolled in services they required and concluded that there is a need for improved service coordination and organization, as well as better service provider training.

Liptak et al. (123) conducted a quantitative study using surveys of New York State parents of children, ages 6 to 8, with autism, ID, cerebral palsy, and/or spina bifida to determine parent perceptions of and satisfaction with their child’s primary care provider. Liptak et al. (123) found that parents of children with autism significantly more often rated the primary care providers’ care as fair to poor according to the following categories of satisfaction: (1) connecting parents with other parents; (2) being able to “answer questions” and “provide information and guidance” related to their child’s condition (p245); (3) “understanding the impact of the condition on the family” (p245); and (4) having knowledge of complementary medicine. Although there was a significant difference between the perceptions of parents of children with autism compared to the other three

groups, Liptak et al. (123) found that parents of children with ID were less satisfied with their child's primary care provider than parents of children with spina bifida and cerebral palsy. The rating from parents of children with developmental disabilities, autism, and ID combined were rated poorer in all four categories measuring primary care provider satisfaction than the rating from parents of children with physical disabilities, spina bifida, and cerebral palsy (123). Liptak et al. recommended that primary care providers enhance collaboration with other service providers and decision support and that pediatric nurses enhance their knowledge regarding developmental diagnoses.

Minnes et al. (128) conducted a comparative study to understand Ontario parents' perception of the quality of and factors affecting health services for their children with fragile X syndrome, autism, or Down syndrome, where all children were also diagnosed with ID. Minnes et al. (128) found that all three groups identified physician lack of knowledge of conditions and services, unavailability, and lack of comfort to provide care to people with ID as factors negatively affecting the "quality of health services" received by their children (p251). Parents of children with Down syndrome noted diagnostic overshadowing<sup>3</sup> as a concern related to health service provision. Parents of children with fragile X syndrome or autism identified that delayed diagnosis of their child's condition negatively affected the response time they had to access intervention services (128). Parents of children with autism noted that they equated attainment of the diagnosis of autism with access to services, an assumption not shared by parents of children with fragile X syndrome or Down syndrome, who described experiences of physician disinterest in their child's diagnosis, waitlists for services, and feelings of "being left to their own devices" in identifying beneficial interventions for their child (128)(p252). Minnes et al. (128) recommended enhanced physician education regarding developmental disabilities and early developmental screening.

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<sup>3</sup> Diagnostic overshadowing is defined as disregarding physical or mental symptoms by attributing them to a person's intellectual disability 7. Ouellette-Kuntz H, Garcin N, Lewis M, Minnes P, Martin C, Holden J. Addressing health disparities through promoting equity for individuals with intellectual disability. *Canadian Journal of Public Health*. 2005;96:S8-22.

The knowledge base of direct service providers related to developmental disabilities is important in the delivery of coordinated, comprehensive, and family-centred care. Shannon et al. (131) cited literature that indicates children with developmental disabilities are 1.5 to 10 times more likely to experience maltreatment from their parents than children without developmental disabilities. Such forms of maltreatment included neglect and emotional, physical, and sexual abuse (131). Consequently, Shannon et al. (131) performed an ethnographic study to examine the preparedness of child protection services' ability to identify maltreatment of a child with a developmental disability. They found that child protection workers perceived that a large percentage of clients had developmental disabilities, but often this diagnosis was inconsistently included or not communicated in the child's file. Further, workers discussed lack of developmental disability-specific training and understanding of developmental disabilities. Workers spoke of challenges specific to interviewing a child with developmental disabilities as part of their assessment to determine if the child had been maltreated. The themes which emerged related to communication barriers of the child, limited translation resources and reliance on family translation, and uncertainty about the accuracy of the child's report (131). Shannon et al. (131) recommended inter-professional collaboration and training on the definition of developmental disability to improve consistency in assessment.

To summarize, a consistent primary care provider is associated with improved service navigation and access. Persons with ID, across the lifespan, residing in Canada and the United States were generally found to have less access to consistent primary care, with the exception of the Shooshtari et al. (21), who found Manitoban children with ID to have greater access than children without ID. From this literature review, I identified that parents of children with developmental disabilities, and ID specifically, perceived that primary care providers and specialists lack knowledge about cognitive developmental disabilities, available services, and how to support parent concerns.

**Barriers within service navigation.**

From this literature review, I identified that parents of children with ID and primary care providers encountered barriers navigating tertiary services. A foundational barrier for parents and primary care providers to navigate services was a lack of accessible and comprehensive information about available services and how to navigate service trajectories (30, 31, 33, 44, 121, 122). Challenges in understanding service trajectories, eligibilities, and regional mandates were also reflected in the findings of a community assessment of primary care providers within this rural area of Ontario, Canada (132).

Services overall were critiqued according to parents' perceptions of the quality and suitability of services to meet their children's needs. Reichard et al. (44) identified barriers within auxiliary services and the overall health system, in addition to the aforementioned findings of parents' perceptions of primary care provider limitations. Although some auxiliary services were found to be comprehensive, others were found to be of poor quality, not meeting the needs of service recipients (44). Factors detracting from the quality of services were lack of coordination, case managers, funding, information on access, and capacity of services to meet demand (44). Phelps et al. (119) found that families of children with Down syndrome and ID reported lower rates of feeling like "partners in their child's care" and satisfaction with services their children received (p217). They were also less likely to receive support in coordinating their children's services from a case manager, although no parent reported difficulties coordinated the care themselves, and "more likely to report unmet needs" for health services compared to the overall population of children with special healthcare needs (119)(p217).

In a cross-sectional comparison study of data from the NSCSHCN, Vohra et al. (117) compared the perceptions of caregivers of children with autism, developmental disabilities, mental health conditions, or developmental disabilities and mental health conditions about "access to", and "quality of", health services and the impact of financial, emotional, and time related "burdens" on the family because of the children's condition (117)(p817). The caregivers of children with

developmental disabilities and mental health conditions and autism equally reported difficulty accessing services. Of the children with developmental disabilities, 43.7% reported difficulty using services, and 82.2% reported lack of service coordination. These findings were more likely for children with autism, 55% and 86.7% respectively. Difficulties in obtaining referrals were reported equally among children in all groups. It is important to note that the authors of this study believed that children with autism required care from medical specialists and thus also required referrals. In this study, Vohra et al. (117) examined the perception of caregivers of different disabilities using the assumptions that the services and referrals that caregivers pursued and wanted were needed. Caregivers were asked if they perceived they had experienced difficulties accessing services because of service ineligibility and lack of availability and the needs for but not obtaining a referral.

Lack of care coordination and accommodation emerged as an overall barrier for children with developmental disabilities and their families to navigate tertiary services. In this literature review, I identified general barriers encountered in the navigational process of tertiary services: lengthy waitlists; lack of available resources; diverse geographic, age, and diagnosis criteria for eligibility; gatekeepers of diagnosis and referrals; family financial barriers to accessing services; and fragmented service silos (30, 31, 33, 43, 117-119, 121, 122, 124).

#### ***Navigational barriers within specific tertiary services.***

Provider and community knowledge gaps related to developmental disabilities, complex eligibility processes, and not having continuous primary care were identified in the literature as challenges regarding navigating specific primary healthcare services.

Doig et al. (31) conducted a grounded theory study in Calgary to understand barriers to respite services experienced by families of children with diverse developmental disabilities. The children were ages 6 months to 17 years. The participants described the process of acquiring respite services as “jumping through hoops” because families were required to navigate complex systemic barriers (31)(p236). Families identified barriers to respite service navigation and access

as follows: lack of information related to available services and how to access them; meeting eligibility requirements of age, behaviour, and diagnoses; needs assessments; paperwork completion; obtaining and coordinating multi-sourced funding and complying with restrictions of how funds could be used; operating within the nonflexible delivery model of service use; finding a respite service that met the requirements of the families using them; and waitlists (31). Getting help was perceived as dependent on the willingness of service providers to advocate for families (31). Families believed that more services, providers, and funding would reduce such barriers to respite services. Doig et al. (31) acknowledged that the respondents' reports of extensive waitlists, narrow service eligibility, and difficulty finding respite services indicated that respite supports may not be "readily available at the community level" (31)(p240). Doig et al. (31) recommended a system navigator to assist families in accessing what services and resources are available and improved coordination, integration, and flexibility of services (31).

McGrath et al. (118) conducted analysis of the 2005-2006 NSCSHCN to determine the demand for and access to genetic counselling services by children with ID, autism, and/or Down syndrome, compared to children with other special healthcare needs. McGrath et al. (118) examined caregivers' perception of need for genetic counseling "advice about inherited conditions related to medical, behavioral, or other health conditions" and if they received "all genetic counselling that was needed" (118)(p445). The results of this study showed that this group "perceive[s] significantly higher need for [genetic counselling services] than other children with special health care needs", were more likely to report facing challenges in obtaining referrals and adequate school resources, yet received genetic counselling services comparatively to children with other special health care needs (118)(p443). As presented in the primary care section of this literature review, McGrath et al. (118) found that having a medical home was a leading factor to obtaining the service; however, the study group was less likely to have a medical home. McGrath et al. (118) recommended that barriers to primary care access be reduced and connections between specialists and primary care providers be improved.

In a descriptive qualitative study, Schleien et al. (124) found challenges and barriers to access, participation, and inclusion in integrated recreational programs for children with autism, ID, and/or other developmental disabilities. From focus groups with parents, the authors found that parents reported they had a “continuous battle to access recreation and social opportunities” because of their child’s diagnoses, which increased as the child aged (124)(p66). Schleien et al. (124) also found that parents perceived that staff frequently lacked knowledge and were unwilling to accommodate and support the children in the recreational programs, requiring parents to be “on the field” accompanying their child for the entire activity (124). Because of this perceived limited support, parents expressed feelings of exhaustion, hopelessness, social isolation, as well as concern for their child’s self-esteem and social development with peers because of their parental presence, yet fearful for their safety without it.

#### **Implications of service navigational barriers.**

The significance of service navigational barriers to health and social services for children with ID can be articulated through their influence on the individual, family, and society. It is estimated that 78% of people with ID, within North America, reside with relatives for the duration of their lives because they require support (7, 133). Many parents and families of persons with ID thus have the lifelong responsibility of negotiating, coordinating, and advocating within the health and social system for their family members with ID. Parenting a child with ID and complex health needs, and coordinating service navigation within a socio-political context of navigational barriers, may contribute to parental stress and burnout (31, 124, 134). Financial and employment strain were found to be prevalent in families with children with ID, autism, Down syndrome, and other developmental disabilities (117, 119, 120). Lindly et al. (120) found “that unmet child and family health service needs were associated with a higher likelihood of adverse family financial and employment impacts in the same year” (p718) regarding families with children with developmental disabilities. Parents of children with developmental disabilities and functional limitations were

more likely to reduce or cease their employment hours and to spend more than 11 hours per week providing and coordinating care (120). Phelps et al. (119) similarly found that parents of children with Down syndrome or ID were more likely to experience a higher negative financial impact because of their child's health care needs, compared to parents of children with other special healthcare needs. Vohra et al. (117) found that parents of children with developmental disabilities and mental health conditions, and also with autism, experienced greater negative financial impact compared to parents of children with only developmental disabilities or only mental health conditions.

McManus et al. (33) conducted a quantitative study using structural equation modeling to determine the predictors of the caregiver burden of children with developmental disabilities navigating the healthcare system. The ease of system navigation was negatively associated with caregiver burden and the unmet healthcare needs of the affected child. Having a primary care provider was the strongest factor positively associated with increased ease of service use (33). In this model, decreased parent burden related to ease of system navigation was related to decreased parent time and financial efforts to access services and unmet healthcare needs of their child (33). The greater the unmet healthcare needs of the child, the greater the parent burden identified (33). The inverse association of parent burden with ease of service use is of particular concern where respite access has also been found as fraught with barriers (31). McManus et al. (33) recommended review and evaluation of usability, availability, and adequacy of policies, programming, and services (33).

Problematically, when children with ID and their parents' needs go unmet, placement of the child outside of the home may result (135, 136). Indeed, Shooshtari et al. (21) found that Manitoban children with developmental disabilities were five times more likely to be removed from their families and placed in the care of others for seven days or more, compared to children without developmental disabilities.

**Those most vulnerable to experience service navigational barriers.**

A prominent theme of the literature review was the identification of which children with ID are most vulnerable to experience service navigational barriers; this provided context to the subsequent review findings. Families with lower socio-economic statuses were found to be more vulnerable to service navigational barriers (33, 43, 44, 118). McGrath et al. (118) found that as US family income levels decreased, caregivers' reported barriers to accessing a medical home and genetic counselling services rose. The socio-economic demographics of the children with autism, ID, and/or Down syndrome revealed that these children were "less likely to live in a household with an income of at least 200% of the FPL [federal poverty level]", thereby increasing their risk of experiencing barriers (118). Incomes 100% to 400% above the FPL were associated with decreasing degrees of poverty. Shooshtari et al. (21) found that Manitoban children with developmental disabilities, residing in urban areas, were more likely to live in poverty than children without developmental disabilities. Interestingly, Manitoban children with developmental disabilities were also found to have a higher rate of receiving continuous physician care (21). It is not known whether the differences related to acquiring a medical home are related to the differences between Canadian and US healthcare delivery; however, residing in poverty has been well documented as an adverse determinant of health (137). Parents in poor health, and children with unstable health issues were also found to be more vulnerable to experience health and social service navigational barriers (28).

***Cultural, language, and translation service navigational barriers.***

Parents' cultural perception of ID, culturally insensitive care, language barriers among parents, and gaps in translation services were found to compound service navigation for parents from cultural minorities. Baker et al. (121) conducted a participatory community research study in California involving Southeast Asian American families of children aged 8 months to 34 years with developmental disabilities to determine their perceptions of developmental disability and

accessibility of education and healthcare services for their child. Baker et al. (121) identified cultural influences as formative to the parents' perception of developmental disability as shameful, associated with stigma, and caused by parents' spiritual mistakes (121). Parental shame and self-blame were associated with parents feeling responsible for their child's disability and care, and undeserving to seek treatment for their child and, thus, likely to seek fewer services (121). Parents who did seek treatment reported that there was a lack of information about services, and that they experienced language, financial, and transportation barriers to access services (121). To mitigate these challenges, Baker et al. (121) recommended that service agencies implement family navigators to inform parents of available services and how to access them.

Bogenschutz (122) reported similar findings from a qualitative case study, in which he aimed to determine the factors that create barriers to healthcare access for Hmong, Mexican, and Somali immigrants who have an ID or developmental disability or are parents of children with IDs or developmental disabilities. Bogenschutz (122) found that participants reported that an information gap was a barrier to accessing services, specifically inaccurate or insufficient information about the healthcare system and insurance, as well as how to find culturally sensitive healthcare providers knowledgeable about disabilities or even general disability information. Additionally, participants reported language barriers and limited access to interpretation services which complicated their ability to independently navigate multiple, uncoordinated services. The participants reported that providers' lack of recognition of cultural beliefs and practices led to parental mistrust and provider-parent conflict (122).

#### ***Parent education and navigational barriers.***

Four of the included studies in this literature review indicated that there is a contrast between higher and lower levels of education in the vulnerability of parents to experience service navigation barriers for their children with ID. Researchers conducted all four studies using secondary analysis of results of the 2005 through 2010 NSCSHCN conducted in the US (28, 43,

118, 120). The NSCSHCN indicated that parent education was as a covariate “predisposing factor” for “unmet health care needs” “among CSHCN [children with special health care needs]” (120)(p714). McGrath et al. (118) found that having “less than high school” education was associated with lower access to insurance and more financial strain (p446). A post-secondary education was associated with greater parent reports of challenges regarding accessing specialists, using services, and unmet needs (28, 43, 120). Nageswaran et al. (43) proposed that parents with different education levels may have perceived service navigational barriers differently because parents with less than a high school education may have received more social supports than parents with higher education and parents with higher education may have had a better understanding of the functioning of the health care system (p639). Similarly, Lindly et al. (120) suggested that a post-secondary education may better equip parents to recognize “unmet need for family health services” (p720). The articles included discussion about the factors that may have created greater challenges for parents with higher education; however, these factors were not specifically examined within any of these or any other studies found within this literature review. The studies’ indication of association between high education and higher parent report of challenges navigating the health system present an interesting finding requiring further research to explore the relationship between education and expectations, capacity of self-expression, and/or privilege of knowledge.

### ***Who is most affected among children with special healthcare needs?***

Researchers of seven studies included in this literature review compared health service access challenges between subcategories of developmental disability in contrast to children with other special healthcare needs. Researchers conducted six of these studies using secondary analysis of results of the 2005 through 2010 NSCSHCN (43, 117-120, 127). The results from these studies showed the adverse effects of the US non-universal healthcare system (43, 117, 118). McGrath

et al. (118) found that children with ID, autism, and/or Down syndrome were less likely have insurance or to be publicly insured (p445).

When the results of the studies of this literature review were compared, overall, children with developmental disabilities experienced greater navigational challenges and unmet needs, compared to children with other special healthcare needs (43, 118, 119). Researchers of four studies compared service navigation challenges and outcomes between children with autism and children with developmental disabilities and/or ID, mental health conditions, and/or other special healthcare needs. Although, children with autism were found to experience greater navigation challenges than children with ID and unmet healthcare needs (28, 120), children with ID were identified as more likely to experience fragmented services and barriers in accessing specialized services as well as to have unmet family health service needs (120) than children with physical disabilities and other special healthcare needs, especially if the child with ID concurrently had a mental health disorder (43, 123).

Vohra et al. (117) found that parents of children with autism reported greater challenges with services use, coordination, findings sources of care, and shared decision-making than parents of children with developmental disabilities. Children with developmental disabilities, with or without mental health conditions, experienced similar challenges obtaining referrals and routine screening as well as having inadequate insurance as children with autism. Vohra et al. (117) explicitly made known their perception that autism is a unique and complex disorder, often with comorbidities, that requires complex pharmacological interventions and treatments that are lacking a strong evidence base (p816). Similarly, Krauss et al. (28) stated in their study that they held the assumption that autism is set apart from other developmental disabilities because its unique complexities necessitate early intervention (28). These views negate the ample body of literature that shows these factors to be true also for children with ID and suggests a belief of enhanced priority of treatment of one diagnosis over the others to which it was compared. Liptak et al. (123) speculated that parents of children with autism may be “less satisfied with primary

care” (p246) than the other groups because “they may feel as if they have less stability and more doubts and uncertainty related to their child’s disability” (p. 250). Although not addressed by Liptak et al. (123), this point may be related to parents’ conception of autism and possibilities for treatment, which may heighten the sense of urgency in acquiring treatment in contrast to conceptions of ID which may be more static and final as Krauss et al. (28) assumed.

Nageswaran et al. (43) conducted a quantitative comparative study of caregivers’ perception about healthcare system access among children, mean aged 10 years, with developmental disabilities, mental health conditions, physical disabilities, and/or multiple conditions. Caregivers of children with developmental disabilities and caregivers of children with mental health conditions were found to be 2.3 and 2.6 times more likely to report experiencing challenges using services for their children than caregivers of children with physical disabilities, respectively (43). Children with health conditions in more than one group, classified within the multiple conditions group, were four times more likely than children with physical disabilities to encounter barriers to healthcare use (43). Nageswaran et al. (43) recommended review of public policies regarding service access, and evaluation of the effect of a care coordination model in improving health service access.

When comparing navigation of genetic counselling services between children with ID, autism, or Down syndrome and children with other special healthcare needs, McGrath et al. (118) found that parents reporting their child’s “condition as minor were 1.8 times more likely to receive all needed [genetic services] than those who reported them as severe” (p446). Thus, parents who perceived their child’s condition was less severe were more likely to perceive that they received adequate services. Alternatively, parents who perceived that their child’s condition was more severe were more likely to perceive that they did not receive the services that they needed. Parents of children of each study’s inclusion group were more likely to rate their conditions as severe compared to parents of children with other special healthcare needs (118)(p446).

## Summary

In this literature review, I identified important themes about the impact and interrelatedness of the determinants of health – specifically socio-economic, employment-related, cultural, and health service navigational barriers – to the health and well-being of children with ID and their parents. Within primary care, the perceived primary care provider attitudinal barriers and knowledge deficits related to ID predispose children with ID and their parents to perceive that they have heightened navigational challenges regarding primary, specialized, and community social services. A medical home, or continuous care from a primary care provider, was found to increase service access and reduce navigational barriers. This subtheme was found to connect all themes.

My findings of this review are interconnected in that primary care knowledge gaps may contribute to inadequate care and service navigational barriers. Where this occurs, the needs of parents and children with ID are at risk of going unmet. Further, without determining a representative prevalence of the children with ID and the estimated costs associated with meeting their potential needs, it is unclear how and with what justification health and social service trajectories are organized and implemented. Researchers of compiled studies of the past decade have explored service barriers for this population and have merely shown the variety of navigational barriers present within the system and compared and contrasted populations to identify those who are *most* vulnerable to experience them (28, 43, 44). A remaining gap in knowledge is understanding how navigational service barriers persist despite representation within the literature over the past decade.

In this literature review, I found that many authors perceived that autism was distinctly unique and requiring more urgent and intensive interventions than other developmental disabilities, including ID. Alternatively, in this literature review, I identified a prevalent operating assumption that parents and families of children with different disabilities understand these disabilities in the same way and that health and social service opportunities are comparable across disabilities. These assumptions reveal a gap in understanding and interpreting the

perception and beliefs of parents that composed a significant proportion of the study findings. This knowledge gap provides justification for this thesis.

## Chapter 3

### Theoretical Framework

A theoretical framework maps concepts and constructs specific to a research issue intended to direct a study (51). This framework is developed by the researcher to explain his/her interpretation of the functioning of the environment in which the research problem exists, and how s/he intends to approach the research problem and make sense of the collected data (138).

Within this study the research problem and subsequent research questions concern how intellectual disability (ID) is currently constructed and the subsequent materializations of this construction in health and social service trajectories for children with ID. The main focus of this study is thus understanding how individuals are differentiated, organized, and prioritized. Within the theoretical framework for this study I will, therefore, draw on the constructs of stratification and biopower to articulate the theoretical alliance of the researcher, and guide the data collection methods and study interpretations. In this chapter, I present a theoretical framework that contextualizes how technologies of biopower inform social order, according to an antifoundational lens. In this chapter, I will also explore the technologies of anatomo-politics that discipline individuals and the techniques of biopolitics that regulate populations to understand how subjects and their associated citizenships are developed. I use Powers' (60) analytic framework will help explain how the findings of this study will identify the discursive components of ID.

#### **Mapping Social Ordering: Rhizome, Becoming, Difference, Stratification, Discourse**

##### **The contributions of Deleuze and Guattari.**

##### ***The rhizome.***

Deleuze and Guattari's (66) work provides a poststructural conception of the world and reality as rhizomatic. The heterarchical structure of the rhizome is borrowed from its botanical meaning, a system of root tubers which grow horizontally in all directions, overlapping and connecting to other parts in no particular order (66). The World Wide Web, prior to the invention of search engines, is

another analogy to the rhizome as a heterogeneous mass (of information) which develops horizontally (66). A rhizomatic ontological conceptualization is an alternative perspective to Habermas' work, which views reality as an arborescent schema with roots composed of foundational truths (139). In the arborescent schema, envisioned as a tree, knowledge and concepts of reality originate linearly and hierarchically from foundational sites (66). Deleuze and Guattari (66) distinguished the rhizome from the tree in the following way:

A rhizome has no beginning or end; it is always in the middle, between things, interbeing, intermezzo. The tree is filiation, but the rhizome is alliance, uniquely alliance. The tree imposes the verb "to be," but the fabric of the rhizome is the conjunction, "and...and...and...". ( p25)

The development and growth of the tree and the rhizome are compared through Deleuze and Guattari's (66) analogies of the tracing and the map, respectively, which illustrate the divergent critical and poststructuralist approaches of analyzing discourse. The tree or arborescent schema is compared to a tracing, which originates from a structured base of a genetic axis, from which all emergent tracings of reproductions derive, and can also be traced "back to the same" (66)(p12). The concept of reproduction of "the same" can be further explained through Deleuze and Guattari's (66) example of the X-ray. The X-ray represents a tracing within which parts of the map can be recognized, but the map is not organically reproduced; instead, only parts of it are isolated and organized for display (66)(p13). The arborescent lens on discourse analysis can produce findings which claim to objectively display the world and its makeup, but instead merely impose an order on the world. From this logocentric position, discourse is a tracing of the linear evolution of reality from an objective root (66). This formulated discourse has made it possible to speak, but only of those constructions formulated within it. What has not been demarcated within the tracing cannot be recognized (65).

Alternatively, the rhizome, like the map, makes connections over and across everything; it has "multiple entryways" and no genetic axis from which the direction of development is based or orchestrated (66)(p12). The map, referred to as an "antigenealogy" by Deleuze and Guattari

(66)(p10), illustrates a poststructural position from which to envision the development of discourse. The map analogy illustrates the Foucauldian vision of discourse formulation in a non-linear and ever-changing way from an undistinguished, intertwined rhizome (66, 140). To begin to unravel how a discourse or construed objective truth of the world came to be, Deleuze and Guattari (66)(p14-15) suggested exploring a tracing to locate the “footholds,” or power relations, which facilitated that phenomenon to formulate a tracing out of the rhizome. This approach facilitates fixed beliefs to be reconsidered as imposed strata upon an otherwise heterarchical middle position of the rhizome. A rhizomatic ontological perspective can be useful to explore how ID is understood and how service navigation barriers function without promoting “truth claims” that limit what can be questioned and how (63)(p130). To explain, although I cannot stand outside the discourse and recognize all of the held truths that form the scaffold of my understanding, I recognize that political ideologies about inclusion and segregation and beliefs about the representativeness of diagnostic labels are some of the held truths in discussions about disabilities that are often left “unchallenged” or even “ruled out of bounds” (63)(p130). Application of the rhizomatic lens will help me to “question over and over again what is postulated as self-evident, to disturb people’s mental habits” while avoiding or reducing the preservation of these limits and “telling people what to do” (141)(p265).

### ***Becoming.***

Deleuze, in his independent writings (142, 143), and later with Guattari (66), drew on the rhizomatic ontology to undermine the fixed arborescent construct of identity (i.e., being). *Being*, according to Deleuze (142, 143) and Deleuze and Guattari (66), represented a dominant, structural framework for the formula for identities according to the order of assembly of the arborescent schema ontology. This concept of being prescribes, stabilizes, and hierarchizes what can be, while simultaneously limiting or preventing other possible identities (144). Being is evaluated based on a derivative difference, or contrast, from the original sameness, to which

everything is compared (142, 144). Deleuze and Guattari (66) further described being as a reductive process which excludes difference by fitting everyone and everything into a predetermined model of what has been conceived as possible and acceptable (p280). In *Difference & Repetition* (142), Deleuze rejected the conception of being as a univocal, foundational representation of reality, through demonstrating that being is instead a contrived method of “analogy” (p33). According to Deleuze (142), through judgement the method of analogy is applied to facilitate distribution and hierarchization of subjects, or entities, within reality. Therefore, the construct of being represents a template for the structural organization of our world.

Deleuze (142, 143), and Deleuze and Guattari (66), countered the construct of being with that of becoming as a *subversion* of the stable, dominating construct of identities or reality traced by the tree. Becoming is the multiple, continuous, unstructured developments and growths which facilitate conceptions of infinite possibilities of identities and realities (142, 144). May (144) described *when* becoming occurs, as opposed to *what* becoming is, to demonstrate congruence with Deleuze’s conception of becoming as a dynamic web and flow which is starkly different from the predominantly held notion of being and identity as static and objective.

Deleuze and Guattari’s (66) conception of becoming as everyone and everything within a state perpetually changing provided a reprieve to the confines of the conception of being (145). To engage in the becoming process, one must render oneself and “break with the arborescent schema” (66)(p293) and its genealogical classification of the majority identity, or being, described by Deleuze and Guattari (66) as the white, adult, European male (p291-298). Deleuze and Guattari (66) referred to this process as *becoming minor*, through which the points of reference and origin of the majority identity of being are overthrown. This liberates one to become everything uncharted, and between structures. The end product is becoming imperceptible (66)(p279), where a person is completely declassified and returned to a rhizomatic state. The “unfolding of difference” and return to “difference in itself” are the methodology and definition of becoming (66)(p279) (144)(p151).

### ***Difference.***

Deleuze (142) again presented the arborescent schema to contrast the construction of difference from a critical realist ontological and from a relativist poststructuralist view to illustrate the divergent approaches to demarcating “normal” and “different” (145)(p76). Difference is understood from an arborescent lens as a degree of variation or deviation from a foundational normal (66, 145). In this way, a binary of normal/different is established that defines normal by distinguishing differences from it (65). Thereby, a hierarchy is created between those who are identified as meeting the classifications of what is considered normal, according to its foundational conception, and those who are not. Those classified outside normal are subjugated and subordinated along a spectrum of classifications of difference (145). Hegemonic conceptions of normal influence not only how subjects are perceived, but also their treatment (145). Foucault’s analytic tool of biopower illustrates the techniques used to order individuals within society to optimize its function. These techniques are reinforced by the larger state that informs the categories and corresponding treatment of each ordered group (146, 147). Biopower is explored in detail further in the text.

Deleuze (142) rejected the former conception of difference, and instead reframed it through a heterarchical definition, to reconsider the structure and operations of current societies. Rather than consider difference as a departure from an agreed-upon norm, Deleuze (142) excluded a foundational normal from consideration. Through this removal Deleuze positioned difference as the foundation (145), where a predetermined ordering or categorization of individuals no longer exists and is instead replaced with recognition of “difference in itself” (142)(p28-69). Difference in this view is synonymous with the heterarchical, “diagonal” movements of the rhizome in that within and between difference there exists no hierarchical attribution (142)(p267)(148). Stagoll (145) summarized this conception:

Every aspect of reality evidences difference, and there is nothing behind such difference; difference is not grounded in anything else.... Even if things may be conceived as having

shared attributes allowing them to be labelled as being of the same kind, Deleuze's conception of difference seeks to privilege the individual differences between them (p75).

This radical alternative to considering individuals and problems in current society, although challenging in its application to reconfiguring tacit conceptions, creates an opportunity to envision social issues differently, which have remained unchanged despite awareness or efforts to change them. Rather than recognizing people by their degrees of difference corresponding to the norm, they could be appreciated simply as entities, "with no category imposed with which to anchor" understanding (148)(p 27). Although social order created by categories structures the functioning and productivity of society (66), recognition and consideration of the implications of this order on classified subjects enables a nuanced perspective to evaluate entrenched social workings. The process of hierarchical differentiation will be described in the following section detailing the construct of stratification. The concepts of being, becoming, and difference can be used to identify and interpret the ontological and epistemic perspectives present within different understandings of ID and to map how these perspectives may reinforce perceptions of a fixed identity of ID or identify nuanced and uncategorized ways of conceptualizing ID (141).

### ***Stratification.***

*Stratification*, as defined by Deleuze and Guattari (66), is the process which imposes order on unmarked or unorganized planes of nature or matter, contributing forces which influence becoming (66, 145). What is considered as truth and reality represents the products of these influences (145). Matter becomes organized and stratified based on chosen modes of organization (66). The organizing borders or strata, informed by and informing knowledge, situate people within society (66, 149).

According to Deleuze and Guattari (66) stratification occurs through "double articulation" (p40). The first articulation gathers and sorts heterogeneous components of the rhizome. The second articulation ranks and labels groupings into hierarchies through the classifying of, in this case, people against societal priorities and ideals of normal. Designated outcomes are then

assigned according to the level of rank attributed. Hardt and Negri (150) constructed the sequence of inclusion-differentiation-management to articulate this stratification process, whereby everything is included and then differentiated by societal priorities and then managed to optimize each person's potential to contribute to the "functioning of (society)" (149)(p52).

Although anything can be stratified, in this study I investigate the stratifying methods that organize and rank children with ID in current society which are reflected in social perceptions of their citizenship and priority within health and social systems. The phenomena explored in this research study are the stratifying outcomes of discourse, which Deleuze and Guattari (66) view as highly influential to understanding reality and subjectivities.

### **Contributions of Foucault.**

Foucault, through much of his work, developed theory to explain how knowledge, power, and discourse are connected and act as stratifying agents to organize society and facilitate the power over the life of that society, otherwise known as biopower (140, 147). I explore Foucault's constructs of knowledge, power, and discourse, as well as resistance, in greater detail in the following section.

### ***Knowledge.***

In *The Archaeology of Knowledge* (68) Foucault discussed what Deleuze and Guattari (66) would call stratification in relation to history, knowledge, power, and the construction of the object/subject. Foucault (68) rejected the idea that knowledge of history is neutral, linear, or objectively true, and resisted seeking origins of knowledge. Instead, Foucault (68) examined the constructed knowledge of history as a mapping of the development of language and discourse, "the work of meaning..., the interplay of material determinations, rules of practice, [and] unconscious systems" (p15) of disciplines. Knowledge, returning to the work of Deleuze and Guattari (66), can instead be understood as the stratified and formed matter originating from historical and political developments (68, 142). Foucault developed a genealogical method to

explore the contextual influences that make certain knowledge possible, widely dispersed in a culture, and adopted as “common sense” and “fact” (151)(p57). This knowledge constitutes how a culture understands and perceives differences between people (sex, disability, mental illness)(151). The exploration of the function of “common sense” knowledge provides insight into the rules of how we can speak about things and thereby also “piece back together”(141)(p30) the ontological and epistemic position contributing to and reinforced by this knowledge (152). Foucault theorized that the sciences, “institutional game-playing, class relations, [and] professional conflicts” (141)(p30) have great influence on the “emergence of different interpretations”(153)(p152) taken up as knowledge. Foucault proposed that there is a connection between the production of knowledge and the “advances of power” of these influences (151)(p60). Foucault thus examined knowledge according to its “relation” to power (141)(p43).

### ***Power.***

Foucault did not conceive of power as sovereign, top-down, or repressive (140, 147, 154); but rather a productive, and often ignored, set of relations. Power is not possessed or centralized within an individual or institution, nor is it held over an individual, separated from freedom (140, 155). Instead, power is omnipresent and everywhere, present within all relations, whether between individuals or individuals and the state, and dependent on the coexistence of resistance within power relations (140, 154). The functioning of power is not an external factor, secondary to the development of relationships; rather, through power, relations and outcomes are formed and are continuously transformed (146). Power is, as stated above, positioned by Foucault as productive (146). Power is not conceived of as a thing but as an exercise or action of power relations which form and reform the “social nexus” (155)(p791). Foucault (155) theorized that power consisted of three interconnected relationships: (1) relationships of communication representing power effects in constituted discourse; (2) power relations between people stratified

into working groups; and (3) finalized activities which dictate hierarchies and reinforce the stratifications which dictate the order of societal functioning.

Foucault linked power to knowledge through his belief that, because no concrete truth exists, those which are considered “regimes of truth” in a particular time and by a particular society in actuality represent hegemonic influences in the construction of this knowledge (154)(p131). In other words, those in hegemonic social positions of authority are “allowed to speak,” such as in medicine and psychiatry (140). Through this privileged speaking position, authorities may disproportionately contribute to the formulation of societal knowledge regarded as unquestionable objective truth (140).

Further to the construction of naturalized “scientific truths,” power, constituting and reconstituted with knowledge, informs the stratification of a society to structure what categories of people and objects can be recognized and conceived of (154). Power is productive in its effect of creating social order, and thus in enabling a society to function (140)(p93)(154).

### ***Discourse.***

The discourse derived from hegemonic positions is the merging of accepted knowledge and manifestations of power in a culture through language. Discourse represents the “effects of power” (155)(p787)(140). Hall (156, 157) clarified the difference between the linguistic meaning of discourse and that intended by Foucault, saying, “Discourse is about the production of knowledge through language” (156)(p291). Furthermore, “It governs the way that a topic can be meaningfully spoken about and reasoned about. It also influences how ideas are put into practice and used to regulate the conduct of others” (157)(p72). Congruent with his poststructuralist antifoundational position, Foucault (68) illustrated through the relationship between power/knowledge and discourse that “nothing has any meaning outside of discourse” (p32). In this way, the discourses which stratify a particular society in a particular time by “dividing it up, describing it, explain[ing] it, trac[ing] its developments” may organize and facilitate function and

communication, although the categories created are not objective, static truths, but instead continually changing across time and cultures (68)(p32)(140).

### ***Resistance.***

Foucault's approach to discourse analysis not only stresses the necessity of discourse in the communication and organization of cultures, but also maintains that this discourse is formulated in an environment where power is in every relation and exercised by all (154). In this way, a reverse discourse of marginalized groups may influence the flows of discourse in a counter-movement within members' power interactions with those in hegemonic positions (140)(p101). This conceptualization aids in the development of resistance. In *The Subject and Power* (155), Foucault described the main indicators of resistance to forms of power. Primarily, forms of power which influence the formulation and actions of the individual, specifically subjectification, ignite responses of resistance (155). Resistance to these forms of power includes traversal and anarchist struggles which attempt to sever stratifications, which mold subjects out of individuals, and defuse the effects of power that direct their actions (155). The exploration of service navigation barriers experienced by children with ID may thus illuminate the power relations and discourses at play that define ID but also alternative ways that ID is understood with the navigation challenges.

Davies (158), whose writings are inspired by Foucault's work, stated that when a person is made a subject, this "is a move away from the self as a noun, to the self as a verb, always in process" (p137). The privileged power/knowledge within the given social context that has been naturalized within the discourse, and informs the stratification of the individual into a subject, becomes the focus of resistance struggles (154, 155). Foucault (155) described the use of resistance as "a chemical catalyst so as to bring to light power relations, locate their position, and find out their point of application and the methods used" (p211). Accordingly, resistance can be facilitated through a methodology that critically analyzes discourse (159).

Discourses “structure and regulate what statements can be said, what is considered true or false” (159)(p772), and thus represent a form of power/knowledge. Discursive resistance can be used to reject subjugation to power discourses that construct particular bodies, gestures, discourses, and movements, and expose the history of the present that has contributed to the current construct of the subject (159). Because power is fluid, through revelation and critique of discourses, new discourses can be carried out to change and redefine the self (159, 160). There are no limits within this resistant process of self-reflexivity. Every ideation is the construct of history, culture, and politics; therefore, the “subject... [can be] wiped clean to be historically written and rewritten anew” (159)(p780). This rewriting ties into Deleuze’s understanding of the origins of social order as rhizomatic, releasing the subject from the structured possibilities of the tree and being, and providing new unencumbered opportunities for becoming. In Chapter 2, I reviewed the different ways that ID has been understood historically and how people with ID were treated according to these understandings. ID has been understood broadly by diagnostic and medical discourses that problematized the individual and promoted their treatment but also by ideological discourses that focused on societal barriers and promoted social change and inclusion of all people. The discursive changes in how ID has been understood across events in time illustrates the instability of how ID is understood and supports the examination of current and future constructions of ID to continually critique settled truths.

The framework of biopower and the concept of citizenship will help me to explore the constructed knowledge and stratification influencing current conceptualization and regulation of children with ID (157). Through this exploration, I intend to make explicit the tacit strata in society, to facilitate nuanced inquiry of what could be outside of these strata, and what could be possible where hierarchical social structures have previously contained, limited, and predetermined the movements of marginalized groups (66)(p503).

### **Biopower.**

A biopower analytic lens reveals the power relations that have constructed individuals, managed their behaviours, and problematized deviants outside of the constructed norm (72). Biopower is an analytic alternative to understanding issues specific to disabilities over the individualizing medical and social models which focus on the debate of “who we are,” as though a naturalized concept can be grasped (114). Biopower is an undercurrent of power over life and the management of a population (146). It seeks to establish equilibrium within the population by achieving order among its many inhabitants, and optimizing the populations’ overall functioning (147). It constructs a distribution of the norm, creating normalizing power which is dispersed through the two poles of biopower (140). The anatomo-political pole comprises the disciplinary technologies that are applied at the individual level (140, 161). The biopolitical pole encompasses the regulatory technologies applied at the population level (140, 147).

Biopower categorizes individuals into materialized, or constructed, hierarchical tables of classifications which are the construction of history, society, and politics (i.e., stratified knowledge)(114). Social-economic class systems and diagnostic categories are examples of hierarchical tables. The knowledge used by the state is naturalized because it is accepted as a product of nature and biological truth that is pre-existent to cultural perception (114). This knowledge then informs management and social policies regarding specific classifications of people (114). Therefore, examination through the lens of biopower may reveal the constitution of the state’s knowledge and inform a critical ontology of the self. To explain further, Foucault (162) described a biopower lens as “an investigation into the events that have led us to constitute ourselves as subjects of what we are doing, thinking, saying” (p315). This investigation facilitates the “questioning of who we are and how this ‘we’ has emerged” (163)(p122). Shildrick and Price (164) explained that constructs of identity are developed by and reinforce societal norms that regulate a population and are applied to individuals to make them understood subjects (p99). The nuanced stratified knowledge incorporated within biopower provides a consciousness to the

entrenched yet subtle marginalizing, regulatory operations. This consciousness can further elicit provocation of resistance and transformation from these operations and internalized technologies of the self previously unrecognized by the individual (114, 162).

The anatomo-political and biopolitical axes, defined by Foucault (140) will now be explored in detail to articulate the fluidity and influence of biopower, from the training of individuals to state regulations (see Perron et al. (161) for a schematic).

### ***Anatomo-politics.***

In *Discipline and Punish*, Foucault (165) outlined the anatomo-political axis of biopower, also referred to as the “body-organism-discipline-institutions series” (p250), that encompasses the disciplinary focus on the individual. Techniques of discipline are intended to modify and correct the abnormal behaviours, bodies, and souls of individuals to produce docile bodies (72, 162). Docile bodies are produced by the subjection of individuals to techniques of normalization that conform them to the ideal norm of society (147, 166). The techniques of hierarchical observation, examination, and normalizing judgement are incorporated into and reflected in the individual’s training by appointed professionals within institutions (165). These techniques are informed and “explicitly laid down by the law, a program, a set of regulations” (165)(p179) derived from the biopolitical stratified knowledge of what is normal. The appointed professionals are “entrusted with the task of applying the regulations to individuals (165)(p174).

Disciplinary power operates in secrecy and invisibility, but its objective is to make its subject visible and known (72, 165). The transformation of an individual into a docile body occurs when the individual is “approached as an object to be analyzed and separated from its constituent parts” (72)(p153), with the aim that the emerging docile body “may be subjected, used, transformed, and improved” (165)(p153). Anatomo-politics provide a micro-level perspective of the implications of ideologies and social policies from the macro-level on the functioning of health and social systems, and how the individual is approached by the system.

Below, I present the anatomic-political components of the docile body and training.

*Docile bodies.*

Foucault (1977) described the application of distinct and purposive disciplinary techniques that manipulated, individualized, “subjected, transformed and improved” the individual body to create a docile body (p136). The docile body is intended to be useful and to contribute to the workings of society (1977, 1978). Foucault (1977) described the conscious transformation of subjects into docile bodies as a “political investment of the body” (p139) as a response to particular needs in society. Foucault illustrated his conception of docile bodies as “political puppets, small scale models of power” (1977)(p136). The disciplinary mechanisms used to create docile bodies applicable to the focus of this thesis are the art of distribution and the control of activity (1977).

The art of distribution is the disciplinary process concerned with strategically and spatially positioning individuals (1977). Individuals are first separated through partitioning from others so that their behaviour may become visible and known, and order may be made of a mass of people (1977). Partitioning advantageously positions individuals where examining authorities may analyze and judge them (1977). Foucault (1977) described the “distribution of bodies” through partitioning as a process that ranked and classified (p144-145). The intent of classification was to situate the individual within a “network of relations” corresponding to the classification bestowed upon them (1977)(p146). Disease represented one of many classifications. Returning to Foucault’s (1977) definition of classification, “a technique of power and a procedure of knowledge,” it becomes clear that partitioning through disease classification reflects stratified knowledge (p148). The concept of the art of distribution may help me to understand how carer and governmental agencies’ definitions and understandings of ID distinguished and classified children with ID within the service system.

The classification prescribes the subsequent control of activity through the temporal elaboration of the act (1977). This facet of controlling activity deals with the precise movements of

the body (165). Foucault (165) described the control as a program applied from the outside onto the body to assign the direction, duration, and order of its movements, behaviours, and gestures. The classification of disease can be viewed as the first of two steps, dictating the second step of prescribed movements within the program or designed system trajectories. In this thesis, the concept of the temporal elaboration of the act helps me understand how classifications of ID “inscribe[]... meaning” on children with ID that locates their needs and directs their treatment within the service system (164)(p100).

The biopower framework provides an approach to identify ideologies which create unjust power distributions and contribute to the marginalization of subjects who do not reflect the *status quo* of dominant discourse and societal citizenship ideals. Exclusion may result for those who do not conform to represent the subject recognized within the system. If left at this point, the marginalized group under focus would perceivably have a bleak existence. Many authors have critiqued Foucault’s work for overestimating the power of discipline on the subject, and suggesting that the docile body possesses no self-agency or self-reflexivity (159, 160, 168, 169). Reconciliation between the Foucauldian concept of the subject constituted by “power-knowledge relations” (168)(p44) within history, society, and politics and methods of resistance have been an issue of contention within the literature (160). Foucault conceived that power is within all relations that mold people into certain kinds of subjects (170). People cannot be outside of power relations and thus cannot perceive all of the disciplinary techniques at work on them (170)(p79). Because power is within all relations, Foucault conceived that freedom is available to everyone within them (141)(p36). Indeed, Foucault stated that “there cannot be relations of power unless subjects are free” and have the “possibility of resistance” (171)(p123). Foucault’s conception of freedom is “situated” within the power relations of a society or culture that are “changeable, reversible, unstable” (p123). People are thus free to resist within the relations of power that they are aware of (141, 170). Foucault presented discursive resistance as a methodology to analyze and critique the power/knowledge that underpin constructs to locate constraints (159, 168). Within this thesis,

the concept of resistance adds to my examination of service navigational challenges and conflicts, and identification of constructs of ID that have been accepted, rejected, and resisted by carers and within governmental agency documents. By making these constraints explicit, places for change can be identified.

*Training.*

The training mechanisms of hierarchal observation, examination, and normalizing judgement represent operations to control and further objectivize and normalize individuals classified as specific subjects (165). The expectation is that the resultant docile bodied subject will contribute to the functioning of societal operations (165).

*Hierarchical observation.* Foucault (165) described hierarchical observation as an approach to optimize the surveillance of each individual within a particular system. Foucault (165) identified architectural examples of this process within prisons, military camps, and schools. Non-structural examples of hierarchical observation were “specialized personnel” who were positioned as superior authorities to carry out supervision (165)(p174). Foucault (165) detailed the two-part role of supervisors within this system. Supervisory personnel were required to distribute state-designated physical resources and services to specific individuals, and to survey and correct deviant individuals (165). The supervisory role was positioned as a piece of machinery within the functioning of biopower (165). The state evaluated in supervisor the same attributes it required the supervisor to isolate and report about the individual (165).

*Examination.* Disciplinary power carried out by examination incorporates hierarchical observation and normalizing judgement (165). Examination represents the very personal appraisal of the individual under the professional's normalizing gaze. The individual is perceived as an object requiring the objectivizing techniques of classification, organization, and arrangement to transform the individual into a docile subject (165). The examination works on fixed categories of classification. Foucault offered examples of categories such as "the child, the patient, the madman" (165)(p192). Relational power also exists between the examiner and the subject, where the examiner determines the category to which a voluntary subject belongs, and thus whether the subject's behaviour is abnormal and requiring correction or if a reward is due.

Through intense examination of the subject, the examiner produces documentation which captures and fixes them, and further creates data that may be used for comparative analysis and to inform epidemiological inquiries (165). The purpose of this examination is to make visible those who deviate from the norm, to clearly reveal the gaps between them and others, and to make known their place within the "distribution of the population" (165)(p190). The resulting documentation is used to construct the individual as a case within a fixed category (165). Foucault (165) described this process as "a means of control and a method of domination" because in effect the individual is erased (p191). What remain to be acknowledged by the professional gaze are the characteristics of the subject which have been specifically isolated and objectivized to fit a fixed construct of a case (165). The individual becomes the case and "an object for a branch of knowledge and a hold for a branch of power" (165)(p191). This knowledge reflects the stratification of knowledge and what is perceived as truth, which thus infiltrates who receives corrective training or becomes excluded and how, and also affects who is rewarded (165). Foucault articulated this point when he stated, "the individual is no doubt the fictitious atom of an ideological representation of society... also a reality fabricated by... discipline" (165)(p194).

*Normalizing judgement.* The gratification-punishment system of normalizing judgement is the disciplinary apparatus which develops a hierarchy between “good and bad subjects in relation to one another” based on the norms of reference of the constructed knowledge of biopolitics (165)(p181). The activity, behaviour, speech, body, and sexuality of an individual are compared to ideologies of the norm within the examination process (165). Those examined and judged as deviants, abnormal, or non-observant receive penalties of specific training to be corrected and conformed to the model of norm for society (165)(p182). Individuals are differentiated, hierarchized, and ranked against one another based on skills, aptitudes, potentialities, and the value perceived by the judge (165)(p181). Although the goal is to rehabilitate (or at least fall within the “deviations of the norm”), Foucault (165) identified a limit in the lengths that institutions will go to reform deviance. Foucault noted that those classified and ranked as abnormal were considered the most shameful and may have been excluded if training did not result in conformity (165)(p183). Positive ranking, reflective of the normalized presentation of the subject, serves as a reward (165)(p181).

Individuals submit themselves to disciplinary practices to gain entry to the functions and resources of society. In submitting to these disciplinary practices, individuals must, however, cease Deleuze and Guattari’s (66) becoming-imperceptible, and instead become static, stratified, and recognizable subjects; i.e., docile bodies. I applied the concept of anatomo-politics to help me think about how constructs of ID are reinforced within service system practices and the effects on children with ID.

### ***Biopolitics.***

The biopolitical axis represents practices by the state to promote regulatory control and sustainability of the population as a whole (172). Although biopolitics is concerned with regulating determinants regarding the viability of society, this axis will be used to evaluate the construction and regulation of citizens identified as deviants from the norm because of their “illness”, which is

perceived to “sap[] the population’s strength..., waste[] energy, and cost money” (147) (p244), and the subsequent distributive process of resource allocation. A societal norm derives from the “curves of normality” (146)(p63). Curves of normality are population specific and formulated by statistics, which determine the “optimal normal,” or the peak of the distribution curve, and the variation of norms from it (146, 166). The optimal normal, determined by the curve of normality, serves as the yardstick to identify, problematize, and regulate “deviations from the norm” (173)(p162). In *Society Must Be Defended* (147), Foucault stressed that the focus of biopolitics was the flourishing of the collective population’s health, thus strengthening the state. To this focus, Foucault connected systemic acts of racism and eugenic actions, which at times could be justified to manage and protect the population by passively or actively excluding problematized groups (72, 147). Dreyfus and Rabinow (72) articulated Foucault’s interpretation:

Human needs were no longer conceived of as ends in themselves or as subjects of a philosophic discourse which sought to discover their essential nature. They were now seen instrumentally and empirically, as the means for the increase of the state’s power. (p139-140)

Foucault (147) described mechanisms used in biopolitics to manage and enhance the population and protect the state. Consistent with the schematic developed by Perron et al. (161), the mechanisms explored in this framework include morbidity statistics, health initiatives, and the distribution of resources. Statistical measurement of morbidity of a population, according to Foucault (147), is to make known to the state’s problematic areas of function and abnormality. These data inform the state of areas requiring regulation and intervention at the population level (147, 161). The knowledge gained from the statistical results informs governmental policies of health initiatives and resource distribution (161). The power/knowledge generated within the biopolitical axis influences disciplinary power and deliberate training actions imposed on subjects. Foucault’s concept of biopolitics can be used as a theoretical framework to examine how children with ID are constructed and regulated within national statistical data, the DSM-5, and by Ontario governmental agencies that distribute resources.

### **Objectification practices.**

In this study, I explored the construct of objectification within the two poles of biopower to illustrate the practices which identify individuals who deviate from the norm to impose regulation and discipline upon them (65, 113, 152). Objectification is the process which molds humans into governed subjects through the systematic, fluid operations of biopower (161). The objectivizing practices of classification and division represent the first two modes of this process, where social policies and training by professions classify and divide subjects, to exercise power over the “body,” its choices and actions (155, 161, 174, 175). Ultimately, objectivizing processes implement hegemonic discourse that is applied to persons and in turn produce docile bodies that can be better managed and that will begin to manage themselves (174, 176). Therefore, the investigation of objectification processes will reveal practices that influence power and provide focus for future actions for change through resistance (155). Foucault (177) theorized that the social perception of the “normal” body was not the construct of a fixed, natural occurrence without history but, instead, a formulation of history, society, and politics (167). The significance of this view reflects the connectedness between the anatomo-political and biopolitical axes and the engrained and hidden methods of discipline that manipulate the body to behave and demonstrate gestures, habits, and skills valued by the one who has hold over the docile body (165). The “pervasive apparatus” of power/knowledge informs social norms and the way subjects are perceived and how they perceive themselves (151)(p66). Therefore, the disciplinary mechanisms reinforcing these constructed truths and the subsequent desired, normalized behaviours are intended to pervade the subject’s self-perception so that the subject begins to self-regulate (161, 175). Self-regulation represents the third and last mode of the process of objectification: technologies of the self which are “a reflex of domination” (174)(p87). The concept of objectification is useful to identify the categories that have stratified children with ID and recognize the subject position taken up by these categories. Further, the mode of self-regulation can be

used to interpret the degree to which carers' participation and agreement with or resistance the practices of the service system.

### **Citizenship**

From a poststructuralist perspective, all categorical orderings of people are constructed historically, socially, and politically. These categories represent stratification of world order and knowledge that inform perceptions of citizenship and subsequent treatment of various groups (113). The concept of the ideal citizen is directly linked to the norm, distinguished according to "the curves of normality" (146)(p63). The construct of citizenship is crucial when considering the stratifying objectivizing processes developed in social policies through normalization within biopolitics, and implemented by professionals in anatomo-political training and management procedures of normalization to produce conformity (147, 161, 166, 177, 178).

Diderot, an 18th-century philosopher, defined citizenship as the biological classification of soma-normative hegemony that classified independent and able-bodied persons as free full citizens and all others as deviants (178). This classifying dichotomy was imperative to identify those "in possession of monstrous bodies... or diminished faculties" who would not contribute to the function and viability of Diderot's 18th-century French society (178)(p83). This dichotomy represented the inclusion/exclusion mechanism of formal citizenship, which differentiated citizens from non-citizens (173, 179). Rioux and Valentine (180) associated formal citizenship with civil disability, where people with disabilities belonged to and were granted protection by the state, but were excluded from decision making and other benefits granted to full citizens (173). This association reflects Foucault's conception of the application of biopower to "make live and let die" (147)(p241) by rejecting or excluding those determined to be inferior and by not actively supporting people who are problematized in the biological hierarchy. Goffman (181) developed the concept of social death that is different from a biological death. Goffman proposed that a person has a social death when they are separated from the rest of society through lost

opportunities to participate and through losses of their identity. A person's unique identity is lost when they are "squared away... shaped and coded into an object that can be fed into the administrative machinery of the establishment, to be worked on smoothly by routine operations" (181)(p16). To explain further, the individuality of a person can be covered up by the new label applied by the system. In this way, people can be let die by being excluded from society and its resources and by being excluded from their own unique identity.

Formal citizenship and civil disability are also facilitated through a medical model framework. Siebers (182) concurrently related the "medical gaze" of examination, determining the "potential of a person," to subsequently determining a person's entitlement to "admission or acceptance" to membership and citizenship in society and the distribution of resources that this brings (p184). To explain further, the diagnosis assigned to the individual is considered a true interpretation of that person. Attached to that diagnosis are treatments reflective of society's understanding of it and its potential to be cured or modified. Van Houdt (179) demonstrated how formal citizenship has been used as a biopolitical instrument in immigration policies in Holland. Inclusion/exclusion criteria managed the influx of citizens by granting citizenship to those with characteristics deemed to benefit the population and excluding all others. Within Canada, Capurri (183) detailed cases of denied immigration applications to persons with ID based on the perception that they have no potential to economically contribute and pose a "burden to the social service system" (p1).

Moral citizenship encompasses the societal ideals of how a good citizen should behave and act within a given society (173). A real and included citizen actively participates in the political and social spheres of society, in a manner consistent with the expected social norms, whereas an inactive citizen does not or cannot (173, 179). Devlin and Pothier (184) proposed that citizenship requires productivity, and those not deemed productive are considered less worthy of citizenship and its social resource benefits. The constructed "good citizen" deindividualizes citizens to resemble a collective "normalized society," while also revealing those who fall outside

the normative curve (146, 173). As a mechanism of defending society and thus regulating the population, society excludes flawed citizens not contributing to the societal capital (147, 173). Goffman proposed that people are stigmatized when they have attributes that differentiate them from 'normal', that are undesirable to other people, and that reduce the person to be understood as "lesser" or "discounted" (185)(p3).

Comparable to Foucault's analysis of sexuality within the context of biopower, citizenship is positioned at the crossroad between biopolitics and anatomo-politics (147). The construction of knowledge/power informing the ideologies of citizenship at the population level, within biopolitics, manages the population by differentiating and problematizing individual deviants from the norm, identified through anatomo-politics. The individual is subjected to rehabilitation and reform within the techniques of anatomo-politics in order to discipline and produce a docile body reflective of the dominant state ideal of citizenship (177). Within social policies, governments may either adopt a formal, moral expectation of citizenship or abandon these criteria for a citizenship that is based on intrinsic worth of all citizens with the aim of meeting needs and producing equitable outcomes (180). The construct of citizenship may help me to analyze the governmental agencies' documents and carers' reports of how children were treated to identify the citizenship status granted to children with ID within the service system.

### **Integration of Theories**

The rhizome serves as an alternate lens to the arborescent scheme to consider the origins of world order and truth. Awareness of multiple lenses through which to view world order and structure allows a critique of how current structures are formulated. The rhizome provides a framework to guide nuanced critique and questioning of previously naturalized stratification. Positioning discourse analyzes through the rhizomatic lens provides a method of asking, "what has to be assumed to enter into the discussion regarding X?" (144)(p53) and no longer beginning with certain, unquestioned, foundational truths.

Cognizance of the formulation of truth discourses as “corresponding to stratum and its thresholds” (186)(p53) from the rhizome facilitates boundless unravelling of the stratified order. Through this lens of appraisal, settled and closed constructions of being and difference, adopted as foundational truths informing identity, can be recognized as manifestations of current regimes of truth (66, 142, 143, 154). The biopower framework maps and links discourse, and thus the power relations, practices, and social order which stratify societies (66). Anatomico-political and biopolitical practices are recognized as stratifying individuals within populations into context-specific subjects, contributing to the function and well-being of society as a whole (147). The partitioning of individuals through diagnostic classification positions them within “networks of relations” (165)(p146) that inform how they may move and act within the society. Specific to disease classification, this partitioning, conducted by the training practices by professionals granted the authority to judge, directs which service trajectory an individual may take. When an individual internalizes these objectivizing practices, believing them as truly self-representational, the individual becomes a docile body who willingly participates in this process. Analyzing this process, cognizant that classifications represent socially constructed stratifications intended to maximize the functioning of society, aids in the deconstruction of “truths” about any one individual and resistance to their applications within the operations of society (155).

Citizenship discourse represents the societal construct of normal defined within a given social context, determined through an arborescent comparison to attributes considered objective and that which is construed as societal well-being (177, 180). Individuals within society are expected to embody the attributes of this conceptual “normal” citizen through docility and compliance with social training practices. Citizenship discourse is influenced by and influences the practices of biopower, through the biopolitical practices of statistics gathering, healthcare trajectory development, and the anatomico-political prioritization and treatment of individuals.

Envisioning the rhizome as the origin of order presents a conceptual exercise to question and resist the stratifications and confines of social order, previously arborescently perceived as

linearly derived from objective, foundational truths. Conceiving of the potential of the individual as an unstratified becoming, each one different from the other, creates a realm to question all “truths” and social order as boundaries susceptible to change.

I will apply this combined theoretical framework to aid my understanding of how ID has come to be constructed and more importantly how this construction might have determinant impact on people’s lives.

## Chapter 4

### Methodology

In this chapter, I outline the methods of Foucauldian discourse analysis used to explore and understand societal perceptions of intellectual disability (ID) and the subsequent treatment of children with ID within health and social service. I detail the settings, methods of sampling, data collection, and preparation of the texts of provincial documents and carer interviews. Next, I describe the analytic processing of the data, distinguishing the flow of data derived from the documents and interviews. Then I present criteria of rigour for this study.

#### **Design: Foucauldian Discourse Analysis**

Discourse is the scaffold of social order and classifications, not the description of social order (59). A discourse analysis questions how social structures and beliefs represented within talk, text, and practices have developed (59, 61). Data obtained from various sources contribute to this method of inquiry (9, 61, 187). Examples of data are interviews, historical artifacts, political documents, natural observational data, and art (188, 189).

Diverse approaches to discourse analysis exist, ranging from conversational analysis and critical analysis to Foucauldian analysis, to name a few (10, 57, 189). These approaches are set apart through the divergences found within their epistemic stances, definitions of discourse, points of analytic focus, and analytic approaches (59, 188, 189). Of significance to the methodological and interpretative rigour of a study is the identification and delineation of the selected methodological approach within a study from other divergent approaches (59, 189).

I selected a Foucauldian discourse analysis for this study because it can be used to question discursive formations and the power/knowledge contributions within a particular time and society which create order and inform social practices (68, 190). Rather than attempting to illustrate unity and historical consistencies within discursive formulations, Foucault strove to reveal dispersions, or disconnections, and discontinuities among the groups of statements

composing a discourse, and thus dispel realist notions of foundational truths incorporated within held epistemes (68, 190). Dreyfus and Rabinow (72) emphasized Foucault's radical dissolution of inherent foundational meaning within the discourse under analysis as a different approach than was found in phenomenology, where findings were perceived as merely a reflection of current discursive formation, without understanding or critique of how that formation came to fruition. Locke (191) identified Foucault's focus as "not on the sayer but on the said" (p29), referring to Foucault's interest in the limits, and their development, in the discourse of a particular time rather than interpretation from the subjects within discourse. Researchers can delve into the analysis of the power/knowledge relations that influence the development, naming, and treatment of particular groups in society (140). Foucault's antifoundational, poststructuralist analysis of the discourse provides an approach which facilitates new possibilities of understanding discursive order and its effects, and opportunities to begin to question what that which was once considered irrational and unintelligible (68, 72).

The questioning of truths distinguishes a Foucauldian discourse analysis from a critical discourse analysis. Fairclough (192)(p4) conceptualized critical discourse analysis from a critical realist position reflective of Habermas'(139) transcendental-pragmatic pre-supposition conception. Habermas conceived that certain presuppositions of truths, determined through communicative action, are exempt from questioning or critique because doing so would be considered "incoherent" and "unintelligible" (139, 166)(p102). Fairclough (192) maintained that certain foundational truths must remain when he stated, "we cannot transform the world in any old way we happen to construe it; the world is such that certain transformations are possible and others are not" (p5). Taking this position further, Fairclough (193) critiqued Foucault's belief that objects and subjects are wholly constituted through discourse, countering rather that "these practices are constrained by the fact that they inevitably take place within a constituted, material reality, with pre-constituted 'objects' and pre-constituted social subjects" (p60). The associated limitation of Fairclough and other critical discourse analysis proponents' approach is that by

maintaining foundational truths and insisting on attributing social orders to ideologies, discourse analysis is reduced to an appraisal of “what” and “why,” as though a superior, more accurate interpretation could be obtained (194)(p15)(10, 190). Hook (195) added that these efforts, reflective of a “will of truth,” formulate interpretations from a discourse analysis and deny discourse as establishing truth. Further, Hook (195) claimed that the logocentric position that truths inform discourse additionally establishes the author as authoritative on the subject under analysis. In this way, normalized truths considered common sense are preserved, and decentred questioning which aims to challenge any settled truth is limited (10). Foucault (196) described this limitation on the propagation of discourse:

The open multiplicity, the element of chance, are transferred [restricted], by the principle of commentary, from what might risk being said, on to the number, the form, the mask, and the circumstances of the repetition. The new thing here lies not in what is said but in the [predetermined] event of its return. (p58)

To conclude, analysis of discourse from a perspective that maintains foundational truths creates boundaries regarding what can be questioned and the conclusions that can be made.

Foucault’s conceptualizations of power and resistance are important analytic Foucauldian discourse analysis lenses that also set Foucauldian discourse analysis apart from a critical discourse analysis. Critical discourse analysis theory from a Marxist perspective which defines power as a possession “with a unidirectional flow” held by those in dominance over those without power (197)(p192-193). Stoddart (197) proposed that this method of critical discourse analysis evolved from applying ideologies of class to the critique of ideologies of race, gender, and culture. Foucault’s conception of power as productive, circulative, within every relation, and formulated by and informing knowledge, truths, objects, and subjects entails an entirely different line of discourse appraisal (154). Foucault (155) questioned “How is power exercised” (p216), and how have particular objects, subjects, and truths become visible and “constituted in discourse” (10)(p156) instead of asking, what power exists in society and where it comes from. Foucauldian

discourse analysis provides a way to question discourse, and in doing so to map the power and knowledge nexuses that formulate it and the *materialities* that influence and result from it (10).

The mapping focus differentiates Foucauldian discourse analysis from a critical discourse analysis, which views power as a top-down entity (10). The power perspective taken within critical discourse analysis correlates with that of seeking emancipation for the oppressed, concepts which are theoretically different from Foucault's power and subject (10). Foucault's subject is always constituted and, therefore, within power (190). Emancipatory goals from "under" power, therefore, are considered illogical from a Foucauldian perspective, where instead resistance is posed as a response within power (198). Foucault (154) perceived power as exercised and practiced rather than as a thing:

[Power is] never in anybody's hands, never appropriated as a commodity or a piece of wealth. Power is employed and exercised through a net-like organization. And not only do individuals circulate between its threads; they are always in the position of simultaneously undergoing and exercising this power... individuals are the vehicles of power. (p98)

Foucault's intent was not to promote one perspective as more truthful, or to present a solution to social issues (155). Instead, he sought to question perspectives and make known the power relations at work within their formulation (190, 195).

Foucault did not provide a methodological formula for conducting discourse analysis (199). Instead he guided readers to envision his work as a tool kit to be applied creatively (72, 199). Based on the writings of Foucault, Rawlinson (200) developed a three-axis structural analysis guide designed to flesh out how classifications within populations have developed and which power relations were involved. Powers (60) incorporated Rawlinson's structural analysis into a framework which I use to structure interpretation of the findings within the discussion in this thesis.

## **Data Collection Protocols and Procedures: Document Review**

### **Setting.**

The setting of the document review was Ontario governmental agencies' internet websites: Ministry of Children and Youth Services (MCYS), Ministry of Community and Social Services (MCSS)<sup>4</sup>, Ministry of Education (MEDU), and Ministry of Health and Long-Term Care (MHLTC). I selected these settings because these governmental agencies establish regulations and distribute resources to agencies to provide health and social services to children with ID (64).

### **Sample.**

#### ***Sampling.***

I used purposive sampling techniques to select documents according to the inclusion data relevant to service distribution for children with ID, as well as those which would specifically contribute to understanding related political discourses (138, 201). The techniques included maximum variation sampling, emergent sampling, intensity sampling, and reputational sampling. The objective of maximum variation sampling is to obtain a sample that will provide "different versions" or ways of talking about the issue under study (202)(p79). I conducted maximum variation sampling by sampling different governmental agencies to identify, if they exist, constructs of ID, and prioritization for services; this was done to further develop analysis of how ID is understood within service agencies. Maximum variation sampling is consistent with the discourse analysis objective to enhance heterogeneity of representations and identify contradictions (64, 202). I used this sampling technique to extrapolate variations, exceptionalities, and patterns related to constructs and prioritizing of ID within the discourse (203).

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<sup>4</sup> At the time of data collection, the MCYS and MCSS were separate ministries. At the completion of this thesis, these ministries had merged to form the Ministry of Children, Community and Social Services.

I used an emergent approach to identify new documents from references made to them by documents already collected (64, 138). I used this approach to allow for flexibility to sample additional documents that may have contributed to understanding the research problem (138).

I gained understanding of “the nature of the variation of the situation under study” (204)(p172) through iterative reading and interpretation of the sampled documents. I then employed intensity sampling to funnel the full sample of potential texts into a manageable sample (138, 193, 205). Researchers employ intensity sampling to reduce a sample obtained by maximum variation sampling to a manageable sample of cases that best represent the research issue (138)(p518). I included information-rich samples related to the research question and excluded texts determined to not offer any additional information (201, 204, 205).

I conducted reputational sampling through asking key informants from governmental agency settings for suggestions on appropriate document selection (138, 193). I identified key informants by using the “contact us” links on the governmental agencies’ webpages to email and/or phone the agencies to inquire about publicly available documents regarding services for children with ID. Through these inquiries, I was put in communication with governmental agents considered knowledgeable about their agency’s documents regarding ID services.

#### ***Inclusion and exclusion criteria.***

The document inclusion criteria for Ontario governmental agencies sampling were those that addressed children under the age of 18 and were produced from 2008 onward. At the time of this study, the governmental agency responsible for providing services for people with ID changed when the recipient turned 18; therefore, documents addressing children under 18 were considered to be the most encompassing of service navigational issues relevant to the population under study (206). The publication range of the inclusion criteria was based on legislative change in Ontario. From 1974 until 2008, the *Developmental Services Act* directed services for people with ID in Ontario (206). In 2008, the *Services and Supports to Promote the Social Inclusion of*

*Persons with Developmental Disabilities Act* was first introduced as Bill 77 to replace the Developmental Services Act (207). In 2011, the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008*, was passed as law, repealing the *Disability Service Act (207)*. Incurred changes specific to this legislative change were the complete transition from institutional care to community-based services, directives for developmental service agencies related to service delivery and eligibility, and the division of service distribution between people under and over age 18 with ID (207).

To not exclude potential texts which may address children with ID, I included provincial governmental agency documents specific to children with ID and also developmental disabilities. I excluded documents specific to diagnoses of physical disability in children or adults with ID because they do not contribute to the information goals of this study.

#### ***Sample size and saturation.***

Authors on Foucauldian discourse analysis believe that a sample of a few texts or interviews generates an adequate data to conduct the intensive interpretive analysis required in this methodology (9, 187, 202). Authors have described larger samples as an overwhelming hindrance to the analytic process, not equated with greater understanding (187, 191, 202). I determined sampling completion based on theoretical saturation: the quality, thoroughness, and adequateness of the sampled data to support mapping the discourse to address the research questions (see Appendix B for the data saturation table)(9, 187, 195, 208, 209). I used an emergent approach and constant comparison of the collected and analyzed documents and interviews to allow flexibility of the sample size (57, 58, 210). I conducted peer debriefing with my supervisor to enhance confidence in the theoretical saturation of the sample (138).

#### **Data collection.**

I conducted a review of the governmental agency documents. I searched the governmental agency websites for policies, mandates, and position statements, which satisfied

the inclusion criteria and appeared relevant to the research questions (188, 208). I printed and referenced hard copies of the selected documents (211).

### **Data Collection Protocols and Procedures: Interviews**

#### **Setting.**

I conducted the interviews within a rural area of Ontario. I selected this location because it was identified as having the second highest poverty rate in Eastern Ontario (212-214); barriers and complicated navigational trajectories have been identified as challenges for primary care providers of children with ID in this rural area, and residents residing in rural areas have been identified as especially vulnerable to experiencing barriers to services (132). Furthermore, I reviewed the submissions to the Legislative Assembly of Ontario's Select Committee on Developmental Services and found no entries from carers of children with ID from this rural area (35). Therefore, I believed carer discourse would elicit relevant and nuanced findings, which could generate potential future policy changes in this community (132). I conducted the interviews at the participants' selected location of a private meeting room at a developmental services centre or their homes.

#### **Sample.**

#### **Sampling.**

I used convenience sampling by distributing study information letters (see Appendix C) to potential participants who were receiving case management services and/or respite services. I attempted to obtain heterogenic perspectives by sampling from different settings, including this rural region that had not been represented within the research literature or within the Select Committee on Developmental Services, and making the study letter accessible to carers who may have had reading literacy challenges, (9, 187, 202). I believed that carers sampled from different settings and demographics may have held different perceptions. I also used convenience sampling by handing out study information letters to potential participants who were attending

Special Olympics sport practices with their children. Sampling potential participants from sport practices was a sampling strategy that emerged from my learning about the existence of this location from study participants and because more participants were required to achieve theoretical saturation (138).

***Inclusion and exclusion criteria.***

The inclusion criteria for the carer interviews was parents and permanent adoptive families who spoke English and who had been a carer to a child with ID between the ages of six and 14 for more than one year. I established the inclusion criterion of age six to 14 because the diagnosis of ID is most commonly acquired by six years of age and health promotional services are decreased for children with ID after six (29). Respite and foster carers were excluded because their longitudinal recall and access to health and social services may not reflect the experience of permanent carers (215). Children not diagnosed with ID or dually diagnosed with autism were also excluded because of the differences in service allocation based on diagnoses and, therefore, differential service distribution experiences.

***Sample size and saturation.***

I collected and analyzed interview data through constant comparison with the document review data, until theoretical saturation was achieved (9, 10, 187, 193, 202, 210). Authors on Foucauldian discourse analysis deem that a smaller sample size of a few participants is adequate for this intensive methodology (9, 187, 202). From a general search of recent studies applying a Foucauldian discourse analysis methodology to interview data, however, I identified that a sample of 8 to 20 participants was often required to achieve theoretical saturation (216-219).

***Recruitment.***

I solicited participants for this study through the distribution of study information letters that detailed the study and provided my contact information. Case managers at a developmental service centre distributed the letters during home visits with families of children with ID to reach

potential participants who may be geographically isolated. Further, with participant consent, case workers offered to read the contents of the letter to potential participants with reading literacy challenges (see Appendix D for the case manager script) (220, 221).

I attended Special Olympics Ontario sporting practices to hand out study information letters. The coach of the sporting events informed the carers of the athletes of my presence. I provided interested carers with the study invitation letter, and determined their eligibility for the study and appointment for the interview at that time.

I used snowball sampling recruitment to encourage already enrolled participants to invite others who may be eligible to participate until theoretical saturation was reached (221). Snowball sampling recruitment is a method of respondent-driven sampling that helps researchers access hidden populations (222). Carers of children with ID can be considered a hidden population, because attainment of an ID diagnosis does not necessarily equate to a child receiving services and therefore being accessible through the direct recruitment of the service agency.

### ***Compensation.***

Within the study information letters, I offered participants prepaid incentive choices of either ██████ Transit passes, Walmart gift cards, or ██████ Aquatic Centre passes valued at \$25, or else \$25 cash that could be used for child care during the interviews (138, 223).

### **Data Collection.**

Data collection through carer interviews consisted of two steps: the pre-interview contact and the interview meeting. The pre-interview contact consisted of either a face-to-face meeting at Special Olympics practices or participants contacting me via telephone or email. During this step, participants relayed their interest in study participation, and I confirmed eligibility, reviewed the purpose and procedures of the study, and arranged a time and location for the interview with me (see Appendix E for the pre-interview script).

I conducted semi-structured interviews one-on-one with each participant. I informed participants they were welcome to have partners or support persons present during the interviews. I commenced the interview with a settling in phase, where I presented the objectives of the study to the participants, thanked them for their input, and encouraged them to share their perspectives. I then asked broad, prompting “grand tour” questions to initiate dialogue: “When you heard about the study, what made you want to participate? What did you want to share?” I used open-ended, follow-up questions and probes that emerged from participant responses to these questions, to further explore, expand, and compare topic areas raised by participants. I concluded the interviews with a question facilitating participants to address further points of interest and encouraging them to provide other carers with the study information letter; I also thanked them for their contribution (see Appendix F for the interview guide). Because of the semi-structured nature and depth of the interviews, they lasted the expected time of 60-90 minutes (138).

### **Data Analysis: Documents and Interviews**

#### **Overview of analytic process.**

I conducted data analysis of the collected data from the document review and carer interviews over four steps, informed by the process of applied thematic analysis: procedural preparation of the texts, segmentation, coding, and theme development (60, 187, 224). Applied thematic analysis is congruent with a Foucauldian discourse analysis in that it is used as a procedural *guide* to aid in the application of the theoretical questions of a Foucauldian discourse analysis and facilitate the recognition of emergent themes. I commenced analysis of texts as they were collected, and in an iterative process of constant comparison (59).

I analysed the data sets of carer and document discourse first separately, to uncover the aggregated discourses which constituted the construction and function of discourse related to ID, and the current social and institutional influences on discourse; this occurred to develop themes (11, 193, 225, 226). I compared and contrasted the data set themes throughout collection and

analysis, to explore the relatedness and contradictions between the carer and document discourse. This examination led me to formulate the themes of an interpretive explanation of how ID came to be constructed and navigational barriers legitimized, as well as identify areas for future policy change (11, 225).

I then interpreted and discussed the integrated finding themes of the two data sets through applying the theoretical framework described in Chapter 3 and Powers' analytic framework (60) – see immediately below. I employed the theoretical framework to focus the study discussion points through a biopower lens. I used the questions within Powers' framework to form codes within a structural guide book that I used to code and further interpret the themed findings and discuss the research questions (see Appendix G for a list of the structural guide questions) (60, 200)(p59)(224)(p55). I briefly and fully defined the structural codes and provided instruction for when to use them within the structural code book (see Appendix H for the structural code book) (224). In Chapter 6, I detail the interpretation and discussion of the study findings according to the analytic and theoretical frameworks.

#### **Powers' analytic framework.**

I will now explicitly describe Powers' (60) analytic framework to illustrate how discourse and its function, in the constitution of children with ID as subjects within political and parents' discourse strands, were fleshed out in this thesis. The flows of power influencing the social order that I described within the theoretical framework will further be extrapolated. This framework consists of two parts: structural analysis and power analysis (60, 227). Analytic questions emerging from this framework formed the basis for structural codes within a structural codebook that guided the discussion of the findings.

#### ***Structural analysis.***

Powers' structural analysis illustrated the current functioning of discourse within the documents and interviews, constructing and defining objects and further creating subjects (60,

68, 72, 200). Rawlinson (200) provided the three axes of knowledge, authority, and value or justification to unpack the web of power relations between power/knowledge, discourse, objects, and subjects, to adequately “objectivise (the) discourse” (200)(p377). Questioning what links interconnected and conflicting discourses together (60) reflects Foucault’s (68) position that discourses are not distinct entities but representations of power/knowledge relations within a given social context.

Power and knowledge are merged within discourse, where prominent discourses produce what is consumed and perceived as objective, unquestioned truth and ways of thinking and knowing (60, 68, 227). The power/knowledge of the discourse of medicine, for example, discerns or formulates medical objects, such as people with ID, who become patient subjects (68, 227). Foucault (68) defined the rules of such subject formation: “surfaces of emergence”, “authority of delimitation”, and “grids of specification” (p41-42). Surfaces of emergence refer to where discourses which create or transform an object emerge from, be it a pre-existing field (such as the family), a social group, or a discipline (such as psychiatry), or else from a new surface of emergence (68). An authority of delimitation refers to those to whom society has granted authority in identifying, naming, and defining the components of an object, and therefore those who hegemonically contribute to the construction of the discourse surrounding that object (68)(p41-42). Foucault (68) provided the medical profession as an example of an authority of delimitation in the establishment of madness as an object. Lastly, grids of specification are hierarchical organizational tables which divide and classify subgroups of objects of a discourse to further make diagnosed subjects visible and known (68). Powers (227) offered the DSM as an example of a grid of specification.

Rawlinson’s three axes facilitate this line of questioning, addressing the web of power in discourse, and the subsequent functions of that discourse in creating subjects. Rawlinson developed the axis of knowledge to analyze the rules and concepts required to produce statements, truth, and what can be said about the “constitution of the object” (200)(p377) or, as

O'Grady (228) referred to it, "the rules for the sayable [discourse]" (p82). Powers (227) stressed the epistemologic importance of this axis in light of its central tenet of truth. Rawlinson developed the axis of authority to examine the systems of power which support, preserve, and maintain a particular truth discourse (200, 228). This axis relates to the rules of authorities of delimitation, which determine what can be said, what is considered to be true or false, and who may speak (60, 68).

Rawlinson developed the axis of value or justification to question the justification of the application of discourses on individuals to create subjects (200, 227). The structures under view in this axis are systems of regulation, organization, normalization, and technologies of power (200). The group, organization, or institution which holds the authority to pronounce truth and discourses determines the composition of normal, against which the abnormal are judged and laden with restorative or corrective technologies of power to optimize the life and health of the overall population (161). I will use the questions of this axis to illustrate the relationship between the carer and document discourses, and their connection to the biopower framework.

### ***Power analysis.***

Powers (60) developed power analysis to examine the current effect of the discourse on dominant power relations between groups of people and institutions, or in this case individuals and biopolitical actions (200, 227). The analyst will search for alternative discourses within the dominant discourse which signify potential points of resistance (60).

To conclude, I will apply the lens of the theoretical framework to the findings of this study. I will use Powers' analytic framework to form a structural codebook to examine the findings and identify the intricate concepts that construct the larger theoretical framework components.

The four procedural steps (see Figure 1), are explicitly detailed in the following text.

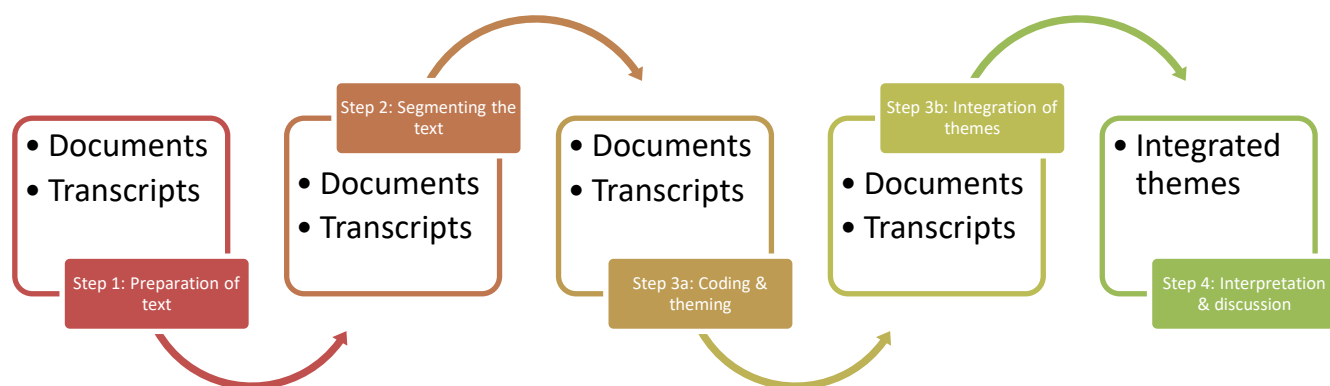


Figure 1. Flow of Text through the Analytic Process.

### **Step 1: Preparation of the texts.**

#### ***Documents.***

I read and reread collected documents, making tags and memos, to make note of potential emergent patterns (224).

#### ***Interviews.***

I transcribed verbatim the interview recordings with an emphasis on retaining the highest resolution of the data possible (187, 202). I kept analytic notes through the transcription process to record the initial themes and responses elicited in this phase (188). I then numbers each line of text to segment it into workable units for analysis (187, 202).

### **Step 2: Segmenting the text.**

I created segments by defining where “meaning begins and ends” (224)(p51). I sectioned off text which appeared meaningful to the research questions and which identified contradictions or points of conflict in the data (187, 224). Congruent with Foucault’s (68) intended focus, I paid attention to the “said” and “not said,” subjects’ positioning within the discourse, and the functioning

of that positioning within the text. The “said” referred to isolating tacit sentiments about the social context under analysis, and the “not said” to what was not discussed (60, 191). The “not said” also included the assumptions the participants’ held to have made the statements they did during the interviews. I used inclusive segmenting to capture vague, poorly understood, and borderline text segments to not overlook potentially relevant data (187, 188, 202, 224). I labelled the document, transcript, and context from which segmented data were extrapolated to allow future review and retrieval of the data from the original corpus of text (229). I flagged the segmented data and their origin in a codebook. The data sets were separate at this stage.

### **Step 3a: Coding and theme development.**

Throughout the coding process, I kept tags and notes to record impressions of possible emerging themes separately and comparatively between the interview and document data sets (224, 225). I then grouped the coded data segments of each data set into clusters, according to similarities, on a large poster. The data set clusters remained separate at this point. The coding process was cyclical in that constant comparison between what was collected and what new codes emerged from newly collected interviews and documents returned me to the earlier analyzed transcripts for further review (188). When the coding process was complete, I compiled and grouped the codes, notes, tags, and clusters into themes in an Excel document (224). Separate grouping of the data sets was aided with the following cues: repetition of the same ideas or concepts, categories referring to the unique meaning placed on a term and the way that a community uses it, and identification of similarities and differences between sections (229). I reread the texts to evaluate the organization of codes and to determine if other themes emerged.

### **Step 3b: Integration of themes.**

I compared and contrasted the themes between the data sets to develop a thorough interpretive explanation of the web of power between the discourse strands of the data sets.

#### **Step 4: Interpretation and discussion of themes.**

I read and reread the separate and integrated themes to formulate the most pertinent emergent discussion points. I interpreted the discussion points through linkages with the theoretical framework. The structural code book was also used to code sections of the findings to assist in locating the aspects contributing to the construction of ID within a biopower context. I used these codes to facilitate theoretical discussion and interpretation, while leaving the findings open to alternative interpretations, and providing transparency to my interpretations.

#### **Rigour**

The quality of a Foucauldian discourse analysis is evaluated according to the thoroughness of the methods and the interpretations, the reflexivity of the researcher, and the internal coherence or congruence of the study (57, 58, 60-63). I will explain each of these criteria, with examples of approaches that I took within this study.

#### **Thoroughness.**

Practitioners of Foucauldian discourse analysis reject the criteria of reliability, validity, and dependability as measures of rigour because these criteria employ a realist assumption of truth considered impossible and incompatible with the “radical scepticism” relativist stance and explanatory aims of Foucauldian discourse analysis (62, 63). The tenets of Foucauldian discourse analysis are that there is no truth to be discovered; instead, exploration maps how a perceived truth came to fruition (60-63). Mapping of discourse formation is not considered generalizable, stable, or representational of an uncovered truth (57-59). According to Crowe (57), the mapping of Foucauldian discourse analysis is intended to illustrate the power/knowledge relations that have constituted discourse and particular objects within a specified society and time. Any Foucauldian discourse analysis mapping is considered one of infinite possibilities of interpretation, itself subject to analysis and critique (59, 60). Authors on Foucauldian discourse analysis thus situate the thoroughness of an interpretation as a measure of rigour for this methodology. Researchers’ demonstration of thoroughness does not indicate acquisition of truth, the totality of

what can be concluded, or that bias has been bracketed. Researchers' demonstrated thoroughness establishes the quality of the study and the discursive mapping developed in "its own right" (63)(p156). By thoroughly disseminating study findings, researchers may generate nuanced debate regarding the discursive formulation under critique (59, 62).

In this study, I adhered to the criteria proposed by Crowe (57), Madill et al. (62), and Phillips and Hardy (59) to enhance the thoroughness of Foucauldian discourse analysis methodological process and results: inclusion of a plurality of texts representing diverse voices within the collected samples (195, 230); detailed description of the theoretical framework, collection, and analysis processes; clear linkages between analyzed data, findings, and interpretations; and inclusion of sufficient raw data to allow readers to appraise the analysis (57, 59, 62, 187, 202).

I sampled carers of children with ID and from governmental agency documents, to enhance the study objective of conducting a nuanced critique of the discursive formulation of ID through expanding the inclusion criteria to voices often unheard (59)(p83). Phillips and Hardy (59) stress, however, that although effort may be placed on identifying voices which are often missed, because of the discourse in which even the researcher stands, it is impossible to determine if all silenced voices have been heard.

I explicitly detailed the theoretical framework guiding this study and linked it to the justifications of the methodological choices that I made: for example, sampled data and data collection techniques. My prolonged engagement through transcription, reading and rereading of documents and transcripts, and repeated listening to recordings enhanced the thoroughness of linkages informing resulting discursive mappings of the study data (57, 58). I used a structural code book to guide the analysis and discussion of this study through the amassed line of questioning of the discourse, formulated from the writings of Foucault (60, 200). I used the structural codes and the separate steps of analysis to provide transparency and direction to the

questioning applied to the data so that the origin of the resultant study findings can be understood by readers and opened up for constructive debate (57-60, 224).

I prioritized achieving theoretical saturation to determine sampling, data collection, data analysis, and the conclusion of this iterative process (9, 187, 202, 208). I believe that theoretical saturation bolstered the thoroughness of the explanation to the research questions that I developed in this study.

In this study, my findings emerged from addressing the research questions and I interpreted these findings in the discussion using the analytic and theoretical frameworks. I used these frameworks to transform the study themes, through analysis, into discussions that contribute to the topic under study, and thereby develop linkages between the guiding frameworks and achieving the discursive mapping goal of Foucauldian discourse analysis (188, 195, 196, 231). I used excerpts from the collected data to establish linkages between data, frameworks, findings, and interpretation (62, 187, 231). I was cautious to not include superfluous data segments or stand-alone quotes that were devoid of analysis and interpretation (231).

### **Reflexivity.**

The internal cohesion and reflexivity measures of discourse analysis quality are relational in that determinacy of internal cohesion within a study depends on the researcher's declaration and transparency of their subjective position within their specific discursively constructed context, and the paradigm and epistemology informing their world view (9, 72, 191, 232, 233). As no one stands outside discourse, the practice of reflexivity reinforces the position that no voices are "truer" than others or should be privileged over others; each voice is "but one representation" (59)(p84). Powers (60) emphasized that discourse analysis places a "lack of focus on... the deeds of great people" (p63). To clarify, no interpretation should be adopted as truth, defended as such, or used as a measure to critique others (59). Instead, transparency of the researcher position and

researcher awareness of their constituted and constitutive role within the discourse, through practices of reflexivity, aid in reducing a biased interpretation (59, 210, 231).

My position and personal objectives were made explicit in Chapter 1 to demonstrate reflexivity within this study and situate the study's aims (9, 61, 64, 191, 232, 233). My reflexivity during formulation of meaning within the analysis stage was enhanced through peer debriefing with my supervisor regarding the formulation of the structural code book, coding, and theming (59, 138). Through these reflexive steps, I explained my methods and thought processes guiding them to facilitate appraisal and critique of my interpretations and to promote dialogue and debate about the "multiple meanings and readings" (59)(p84) that can be devised from this discourse analysis.

#### **Internal coherence of the study.**

Although discourse analysis approaches vary (62), many authors of discourse analysis agree that it is the imperative to strive for internal congruence of the study (57, 58, 61, 63, 188). A researcher demonstrates congruence within their study when the epistemic and ontological stance is compatible with the objectives of the selected approach of discourse analysis, the research questions, the theoretical framework, and the conducted analysis (57, 58, 62).

I demonstrated that there is internal congruence in this study by establishing the compatibility of the poststructural epistemic stance with the theoretical framework that I used to employ the constructs of stratification and biopower to critique social constructions. I used this developed framework as lens from which the research questions emerged. Questioning how the object of ID is constituted within the discourse, and the implications of ID subjectivity within the current social context, is a congruent progression from the epistemic stance and theoretical framework of this study. Furthermore, in this inquiry, I aimed to produce an interpretive explanation of the discursive formation of ID that is compatible with the objectives of Foucauldian discourse analysis.

## **Ethical Considerations**

The University of Ottawa Research Ethics Board granted permission for me to conduct research involving people with ID and to distribute study information letters through a developmental services centre and Special Olympics Ontario (see Appendix I for approval letter)(138, 215). I obtained organizational permission from Special Olympics Ontario and the developmental services centre. Ethics review and consent was not required from the provincial governmental agencies to conduct a critical inquiry of policies they produce (215). I informed individuals approached within the governmental agencies of the study, of the potential consequence of stigmatization from participating, and that agency consent was not required or obtained (215). The potential critical or negative societal response to provincial governmental agencies ignited by this study's findings is a minimal risk in that it is no greater than that experienced by public organizations everyday (138, 215). Therefore, the names of the governmental agencies were disclosed to identify specific areas for future action or change (215).

The developmental services centre case managers distributing the study information letters emphasized that participation had no influence on service provision, nor would the agency have knowledge of who participated or what they disclosed. The case managers initiated no further dialogue to potential participants about the study (193, 221). The case managers identified eligible carers who had or were suspected to have literacy challenges and offered these carers a reading of the study information letter to ensure distributive justice of inclusion of minorities who may benefit from representation in the research (138, 215). I informed the potential participants at Special Olympics sport practices that participation was voluntary and was not affiliated with the Special Olympics Ontario and ensured confidentiality of participation and contribution.

I scheduled appointments according to participant convenience to mitigate the inconvenience of the participant time commitment for the study (138, 215). I provided the participants the choice to meet in their homes or a private meeting room at the developmental services centre during operational hours. I informed the participants in the initial phone contact

that staff personnel would be present in the building for security purposes set out by the agency, outside of the interview room, removing anonymity of participation.

I began the interview by reviewing the consent form to obtain participant consent to participate in the study and for the interview to be audio-recorded to aid in transcription (see Appendix J for consent forms) (187, 188, 202). I obtained participant informed consent following full disclosure of the following: purposes of the study, the collection and use of the interviews, participants' role in procedures, potential risks and benefits, my academic requirement in the study and contact information (email and cell phone number), assurance of privacy and confidentiality, legal and professional requirements of disclosure, and voluntary participation and right to withdraw at any time (138, 215). I also informed participants that the opportunity to discuss experiences in a supportive environment may be a potential benefit for them (138, 215). I provided participants a copy of the signed consent form and their chosen incentive, not contingent on interview completion. Some researchers who have used incentives believe that the value of the provided incentives is an appropriate gesture of appreciation for participation, and is not coercive or demeaning of participants (138, 215, 234).

The potential for emotional distress related to reflection upon and intensive questioning about possibly upsetting events was greater than that occurring in the participants' everyday lives (138, 215). I informed participants of the moderate risk of their participation in this study in the consent form (138, 215). I encouraged participants to contact their case manager within the developmental services centre if they experienced emotional distress or other challenges (215). I made participants aware that discussing their emotions related to their study participation with a case manager from the developmental services centre would breach the anonymity and potentially the confidentiality of participants. I informed participants that a service gap in community social work situated case managers as the only accessible service person providing such a role to carers of children with ID in this rural area of Ontario. Further, the executive director of the developmental services centre suggested that case manager presence may provide

participants with social support. I informed participants via the telephone conversation that their anonymity in participation and confidentiality of information they disclosed would not be maintained if they requested their case manager to attend the interview.

I protected the privacy of participants through deidentifying them by removing names and places during transcription and numbering the interviews and quotes in chronological order (138, 215). Published direct quotes were modified to protect participant identity (138). I kept all data securely in a locked file cabinet, only accessible to my supervisor and me, to be destroyed five years following defense of the study. I will not use disclosed information for any purpose outside of the negotiated terms, except in circumstances where legal or professional obligations require (215).

## **Chapter 5**

### **Results**

In this chapter, I present the results from the interviews and document review. Then, I compare, contrast, and integrate the themes of the two data sets to address the research questions.

#### **Findings of Carer Interviews**

My analysis of the interviews with carers of children with intellectual disability (ID) produced three main themes, each with subthemes, and categories. These are represented in Figure 2. This figure is a useful visual to situate the reader of the results section.

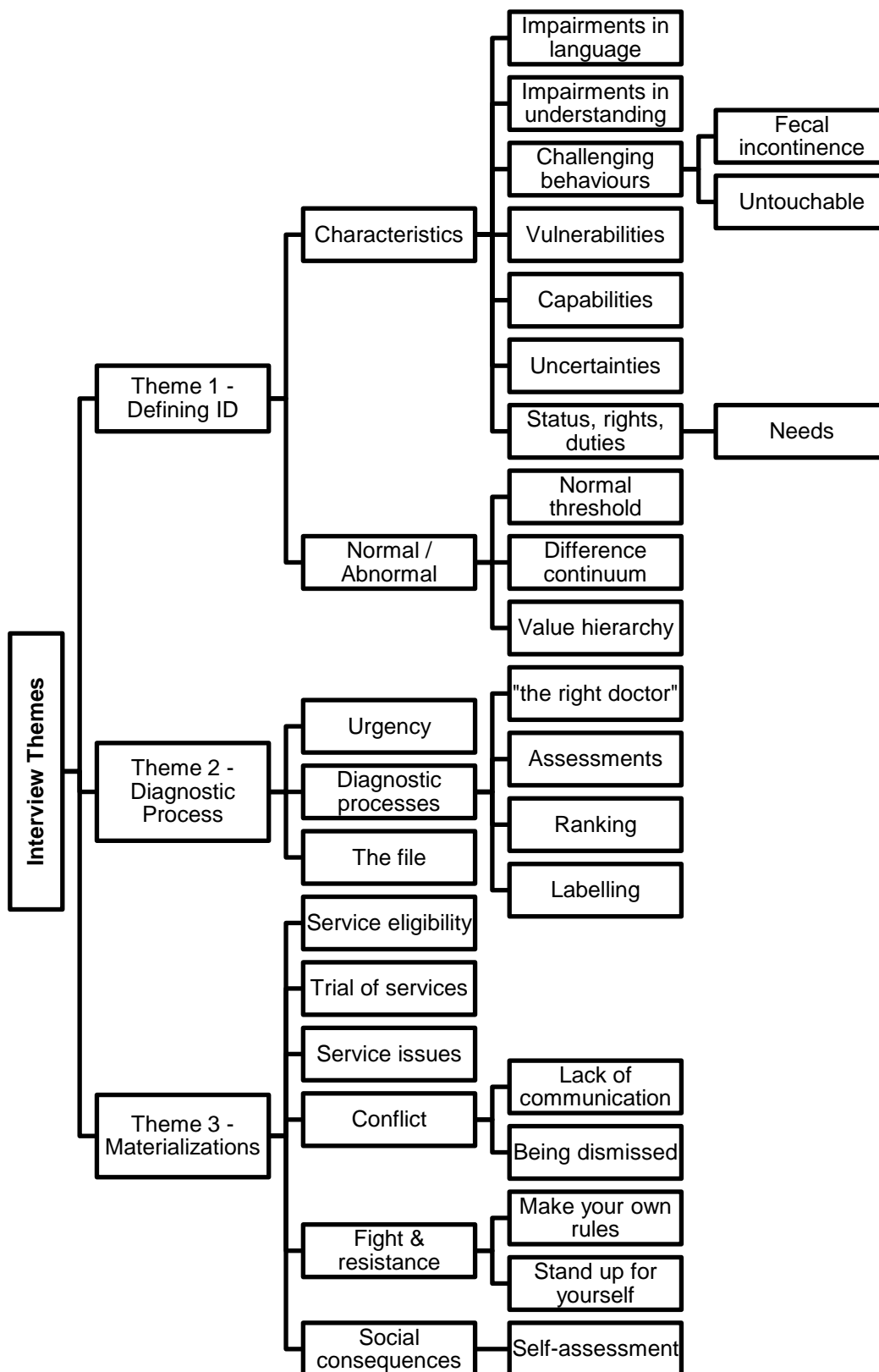


Figure 2. Interview Themes and Subthemes.

### **Theme 1: Defining intellectual disability.**

To address the first research question regarding how ID is understood, I examined the carers' discourse about their children and presented it in Theme 1 to gain an understanding about their beliefs related to ID. A central theme in the carers' understanding is their belief that society views their children as being ID rather than having ID. To explain further, ID was considered to be the children's identity rather than something they experience and live with. The carers referred to incidents when peers and adults used negative and pejorative slurs disparaging ID to refer to their children. As an example, carers repeatedly stated that their children had been referred to by their peers as a "retard."<sup>5</sup> One participant recalled a pediatrician referring to her newborn as a "mongrel" when he told her that her son had Down syndrome (Int 4, 567). In response to their behaviours at school, the children were reportedly called "mean," "rotten," "nuisance," and "bad." The contexts of these behaviours were within one instance, where the child had not followed the direction for the class (Int 5); in another, where the child had hit a peer and spread feces (Int 4). The children with ID, rather than their experienced challenges that may have contributed to the behaviours, were problematized within these situations. Taken as a whole, these data show that, for these carers, the child with ID is known and understood socially as their diagnosis; these negative terms denoted that they "are" intellectually disabled, not that they experience ID. The distinction is between displaying traits, and these traits being viewed as a person's essence. In other words, impairments associated with ID in the diagnostic discourse are not reflected here as challenges but as intrinsic characteristics of the child.

From analysis of the data, I identified specific elements of impairments and capabilities that carers perceived to be characteristic of ID. In Subtheme 1, I detail these characteristics, followed by their implications regarding what the child with ID is assumed to need. In Subtheme

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<sup>5</sup> Int 5, 1649-1651; Int 2, 364-365

2, I explore the more abstract understanding of ID through the designation of ID within normal versus abnormal, its location within a continuum of difference and hierarchy of value.

***Sub-theme 1: Characteristics.***

The carers identified strengths and challenges in areas of development, social interaction, and behaviour that were perceived as characteristics of children with ID.

*Impairments in language: "She needs help in communication." (Int 6, 60-62)*

Impairments in language and communication emerged as the central defining characteristic of ID, which was believed by carers to contribute to their children's challenging behaviours, vulnerability, and needs (see sections on Challenging Behaviours, Vulnerabilities, and Status, Rights, Duties). The carers defined communication impairments as the use of language that was not understood by others, selection of incorrect words, difficulty articulating emotions and thoughts, and, in one case, a child's total inability to speak (Int 4). In the following quote, the carer perceived her child to have difficulty expressing herself through language.

[Child's] problem is communication, verbalizing what is in her head. She's got a lot of good ideas and thoughts and she understands a lot but it's verbalizing it. (Int 6, 107-109)

In the next quote, the carer referred to the verbal dialect the child used as "jibber jabber"; the carer described her daughter's speech as incoherent and excited. Rather than suggest that the dialect is meaningless, the carer believed it was purposeful "and not understood by the listener:

She's a smart kid but she's not very verbal. She is—I've tested her. I've asked her certain things like, "Get me this or that." You're calm enough, she understands what you're saying. She can't come out with the words. Her jibber jabber is talk for her. (Int 1, 746-751)

Although the children's communication was often unintelligible, carers maintained that their children do have cognition, thoughts, and something to say. This belief was evident through the statements carers made in relation to their child's impaired language: "he's smart," "he understands" (Int 5), "she's got a lot of good ideas" (Int 6). The children were described by carers as "knowing what they want to say" (Int 5, part 1), but not being able to "get it out" (Int 5, part 2). The carers believed this inability to communicate ideas, needs, and emotions, or to fully

participate in social interactions resulted in the children's isolation. The carers distinguished that the primary ID element of impaired communication concealed their children's actual cognition and thoughts from others. For example, the carers in the following quotes believed their children had thoughts related to wanting a drink of water, and emotions related to a schoolyard accident, respectively. The children with ID within these situations were perceived to have interpreted their own needs and emotions but were unable to communicate these thoughts through language. The carers believed that this struggle contributed to their children's challenging behaviours of banging, screaming, and self-harm threats.

He's extremely smart and he knows what he wants, he just can't say it. No matter what "it" is. A glass of water, he'll bang and scream instead of saying, "I want a glass of water."  
(Int 5, 48-50)

He got upset one day because he accidentally did something and some kid got hurt... He ended up climbing on this gym thing and walking around it and threatening to jump off. He can't express himself... Instead of just saying, "I'm sorry. It was an accident." He can't get that part out. (Int 5, 372-377)

The carers believed that impairments of communication concealed their child's cognitive abilities and thoughts. Indeed, carers reported translating to convey their child's message (see section on Needs) and the meaning behind challenging behaviours (see section on Challenging Behaviours).

*Impairments in understanding.*

Participants' beliefs about their children's impaired understanding was a second central aspect of participant understanding of ID. The carers perceived their children to have limitations in understanding and interpreting context and social situations that did not impair every life encounter but, nonetheless, demarcated and disadvantaged the children with ID from others without ID. The carers appraised the level of their child's understanding by comparing their child to their perception of the normal level of understanding for a specific age.<sup>6</sup> In the quote below, the

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<sup>6</sup> "He might be twelve years old but he has the learning capabilities of a seven-year-old" (Int 3, 381-382).

carer perceived that her child's impaired ability to behave in a manner consistent with his chronological age and accurately discern social interactions with strangers in a safe way signified the child's impaired understanding and intellect, and justified her apprehension to allow him to walk alone in the community:

He is thirteen but his mentality is not there... When he gets his maturity age I wouldn't care to let him go but I don't want him to walk from there to there and what if somebody stopped and says, "You want to come find my cat?" (Int 5, 825- 832)

The carers perceived that their children lacked understanding related to consequences and messaging in social interactions. The following quote provides an example of a child's perceived challenge to interpret what his peers meant by calling him a "retard."

He was upset. I don't think he really knows what the word [retard] means. He just knows someone called him a bad name. (Int 5, 1662-1663)

The child in the next quote was believed to have difficulty understanding classroom instruction and how to seek clarification:

As soon as she leaves school she shuts off the switch and she knows nothing. In class, apparently she understands. She never asks for help and when she gets here I'm like, "Let's review what you learned today." She has no clue. (Int 6, 74-77)

The children's perceived impaired understanding of social interactions and expected behaviours resulted in strained relationships with their peers and potential lost opportunities for scholastic growth. Below, the carer perceived that her child did not understand that his actions hurt his peer, resulting in the peer's rejection of the child with ID:

A little girl kept coming up to me and saying, "I don't like [child] because [child] hurts me." What do you say to her? "I'm sorry he hurts you. He doesn't understand." But I don't think she understands that he doesn't understand. (Int 4, 466-471)

Impaired understanding was not described to mean that the child had no understanding but, rather, that certain understanding limitations were great enough to cross a threshold to be significantly greater than those of their chronological peers.

*Challenging behaviours.*

Every carer described challenging behaviours that their child exhibited (aggression, defiance, tantrums, and fecal incontinence) as another common characteristic of ID. The carers believed these behaviours were reflective of their children's impairments related to ID: communicative, social, and developmental. The carers expressed feelings of concern and fear for their child's safety, the perception of others witnessing their child's challenging behaviours, and managing their child when the child was being aggressive. Aggressive behaviours were described as verbal and physical attacks by the child with ID against siblings, carers, peers, and teachers. One participant specified that aggressive actions included "banging and screaming and being disruptive" (Int 5, 1031). In the following quote the participant recalled informing a new teacher of her son's challenging behaviours:

He bites, he slaps, he's not potty trained. He's got behavioural issues. You've got to be on him. He'll run. He'll go out the door—safety concerns. He's not aware of the dangers around him. He'll drink anything that's there, or put things in his mouth. (Int 4, 233-239)

The carer in the quote below describes "freak out" behaviour as a reoccurrence in the home, associated with risk towards the child's sibling:

I had to keep [sibling] away... She knows when [child with ID] is freaking out to walk away. It started when she was young. When he would freak out [partner] would deal with him, and I would take [sibling] and lock myself in the bathroom. It was the only door that locked, just so he wouldn't hurt her because she was just a newborn. (Int 5, 1390-1394)

Examples of acts of defiance were elopement, as presented in the above example, and as reported by two other carers.<sup>7</sup> Further, all participants reported situations where their children did not adhere to requests made by carers or teachers. Carers understood challenging behaviours in some situations as serving as an alternative form of communication, as explored in the previous section. In other situations carers understood challenging behaviours as serving no purpose and as one-dimensional characteristics of ID. As an example of the latter understanding, the carer in

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<sup>7</sup> Int 3, 471; Int 5, 793

the following excerpt positioned her son's stubbornness as a way "he can be", rather than questioning whether his stubbornness expressed his preferences.

It's hard to find someone because he can be obstinate sometimes... You want him to go this way and he'll go the opposite way." (Int 3, 410-412).

Challenging behaviours were perceived as characteristic norms of ID when they were not interpreted by carers to communicate anything except the state the child was in. Alternatively, carers frequently discussed the function of their children's aggressive behaviour, defiance, and tantrums to evidence their children's needs for support persons at home and school. To summarize, the carers positioned challenging behaviours as both intrinsic to the child with ID and alternatively as an expression of their impairment.

*Fecal incontinence.* The carers specified that fecal incontinence was a key aspect of challenging behaviours of ID. Five of the eight participants<sup>8</sup> reported that their children with ID experienced fecal incontinence. While conducting one interview, a carer excused herself temporarily to assist her child with a changing following fecal incontinence. Incidents of fecal incontinence occurred in front of peers at school, where the children required assistance because they were either not toilet trained or could not independently clean up following toileting or incontinence. In all quotes regarding fecal incontinence, the carers framed it as a consequence of the child's self-care, communication, or neurological limitations from ID. The carers also discussed fecal incontinence according to how school staff and peers responded to the child when they were incontinent (see section on Untouchable). In the example below, a carer related her child's incontinence to his disinterest in toileting, combined with interruptions in his brain's messaging prompting him to toilet.

After he got off the toilet he did it [fecal incontinence] because he could do it but he didn't bother thinking about going to the toilet to do it. So here to here—[carer motions from head to stomach]

**It doesn't bother him that it's [feces] in his pants?**

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<sup>8</sup> Int 2-5

No. He's done it for so long he doesn't care. (Int 2, 1209-1214)

Another carer associated her son's impaired communication with his fecal incontinence:

He'd tell the teacher he'd pooped his pants. She'd call home right away. By the time that I'd got there, of course he did but he had to go to the bathroom. (Int 5, 222-225)

The child would state that he had been incontinent but his presumed intended message was that he *needed* to defecate. Because of the impaired communication, the teacher did not understand that the child needed to be permitted or assisted to go to the bathroom, resulting in the child being delayed or restricted from using the bathroom and therefore experiencing fecal incontinence. Three participants believed their children had impaired ability to independently perform personal hygiene following defecation or incontinence.

He still has trouble wiping himself so usually after he goes he takes a shower so at school he won't go.

**When there were accidents at school...**

They [school staff] won't change him. (Int 5, 233-237)

They used to call me at work to go to school to help him clean up because he said he couldn't do it himself. (Int 2, 1108-1110)

In the following excerpt, a carer recalled receiving a notable call from the school to assist her son who was not toilet trained and had been incontinent and engaged in scatolia behaviour.

I got a call from the school. I was so insulted. [Secretary] said, "You need to come and get [child] right now. He's put his hands in his poop and he's putting it all over the place." (Int 4, 258-260)

Carers discussed the problem of fecal incontinence in relation to its reflection of the child's impairments in communication, and as a challenging behaviour. Further, they attributed the children's inability to independently toilet and perform self-care to the children's impaired development related to their ID. Through associative carer talk of fecal incontinence and ID, fecal incontinence was classified as a characteristic of ID.

*Untouchable.* The carers perceived that their children's fecal incontinence, and to a lesser extent aggressive behaviours, contributed to society defining ID, and specifically children with ID, as untouchable. The carers articulated their perception that their children were viewed as untouchable through reports of school staff refusing to assist the children with ID to clean up following fecal incontinence: "They [staff] won't change him" (Int 5, 237). The child's dignity was negated in this manner and was highlighted in the following text:

There were seven adults standing in the room and he was standing there covered in poop. No one would touch him. (Int 4, 261-264)

Further, the child's dependence on staff was rejected. This rejection was evident in the above participant's description of her son surrounded by, but not supported by, school staff. She noted a school staff member justified the lack of attendance to her son by referring to an unspecified rule that staff were not allowed to have physical contact with students, saying, "We can't touch him" (Int 4, 272). The school staff projected that the school system had taken the position not to touch children with ID requiring assistance in these situations.

Further, the carers reported that occurrences of their child's fecal incontinence became known to their peers because the children were left in their soiled clothes for the duration of the day or until their carers came to the school. This resulted in the child's peers being repulsed. One carer described her child's school peers noticing the odour of his feces-soiled clothes.

He'll come home smelling.

**How does that go with his peers? Is he having any issues?**

Sometimes they say, "[child] stinks." (Int 2, 1116-1118)

The carers reported that their children's peers witnessed the school staff segregating and not supporting their children with their incontinence. In the excerpt below, a carer stated that her child's classroom was evacuated following his fecal incontinence.

I know that when the whole poop thing happened they removed the class. That happened in front of the class. (Int 4, 487-489)

The above reports highlight that the child with ID was seen as abhorrent by peers and that school staff felt the incontinence was the carer's responsibility. The child with ID was thus socially and physically segregated because of being perceived as untouchable.

*Vulnerabilities.*

Vulnerability was another defining feature of ID. Limitations in communication and understanding as well as challenging behaviours led carers to identify their children with ID as vulnerable. Vulnerability was discussed in relation to the children's susceptibility to being mistreated, neglected, and taken advantage of, as well as their compromised ability to interpret situations and defend themselves. One carer believed her adopted child may have had negative experiences in foster care but could not fully verbalize them:

[Child] said, "I wasn't allowed out of my room at night. They locked the door." Because her speech was so delayed, God knows what else. There were some alarms there. (Int 6, 485-487)

The carers were concerned for their children's care and safety at school. One carer was fearful that school staff were not assisting her son with self-care:

I made him go in the washroom and I cleaned him up. He knew that I was angry and I felt bad because he's not being assisted. It took me to come down there... I'm scared that I'm sending him there to get babysat but I feel like he's being abused. (Int 4, 284-289)

She also reported that a school staff member had physically mistreated her son:

It scares me. He's had an incident this year where he slapped an educational assistant and she slapped him back. (Int 4, 183-184)

In the following text, another carer spoke of her concerns about her child managing on his own, and his vulnerability to harm from his peers:

You wouldn't allow him to go to the washroom alone because what if something happens and he takes off? (Int 5, 350-351)... It's him coming home and "Mom, [child] put his penis on my penis in the bathroom." (Int 5, 466-467)

A general mistrust of society to provide a safe space for their children with ID created, for carers, a heightened sense of their children's vulnerability and risk. A carer was concerned that her child's inability to read and write as well as understand social interactions positioned him as vulnerable,

stating, “Anybody could take advantage of him” (Int 2, 750-756). The carers in the following quote responded to the elopement of their teenage child by contacting police and requesting the issuing of a missing child protocol. The immediate response of calling 911, following not being able to find their teenaged son, highlights the carers’ heightened belief that their child is vulnerable.

Resp 1: As soon as I realized what took place, I couldn’t see him, I was right on to 911 and was putting an “amber alert” out...

Resp 2: Because you never know... (Int 3, 523-526)

The mother justified her actions, saying, “because you never know.” In this statement, the carer alluded to her concern about negative possible outcomes for their teenager with ID being unaccompanied. Carers’ fear of risk to their children and the ID characteristics of impairment and challenging behaviours are interlinked with and substantiated vulnerability as a characteristic of ID.

*Capabilities: “He’s capable of doing well.” (Int 5, 1568)*

The carers identified and highlighted their children’s capabilities in all areas of development as an important characteristic of ID. The participants identified characteristics of challenges and capabilities as coexisting even within the same areas of development. Capability was discussed through the carers’ descriptions of their children as thoughtful, interested, and able to learn scholastics and life skills, and achieve their potential. One carer spoke of her child’s ability and desire to learn that led him to seek to be taught:

He can learn and he wants to learn. He comes home and he watches YouTube videos of grade six teachers teaching a class. (Int 5, 1070-1071)

The carers recognized the practical skills their children had mastered and took pride in: learned routines, self-regulation, self-care skills, and participation in household chores and activities.<sup>9</sup> The carer shows her recognition of her child’s abilities in the following quote:

He feeds himself. You have to get him changed and bathed and he’s not potty trained but you’ll give him his plate and he’ll eat himself and he’ll put his food in the garbage, put his plate in the sink. He sleeps all night and he really does his own thing. I don’t follow him

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<sup>9</sup> Int 3, 1140-1146

around. I don't have to keep a constant eye on him. He goes and plays outside. He stays in the yard. He's pretty easygoing. (Int 4, 688-693)

One carer highlighted and celebrated her child's abilities and developing social adaptive skills through recounting when her child independently set personal goals and assessed social situations to resolve her fear of public speaking and develop her self-esteem:

She thanked everybody for supporting Special Olympics and that she was very happy in swimming, with a mic and spoke. That is so out of character, but now at school, this past week she's like, "I want to audition for the talent show... I know I might not get a part in the talent show, but I think it will help me with my stage fright." I thought, "Wow! The fact that you want to—I support you a thousand percent on that. Good for you for thinking and linking the two together. That could help you." (Int 6, 584-592)

Two carers discussed how their children pretended to be ill to delay a test or to leave school early.<sup>10</sup> The participants perceived this as demonstrative of the children's capacity to interpret social situations, strength in interpersonal skills and communication, and recognition of the consequences of their behaviours for the responses of others:

I had to go get him at 8:30 because he was telling his teacher he was sick... He came here and he played with toys and video games and went to soccer last night. He'll do that once or twice a week. Just make up an excuse to come home... He's very good at manipulating people. (Int 5, 237-242)

Characteristics even within the same child were seen as non-uniform and multi-dimensional, with diverse strengths and challenges co-occurring. The characteristics of children with ID were thereby constructed with fluidity within and between children with ID.

### *Uncertainties.*

The carers described uncertainty as a fluid characteristic of ID now and in the future through discussion of their goals for their children and their perception of the unpredictability of their children's achievable level of independence required to reach these goals. The carers voiced their desire for their children to be able to "do what they want" without "any boundaries," to be "happy," to succeed, and to be members of society.<sup>11</sup>

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<sup>10</sup> Int 6, 101-106

<sup>11</sup> Int 1, 729-732, 744; Int 2, 930-940; Int 4, 722-723

We want him to be an active citizen... I would like [child] to get out and be in with other people. [Child] wants to get a part-time job. (Int 2, 333-339)

The carers envisioned their children in the future seeking and achieving transitional development goals typically expected of young adults, focussing on autonomy and new roles, while remaining resigned to the possibility that their children may not actualize these goals or become independent. Below, the participant envisioned her son living alone or attending college but perceived that he would always be dependent to some degree:

He can go and work. If he wants to live on his own, he can do that. He's obviously always going to need support. I hope that that can be there. If he never leaves home, I'm fine with that... If he wants to go to college then I want him to do that. I think he can. (Int 4, 722-729)

The uncertainty of where the characteristics of ID would stabilize and how this stability would influence the resultant level of independence contrasted with carers' discourse of future goal achievement of their children. Independence was spoken of as a "need" and a priority for the children.<sup>12</sup>

Our goal is independence for [child]. Some days we think it's possible, other days we're like, there's no way. (Int 6, 115-117)

The carers' fear, combined with uncertainty, about their children's survival as adults, "without" their carers, was the emotional influence behind the perceived "need" for independence. In the following quote, a carer described her child's dependence on her: "I get worried about [child] because without me, he'd be lost and I'm not going to be here forever" (Int 2, 927-929). Below, the carer specified the ways of being within a community that represented her child's future independence and reduced her vulnerability:

**What do you think it [independence] would look like?**

Her to be on her own. She could live in the city. She could take the bus, maybe have a little job... I know she's going to shower even though I'm not there. I know she's not going to starve to death because I'm not there. Whether she's with us or she's alone, she can survive. (Int 6, 121-124)

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<sup>12</sup> Int 5, 1210-1211

In this way, the child with ID who becomes an adult is constructed as vulnerable through dependence. Vulnerability is mitigated through the ability to be independent. The cumulated construction of a child with ID was being unknown and creating uncertainty in others related to degree of future independence and resultant vulnerability.

*Status, rights, and duties.*

The status, rights, and duties of children with ID are informed by how ID is understood in relation to the characteristics of impairments, vulnerabilities, and dependence, and the children's corresponding needs. Participants believed that needs were a central defining element of ID. Carers repeatedly spoke of their children's need for supervision, authoritarian instruction to learn, translation, and advocacy. In the following section, I detail the specified needs and explore how they influence the status, rights, and duties of children with ID.

*Needs: "... to be taken care of" (Int 4, 90).* Fears about their children's vulnerability and exposure to risk, as well as the impairments they identified, informed carers' identification of their children's need to be "taken care of" through constant supervision.<sup>13</sup> Following the previously detailed incident, in which a participant alleged that her son reported being inappropriately touched by a peer in the bathroom, the participant rationalized that continuous staff presence at school could reduce risks to her son and support his needs: "He needs somebody with him on a constant basis" (Int 5, 407-409). Below, a participant speculated that his sons' potential to live independently was unlikely given their current level of dependence and need for supervision:

They can't be left alone for a long period of time. A couple of hours in the day, there's no issues. If they had to live on their own, [they] can't do it. They need supervision. That type of supervision is hard to come by. (Int 3, 101-109)

The children with ID were constructed depending on ongoing supervision, which justified the children's loss of privacy.

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<sup>13</sup> Int 2, 1028-1038; Int 4, 90

*Needs: Authoritative control and to assimilate.* Authoritative control emerged from the data as another need of the child with ID: to force the child with ID to comply, change, and progress developmentally to reduce the child's challenging behaviours or impairments. The carers perceived themselves, school staff, and therapists to be tasked with implementation of this instruction because of their authoritative position over the children. The carers used the terms "control," "on top of him," "force," and "grab him by the arm" to describe authoritative methods of instruction. As evidenced by these terms and the following quotes, certain situations called for removal of choice, and required compliance from the child with ID. The child's rights to autonomy and self-determination were thus reduced or removed to prioritize their duty of compliance to directions to optimize development improvement. In the following quote, the participant believed that her son had some capability of independence but also required support and control:

He needs someone there who's going to know him year after year and keep him on track. (Int 4, 60-61)... We were always on top of him. We didn't coddle him. We made him do things on his own. (Int 4, 79-81)... He's special needs. He needs you to have that interaction with him. You're at some point going to have to grab him by the arm and say, "It's time to go or it's time to get up." You have to give him that assistance. He's not a typical child. He's not going to move when you tell him to. (Int 4, 272-276)  
If they can't control him now and he continues to hurt people or puts his hands in his poop... (Int 4, 453-454) You be strong and be on them. Get on them. (Int 4, 775-776)

In the next quote, another carer maintained that her child requires to be in situations and contexts outside of her comfort to be challenged and learn: "You need to put her in a situation that forces her to ask a question" (Int 6, 536-537).

It's only going to help the kids later on because they need to go out. They need to learn proper behaviour in a social environment. You may not think that you're teaching your child something but you are. (Int 6, 728-730)

In the above examples, the carers' assertions imply a connection between actions of control and facilitating the child with ID to assimilate in society with reduced dependence.

*Needs: Translation/advocacy. "I need to do what's best for him because he can't speak"* (4, 808). Directly linked to the defining item of communication impairments (see section on Impairments in Language), carers identified translation and advocacy as corresponding characteristic needs of ID.<sup>14</sup> Carers detailed the approaches they took to translate what their children were trying to communicate when they behaved or communicated in non-normative ways and the unique needs being reflected. The carers perceived their children required them to make their communications intelligible and provide context on their behalf. The child's status in these cases is portrayed as dependent on their carers translating their intended message to others. The child's status is simultaneously elevated through translation and being advocated for because the child's behaviours are validated and humanized, with their meaning exposed to others. For example, in the following quote, the participant explained that when her son plays with shoes it reflects a sensory need. The child's right to self-expression and accommodation of individual needs is promoted through his mother's translation and advocacy.

**You said that his needs aren't being met. What does that look like for him?**

He needs to self-stim[ulate]. He wasn't getting that... Not giving him the time he needs to collect himself... giving him his body breaks. They weren't meeting him in that sense. There's just things that he needs to do during the day. He plays with shoes. He waves them in front of his face. I don't know if it calms him down. He just goes into his own world but they weren't doing that. (Int 4, 140-154)

Below, the carer recalled communicating to her child's teacher what her child would predictably try to say, identifying his impairment in communication, and translating his intended message to ensure he receive the correct size of shoe:

Today they took him bowling so I was trying to prepare him for bowling. "You're going to have to put bowling shoes on." He's been bowling before but just that "you wear size thirteen shoes... They're going to ask you what size." He can't say thirteen, he says "fourteen." I'm like, "thirteen." I wrote in the agenda that he's going to ask for fourteen shoes but he's trying to say thirteen. It's just hard. (Int 5, 1590-1595)

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<sup>14</sup> Int 6, 1360-1366

Similarly, the carer in the following excerpt explained that her son's tantrum was his way to communicate thirst. From this behavioural analysis, she recommended persons in supportive roles attempt to find the purpose of his behaviour to understand his needs:

To discipline him is hard because you have to understand why he's doing it first because he won't stop until you understand... That's the hard part because he can have a tantrum for hours and not stop until you figure out, he just wants water. Why can't you just say that or point to it or get it yourself? (Int 5, 191-195)

Text related to translation and advocacy was not focussed on changing the child but, rather, on what "*you* have to do," and the change in approach and understanding required by others to meet the needs of the child with ID. The focus on the translation and advocacy duties of persons other than children with ID represents counter-discourse even within participants' perception of needs, coexisting with the need to forcibly change the child. To explain, the carers' definition of ID according to the responsibilities of others was very different and outside of the impairment understandings of ID that focused on the child's limitations.

Participants perceived their children needed to be taken care of, to be authoritatively controlled, and to have translation and advocacy to be co-relational to ID characteristics of impairment and vulnerability. The status, rights, and duties of children with ID were constructed through the participants' detailing of these characteristics. The perception that children with ID need supervision and authoritative instruction constructs and reinforces children with ID in a status of dependence on others because they lack abilities held by the majority. The child's rights to autonomy, self-determination, and privacy are then reduced. These weak rights were evidenced by examples of the children reportedly being "forced" to comply and five participants advocating for one-to-one support persons to be with their children at all times at school. The continuous presence of support staff was perceived by carers to support their child's needs but simultaneously reduced the child's privacy. The child's assumed duty was to comply with being monitored and to adhere to direction from persons in authority because the child "needed" this supervision and guidance. The belief that children with ID require their carers to translate and

advocate maintains the children's status as dependent, but also improves their status through elevating their worth and deservingness by carers' advocacy efforts explaining the meaning behind their children's behaviours. The children's right to self-expression and accommodation for it is promoted through belief in the need for translation and advocacy. Support persons thus have the duty to uphold the rights of accommodation of children with ID.

***Sub-theme 2: Normal/Abnormal. "He's not a typical child" (Int 4, 275-276).***

Taken as a whole from the carers' description of ID, the characteristics of ID denote a breach of the normal/abnormal social threshold. This normal/abnormal threshold is presented in the section on Normal Threshold. Beyond this breach, carers defined and understood the children with ID through their severity of deviation from the norm. This deviation is explored through the continuum of abnormality of ID in (see section on Difference Continuum). The section on Value Hierarchy explores the hierarchy of value incorporated into constructions of ID.

*Normal threshold.*

The carers frequently used the terms "normal" and "typical" to label and name what they perceived to be the ideal, expected person. Indeed, they applied their perception of normal ideals as a benchmark to compare and distinguish their children as different from and "abnormal" compared to children without ID. For example, below, a carer discussed how "normal" children were exposed to her child through integrated schooling, which potentially reduced the novelty of ID:

It gives those "normal" kids a chance to see how, because they don't see kids like that [with Fragile X] everyday... (Int 3, 329-330)

The carers specified that their children's differences in cognition, plus their delayed developmental achievements in speech, social, and self-care abilities, were what they perceived distinguished them from "normal." In the following example, the carer compared her perception of typical brain functioning to her child's functioning. The carer's use of the term "others" articulates her assumption of a "normal" standard that her child does not meet:

When it's your brain doesn't function the way others do and physically you look like a normal teenager. (Int 6, 332-333)

In the quote below, the carer believed his children had greater strength than children without ID:

What a lot of people don't realize is people who have a handicap, especially our boys, when they get angry, they have the strength of ten kids. (Int 3, 413-415)

The carers also recognized areas in which their children aligned with social norms<sup>15</sup> and described their children's behaviour as characteristically normal. The following two quotes reflect a carer position that decentralizes ID as the location of their children's differences and instead locates their children's behaviour and needs as overall childhood characteristics.

He loves to play. He's got a lot of energy. He's cuddly, he's hugs and kisses. He slaps once in a while and sometimes he's a little mean but what kid isn't? (Int 4, 333-336)

I do find that by speaking with other parents the same age as [child], that don't have needs, there's a lot of things that are similar because of the teenage years. Which makes me happy because I think, it's not all intellectual delays. (Int 6, 558-561)

These excerpts demonstrate the malleability of use the term "normal" and its application. Children with ID were viewed both as "normal"/similar and "abnormal"/different, within social contexts. The fluidity of counter-discourse related to "normal" illustrates that what and who is understood as normal is not consistent. What was consistent was that children were always compared to a situationally dependent benchmark to distinguish them as normal or abnormal. Most often the carers determined their children to be "abnormal."

*Difference continuum.*

Where the carers viewed their children as "abnormal," they further identified and classified their children's degree of difference from expected norms. The participants used terminology consistent with the labels within the DSM-5 denoting the levels of severity of ID, which range from mild to severe. The participants who described their child's ID as "high functioning" inferred higher expectations of the child's capabilities and potential: "To me high functioning is you can eat and

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<sup>15</sup> Int 3, 315-317

dress yourself. Even though you have other problems...” (Int 5, 781-782). Conversely, the participants who described their child’s ID as “severe” spoke of lower expectations for their child’s capabilities and potential: “He’s going to do better in life than [child] because his intellectual disability is not quite as severe” (Int 2, 944-945). In the following quote, the ambiguity of the severity label of “borderline” resulted in the carer’s uncertainty related to appropriate expectations for her child’s future development:

In [child’s] case, it’s hard to get a diagnosis because she’s borderline for a lot of different things. (Int 6, 13-14)... Our goal is independence for [child]. Some days we think it’s possible, other days we’re like, there’s no way. (Int 6, 115-117).

The carers perceived that higher functioning equated to their children’s greater capacity to master specific activities of daily living. The labels carers used to identify the level of severity of ID and inform expectations and predictions of future capabilities were adopted from the labels applied to their children through assessment and testing, discussed further in Theme 2. Carers used the labelling terminology of service agents and diagnostic professionals to facilitate communication with professionals and to justify their children’s perceived needs for support, while simultaneously refuting that their child reflected these labels.

*Value hierarchy.*

Beyond the breached benchmark of normal and the determined severity of abnormality, ID was further understood by the value that carers and society placed on it. The interview data overwhelmingly revealed that carers viewed children with ID positively; however, carers most often experienced and perceived ID to be socially characterized as negative, belittled, and stigmatized. Participants used and reported other people’s use of positive terms to refer to their children including “awesome” and “beautiful,” and reference to them being “lucky” to be carers to their children. Interestingly, three participants believed children with ID to be a divine intervention

and blessing from God.<sup>16</sup> The carers only drew positive associations between ID and God. Below, the carer stated that while ID is socially constructed as an affliction she viewed it as a gift:

I don't look at it [disability] as a curse as some people say. It's a blessing because God made us... It's His gift to us. We just have to know how to use it. There's a reason why the Lord blessed me with this genetic disability. Maybe I'm meant to slow down and smell the roses... (Int 1, 765-769)

It is not clear whether carers chose to positively frame ID or that they actually identified positives about their children having ID. The carers described their child having ID in general positive terms but did not identify specific attributes about ID that they perceived were positive. Counter to the above examples of positive constructions of ID, the following excerpt illustrates the participant's perception of a prevalent negative view of ID:

Everybody has a disability. You don't want to be too normal. (Int 1, 244)... I try to make a negative [participant's disability] into a positive thing because it makes me feel better. (Int 1, 251-252)

In the above example, the carer who self-identified as having an ID acknowledged a normal benchmark to which she compared herself. Beyond recognition of her deviation from a normal benchmark, she perceived her disability as "negative". She reframed her vision of herself as being positive to "feel better." The carers believed their children were positioned lower in the hierarchy of society. When asked how she felt her son was viewed as a person when he was not attended to following fecal incontinence at school, she stated, "It's not good" (Int 4, 452). The quote below followed another carer's reports of frustration with wait-lists and the disinterest of the public to be employed in the developmental service sector:

**Where do you feel people with intellectual disabilities are prioritized in society?**

They're at the bottom of the ladder. Sadly, the bottom of the ladder. (Int 2, 982-984)

The carer perceived that society's low prioritization of children with ID contributed to their unmet needs and societal disinterest and discrimination toward them:

It's very sad and frustrating as a caregiver to not have the programs out there to help developmentally disabled children. There's lots of programs if you're a relatively normal child,

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<sup>16</sup> Int 1 & 2; 4, 593-594

but not all children are normal (Int 2, 822-825)... They [children with ID] have the right to anything a normal person has but they're not given that right. (Int 2, 985-986).

ID is distinguished according to a normal/abnormal threshold. The distinguished difference of ID equates its assignment with a lesser position within societal functions, priorities, and worth.

### **Theme 2: Diagnostic process.**

It was apparent in the data that the participants sought to determine the source of their child's impairments and a diagnosis to name them. This pursuit coincided with their sense of urgency to access interventions addressing these impairments, which led to an engagement with the health and social service system. Prior to achieving access to interventions, however, the children were required to be assessed, ranked, and classified according to diagnostic labels or classification systems by primary care providers, specialists, and the school system. The carers believed that their child's diagnosis or classification determined their child's eligibility for services. The carers reportedly had an unresolved sense of urgency to search for support when their child's diagnosis or classification did not equate with service access or legitimization of the child's needs. Although this urgency can be perceived as a tension existing between the carers' perception of what their children require and what they are actually provided, there exists a second dimension of interpretation. The carers frequently reported that their children's impairments and need for services were identified by professionals but that a qualifying diagnosis was required to access services, regardless. In Theme 2, I present the reported motivation of a sense of urgency felt by carers and the process of diagnosis for children with ID. I also partially address research question two: what are the materializations of how ID is understood? The carers' perception of the diagnostic classification of their children further contributed to how ID is understood.

#### ***Sub-theme 1: Urgency.***

The carers expressed urgency to access "early interventions" for their children's impairments and needs. The carer highlighted his desire for early intervention in following quote: "I recommend anybody that has a child that has any kind of disability, recognize it as early as

possible... Get them into daycare with a resource teacher” (Int 3, 140-142). The opinion of experts about the importance of early intervention was impressed upon the carers and taken up in carers’ frequent discussion and pursuit of “early intervention”: “Early intervention, they talk about it all the time” (Int 6, 26). The carers perceived that their children’s optimal window for benefitting from interventions was in their young childhood and into the school-aged years. In the next quote, the carer associated early interventions with future abilities and opportunities:

If he wants to go to college then I want him to do that and I think he can. As long as he gets the support, early on now. Kids are very susceptible. They need that early on to learn for the future. (Int 4, 728-732)

The carers also perceived that their children’s impairments would become cemented with age beyond the early years. The carer highlighted this sentiment in the following quote by placing blame for the present-day challenges her older son with ID experienced on the lack of support he received when he was a child: “He would have been a different person today if he had got the proper help when he was younger” (Int 2, 177-178). The carer in the following quote shared this view: “The later you start, the worse it is” (Int 6, 25). The carers implied risk of negative future outcomes through use of the terms “different person” and “worse.” The carers’ efforts to prevent poor future outcomes for their children illustrated their focus on attempting to reduce the impairments they perceived their children to have.

The participants also expressed that their sense of urgency to access early interventions increased as their children aged because they believed that after the early years the quantity of direct therapy services declined. Specifically, the participants reported that speech therapy services drastically declined or completely discontinued past a certain age. As highlighted in the following quotes, the participants reported that the duration of speech service offering depended on the age cut-off determined by individual school boards and not on the child’s communication needs. As expressed below, the careers reported a sense of abandonment after the “early intervention” period:

Their belief is early intervention. We [school board] will focus all of our money towards early intervention, kindergarten to grade three. After grade three, sorry, you're on your own. (Int 6, 396-398)

They used to have speech but they don't anymore because after a certain age they don't do it anymore. (Int 5, 751-753)

Although the participants reported that they and professionals identified impairments that indicated their child's need for early intervention, they perceived that a formal diagnosis was a prerequisite to access some early interventions:

If you have a diagnosis, there's services out there that you can get. Sooner rather than later. At school, it also helps get services. The earlier you have a diagnosis, the better the school will be at providing certain things for the kids. (Int 6, 38-41)

Professionals impressed upon carers the need for their children with ID to access early interventions; however, the carers' sense of urgency was enhanced because they perceived that access to early interventions was delayed or restricted until their child received a diagnosis or identification.

***Sub-theme 2: Diagnostic processes.***

The carers perceived that their children required the right assessment, testing, ranking, and diagnosis from the right provider to validate their needs with a label that denoted meaning and was equated with early intervention and other service eligibility. I review each of these aspects of the diagnostic process below.

*"The right doctor" (Int 6, 146).*

The carers perceived that medical practitioners were privileged within the service system as experts in identifying and validating the challenges of children with ID and recommending treatment. The carers also believed that many service agencies determined children's eligibility for services according to medical diagnoses. In the text below, the carer believed that practitioners at a children's hospital were authorities with privileged speaking positions that were unquestioned. When denied funding allocated for children with severe disabilities, the carer presented "paperwork" reports from a source he perceived to be a credible within the healthcare community

to justify and validate his child's need for funding support. The carer revealed his tacit belief that the opinion of carers "going up against them [service agency]" was not viewed as legitimate, thereby requiring carers to "get all their paperwork aligned" to substantiate their claims, particularly if the carers' children received care from a prominent children's hospital:

[Children's hospital] sent us the report from genetics on both boys because they didn't know their disability and how severe it was... There's no way to discredit them [children's hospital]. What parents have to realize is if they're going up against them [agencies determining eligibility], they have to get all their paperwork aligned and if they are dealing with [hospitals], get them to send the proper paperwork to you. (Int 3, 58-69)

The carers perceived that a hierarchy to assessments and diagnoses also exists between the legitimacy that agencies provide professionals independently and that prominent institutions offer. The carers alleged that service agencies evaluated the accuracy of diagnostic reports they received, and frequently disregarded them, privileging diagnostic findings from professionals within their own agency to determine service needs. The carer in the following quote lamented that through her pursuit of a diagnosis for her child, her child had had negative experiences and did not acquire a diagnosis equated with service eligibility:

We haven't met the right doctor yet. One doctor that we met was, "Pills. That's the answer"... it took three or four different meds before we actually got the right one... I was like, "I don't see improvements except for maybe the rage. She stays in her room. She's even more closed in now than she was before"... We had a psycho-educational assessment done. We found out later that he wasn't licensed to do it. (Int 6, 146-168)

The carer was frustrated by school personnel providing her with conflicting directions to establish her child's eligibility for school services. Further, she expressed helplessness because she perceived that her child was required to remain in the assessment and reassessment phase to obtain a diagnosis equating with service eligibility. There was conflict between agencies and external diagnostic professionals regarding who could make pronouncements:

You get somebody from outside the school board to do anything, any kind of report, the school board has to look at it again. If they don't agree, they have their psychologist, speech therapist, or professional come and evaluate you... You didn't want to do it in the first place because you don't have the budget. You made me go outside. I did. I'm giving you the report. You gave me suggestions of who to see. Now you're saying that's not good enough. Your professionals have to re-evaluate my kids? (Int 6, 436-444)

Similar to the above example, the carer in the following excerpt recalled her son's restricted admittance to a specialized class by school administrators, regardless of a documented recommendation by his physician to support the classroom placement:

My doctor's written letters, the Down syndrome clinic at [children's hospital], and still nothing. I still just can't get—I've asked for him to be taken out of integration. They [school] have a special needs class. (Int 4, 65-69)

The above quote also shows the dominance of institutional professions in general through the carer's report of having recommendations from professionals external to the school board disputed and requiring her child to be reassessed by "their psychologist, their speech therapist, or their professional." An expert and hierarchical economy of professionals granted the authority to make statements about children with ID and their needs was created and perpetuated through the requirement of children to submit to assessment and diagnosis from these professionals.

#### *Assessments.*

The carers reported feeling expected and required to submit their children to participate in continual assessments and tests by developmental service and school board clinicians to determine service eligibility. The carer in the following excerpt recalled her child's protest to repetitive assessments:

Your professionals have to come back and re-evaluate my kids? At one point [child] says, "I don't want to do this again." After three times he's like, "It's the same questions every time." I'm like, "I wish I could..." I don't know what to say to that. He's absolutely right. Why does he have to go through it three times? (Int 6, 443-447)

The carer expressed "having to go through it" and "not knowing what to say" and "wishing [she] could" excuse her child from undergoing the assessment again. The quotes below provide further examples of carer reports of the many assessments and appointments they attended.

[Developmental services], they do that psychological assessment. Through the [private] school board they do that too. Right now they're doing it with [child]. (Int 5, 979-982)

We visit [children's hospital] and the [city] area fifteen times a year (laughs)... Those are just regular appointments so now that I'll be seeing other people, it might be more. (Int 4, 420-423)

My kids all got tested through [developmental services], through [psychologist]. They all got testing through that that's why they're all developmentally delayed. (Int 5, 910-911)<sup>17</sup>

In addition to acquiring a diagnosis for service eligibility, the carers explained that another motivation for pursuing testing was to find a reason for, or the cause of, their children's challenges by seeking "answer[s]" and "rul[ing] out" potential issues.

We're waiting for genetic testing to be done on [child], to see if we could find an answer to something but it's been a year that we are waiting so I don't know. (Int 6, 167-173)

We've had him tested for everything. We ruled out, maybe he's got something wrong with his hearing. Maybe that's why he's not talking properly. (Int 2, 70-72)

Adherence to the assessment and testing circuit preserves the medical and therapeutic discourse that purports testing and assessment aid in making children with ID eligible for services.

### *Ranking.*

The carers reported that their children's determined diagnosis of ID was subsequently ranked according to severity by professionals and agencies. The carers believed that the degree of service allocation was associated with the child's designated degree of severity. In the following quote, the carer expressed her belief that children with a greater severity of ID had greater needs that made them eligible to receive increased service allocation:

I understand that she's [educational assistant] in that classroom to support. There were four of them with special needs. His are the most extreme so he gets more of her time but there are three other children in there that have some special need. (Int 4, 909-912)

The above quote simultaneously illustrated the carer's belief that children considered to have a less severe level of ID were viewed to have less needs and were lower priority for receipt of services or excluded entirely. The participant referred to "the three other children" with special needs who she believed received less of the educational assistant's time. The carers discussed ranking to justify and also contest school resource distribution to their children:

[Developmental services] know why he wasn't qualified for their things. I know her kids have special needs but I find them higher functioning than mine. I don't know how they

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<sup>17</sup> Although this quote appears to be a casual statement suggesting that the children's testing resulted in their disability, the carer was actually referring to where and from whom they received their diagnoses.

get services and [child] doesn't. I'm not mad at her but I just feel that's not fair. (Int 5, 1265-1269)

The carers recognized that the impairments their children experienced required illumination for their child to receive services. In the following quote, a carer reported that her child was determined ineligible for developmental service supports because of his assessed capabilities. She identified, however, that her child had impairments to performing activities of daily living:

We tried to get [developmental services] to help us but they say [child] is too high functioning. I don't know how high functioning he is. He can't dress himself. Their test that proved that he was high functioning was that they showed him pictures and he always ended up picking the right one. He has a 50% chance of picking the right one. (Int 5, 762-765)

Following from the above quote, the carer perceived there was a tacit threshold of ID which prompted a response and service allocation from agencies to children with ID. The carer contested the method of determining level of severity as arbitrarily measured because her son "ha[d] a 50% chance of picking the right [picture]" and "he always ended up picking the right one." She associated activities of daily living, specifically "dressing himself," as more reflective of high functioning. Those who can assimilate and blend in to their surroundings of school or society, and not disrupt the functioning, are derogated from service priority and do not tip the threshold to warrant increased support. The child with ID described in the following text was able to develop positive relationships with her teachers and adhere to the expected behaviours in the classroom setting. Her carer believed that less was expected of her child because "she has an individual education plan," and because her child did not identify herself as struggling by asking questions, she was perceived to be assimilated into her integrated classroom. However, the carer believed that her academic needs were not met:

[Child] flies under the radar. She's so charming. She's got all the teachers wrapped around her fingers. Every time I talk to them, "She's such a lovely girl. She's our best student and our favourite one." I'm like, yes but she has a hard time but they don't—it's like two personalities right? [Child] at school and [child] here. As soon as she leaves school she shuts off the switch and she knows nothing. In class, apparently she understands. She

never asks for help and when she gets here I'm like, "Ok, let's review what you learned today." She has no clue. (Int 6, 70-77)

**Her performance on tests and things, does that line up with what they are telling you?**

Not really. It's what I see. They're like, "She has an individual education plan." (Int 6, 89-91)

The carers thus believed that their children's determined severity of ID was ranked and equated with their expected needs. The carers contested that the actual needs of their children were not represented by their determined level of severity. Further, the carers in the above quotes suggested that their children's individual needs for support in academics and to develop independence were ignored.

*Labelling: Developmental delay, an expired diagnosis.*

The carers perceived that the diagnoses of developmental delay and ID, which the majority of the carers' children had received, were not validated diagnoses and thus their children were ineligible for services. The participants reported that their school-aged children were often labelled and diagnosed with having a developmental delay. The persistence of this diagnostic label is problematic and invokes questions related to diagnostic practices because the diagnosis of global developmental delay is a temporary diagnosis, applied to children under age five and requiring reassessment (94). The carers' children diagnosed with a developmental delay were between the ages of seven and 14. The carers recalled their children being tested and identified as having a developmental delay.<sup>18</sup>

I just went for his, not his individual education plan, but where they identify him.

**Identification, placement, and review committee?**

Yes. He still identified as special needs, developmentally delayed. (Int 4, 93-97)

The carers did not convey awareness that this diagnosis was temporary, and therefore lapsed, according to their child's age or report that further diagnostic reassessment was planned. All carers remained active in seeking assessments to receive a recognizable diagnosis linked to

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<sup>18</sup> Int 2, 17-19; Int 5, 910-911

services. The carer in the following quote had two children with special needs; one was diagnosed with autism and the other with an “intellectual delay.” Although “intellectual delay” is the early childhood designation used prior to solidifying ID, the carers did not perceive the diagnosis to be recognized or equated with access to services.

We still don't have diagnosis. Intellectual delays is what they told us and that's it (Int 6, 33-34)... I met with [pediatrician] in [city] and she's like, “Until you have a diagnosis, you can't—” She understood the frustration of not having a diagnosis and how difficult it was. She tried to write us a letter for the school to say, “[Child] is this way. She functions at the second percentile.” But the school, they're like, “No. It's not a diagnosis.”

**The intellectual delay was not enough for them [school]?**

No. It's because at school they see [child] as functioning fine. They don't see her. They know she has a hard time but I can't get her an educational assistant. I can't get her any extra services. She has an individual education plan and that's about it. We had to fight to get her into the life skills program at [school]. [Other child] has multiple diagnoses. I have an educational assistant. I have applied behavioural analysis services through [children's hospital]. I've got all these things going because I have a diagnosis but if it's *just* intellectual delays, what do you do? (Int 6, 45-56)

**Do you find for [child], because she doesn't have a more familiar label that there's more difficulty?**

Yes, because it's easy when you have a diagnosis. It's “Ok, it's because of this.” (Int 6, 329-332)

The above quote illustrates that neither the carer nor the child's pediatrician or school personnel perceived “intellectual delay” to be a legitimate diagnosis: “We still don't have a diagnosis. Intellectual delay is what they told us”; the pediatrician disregarded the diagnosis and the school board stated, “It's not a diagnosis.” The carers thus pursued diagnosis to access interventions but did not acquire diagnoses that provided any currency for service supports.

***Sub-theme 3: The file.***

The carers reported that they kept files of documents related to their children's identification, placement, and review committee and clinician reports of assessment findings, diagnoses, and recommendations. In the quote below, a carer recalled gathering documentation from physicians at a children's hospital stating that her child required increased educational assistant support. The carer presented these documents to school staff to demonstrate that her

requests were substantiated and validated by physicians who the carer felt had the authority to speak to these recommendations. The carer also stated that the school collected documents within a file of clinicians' reports regarding the child.

**You had said that the doctors and [children's hospital] had written notes to support you? How was that received from—**

Ok. We'll put it in a file. (Int 4, 833-837)

The above participant's actions were consistent with the participant quoted in the section on "the right doctor", who also recommended that parents of children with ID "get all their paperwork aligned and if they are dealing with [children's hospital]... get them to send the proper paperwork to you." One of the functions of the file is to serve as proof of the diagnoses of the children, thereby validating and corroborating the opinion of carers related to their concerns about and ideas of how to support their children with ID by referencing the opinion of clinicians. A co-occurring function of the file is the reinforcement of clinicians as experts on children with ID over their carers. The file transmits specialist reports and diagnostics to service agencies to validate the needs and formal identification of the child, and is a form of authorized or required communication. The carers perceived that they were required to collect and present these documents when communicating formally with agencies regarding service requests. This belief was evidenced by a few of the participants bringing their child's file to the interview or referring to the file they kept "on" their child, unsolicited (Int 2, 4, 5). This pattern translates how medicalized understandings of ID are disseminated through diagnosis, transmitted through reports collected in files, and preserved by carers and agencies maintaining and sharing files as a whole. In the excerpt below, when I asked why the carer had brought the file to the interview, the carer responded that she was unsure if I would request the documents to address my questions.

**You have some books. Were there some things that you wanted to share or talk about with the books that you have there?**

I didn't know if you wanted that. It was [child's] files. I wasn't really sure what questions you wanted. These were just his diagnoses.

**Is there anything in there that is really meaningful to you for any reason?**

It's just his diagnoses and all the assessments that he went through. (Int 5, 1253-1261)

The above quote highlights that the file further serves to standardize children within diagnostic classifications that allow them to be better understood: “It’s just his diagnoses and all the assessments.” The notes, findings, and labels within the documents of the file are considered to represent the child with ID, the progress made to present and inform direction for next steps in services and programs. The carers conveyed their implicit perception that the reports about their children contained within the files were necessary to inform decisions related to service distribution by service agencies. In the following quote, the carer encouraged a teacher new to her son to read the file of notes from her child’s previous teacher to facilitate her son’s and his new teacher’s transition to a new school year. The carer believed that all the pertinent information for the new teacher to become acquainted with her child was contained within the file:

She [teacher] gave me an idea of what was going to happen next year... She said, “He’s [child] going to be moving to grade one. This is going to be his teacher. I’m giving her all these notes.” She gave her a file with all of his information. (Int 4, 226-228)

The file thus serves chiefly to represent the child with ID through specifying the results of their systematic assessments, making them understood and discussed in a systematic and diagnostic manner. Through giving higher value to this form of communication regarding the child, the speaking position of clinicians and teachers is provided authority and privilege to convey truth about the child, and is preserved through their requirement and use in decision making and for new clinicians and teachers learning about the child. The speaking position of the carer and child with ID, where able, is consequently from a lesser position, evidenced by carers using the file to validate their own opinions.

### **Theme 3: Materializations.**

In theme 3, I map out how service navigation, limitations on the actions of children with ID and their carers, and individual and societal responses can be interpreted from the carers’ statements about how ID is understood and their perception of the process of identification. In theme 3, I thus articulate carers’ perception of (1) the prescriptive and restrictive movement within

service trajectories, as well as (2) services for which their children with ID were eligible and carers' willingness to try available services. I then present the carers' reported barriers, futility of received services, and tensions with agencies to explain a transition in the participants' responses from compliance to escalation to resistance.

***Sub-theme 1: Service eligibility.***

Being diagnosed with ID resulted in children's eligibility or ineligibly for referral or direct application to services. Eligibility for referral did not equate to service access, but often resulted in the diagnosed children being placed on wait-lists for further assessment from a service agency or because of lack of service capacity. For example, the carers reported that professionals assessed, recommended, and referred their children to speech and occupational therapy. The service agencies reportedly then reassessed and frequently denied the children access because their level of function, age, or disability did not meet eligibility criteria. In the following quote, a carer reported that health and school professionals informed her that her child required speech therapy, but that the child's age was outside of the service eligibility criteria:

What I found difficult was the school boards, after grade three they cut you no matter what, because of budget. Their belief is early intervention, "We will focus all of our money towards early intervention, kindergarten to grade three. After grade three, sorry you're on your own"... The reports come back from the professionals, of their own school board, saying, "This child needs a lot of health, speech, occupational therapy, or whatever," and they're like, "Sorry." (Int 6, 395-401)

The carer speculated that the rationale for prioritizing services to younger children was a "belief in early intervention" and "budget." The consequence of her child's identified need for services and subsequently determined ineligibility left the carer feeling that her child was "on [her] own" "after grade three" for support for speech development. Regardless of the determined need for therapeutic services, carers reported that a specified eligibility age cut-off resulted in service termination. Children diagnosed with ID thus experienced challenges related to their eligibility for services that prioritized specific functional levels and age ranges (discussed in section on Urgency).

The carers perceived that a diagnosis of autism was privileged because of being better understood and prioritized for the distribution of resources of applied behavioural analysis and smaller specialized classrooms, which were not ensured for children with ID. The carer in the following quote described another child who had struggles but was not in what the carer perceived to be a suitable classroom because the child was not diagnosed with autism:

A girl in the other special education class screams through class but because she has a developmental disability, she can't go into the autism spectrum disorder class... There should not be autism spectrum disorder specific classes, just special education to meet everyone's needs. (Int 5, 1834-1837)

The carer in the following quotes questioned whether her daughter's needs were prioritized less than others because she was not diagnosed with autism:

I don't know if it's because there's just so many kids that need help and there's not enough workers or is it because she's not autistic—does she get put down to the bottom of the list? (Int 6, 65-67)

The [treatment centre] was remarkable when he [other child with autism] was a kid. [Children's hospital] is amazing. We've had genetic testing on [other child]. That department was phenomenal, and now his applied behavioural analysis services. It goes with the diagnosis of autism. (Int 6, 387-391)

The child without autism discussed in the quotes above accessed applied behaviour analysis because her sibling was receiving services. The carer was unsure of how this occurred and perceived it as an exception: "We were able somehow to get [child] into that as well" (Int 6, 493). She did note that her daughter did not "come up on the list as often" for services (Int 6, 508).

According to carers, their children's placement in a specialized or mainstream classroom was also determined according to each child's eligibility to receive rehabilitation services provided within the school setting. The quote below illustrates the inconsistencies and barriers of navigating rehabilitation services, where agencies are intertwined yet not integrated. The carer reported that her child was determined ineligible for speech therapy services because he attended a behavioural program and because of perceptions that his speech impairment "wouldn't improve" with therapy due to his "disability."

**Any speech involved? Like speech therapy?**

... Yes. They [service agency] were giving him speech but because he was in a special behaviour program, they wouldn't help him. They said the special class was supposed to provide everything for him. But the school didn't provide any speech therapy. They said it was his disability and it wouldn't improve his speech. (Int 5, 1575-1586)

The above quote illustrates that the carer perceived that the diagnosis of ID closed opportunities for her child to access speech services. In the following excerpt, the carer reported being told that her child could not use the services sought at a literacy service agency because it was not the objective of the agency to provide services to persons with ID.

How would you expect to teach him cooking if he doesn't know basic reading? Before that, I went to [community literacy program].

**How did that go?**

Didn't go well at all. Because their mandate is not to help people with severe disabilities. (Int 2, 120-126)

In the following quote, the carer perceived that a summer program failed to serve her son's needs because it was not "designed" to accommodate people with disabilities.

We tried one summer with a worker and it didn't work.

**What happened?**

The program wasn't designed for someone who has a disability. (Int 3, 374-379)

The above quotes reflect that persons without ID were served and accommodated through the design of the standardized service. Those with ID could not participate because their needs were not accommodated. Eligibility criteria for access to services reveal the characteristics and diagnoses that have been prioritized by governmental and service agencies that fund the services, particularly for children within the early years and children diagnosed with autism.

***Sub-theme 2: Trial of services.***

I identified two issues from carers' reports of their experiences not acquiring the supports or services they perceived their children required: First, service providers were privileged to make recommendations and decisions related to service acquisition for their children; and second, carers and their children were expected to comply with the prescriptive and structured pathway of navigating the education, health, and social systems to access support for their children. As

presented in Theme 2 and in the section on Service Eligibly, carers complied with the process of diagnosis and service eligibility assessment, and they were receptive to receiving and trying the services offered to their children. Often carers felt unable to change the challenges they experienced, stating, “I can’t.” In the following quote, the carer felt unable to provide the “best” for her child because her “hands [were] tied” in a “society not accepting”:

I feel like my hands are tied. That’s not a good feeling when you want the best for your kids and you want them to be the best person that they can. You teach them all the right things but when society is not accepting of them?! (Int 2, 356-359)

Although the carer in the next quote identified significant shortcomings in her child’s education, she felt she was “going to have to follow that process” in the subsequent school year. She felt she had no choice in acquisition of support staff, improving the situation, or changing the expected placement and treatment of her child:

I’m going to have to follow that process all over again next year because he’s going to get someone entirely new again, because he’s not getting that consistency because I can’t get the support to get an educational assistant who can follow him through school, which is what he needs. (Int 4, 54-58)... I can’t even get that [classroom placement] to suit his needs there. (Int 4, 74)

In the next quote, the carer had strong reservations against the use of safe rooms<sup>19</sup> in schools and her child not being monitored during activities she deemed were risky. Although she communicated her feelings, she felt unheard because “it [her communication] doesn’t do anything.” She referred to herself as “just the mom” who “can’t tell them what to do.”

I’m just the mom (Int 5, 370)... They shouldn’t have it [safe room] but I can’t tell them what to do (Int 5, 406)... If they had just taken the whole classroom to the bathroom instead of letting them go by themselves. There’s not much I can do. I try to explain and tell them, “My kid’s coming home saying this stuff.” But it doesn’t do anything. (Int 5, 456-459)

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<sup>19</sup> A safe room has been defined as “Seclusion rooms – sometimes soundproof, sometimes small with no windows, with dim lighting, soft seating or with locks on the doors – are separate spaces used in many schools across the country to temporarily isolate children who are disruptive or show potentially dangerous behaviour. They go by different names, including time-out rooms.” 235.

Alphonso C. Cornered: Canadian schools reach a turning point in use of seclusion rooms for children with disabilities. The Globe and Mail. 2019 June 11.

The carers altered their discussion points to appeal to service agents and have their advocacy for their children's needs heard. The carer in the following quote felt he required a supporting "document" and to "talk business" to convince the principal to allocate resources to his child:

We applied for services with [developmental services]. We were told we didn't qualify. [Developmental services] told us, "No, you do." We reapplied. Year two, "No." We let it go. But the second time in 2000, when the young one was born, they said, "You guys do qualify." I said, "We'll reapply." This time I got smart. I downloaded a 50-page document to explain one page. (Int 3, 27-31)... When you talk business to them it makes more sense to them. (Int 3, 635)

The carer in the following quote described becoming verbally aggressive with a teacher following her escalated frustration with the teacher "not doing what she need[ed] to do" for her child. The participant felt justified in her actions but felt forced to "choke it up" and apologize because the teacher was "supporting" her child as the staff in his classroom:

My husband's like, "You can't butt heads with her. Right now she's supporting him. We need her to support him there so we need to figure out some better solution. You're going to have to apologize." It took me everything. My pride said, "No, I'm not going to apologize to this lady. She's not doing what she needs to do"... I had to choke it up. (Int 4, 860-866)

The carer's above discussion supports the idea that carers have a lesser speaking position, and that service personnel dominate decision making regarding service eligibility and dictate the behaviour of carers and the service access for children with ID.

***Sub-theme 3: Service Issues: Navigation barriers and limitations of services.***

As a consequence of receiving the diagnosis of ID, the children became eligible to apply for and navigate parts of the service system. The carers reported experiencing service navigation barriers and encountering inflexibility and limitations with the pre-established services that their children received. The carers thus perceived that these services did not meet their children's needs. These reported experiences eventually reduced carers' compliance with the service navigation trajectory. The following section outlines the barriers experienced by carers prior to receiving services and the limitations of the services eventually rendered that resulted in disagreement between participants and professionals.

The carers identified that their children needed summer camps, rehabilitation therapies, education assistants in the classrooms, and behavioural support services. Following their child gaining eligibility to access services, carers reported that they encountered inadequate funding, extensive wait-lists, inconsistent service offerings, and geographic barriers that precluded their ability to access the services. As cited in the following quotes, the carers perceived that program supports for children with ID were the target for funding cuts over other groups because children with ID were valued less than other children.

School is the worst service there is for a child with special needs. It's really unfortunate but they seem to cut funding and that seems to be the area they cut funding and there's just not enough support. (Int 4, 19-22)

It's very sad and frustrating as a caregiver to not have the programs out there to help developmentally delayed children. There's lots of programs if you're a relatively normal child, but not all children are normal. There's children out there like [children] that don't have the services and we're doing them an injustice by that. Don't they deserve the same chances as these other children? (Int 2, 822-829)

The carers in the following quotes expressed their exasperation with waiting lists for services and funding that they were eligible for: "There's a waiting list sometimes to be on a waiting list" (Int 2, 1074). "The thing that is frustrating is the wait times, no matter where you go, no matter what service you try" (Int 6, 393-394). In the following examples, carers spoke of their children's challenges and the wait-lists for needed services.<sup>20</sup>

I would call people crying, "I don't know what to do." Call Children's Aid Society, "I don't know what to do." They're like, "You're doing what you can." They didn't see any child protection issues or anything. They were like, "Get on all these services," but there were such long wait-lists. (Int 5, 258-261)

She definitely needs help in communication. Communication is very poor. Judgement, it's not there. Just the interaction, she's socially awkward as well. We can get workers in to help her but it's a year to 15 months waiting for services. (Int 6, 60-63)

The carers were isolated and forced to cope without support when they experienced wait-lists. Further, the needs of the children with ID remained unaddressed.

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<sup>20</sup> Int 5, 907

The participants also identified inconsistent service offerings and periods of no service availability as barriers to accessing services. The carers in the following texts had found positive programs but these were inconsistently offered, requiring them to find new ones.

There was only one year that the [treatment centre] put on a camp for children with disabilities and that was awesome... They only did it for the one summer and that was it. Never had anything like that again. There are a lot of kids with disabilities that need something. There's nothing that you can just, "Let's go to this day camp. Sign them up for this day camp." There's nothing. It's hard. (Int 3, 384-394)

When they [Special Olympics] did [offer swimming] they were only doing it for a two-month block. They weren't doing like [other city], October to May... They don't compete in any meets. Even basketball, they lost their coach and now basketball is cancelled. (Int 6, 652-656)

The instability of Special Olympics sport programming and summer camps able to accommodate children with special needs highlighted a limitation for children with ID to access activities that they enjoyed and benefitted from.<sup>21</sup>

The carers perceived that residing in this rural area of Ontario was an exacerbating factor to program and service unavailability, specifically to therapies, specialists, family support services, and inclusive recreational activities. Two carers stated, "Everything's in [city]" (Int 5, 1794), and that "living outside of [city], it's hard to get services" (Int 6, 6). The participants reported that specialists were not available or often left their practice in this rural area of Ontario to return to another city.<sup>22</sup>

We go to see the ADHD doctor, then we go see [child's] brain specialist doctor... All these different trips and try to get them in [hometown]—we just can't. It would help a lot instead of travelling all the time... I've got to find babysitters for my other two kids. (Int 5, 720-730)

The carers described their commutes to another city as greater than one hour each way, an expense of taking a full day to attend appointments, and a challenge for those without a car and/or driver's license.

Especially if I don't have a ride to [city] then you have to take a bus and spend the whole day in [city].

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<sup>21</sup> Int 5, 1599-1601; Int 6, 569-570

<sup>22</sup> Int 5, 11-13; Int 4, 378-381

**There's a commuter bus that goes between [city] and [city]?**

There is. It leaves around five o'clock in the morning and comes back around five at night. We have to spend the whole day in [city] when we take the bus. The only reason we can take that bus is because the driver grew up with [partner]. We are lucky for that because I don't think otherwise he'd let kids go on the bus.

**How does [child] deal with that long commute?**

On the bus he's pretty good. In the car it's a little bit harder sometimes because he has to sit still but he's getting pretty good in the car.

**What do you do with [other child] on those days?**

We have to bring her with us. She misses a whole day of school too... (Int 5, 1419-1435)

The burden of frequent travel to another city to receive services led some carers to contemplate or actually move away from their social support networks to reduce the service access barriers described above.<sup>23</sup>

My father lives in [city] and he's offered for me to live out there and I said I won't. It's too big of a city for me. I lived in [city], didn't like it there. It was too far from home because all my family lives here... I don't even have a drivers licence. I'm moving back to [hometown]. I'd rather be here... I've lived here all my life. (Int 5, 739-746)

The requirement for carers and their children to move or travel great distances reflected the mapped out actions carers must take when attempting to meet the needs of their children with ID. Travelling to another city for services was reported as a challenge for seven of the participants.

The participants described the services and programing that their children actually received as inflexible, standardized, and not aligning with or meeting their children's unique needs. The carers reported that their suggestions for alterations to the educational programing for their children were met with refusal and that their children were forced to comply: "He has to do what we are doing" (Int 5, 1051). The carers criticized the educational plans for their children as not challenging, placing decreased expectations on them, and at times patronizing. The carer in the following quote perceived that school staff were disinterested in educating her child and were "wiping their hands of it" and "pushing him along," which led her to conclude that his programing resembled "daycare":

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<sup>23</sup> Int 5, 28-32

They go there and spend their eight hours and then they just wipe their hands of it. I feel this year he's being completely pushed along. I feel like I'm sending him to daycare. I don't know what he's learning. I don't know what he's doing. (Int 4, 314-317)

In the next quote, the carer questioned and contested the value of mandatory "tracing letters" activities to connote that her child had met a grade level competency. She perceived that her child "[didn't] want to do it anymore" because he had been required to complete the same activity for six years and that the teacher believed that she "had to prove that he passed" to allow the child to progress to alternate activities. The carer perceived that the teacher had not evaluated the effectiveness of the current activity on the child.

**You feel like they are not being challenged enough?**

Definitely not because I'm doing grade three-four workbooks with [child] at home and the teacher is making him trace letters. He's been tracing letters since kindergarten. He doesn't want to do it anymore. That's why it's all sloppy. He's tired of tracing letters... he's in grade six... She's [teacher] like, "I have to prove that he passed this [tracing letters]." (Int 5, 964-974)

Beyond having the same learning objective of letter tracing for multiple school years, the same carer contested the learning materials used for their lack of educational content. She recalled that her child's teacher was "mad" at her child because he had an outburst while a television show was being played in the classroom.

[Child] is way beyond watching "The Big Comfy Couch." She was mad that he was bad during the kids watching "The Big Comfy Couch."

**What did "bad" mean?**

Banging and screaming and being disruptive. Seriously, an 11-year-old watching "The Big Comfy Couch"? I don't even know how that's even educational. (Int 5, 1027-1033)

The carers perceived that school personnel placed low expectations on their children and did not support their academic progress.<sup>24</sup>

The other thing that I asked her about that I'm frustrated about is that if he does do good work, put a sticker or a smiley face or a check mark... "You did a good job!" She's like, "I always tell him."... Now she's doing it to everything. If he does a good job or not, she writes 100%... He didn't even try and you put 100% on that? (Int 5, 989-995)

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<sup>24</sup> Int 6, 91-94; 109-112

The programming provided to the children with ID contributed to their invisibility within the education system because the child's unique strengths and challenges were not explored; rather, the child was expected to blend into education, alongside their chronological peers, that was normatively designed to address the average student's individual needs.

Children diagnosed with ID had the options of a mainstream classroom placement with their chronological peers or specialized classroom placement with other children with developmental disabilities. The prominent discourse of inclusive education was reflected in the carers' initial goals for their child's educational placement. In the following quotes, the participants considered the two classroom placement options and strongly expressed their initial preference for a mainstream placement rather than a specialized placement, segregated from their chronological peers. According to carers, the school boards also preferred mainstream placement. In this way, the carers initially agreed with the inclusive approach of the education system: "When he first started school, I wanted him integrated because he always did really well" (Int 4, 78). "Both our kids have been, and for all parents, they should have their kids included in a regular school, not segregated" (Int 3, 309-312). The carers hoped that their children would develop social relationships with their peers and simultaneously expose their peers to persons with ID. Carers reported, in the quote below, that they hoped this would facilitate their children's peers to develop empathy and for stereotypes to be torn down.

Resp 1: It gives them something. It feels like they belong.

Resp 2: It gives those "normal" kids a chance to see because they don't see kids like that every day. If not, they're against them and maybe try to pick on them. If they were integrated with kids like that early on then they would have to learn to access them but it's harder when they're—boom—here, when normal kids are older and they've learnt from their parents that they don't know how to deal with them. (Int 3, 328)

The carers' alliance with integrated education ideology became weakened when they began to perceive their children were not adequately supported to be successful in integrated

classrooms. Three carers<sup>25</sup> perceived their children's school programming was not meeting their needs because they were routinely sent home: "Instead of dealing with him they always threw him out of school or suspended him. Not the right way. It wasn't the right way to handle it" (Int 3, 682-684). Some carers<sup>26</sup> struggled to maintain their work commitments while simultaneously receiving calls to attend to or bring their child home from school.

One day when the school called me... I'm like, "Again?!... I've got a line up. I'm a cashier. I have to find someone to replace me. I just can't go like that." (Int 2, 1119-1123)

The carer in the following quote perceived that her child's needs for "self-stimulation" and "body breaks" were not accommodated in a mainstream classroom.

He needs to self-stim and those things. He wasn't getting that. No they were trying to put too much into his day. Not giving him the time he needs to collect himself or to keep him working and having his self-stim and then giving him his body breaks. (Int 4, 142-146)

Some carers determined that a specialized programmed classroom was the optimal setting to meet their child's needs. In the following quote, the carer believed that her son's "work" was tailored according to his abilities and his need to "get up and walk around" was accommodated through programming in a specialized class:

[School] really helped him to settle down and a special classroom, where if you wanted to get up and walk around, you could. It gave him work more at his level than at the grade level. (Int 5, 167-170)

In the next quote, the carer prioritized the smaller class size, community of peers with disabilities, and life skills focus within a specialized class that enabled her daughter to feel comfortable and enhanced her ability to learn.

I think a full-time life skills program, at a younger age, like grade seven. Right now it's half-time. She's proven that she learns better in smaller groups. In her life skills program there are five students. She's currently doing math and other things in that class. She's doing fine. She's not shy to ask questions. She doesn't feel labelled. She doesn't feel different. She's doing very well. I think that if I had a dream for her right now [it] would be a full-time life skills program, where she can get all the help that she can get. Obviously modify the curriculum because there's some things she doesn't need to learn—I don't feel help her become independent. (Int 6, 179-187)

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<sup>25</sup> Int 5, part #1, 144-147; Int 5, part #2, 535-541

<sup>26</sup> Int 2, 1412-1418; Int 5&6

In addition to the perception of enhanced individualized programming, the carers believed there were greater human support resources within a specialized classroom: “I wanted [child] to be in a special class where he would have an educational assistant” (Int 2, 184-185). Indeed, the carer in the following quote believed her son was placed in a specialized classroom with children with severe challenges because that was “the only way he gets one-on-one support”. However, because of the needs of other children in the class, he did not receive the support.

I know they’re saying he’s in that classroom because it’s the only way he gets one-on-one support but she deals so much with the others kids’ behaviours that he’s not getting one-on-one support.” (Int 5, 1054-1056)

Some carers reported that, when they advocated for a specialized classroom placement, the school board became oppositional to them because the carers no longer adhered to the school board’s approach. The excerpt below illustrates that in most reported incidences, the carers’ preference for a specialized classroom placement was refused because the philosophy of inclusion was cited as the deciding feature for children with ID. The escalation of disagreement between the carers and professionals led to increased tension between them, whereby the professionals’ prioritized speaker positions disallowed the wishes of carers to have their children placed in a specialized classroom. The carer in the following quote described how tensions escalated to the point where she had to “fight” to have her child removed from a mainstream classroom and placed in a specialized “life skills program” operating at the school:

They know she has a hard time but I can’t get her an educational assistant. I can’t get her any extra services. She has an individual education plan and that’s about it. We had to fight to get her into the life skills program at [school]. (Int 6, 52-54)

Similarly, the carer in the next quote advocated for her child to be placed in a specialized classroom but the principal refused; he “[didn’t] want to take him out of integration” because “we’re an integrated school” rather than basing the decision on the child’s needs:

My doctor’s written letters, the Down syndrome clinic at [children’s hospital], and still nothing, I still just can’t get—I’ve asked for him to be taken out of integration and they have a special needs class and because he’s already integrated they don’t want to take him out of integration. I can’t even get that to suit his needs there. (Int 4, 66-68) My doctor feels, and so do I, that he might need to be taken out of integration. Maybe only integrated during

certain activities like music, art, or lunchtime. Whenever things aren't so demanding and there's not too much of a need for him to sit and behave. This way he can still interact. It was just, "We're an integrated school and unfortunately we want them to stay integrated. For now that's just the way it's going to be." (Int 4, 103-108)

In addition to feeling required to abandon their beliefs in inclusive education to acquire educational supports at school, the carers perceived they were choosing between scholastic-centric programming and life skills. They lamented the repercussions to their child's future directly implicated by these choices. In the following examples, the carers felt that their children required the life skills programming offered in the specialized classroom but that it came at the cost of them receiving literacy instruction.

They weren't focussing on the literacy skills. Literacy skills could lead to life skills... Literacy didn't fit because the teachers he had at [school] were so busy teaching life skills to the classroom... (Int 2, 761-775)

... [classroom] is more like living and learning. He takes the kids to the grocery store and they buy groceries and they come back and they cook it. They do school work but it's more stuff he should know. I know he's not going to grow up to be a doctor but he still needs to learn to be independent. (Int 5, 1205-1213)

The carers identified that individualized programming within specialized classrooms was also limited by standardization of education delivery.

The carers reported that respite services were also standardized and did not fit their children's and family's preferences for respite. The participants reported that respite services were offered through an out-of-home option that they did not agree with and thus six of the seven families interviewed did not use the service. The carer in the following quote felt it would be subjecting her children to stress by "putting them through" a stay at a respite home.

They wouldn't stay anywhere.

**They wouldn't feel comfortable with it [respite home]?**

They've been through a lot. I'm not putting them through any more. (Int 2, 1061-1064)

Further, the carers reported that respite funding for purchase of self-selected services was insufficient to cover needs. The carers spent the funding in the summer months when needs for respite were higher, leaving the remaining ten months without relief:

We get Special Services at Home [funding] but I use up all that money in the summer... because the summers are so stressful. Just dealing with him from the minute he wakes up until he goes to bed is so hard. I have a friend, she's really good with him but she wants \$15 an hour. That takes up a lot of the respite money. (Int 5, 1438-1444)

The carers faced the conundrum of having to select which time to be without respite supports.

The carers reported that the services their children received overall were problematic because they were inconsistent. As an example, in the following quotes, the carers expressed frustration with frequent changes of service providers and its impact on their child's functioning.

Apparently this is unheard of, that the same worker gets the same kids. Whatever worker comes up, when it's your turn, that's who you get. When we went to speech we were like, "No, not a new speech pathologist." It's just new people all the time. Then you have to start the connection again and again. (Int 6, 497-501)

The carer in the following quote discussed the struggle of having an entire team of school personnel change from one school year to the next:

This year was his first year in grade one. Everybody's gone. We got a completely new team. I found the teacher was really unaware of his needs. The educational assistant—I'm not even sure she's ever worked with special needs before. (Int 4, 44-47)

Even carer advocacy for the continuity of the same van driver for school transportation was a contentious issue. The children's school van driver was often changed:

**Were they trying to change your driver before?**

They did change them and then we told him, "The kids get used to one person. That driver gets to know the kid." (Int 3, 807-809)

Developed therapeutic relationships were not protected or prioritized. These decisions were made by service providers, without reported consultation with the carers or their children.

The carers reported that when services were delivered they perceived service providers had a lack of knowledge related to supporting their children's unique needs. The carer in the following quotes recounted her effort to access support and information for her child, and the agencies responded that they did not know what to do:

I talked to his teacher about it because I didn't know what else to do. I called the hospital and they didn't know what to do. (Int 5, 1142)... he kept saying he had problems and he didn't want to go to school and she [teacher] was telling me she didn't know what to do

with him (Int 5, 1283)... We've called the Children's Aid Society and we were like, "What do we do?" They were like, "Nothing." They didn't know what to do. (Int 5, 1385)

In the following excerpt, the child got into "trouble" at school because his behaviour was understood not as a communication of his need but rather as him being "bad":

We had so much trouble at school because they couldn't understand him. He's not being bad, he's thirsty or he's hot or his needs are not being met not because he's not getting his own way or like most kids, you know? (Int 5, 123-126)

Carers, consequently, expressed feelings that there was no person of reference to support and guide them in what to do and that they were at a crossroad:

It's frustrating. I'd like to get more support. Maybe they could help guide me too instead of me having to consistently guide them. (Int 4, 820)

In the above discussions, the carers perceived that there was "something that [could] be done," and a "right and a wrong" way to support children with ID. They expected that school, hospital, and other social service agency personnel were informed and had an expert opinion of "knowing what to do" to help children with ID. The carers developed the impression, however, that the appointed experts did not hold this expert knowledge of "what to do" about needs associated with ID. Participants perceived the services that the children were eligible for to be standardized to all persons with ID and delivered without consideration of the individual needs of the child or family. The incongruence between service agency approaches and the objectives of the carers, as well as the perceived needs of the children remaining unmet, produced disagreement between the two groups and weakened carers' compliance.

***Sub-theme 4: Conflict.***

The escalation of disagreement between the carers and professionals did not result in outcomes that better satisfied the concerns and wishes of the carers. The following two quotes articulated the action of school personnel that prohibited changes requested by carers: "We try to do one thing but at school it's like the opposite is happening" (Int 6, 114-115). "I was trying to get the teacher to send home homework and she won't" (Int 5, 938-939). The carers described school

professionals as resistant to including carers in decision making regarding their children's programming and problem solving, and dismissive of carers by not communicating with them. The carers identified the prominent tension was between themselves and service providers regarding who had the authority to determine children's needs.

*Lack of communication.*

Communication books provided by the school to facilitate daily communication between school personnel and carers were implemented for four of the eight participants' children. The carers reported that recordings from school staff in the communication book were routinely absent, and overly negative when present. This point is evident in the following quote, which details a carer's account of the transportation driver receiving more information about her child than she did.

I don't know what he's learning. I don't know what he's doing.

**But you routinely hear—**

It's all negative. I never hear anything good. I'm very close with his driver. She knows more about his day than I do... I'll look at the agenda and it's like, "He slapped twice but it was an overall good day." What else did he do?

**They don't give you the details in the communication book or the agenda?**

No. All negative. The whole first part of the agenda, the first six months are all empty up until the whole slapping thing with the educational assistant. It's now when I'm starting to get something written every day... Out of maybe five pages, there's one little nice comment. (Int 4, 316-331)

Further, the carers reported that their child's daily routine and programming was often withheld. In the following examples, the carers reported requesting greater detail regarding their child's educational plan and progress but received responses they deemed inadequate.

I don't even know what kind of work he does. They weren't giving me enough notes for at home. (Int 4, 162-163)

I email the teachers and say, "[Child] doesn't understand anything. What can you do to help her?" They're like, "She's doing just fine in class." I never get an answer from the teachers of how well she's doing or where she's struggling and she's been in that school for—this is her third year. (Int 6, 82-86)

Below, the carer reported that she was unable to ascertain where her child spent his recesses.

**Where do you think he is at recess time?**

I don't know. In the winter time he doesn't like going outside. I know they're probably putting him—they have a sensory room<sup>27</sup>. I'm hoping he's in there but I don't know where he is at recess. (Int 4, 355-358)

Two carers<sup>28</sup> reported cases of their child being injured or hurt and receiving vague or no information, even upon request from the school.

**Did they start a body inventory where they write down bruises if they saw new ones and give you a call?**

They're supposed to but they don't. They don't call. They don't say anything. (Int 1, 389-403)

Without open communication between school staff and carers, the carers were omitted from collaborative decision making regarding their children, and changes reflective of the carers' preferences did not occur.

*Being Dismissed.*

The carers perceived that communicating their concerns or input with school staff was received with vexation, discouragement, and dismissal. In the following quotes, three carers discussed their interpretation of interactions with their children's teachers as strained and felt that teachers were defensive, "angry," and "annoyed" to be receiving input from them.

[Child] feels that there's tension between the teacher and mommy. She doesn't feel comfortable anymore. (Int 1, 375)

Resp 2: If my kids are giving attitude, I call [teacher] and say "I'm just calling to let you know that [child] gave me a really hard time this morning." I've always called him.

Resp 1: I do too but I stopped because I feel like they sound like they're annoyed. Just, whatever—They'll figure it out. (Int 5, 634-640)

I don't see why they have an issue with a parent calling because at least it's not them finding out later... the kid's acting up... I don't get why they would get mad over that. (Int 5, 656-660)

The carers also perceived that school staff dismissed or suppressed their input. In the following quote, a carer identified that her child's teacher was continually forgetting to send him for an

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<sup>27</sup> A sensory room contains equipment (e.g. Lights, sound and scent machines, different textiles) used to promote relaxation and sensory stimulation.

<sup>28</sup> Int 4, 190-193

integrated class activity. The carer reportedly suggested a solution to which she perceived the teacher “took offense” and did not consider:

We’re working with the teacher, if she would remember to send him. That’s why I asked her to make a visual. She was like, “I have a visual.” But “you’re still forgetting to send him. Put a visual on his desk with the time. He knows the time. He could remind you.” But everything I say she kind of takes offense. I don’t know if she does, it just feels that way. (Int 5, 1639-1644)

In the excerpt below, the carer offered to volunteer and support her child in the classroom because she was not receiving information about his programming but she was denied.

**They’ve not divulged to you his schedule or his day plan?**

No. I’ve asked to come in and observe his day or just volunteer, or I’ll come in when she’s taking her break, and I’ll sit with him or I’ll take him outside. They won’t let me volunteer. (Int 4, 178-181)

The school personnel’s dismissal and irritation with carers began to escalate, which situated the professional’s voice as an authority that suppressed the carer voice. Carers described interactions with staff where they felt intimidated and forced to comply and adhere to the decisions of authorities. In the next quote, the carer detailed her experience of attending a school meeting to review and consent to the decided classroom placement for her child. Although there were reportedly many persons in attendance, the carer stated that she felt “intimidated” and in opposition to the others in attendance, stating, “It’s just me.” This perception of being outnumbered was discussed in relation to her feelings of regret and coercion to sign the proposal for her child’s classroom placement:

**At the bottom of that identification, review, and placement committee [form], you have to sign if you agree with the placement. What did you decide that day?**

I signed it.

**How did you feel about that?**

I didn’t want to sign it. I try to be as strong a person as I can and I’m pretty independent. I usually speak what’s on my mind. They intimidate me... I feel intimidated. I go in a room and there’s a lady who’s there from the school board who deals with special needs, and the principal, and his teacher... Then it’s just me. (Int 4, 110-122)

The carer in the following quote perceived that a principal used a condescending tone, “like the [carer] was a kid,” when speaking to another carer of a child with ID.

When I went in with him and the way the principal was talking to him. I looked and said, “Do you like being a principal in Ontario? Because you keep this up and I’m going to have you permanently removed.”

**How was he speaking to him?**

Like the father was a kid. (Int 3, 672-676)

In the next excerpt, the carer described how she supported her child to reflect on a challenge he experienced at school and to communicate his ideas for solutions to his teacher. The child reportedly overheard his teacher dismiss his ideas as an “excuse” for his behaviour “to another teacher... so that he could hear.”

She said she didn’t know what to do with him one day. He was very upset. I wrote down everything that [child] told me were the problems he was having at school. I asked him, “How do you think you could fix these problems?” I wrote what he said how he would fix all the problems and gave it to her. [Child] comes home and said, “My teacher said it was just an excuse, to another teacher.” I’m like, really, so he could hear that? I didn’t know what to say. (Int 5, 593-599)

These interactions imply a disrespect for or dismissal of the validity of the carer position as informed about their children’s needs and as advocates for their children who may not be able to speak for themselves.

***Sub-theme 5: Fight and resistance.***

The inability to effect the changes they perceived their children required to succeed, coupled with the carers’ reported experiences of escalating disagreement and tension with professionals, produced acts of resistance. It is important to note that the carers’ resistance and fights did not occur in linear sequence, but emerged throughout the escalation of disagreements with professionals. With varying effectiveness in actualizing their desired change, the carers reported alternative approaches and ways they resisted complying with normative educational approaches specifically.

*Make your own rules.*

In the following quotes, the participants articulated the actions they took to make their own rules for how their children’s needs would be supported. In some instances, these actions

occurred independent to any service agency, while in others, the actions created change in how agencies delivered services. Half of the carers spoke of privately hiring a tutor to supplement their child's learning.<sup>29</sup> In the quote below, the carer discussed how she developed learning materials for her child.

We have him tutored all summer. We are going to take some vacations. I'm going to give him a break this year. He's just had such a rough year and we've always been on top of making sure he got tutored and making sure we were moving forward with motor skills and speech.

**Had you done that yourself? All those tutoring goals and things?**

I put them all in place but I had someone come in and tutor him. He was getting two hours a day, Monday to Friday.

**You developed your goals and then found someone who could implement them?**

Yes. (Int 4, 1015-1031)

The carers also fought for a reorganization of human resources and delivery of routine services to better suit their children's needs. The quote below illustrates the carer's refusal to enroll his children in a particular school where children with disabilities often went, thereby challenging how things commonly would occur:

"You need to go to [school]." I told them, "When pigs fly." [School] is one of the worst schools in [city].... That school does not handle people with handicaps very well.... Kids with issues. Whether it's handicapped or behavioural problems. I walked into the school and I said, ... "You can read my lips now or you can read my lips when you're in court. My kids will never set foot at this school... Give me the form. We are transferring them." (Int, 3, 724-745)

In response to the challenges experienced in their attempts to acquire school programming and placements for their children, many carers contemplated or carried out changing schools or moving to alternate school districts: "We changed schools a lot and we finally found [school]. [School] is the best school that we've been at with [child]" (Int 5, 128-129). In the following quote, the carer compared the class sizes of two schools to determine best fit for her daughter, but struggled because one school location was in a neighbourhood she did not want to live in:

There's 30 kids per classroom. I find it's too big and then the [school] I want to put her in, which is a smaller school. I like it and it helped my daughters, but they are supposed to

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<sup>29</sup> Int 1, 4; 5, 932-935

close it, and that's in the east end of [city]. I don't want to ever move to the east end again. I definitely want to take her out of that school. (Int 1, 403-408)

The carers perceived that there were advantageous differences between schools and even school boards regarding the amount of resources and capacity to meet the needs of students with special needs.<sup>30</sup>

I've thought about moving him schools too. I've heard [school], they're really good with special needs, and every kid in that school that has special needs has their own educational assistant. (Int 4, 992-994)

Two participants<sup>31</sup> even contemplated home-schooling:

I'm hoping [child] will want to be in school but if he's not being challenged to where he can be?! Sometimes I tell my husband, "I should just home-school." That's not going to teach him to be social if he's home all the time. (Int 5, 1705-1708)

These moves and considerations of moves reflected carers' effort to contest and change education delivery to their children with ID and an attempt to access resources and programing not provided at the current setting. The participants lamented that they recognized that moving within the school board was likely to result in a similar treatment and resources distribution:

I'm in [school] district so if I want to move him they're going to say, "Why do you want to move him?" Then [when we] get to that school they are going to say, "No. This is how they were doing it at [school]. You have to do it this way." I'm afraid that it's just going to follow suit from [school] or else I would have moved him. I don't know how the [private] board works either. I could switch him to a [private] school... It's frustrating. (Int 4, 1001-1007)

Although the carers were attempting to resist inclusive programing that they deemed inadequate for their children, they were unable to move outside of the ideology which pervaded the school system as a whole. The carers expressed frustration and lack of control and choice over the ultimate classroom placement and resources allocated. Thus these families reported to be in a perpetual state of movement between schools to find one that they perceived met their children's needs. The participants not only determined their own rules of how they believed their children

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<sup>30</sup> Int 2, 204-211; 276-277

<sup>31</sup> Int 4, 133-137

should receive services, but also asserted themselves in situations of tension with service providers.

*“Stand up for yourself” (Int 3, 248).*

The carers detailed their ongoing struggle with school principals, superintendents, and teachers over educational assistant support, funding, and classroom placement for their children.

One carer articulated this clearly:

Parents that have handicapped children learn the word “no” very fast. “No, I’m not accepting your answer.” No to us means yes because we’re going after yes to get what we want for the kids. (Int 3, 1121-1127)

Most carers also discussed their need to fight and advocate for change and access. The carer in the following quote perceived that because of her child’s ID, his rights to receive the same things as others without an ID were removed. Further, she identified feeling alone in her advocacy for her child’s rights, believing that, if not her, “nobody will” advocate:

They have a right to anything a normal person has but they’re not given that right. That right is taken away from them unless there is somebody like me fighting for them or somebody like you, fighting for them. That should not be, but sadly it is. It’s sad. Poor kids.... I have to do it. If I don’t do it, nobody will. (Int 2, 984-994)

In the next excerpt, the carer described his assertive interactions with school staff demanding an educational assistant be secured.

I went to the Minister of Education, back down to the school board. (Int 3, 261)

That’s the other thing that parents have to fight at school, is the educational assistants. The funding is there.... The one principal said, “We might not be able to get the one...” I said, “Yes, you will. The funding’s there, apply for it. If you don’t get it, that’s your fault. That’s too bad but he will have an educational assistant.” (Int 3, 647-658)

Six of the eight carers reported advocating for one-to-one educational assistant support for their children at school. The participants all reported, however, that the school disagreed with the amount of educational assistance that the carers deemed necessary and did not allocate according to their requests. The issue under focus here is not determining relevancy of the child’s need but the tension and action between the carers and professionals. These situations of tension

were multilayered. Under the Ontario Human Rights Commission, “education providers have a legal duty to accommodate the needs of students with disabilities” (236)(Duty section, para. 1); however, the carers and governmental agencies identified that services and funding were inadequate to meet the needs. The carers’ and service providers’ different opinions about how to accommodate the children’s needs also contributed to tensions. The carers in the following quotes articulated their responsive actions to the ensuing conflict between the school and themselves using the terms “fight” and being “forceful.”

They know she has a hard time but I can’t get her an educational assistant. I can’t get her any extra services. She has an individual education plan and that’s about it. We had to fight to get her into the life skills program. (Int 6, 52-54)

“That’s a funded spot, that’s a funded worker. He’s got the funding, he’s going in”... It wasn’t ok for them but they did it. I can be very forceful. (Int 3, 621-625)

In the following quote, a carer recalled a regrettable situation where “butting heads” with her child’s teacher escalated to the carer becoming verbally aggressive and “yell[ing] at her [ the teacher]”:

But I’ve been mean to her really quite often and I hate it because I don’t want to butt heads with her. I yelled at her one time. I yelled at her so much that she refused to talk to me unless the principal’s on the line at the same time. I felt really bad. (Int 4, 855-860)

The context of this situation was that the carer perceived that the teacher had not reviewed her son’s file in preparation to teach and support him. The carer concluded that the teacher was “not doing what she needs to do” (Int 4, 865) for her son. The receipt of prescriptive services for children with a diagnosis of ID contributed to the escalation of disagreement between carers and professionals, resulting in a “fight.”

### ***Sub-theme 6: Social consequences.***

The carers perceived that when their children’s peers or people in the community viewed ID as being their children’s essence, their children were misunderstood and negatively responded to. The carers reported that their children experienced rejection and bullying, and struggled to make social connections with peers at school. All of the children attended community schools with other children with and without disabilities.

When I took him to the group, in the Cubs, they were all regular little boys. [Child] was six then. He has a hard time getting in with little kids because he's not used to being with little kids too much. Now he is because he goes to school all the time but he would stand back away from them. [Child] gets angry a lot of the time when he can't do something. (Int 2, 791-796)

[Child] struggles to make friends because people don't see her as mature. A lot of times she doesn't know what to talk about. (Int 6, 194-196)... Her other friends she's either met through her friend, and they don't call her. They're friends with [child] because they're friends with the other one. (Int 6, 210-212)

The carers reported incidents where their children were verbally bullied by peers at school because of their disability. The following quotes illustrate the social hierarchy within the student population, where the names called were demeaning, belittling, and othering: "His peers, or some of the kids when he went on the school bus... would make fun of him and call him a 'retard'" (Int 2, 364-365). "They were outside at soccer and I guess a kid called him retarded.." (Int 5, 1649-1650). The carer in the following quote voiced her concerns about her child being bullied as his peers "get older":

Kids are mean. If they can't control him now and he continues to hurt people or puts his hands in his poop—The whole class is watching, right? As kids get older they get mean. (Int 4, 452-455)

Returning to a quote discussed in the section on Service Issues, the carer believed that without integrated education, other children would be "against" her children, who would be "picked on": "If not, they're [other children] against them [her children] and maybe try to pick on them" (Int 3, 331-332).

The carers perceived that school staff were generally not accepting of their children's enrollment. "The principal did not want any special needs kids at her school" (Int 5, 1840-1841). "Some principals couldn't care less and would rather not have anybody with disabilities in their school. And the other ones welcome them with open arms" (Int 3, 232-233). "I feel like they [school staff] feel like he's a nuisance. 'We are just doing it [including] because we have to do it. We have no choice.' It sucks" (Int 4, 481-482). The carers perceived that school staff held attitudes of rejection related to their children's inclusion.

In terms of interacting in the community, the carers felt that their children were judged negatively and not understood. Below, the carers linked their experiences of isolation to their children not being understood by their coworkers and society in general:

Nobody knows how I feel and I'm not going to go to work and complain about my life at home. Where I had to go home to clean up a poopy diaper or I had to go home or I had to go to the school. They don't want to hear that and they shouldn't have to hear that because that's my personal issue and I don't want to bring my home to my work. (Int 2, 1372-1378)

One carer noted that members of her extended family were isolating themselves from going out in public with their own child with ID because they were fearful of being embarrassed. The carer related personally to these fears but was unwilling to isolate herself.

Their way of dealing with things is, "I can't take her out to any social event because I'm afraid she's going to tantrum." You are punishing yourself, you're punishing your child.

**What are they afraid of about the public tantrum?**

Humiliation. I get it because I've been through it but I want to go out. (Int 6, 723-727)

The carers in the following quotes also perceived societal condemnation and judgement toward their children in public spaces.

I know he has a hard time with people staring, because people stare. He's dreading the whole comments or things like that... (Int 4, 640-642)

**When you go out in the community, how are people responding?**

We've kind of learned to ignore them. Some people will look at us, like, "Oh, my gosh!" Or they'll come up to us and say, "You're too big to be doing that." (Int 5, 1540-1542)

The presented examples support the interpretation that discourse informing societal understanding of ID has contributed to children with ID being stigmatized through judgement, mocking, and disengagement with them. The process of self-assessment, presented in the next section, is directly informed by how ID is understood and, consequently, by how society perceives and responds to children with ID.

*Self-assessment.*

The carers recalled discussions they had with their children and their perceptions of how their children felt about their ability to read, about being a student, and about what they believed

society expects of a “normal” child. From these carer reports and perceptions, a trend became visible whereby the children experienced challenges or exclusion because of perceived normalized social standards of functioning. The carers believed that their children recognized normalized social expectations and judged themselves according to them. Further, the carers believed that their children identified their ID as outside the norm and viewed themselves negatively because of it, demonstrating this view through self-denigrating talk. In the following quote, this trend is illustrated by the perceived way the child recognized and responded to societal norms:

You could teach him all the life skills you want to but if he doesn't know what the name of that book is or what that door sign says, without a picture, he feels like he's stupid and he's not stupid. (Int 2, 767-769)

Standardized modes of written signage in public spaces, designed on assumptions of normalized literacy levels, created challenges and potential exclusion for the child because his level of ability was not accommodated. The carer believed that her child, in turn, judged himself as “stupid” because he could not consume the information.

The carers spoke of classroom norms that they perceived their children recognized and felt challenged to assimilate to, specifically social, behavioural, and learning. In the following quotes, a carer discussed challenges her daughter experienced maintaining friendships as her interests began to differ significantly from her friend's.

She said, “My brain feels empty when I'm around her [friend].” I said, “What do you mean by empty?” She said, “There's nothing there. I don't know what to talk about. We don't like the same music anymore. We don't like the same tv shows.” (Int 6, 200-203)

In the following quote, the carer believed that her daughter recognized and internalized her differences from the expected standard:

She knows that she learns differently. She knows that she still plays with Barbies and she's 14, almost 15. Socially, she knows not that it's not acceptable, but that it's getting to be rarer. That's why she doesn't want to raise her hand in class. She sits in class and stays there in her little cocoon. She doesn't want to ask for help, saying, “because if I ask

for help then people know that I don't understand." She's very aware of that and she's very concerned with people knowing she's different. (Int, 6, 251-258)

The carer perceived that her daughter assumed that her peers' interests and abilities were the benchmark and that her own were "not acceptable." This assumption was perpetuated by a standardized delivery of academic lessons that did not accommodate the needs of the child. In the above examples, the carer believed that the child removed herself from social and classroom participation because she felt inadequate and ashamed, and feared being exposed.

The marginalizing result of societal normalized ideals was evidenced by the rigidity of expectations of conformity of the child with ID, without alternative, person-centred options. The participants discussed the prescribed ways in which their children were expected to physically move and position themselves within the classroom, to behave as "normal" students. The carer in the following text believed that her child "should" have mastered normative development of bowel and bladder control, and independently toilet, but he had not and was resistant to it:

He should be potty trained. He's got his underwear right in a drawer. He won't use them. He'll use them but he'll dirty them. He'll sit right in it too because he doesn't want to tell anybody. (Int 2, 1097-1099)

The carer did not speculate about the cause of the child's resistance but did note, as detailed previously, that his incontinence contributed to his peers rejecting and marginalizing him.

The following quote explores specified classroom routines that are norms the child was compared to and expected to physically adhere to. The carer perceived that her son felt unaccepted because he could not function in a classroom routine which required him to sit and behave like a normalized idea of a student. She believed that because he could not assimilate into this setting, he felt alienated within it. The carer credited expectations and classroom structure reflective of the child's physical needs with improvements in his communication.

**What do you think was the change when he was able to break out with his speech?**  
I think everybody finally accepting him and letting him be him instead of "you have to be a student. You have to sit at a desk." (Int 5, 163-166)

**Do you feel that before that that he felt that he wasn't accepted?**

I think so. Not that he wasn't accepted, just he didn't know who he was and he couldn't be who he wanted to be. He couldn't sit still and he couldn't. Because everything frustrates him. (Int 5, 171-174)

The above quotes provide insight into the perspective of the children through their carers' reports.

The children's direct talk would provide greater detail and requires further research. Regularity was found in carers *perceptions* of their children's talk and behaviour. The carers believed that their children compared, judged, and denigrated themselves against a perceived normal standard.

Figure 3 illustrates how the interview themes are related.

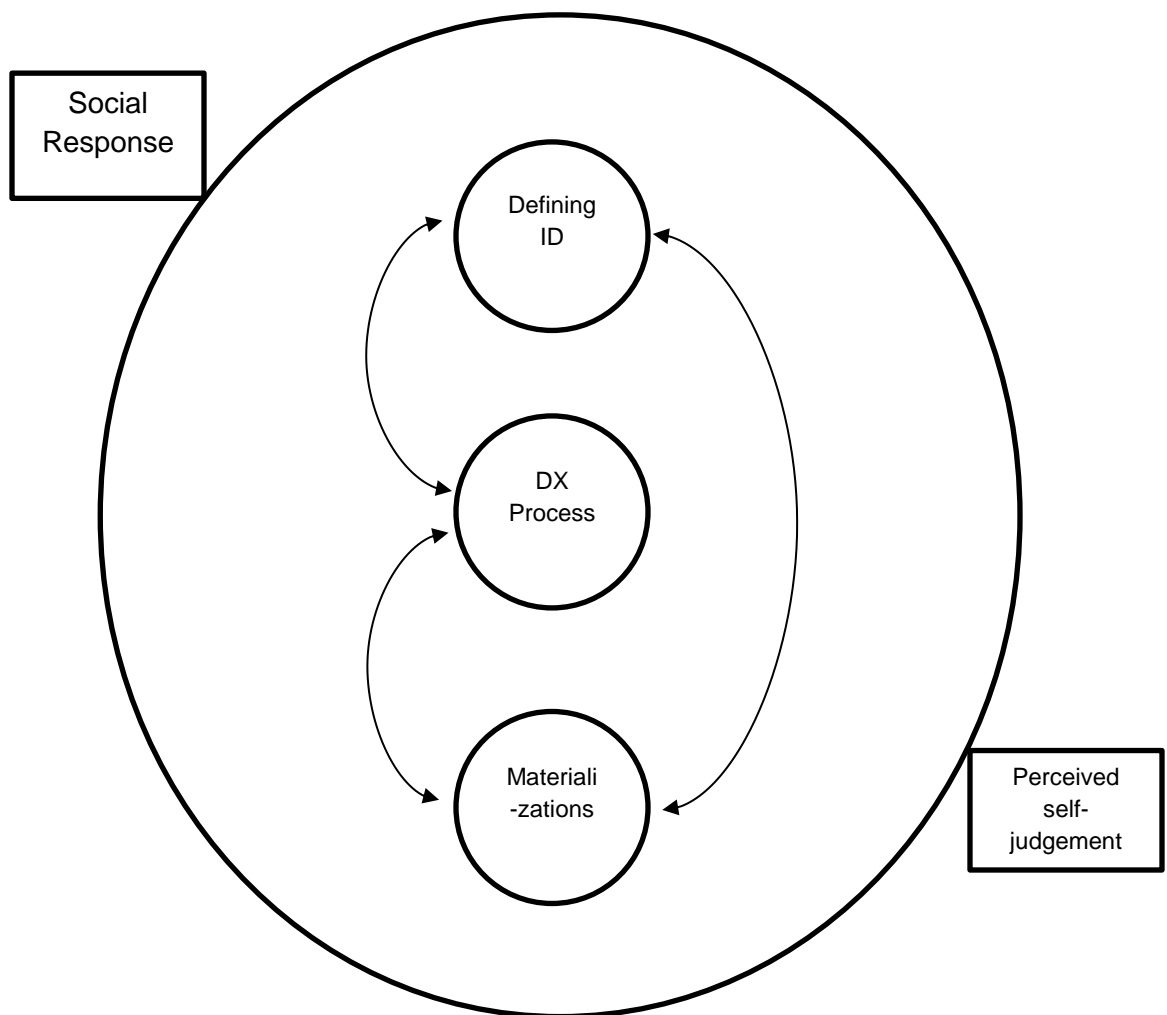


Figure 3. Integration of Interview Themes.

The arrows indicate that the themes are not linear but circular and interconnected. The definitions of ID positioned ID most often as an impairment that implied that children with ID required treatment to be corrected towards socially determined norms of intellectual and adaptive functioning. To receive treatment services, the children were required to be identified and labelled via the diagnostic process. The governmental and service agencies either accepted the diagnostic labels as validating the child's service needs or they rejected the labels. If a diagnosis was rejected by the service agency or the service agency did not align a service with the label of the child, the child and their carer would revolve between the diagnostic process and the evaluation of the eligibility of the acquired label. Tensions and conflicts arose between carers and service agents when there was dis-alignment in their understandings of ID and the children's service needs. The carers understood and evaluated their children's ID in part according to the language used by diagnostic experts and service providers that prioritized autism and lower levels of functioning and did not recognize ID or labels of developmental delay as "real". The carers perceived that their children's peers, service providers, and the community often understood their children as being defective. The carers perceived that their children recognized their own failure to meet functional norms and judged themselves accordingly.

### **Document Review**

From a search of Ontario governmental agencies' websites conducted according to the eligibility criteria in Chapter 3, I identified four pertinent documents. In the document *Comprehensive Government Response to the Select Committee on Developmental Services* (37), the Ministry of Community and Social Services (MCSS) provided context through inclusion of its operating definition of ID and the plans and objectives for inter-ministerial initiatives to address mental health issues for persons with dual diagnosis and coordinated service planning. In the document *Community-based Child and Youth Mental Health, Program Guidelines and Requirements #01: Core Services and Key Processes* (237), the Ministry of Children and Youth

Services (MCYS) presented the guidelines for the Moving on Mental Health initiative and core community child and youth mental health services. In the document *Special Education in Ontario, Kindergarten to Grade 12: Policy and Resource Guide* (238), the Ministry of Education (MEDU) detailed how ID is defined and categorized within the education system and how the educational needs of children with ID are prioritized and met within the education system. In the document *Coordinated Service Planning: Policy and Program Guidelines; Ontario's Special Needs Strategy for Children and Youth* (239), a multi-governmental agency collaboration detailed the outcomes of having a diagnosis of ID on eligibility for coordinated service planning. In addition to these documents, I included the personal email communications with one anonymous source that directed the working group for the Moving on Mental Health initiative and the community agency providing mental health services for the rural area included in this study. The governmental agency document about mental health did not indicate how the moving on mental health initiative would be implemented to improve access to children with dual diagnoses of ID and mental health challenges. I contacted this source to inquire about how children with ID were included within the initiative and within the community agency for this rural area because there was limited information available about the initiative developments or mental health services on the governmental agency website or the mental health agency website. Conversely, there were progress summaries and plans posted on the MCYS regarding coordinated service planning. The MCYS website provided contact links to the anonymous source and invited the public to contact them with questions. In the following section, I present my findings of the review of these documents that detailed guidelines and plans related to the distribution of services to children, including children with ID. The document review themes are outlined in Figure 4.

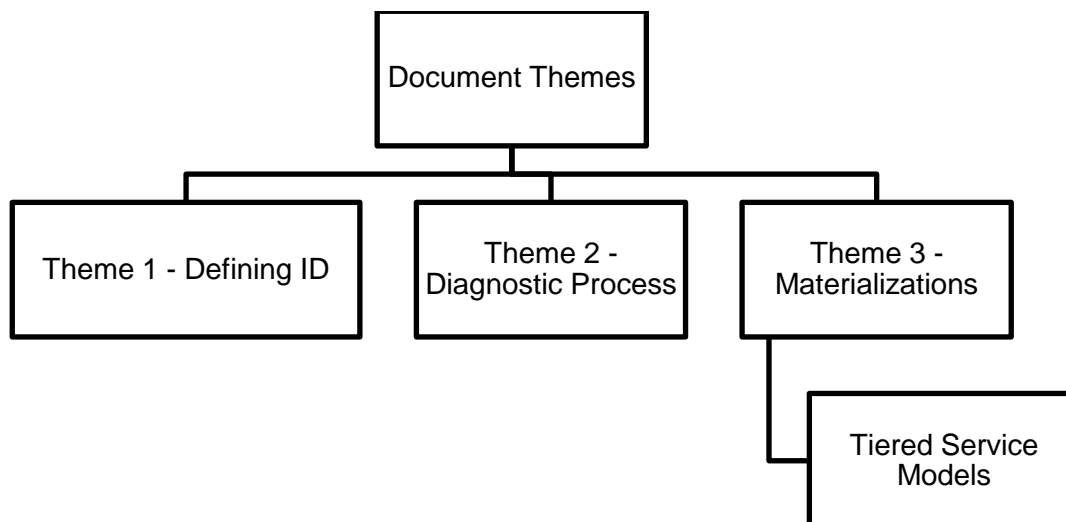


Figure 4. Document Review Themes.

### **Theme 1: Defining intellectual disability.**

My review of the governmental agency documents revealed that ID is understood and defined according to characteristics of impairment in intellect, predictions of scholastic ability, risk to experiencing barriers, and need for enhanced services and supports as well as programming.

The MCSS maintained that cognitive impairment assessed as “significant” or quantified as an IQ score greater than or equal to two standard deviations below the mean was an integral component, in addition to assessed limitation in adaptive functioning, to define and “identify” or “determine” if a person has developmental disability (37)(p13-14). The MCSS aligned their definition with that of the DSM-5 and that provided in the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008*; however, the latter does not specify IQ impairment (37). The community agency that provided child and youth mental health services also distinguished children as having an ID if their IQ scores “[fell] below the second percentile” in addition to adaptive functional limitations (email to Anna Don from anonymous source, June 13, 2018; unreferenced). The use of standardized scores to determine identification of a person within a category of impairment suggests that IQ score margins possess

objective meaning related to the quantification of location of impairment and the identification of the boundary outside of which impairment does not exist.

The MEDU constructed categories of exceptionality to identify students with special education needs (238). Mild ID and developmental disability are the subcategories, under the category classification of “intellectual,” that are pertinent to this study. The MEDU defined mild ID as a learning disorder characterized by a student’s inability to “profit educationally in a regular class because of slow intellect” but who has an “ability to profit educationally within a regular class with the aid of considerable curriculum modifications and support services” and a “potential for academic learning, independent social adjustment, and economic self-support” (238)(pA16). The MEDU defined a developmental disability as “a severe learning disorder” that will not benefit from a special education placement with students with mild ID but requires programing accommodated to “slow intellectual development” with a “limited potential for academic learning, independent social adjustment, and economic self-support” (238)(pA16). A student identified as having a mild ID or a developmental disability is thereby assigned expectations about their abilities and potential. The identification of a student with one of these categories prescribes an educational approach, assigns a degree of impairment, and describes its malleability to change and improvement. This degree of severity and malleability then informs the needs component of the definitions in a standardized fashion, with little room for consideration of individual difference.

Similar to the presumed needs associated with the MEDU categories of exceptionality, in identifying populations with diverse needs related to mental health problems, the MCYS noted that the special needs of children with developmental disabilities “may add to the complexity of their needs and the services they require” (237)(p5). The MCYS also noted that children with special needs were at risk of experiencing barriers to success. The MCYS presented developmental disability as a determinant that influenced the susceptibility of children to mental health problems and potentially heightened the intensity of their service needs (237). Contrary to the MEDU definition of mild ID or developmental disability, the MCYS made no prediction related

to achievable level of mental health for children with developmental disabilities experiencing problems.

### **Theme 2: Diagnostic process.**

In the documents, the governmental agencies outlined differing processes of identification or diagnosis of children to determine the appropriate label for their needs. The commonality among these processes was that the children had to be assessed and tested according to the clinical judgement of various yet specified professional clinicians. According to the MCSS, assessment of cognitive functioning or standardized IQ testing was considered “critical to identifying individuals that developmental services are meant to support” (37)(p13). The MCSS purported that psychologists and their associates were in the position to decipher cognitive assessment findings or make clinical judgements to identify if a person had ID.

The MEDU stipulated that screening for early identification of the developmental level and learning abilities of “every child in the classroom” (pC6) was to occur no later than the beginning of the first grade and to continue throughout the children’s schooling years (238)(pC5). The MEDU specified that “school personnel, other professionals, and parents” were responsible to share information related to areas of concern to facilitate responsive programming (238)(pC6). When a student was identified as having an educational need, the student was then submitted to a formal educational assessment to be identified within pre-established categories of exceptionality put forth by the MEDU. The MEDU noted that additional health or psychological assessments may be requested if the findings would facilitate the identification of the student (238)(pD6). The MEDU stipulated that assessments must be conducted by classroom teachers and may include in-school teams of school principals, special education teachers, counsellors, or board professionals (238)(pC23). Further, the MEDU allowed for school boards and individual schools to decide whether to request or accept assessment findings from out-of-school professionals or whether to have in-school professionals reassess the student (238)(pB18, C18, 21-22). An identification

placement and review committee was stipulated by the MEDU to comprise three members, “one of which must be the school principal or the supervisory officer” (238)(pD2). This committee was to appraise the assessment findings and determine the identification of the student. Carers may agree or disagree with the concluded identification of their child (238). Both the MCSS and the MEDU stipulated specific professionals and personnel from specific agencies were allowed to conduct assessments and identify and label children as having an ID. Although carers were held responsible for conveying concerns related to their child’s development, the inclusion of their input was not required in the assessment of their child.

The MCYS also detailed a developmental surveillance process to communicate carers’ or others’ concerns related to a child’s development and determination of eligibility for coordinated service planning. A child’s referral to developmental surveillance would connect the child and their family to “trained providers” to assess the child and connect them to further services and supports as needed (238)(pC3). Similarly, children with mental health problems would be assessed and triaged according to strengths, needs, and risk to self or others “to support planning and delivery in a way that benefits the children and youth who are in greatest need of the mental health service” (237)(p11). The MCYS instructed “mental health professionals” of regional mental health agencies to consider carer concerns and feedback and complete assessments of a child’s mental health to make recommendations for services (237)(p5). The commonality among each of the discussed services is that the child must undergo assessment by each agency by their appointed professionals to determine their identification according to the agency-specific categories. The outcome of categorization of children along tiered service delivery models is explored in the following section.

### **Theme 3: Materializations.**

Children identified with ID seeking to access services were assessed and prioritized according to tiered service delivery models. The governmental agencies responsible for service

delivery claimed that eligibility was determined based on the triage of needs and not diagnoses. For example, the MCYS defined “target populations” to receive specific core mental health services with the objective of “benefitting children and youth who are in greatest need of mental health service” (237)(p11). According to the multi-governmental agency collaboration, “a diagnosis is not required to access coordinated service planning” (239)(p8). The MEDU also maintained that the categories of exceptionality designated by the MEDU to students were intended to identify and describe the students’ exceptional learning abilities and needs, “not [to] diagnos[e] a condition... [and that] identification should not be interpreted as a diagnosis” (238)(pC17). In this review, I navigated the service eligibility frameworks outlined in each document and found that children with specific diagnoses could be prioritized to receive services delivered at increased intensity. The outcome of navigating service eligibility trajectories was prescriptive services that in some cases specified the exclusion of children with ID and in others preserved the continuity of services from some diagnoses while not ensuring it for children with ID. I further describe this outcome in the following section.

### ***Tiered service delivery models.***

Core mental health services, coordinated service planning, and integrated rehabilitation services shared a commonality of a tiered service delivery structure. The intensity of each service was intended to increase as the needs of the client increased. For example, in the *Community-Based Child and Youth Mental Health* (237) document, the intensity of core services was shown to increase along a continuum according to the child’s increasing level of mental health service need (237)(p6). To explain further, level one of the continuum of “mental health service need” (237)(p7) included all children and youth. Children identified within levels two and three were considered at risk of or experiencing mental health problems that impaired “their functioning in some areas,” whereas children identified as level four had “diagnosable mental health problem[s]” that “severely impaired functioning in most areas of their lives” (237)(p6). The MCYS specified

that the target population for core mental health services were children identified along levels two through four. As noted, the MCYS's objective for core services was to "benefit children and youth who are in greatest need of mental health service" (237)(p11). Children who were identified as potentially requiring services in a level three or four were the target population to receive specialized consultation, assessment, and crisis support services (237). The population "targeted" to receive intensive treatment services were children with diagnosed mental health problems and identified as requiring services at a level four mental health service need (237)(p20). In this way, as the intensity of services increased, the needs of the child were also required to be increasingly substantiated with a diagnosis.

In the document *Coordinated Service Planning* (239), the intensity of coordinated service planning was presented through a tiered service delivery model which increased service intensity according to the determined increasing need of the child. The multi-governmental agency collaboration proposed in the document that the needs of the child and family were determined according to the multiplicity or complexity of the child's needs and requirement for multiple services from "multiple sectors" (239)(p9). The family capacity and external factors that challenged families' ability to manage were assessed to determine eligibility for and intensity of coordinated service planning. Coordinated service planning was intended to improve the timeliness and effectiveness of services accessed by children with special needs to facilitate their participation in all aspects of their lives (239). The multi-governmental agency method of achieving this vision was through the provision of support by coordinated service planning to "decrease family stress by providing families with a formal voice in the service planning process and by assisting families in navigating and coordinating services for their child/youth" (239)(p6). Although within the document, the multi-governmental agency collaboration specified that "a diagnosis is not required" (239)(p8), the child's need and complexity was in part determined by their receipt of services from two or more professionals or sectors (240). The process of becoming eligible to receive coordinated service planning could be interpreted as contradictory to the service

intensity model employed to determine eligibility for coordinated service planning. To explain, children and families who perceived themselves to require the highest level of service intensity according to their psycho-social, service navigation, and coordination needs may not qualify if they were not already eligible for other services. As noted regarding service eligibility for mental health services, many services maintained diagnostic-centred eligibility criteria which could impede some children without diagnoses or without the qualifying diagnoses required and, consequently, service coordination for them.

In the following section, I review the diagnostic requirements and supportive documentation for developmental services and special education to illustrate that tiered service models based on increasing need maintain priority for those with specific diagnoses. The Special Needs Strategy committee was further required to develop a plan for integrated rehabilitation services to improve continuity of therapies from birth until completion of school and to be child- and family-centred in its delivery (241). The governmental agencies providing a patchwork of these services were to integrate and form a seamless plan to ease use and access. According to the MEDU, the rehabilitation services would be accessible also “within a tiered service delivery framework” (238)(pC4). The program guidelines for this framework were not released by the MCYS at the time of the completion of this project. It is therefore unknown whether the increasing level of service intensity will correspond solely with the increasing needs of the child or if there will be further criteria to determine a child’s eligibility for service.

The Legislative Assembly’s Select Committee on Developmental Services found that carers believed “eligibility criteria based on cognitive limitation unfairly excluded individuals who have an IQ above 70 but poor adaptive functioning abilities” (37)(p9). Thus the committee recommended that the MCSS use of a “definition of developmental disability and eligibility for support [that is] based solely on an assessment of adaptive functioning and not cognitive functioning or IQ” (37)(p9). The MCSS refused the request to remove the standardized IQ testing because this diagnostic criterion “identif[ied] the individuals that developmental services are

meant to support” (37)(p13). Although an IQ quantified at or below 70 granted a person eligibility to developmental services, the MEDU stated that IQ scores were not to be included as diagnostic data supporting “the identification of the student’s exceptionality” (238)(pE14). Herein lies an example of competing eligibility criteria that equate with meaning within certain service sectors and not in others. Further, the MEDU document *Special Education in Ontario* (238) claimed that categories of exceptionality were formulated by “the ministry’s definition to describe the exceptionality... indicating an educational category... [that] should not be interpreted as a diagnosis” (238)(pC17). According to the MEDU, the identification of a student’s exceptionality was intended to inform class placement and programing that best “meets the student’s needs” (238)(pD9). The subcategories of mild ID, developmental disability, and autism are, however, diagnoses under the broader term of neurodevelopmental disorders within the DSM-5. The MEDU provided a list of appropriate reports to include in a student’s individual education plan, including “medical diagnoses that support the identification of the student’s exceptionality” (pE14) and provided examples of how to write a summary of the findings of included reports: “Report provides a diagnosis of learning disability... affirms average cognitive functioning... autism spectrum disorder” (238)(pE15). Although the MEDU refuted student identification according to categories of exceptionality as diagnostic, they encouraged medical diagnostic reports be included in individual educational plans to support the student’s identification. To return to the previous point of diagnostic-centric service models, the commonality among the service models reviewed is their shared premise that increased service intensity will be provided to children with increased needs; however, a component of or complete medical diagnosis was seemingly required. In consideration of the data suggesting a prevalent diagnostic-centred service eligibility model, a child could be considered more likely to receive services from multiple providers or sectors with a diagnosis. Thereby, a child with a diagnosis could be interpreted as more likely to be assessed as having multiple or complex needs and becoming eligible for coordinated service planning.

In the document review, I identified that not all diagnoses were equated with service need or equitably served. For example, in the document *Coordinated Service Planning*, the multi-governmental agency suggested that children with complex or multiple needs were likely to have physical and intellectual impairments requiring the use of technology and to require specialized services, with autism services as the example provided (239)(p8). Children with diagnoses of physical impairment or autism would therefore more readily be referred to additional services, which could also enhance their eligibility for service coordination. Similarly, in the document *Special Education in Ontario*, the MEDU noted that “the use of [applied behavioural analysis] instructional approaches has proven to be effective for students with autism spectrum disorder and for other students with special education needs” (238)(pA25). The MEDU only required, however, the “incorporation of applied behavioural analysis methods into the [individual educational plans] of students with autism spectrum disorder, where appropriate” (238)(pE9). The MEDU further detailed prioritization of fostering continuity of needs-based programming for students with autism through the policy requirement that out-of-school personnel who had worked with students with autism must be “invited to provide input and participate in the [individual education plan] process” (238)(pE54). This stipulation ensured an effort to promote continuity of care for students with autism by requiring collaboration with out-of-school personnel, whereas this collaboration and promotion of continuity of programming was not required for students with other exceptionalities, including ID.

As explored in the above section, children with ID were omitted from specific collaboration or programming consideration requirements. Children with ID were specifically excluded from community mental health services and initiatives. According to the document *Comprehensive Government Response to the Select Committee on Developmental Services (37)*, the MCSS expected that service providers from the Special Needs Strategy committee and the Moving on Mental Health initiative would collaborate to coordinate services, including mental health services, for children with dual diagnoses. Further, in the document *Community-based Child and Youth*

*Mental Health* (237), the MCYS directed the Moving on Mental Health initiative and acknowledged children with dual diagnoses within the directive while it also stated that “other conditions or diagnoses do not preclude clients from receiving mental health services, but may add to the complexity of their needs, and the services they require” (237)(p6). The document highlighted the guideline that stipulated that community child and youth mental health core services are not precluded for a child with a dual diagnosis<sup>32</sup> receiving services from another agency but instead that such a diagnosis is an indication for provider attention and coordination (237). Contrary to the presented objectives and guidelines of the Moving on Mental Health initiative, at the time of completion of this thesis, children with ID and mental health problems were considered to be outside the initiative’s scope by the local lead agency (email to Anna Don from anonymous source, June 13, 2018; unreferenced). Further, children suspected to have or diagnosed as having an IQ score “below the second percentile” were deemed ineligible to receive child and youth mental health services within their community and were instead referred to a developmental service agency (email to Anna Don from anonymous source, June 13, 2018; unreferenced). This arrangement exemplifies exclusionary practices within programs and initiatives that contradict their operating guidelines.

In each document, the governmental agencies encouraged service providers to include and promote carers’ preferences in decision making and programing. In contrast to this promotion of collaboration, the MEDU simultaneously specified that it is imperative that “the teacher(s) responsible for providing direct instruction to the student to be the primary decision maker(s) in the process determining the students programing needs” (238)(pE17). Coordinated service providers determined child and family eligibility for coordinated service planning. Although carers were encouraged to participate and provide input, the ultimate decision related to eligibility and delivered programing was that of providers.

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<sup>32</sup> Dual diagnosis refers to a person having both a developmental disability and a mental health disorder.

In summary, following formal assessment and identification through diagnosis or labelling, children with ID entered into service models that were promoted as primarily tiered, structured to prioritize the highest needs. The determination and prioritization of needs was substantiated through a diagnosis-centric criteria. The exploration of tiered service delivery models showed that not all diagnoses were equitably prioritized. The diagnosis of ID equated with general treatment response in some outcomes and direct exclusion in others. Figure 5 outlines the document review themes and relations between them.

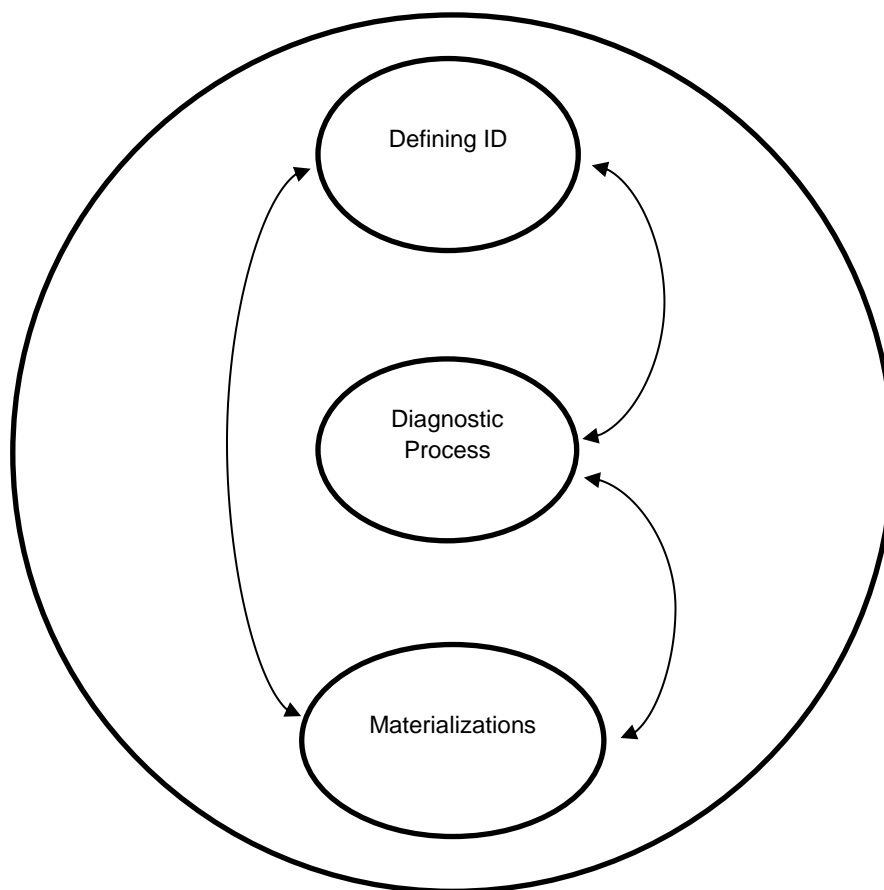


Figure 5. Document Review Themes and Relations.

The themes of the document review are interconnected and influenced by each other. The governmental agencies defined ID using medical diagnoses that included diagnoses within the DSM-5. Service agencies applied the criteria associated with these diagnoses to form taxonomies

to diagnose and organize children with ID. The diagnostic process reinforced medical definitions and criteria of ID by implementing them within diagnostic practice. Children received a diagnosis within the diagnostic process that determined their priority for standardized services according to a tiered service eligibility model. The child were required to repeat the diagnostic process unique to each service agency. The definition of ID as an impairment reinforced the expertise of medical professionals and service agencies to lead in decision making regarding which services were required for children with ID.

### **Integration section**

I integrated the themes of the interview and document review to identify commonalities and differences in how ID is understood, the process of identification or diagnosis, and the consequences of diagnosis. The integrated themes thereby informed my answers to the research questions by identifying the relationships between the governmental agency service directives for children with ID and the perception of the carers navigating these services for their children (11)(p10). Using a Foucauldian discourse analysis methodology, I explored these relationships to aid in my interpretation of how ID has come to be understood, reinforced in practices, and the effects. In the documents, the governmental agencies outlined techniques that regulated children with ID. Within the interviews, the carers' understandings of ID and their perception of how service agencies and medical experts understood and treated children with ID were captured. Legg (242) stated that exploration of how a group has become problematized requires examination of the biopolitical and anatomo-political techniques "that compliment and dovetail with each other.... Locate the individual between the corporeal and the social body"(p140). Together, the documents and interviews thus informed my understanding of the current context of how ID is understood within service navigation.

Through integrating the interview and document themes, I identified converging and diverging ways that ID was defined. There was an underlying discourse within both data sets that

outlined social norms of adaptive and intellectual functioning and established an image of a normal child. The data set themes that defined ID converged by placing focus on the child's impairments that distinguished them from normal. In this way, ID was constructed as the essence of the child in that the label or diagnosis of ID was understood as a comprehensive representation of the child that located ID as a static problem within them. Carers and governmental agencies' shared the understanding that ID is a degree of impairment related to ability to be independent, to be vulnerable, and to need for support and interventions. The primary impairment that was shared by both data sets was that of comprehension; however, terms and connotations to define comprehension differed. The carers described their child's comprehension according to their perception of their child's impaired understanding.

The dataset themes that defined ID diverged where the interviews were threaded with discourses that situated ID as a child's experience of disabling barriers within services. Whereas the governmental agencies' definitions of ID maintained focus on treating the deficits of the child, the definition of ID derived from the carers shifted focus to the ways that the system limited the child with ID by not accommodating their individual abilities and needs. The carers emphasized that language and behavioural impairments were significant challenges experienced by their children. The carers situated communication and behavioural impairments within the context of interactions with school staff who carers perceived had ableist expectations of the children to communicate in normative ways and did not recognize alternative modes of communication, including challenging behaviour. There was a dearth of focus regarding communication and challenging behaviours within the documents. The disabling discourse that influenced carers' understanding of ID situated characteristics of ID as dynamic and inconsistent across contexts. The carers perceived the optimization of their children's capabilities was dependent on receipt of effective interventions. The governmental agencies, however, referred to a child's intellect in a static way through prediction of academic performance ability and future independence according to severity label, as evident in the MEDU definitions of mild intellectual and developmental

disability exceptionalities. The MCSS and the community mental health agency retained the standardized IQ score to quantify and identify children with ID from others.

The document and interview themes indicated similar processes of diagnosis. The interview sub-theme of 'urgency' aligned with the governmental agencies' focus on early interventions. All parties agreed on the benefits of initiating the identification process at an early age. The carers spoke to a sense of urgency imposed on them by the service system in general. This urgency was reflected in the MEDU document, which listed various early intervention services from governmental agencies to be completed prior to school entry, and suggested the focus of early identification occur by the end of kindergarten. The integrated themes converged regarding the underlying discourse that defined ID as an entity with an initial brief period of fluidity and hope that quickly solidified into a static diagnosis that fueled the focus of early interventions. The governmental agency documents outlined diagnostic categories, identified the experts validated to provide diagnoses, and detailed the requirements of the process of diagnosis. The interview dataset sub-theme of 'diagnostic processes' outlined carers' awareness and application of these guidelines into their actions (eg. creating a validating file). The documents validated the carers' reports of their children being required to submit to various assessments and testing from designated professionals specified by each service agency. The carers' perception of rank and prioritization applied to differing diagnoses and severity of need was reflected in the differing service-specific tiered service delivery models. The individual interview and governmental agency themes of 'diagnostic process' diverged in that the carers perceived the process was arbitrary, repetitive, and illustrated the power relations between and within service agencies to accept or reject diagnoses.

The interview and document themes of 'materializations' similarly outlined 'service eligibilities' that prioritized specific diagnoses and children with high needs. Further, in both of the dataset themes of 'materializations', I identified service issues (ie. extensive wait-lists, lack of funding and programing capacity, and lack of services delivered within this rural area of Ontario).

The document review theme of 'materializations' indicated that the governmental agencies aimed to deliver services based on needs; however, service eligibility criteria privileged children with specific diagnoses, particularly autism. The carers indeed did perceived that eligibility to increased intensity and variety of services was associated with specific diagnoses and did not necessarily align with the child's needs (see section on Service Eligibility). Both dataset themes of 'materializations' included description of the services that children with ID were eligible as standardized and predetermined (i.e. Integrated education, prescribed educational programming based on diagnosis, aged-based eligibility criteria, applied behaviour analysis for students with autism). The governmental agencies emphasized the importance of delivering individualized support services while also associating specific services with specific diagnoses or labels. The interview sub-theme of 'service issues' diverged from the governmental agency theme of 'materializations' in that carers contested the fit of standardized services to meet the individual needs of their children. Further, the interview sub-themes of 'conflict' and 'fight and resistance' showed the effects of understanding ID as an impairment to be identified and treated by experts and service agents. Within the documents, the governmental agencies situated specific service providers as the primary decision makers regarding services but also promoted collaboration and engagement with carers as the experts on their children's needs. The interview themes showed that in practice, carers were excluded from decision making and evaluation of services and outcomes for their children and that instead, service providers made programming decisions for their children.

Absent from the governmental agency documents was how collaboration with carers would be conducted to evaluate services and programming outcomes. Tension and contrast was evident between the carers' reports of actual interactions of exclusion with service agency decision making and the objectives of the governmental agencies responsible for the services. Further, the carers often perceived that the services their children received did not meet their needs. The governmental agencies' did not directly detail their approach to addressing carers'

perception of their children's needs not being met within the documents. The documents from MEDU, MCYS (related to community mental health services), and from multiple governmental agencies (related to coordinated service providers) did, however, detail approaches of resolution. The governmental agencies responsible for coordinated service planning and community mental health agencies noted that when it was determined that the needs of a child exceeded an agency's capacity, coordination would be made across service sectors to reach resolution. The MEDU further detailed the process of appeal and mediation in cases where carers did not agree with decisions of identification and placement. In interviews, carers did not mention awareness or initiation of any of these resolution options.

The differences in carer and agency understandings of ID were reflected in how the carers perceived the components integral to their child's ID were not addressed in services provided by these agencies. There was apparent tension between the carers and agency professionals to label children with ID according to the governmental agency-appointed experts and align with diagnostically connected services. Further, although both the carers and governmental agencies shared objectives of carer/agency collaboration and individualized services, there was apparent disconnect in practice.

## Chapter 6

### Discussion

In this chapter I present three discussion points to draw connections and identify contrasts between the findings of this study and the findings of the literature review and the theoretical framework. Next, I explore the limitations of this project. Finally, I make nursing practice recommendations.

To begin, my objectives for this study were to explore how intellectual disability (ID) is understood by carers and Ontario governmental agencies, to identify the discourses and materializations of this understanding, and to explore the how power is exercised within service user and service provider relationships to inform nursing practices with children with ID. To do this, I employed a Foucauldian discourse analysis. I conducted six interviews with carers of children with ID. I conducted four of the interviews one-on-one with carers and in two interviews there were two carers present. I also reviewed four Ontario governmental agency documents. I analyzed the data sets separately and then I combined them into as a single data set which I analyzed. In this study, I found that carers and Ontario governmental agencies broadly understand ID according to expert scientific knowledge, which both positions ID as an identity of being outside of intellectual and adaptive functioning norms and naturalizes the participation of children with ID in the assessment-diagnostic-treatment process. To a lesser extent ID is socially understood as an experience of disabling social barriers or as heterarchical difference. Children with ID and their carers, professionals, and governmental agencies were positioned within hierarchical and competing positions from which to be heard and make decisions.

In this study, the first major finding that I identified is that carers and governmental agencies defined ID according to characteristics that are positioned as a child's identity, an experienced impairment, or individual human differences. The carers and governmental agencies also understood ID as a label, differentiated and hierarchized from societal ideals of normal. The

carers viewed their children as their diagnosis; however, they also recognized the societal barriers experienced by their child with ID, and identified their child's individual human needs. In the literature review, I found that carers identified that primary care providers, recreational providers, and other parents lacked understanding about their children and their needs and identified this lack of understandings as a disabling barriers to their children. Conversely, the governmental agencies overall referred to medical definitions and measured characteristics to identify children with ID; convey a general understanding of the child and expectations around the child's abilities; and prescribe the needs, supports, and educational programming associated with the identified degree of ID. In the literature review of this study, I identified that researchers conducting the studies often understood ID according to medical diagnoses or agency specific categories that essentialized ID and positioned this label as static and predictive. The researchers of the articles included in the literature review did not explore carers' perception of the characteristics and modified nature of ID but instead tacitly assumed that carers' understandings were consistent with their own understandings.

The second major finding that I identified in this study is that children with ID undergo a specific and yet complex diagnostic process. Carers and the governmental agencies shared a sense of urgency to initiate interventions early for children with ID. This urgency justified the governmental agency directives to agency-specific professionals to perform assessments, ranking, and labelling of children with ID. Moreover, the governmental agencies' promotion of diagnostic and identifying processes were intended to identify and legitimate the needs and degree of support the child required. Carers were thus behooved to submit their children to the process for their children's needs to be validated by diagnostic professionals. Carers were critical of the diagnostic process because they perceived that the assessments were arbitrary and applied standardized measures that did not identify their children's unique challenges and needs. Further, the carers perceived that service agencies did not recognize a diagnosis of ID as legitimate or complete. In the literature review of this study, I did not find studies in which

researchers explored the carers' perception of the legitimacy of received ID diagnosis. From the literature review, I identified that prevalence studies of ID were limited by the use of broad and inconsistent definitions of ID (74, 77), and that primary care providers and service agency documentation often missed, inconsistently applied, or did not communicate diagnoses of ID (130, 131). The studies included in the literature review also indicated that having a continuous medical home in part facilitated access to services. In this study, I did not find that a medical home facilitated service navigation. Instead, the findings indicated the importance of a child having the "right doctor" provide the "right diagnosis" to access services. Thereby, in this study I explored and further developed understanding of the value placed on different diagnoses and their ranked severity, as well as the source of the diagnosis within the subthemes of normal/abnormal and diagnostic processes.

The third major finding that I identified in this study is that there are limitations to the services that children with ID are eligible for and receive, and that there are tensions and conflict in decision making and interactions between carers and service providers. In this study, I found a positive relationship between receipt of a diagnosis of autism, mental health disorder, or higher severity of disability and broader eligibility for services. Alternatively, the findings of this study also indicated some governmental agencies deemed diagnoses of ID as ineligible, and carers reported experiences of service agents rejecting diagnoses of ID as incomplete or deeming the children ineligible for services. Comparatively, from the theoretical literature review findings of this thesis, I identified a hierarchy within developmental disability sub-diagnoses that privileged some diagnoses over others regarding service allocation. I also identified within the literature review that complex eligibility criteria—including age, geography, and receipt of a diagnosis—were navigational barriers. Conversely, in the literature review of this thesis, I did not identify details of the specifics of these criteria or explore the influence of tiered or diagnosis-based eligibility criteria. In this study, I thereby conducted nuanced exploration of this aspect of service navigational barriers.

The carers perceived their children's needs and interventions to be individual. Overall, the carers disagreed with diagnostic-prescribed interventions and perceived that standardized services did not meet their children's unique needs. Within the documents, the governmental agencies indicated a shift from diagnosis-based eligibility to needs-based eligibility; however, needs remained heavily determined by diagnoses and the interventions described were predetermined. From my analysis of the carer interviews, I detailed and linked differences in carer and service provider perspectives and unequal decision-making roles regarding determining needs and interventions that included carer and service provider relationship conflicts and lack of collaboration. The literature review findings indicated that carers often perceived that service providers were unwilling to collaborate with them to determine their children's individual needs and interventions (31, 119, 124). In this study, I found a greater depth and nuance to understanding and identifying how collaborative decision making broke down between carers and service agents. Understanding the available roles in service navigation decision making contributes to an understanding of how carers perceive service navigational barriers and to locating potential areas to resolve these barriers. For example, many researchers of the studies included in the literature review concluded with recommendations for service coordination. Similarly, the governmental agencies' documents included an outline about the new service coordinator program within Ontario. As discussed in Chapter 5, the role of this program is limited because only children who are already eligible for other services are eligible for service coordination, and the capacity of services has not been increased. The findings of this thesis may be used to explore how carer-identified decisional conflicts between themselves and service agents can be reduced and collaboration can be improved. These improvements can occur using the extant service coordination that liaises between services, but they do not change problematic existing eligibility criteria or how individual agencies determine need or plan interventions.

I raise three important discussion points that mobilize my nuanced findings of this study with the findings of the literature review and the theoretical framework. From the diverse ways

that I found ID was understood within this study, I highlighted the importance of discussing and theoretically interpreting what truths inform the current understandings of ID. In the first discussion point, I identify what is believed to be true about ID to aid understanding of the context and operational assumptions from which different perspectives about ID are framed. In the second discussion point, I examine how currently held truths about ID have been developed; implemented within carer, service agency, and governmental agencies' practices; and reinforced within service systems for children with ID. In the third discussion point, I critique how power functions within the interactions between children with ID, their carers, and service providers in the service system.

### **Competing Constructions of ID**

In the first discussion point, I identify the truths that substantiate the current understandings of ID that were presented in the findings. Importantly, from the poststructural stance of this thesis, phenomena that are recognized as ID are “taken as real” (200)(p377) but the “grouping” (68)(p22) of these phenomena as representing ID and the truths that are attributed to and frame understandings of ID are critiqued because they are situated as constructed knowledge. Foucault used the example of the “madman” to acknowledge the “occurrence of certain phenomena that come to be understood as mental illness” (243)(p38) but stressed that the meaning and understanding of the “madman” is continually constructed and changed through discourse (68). I used the questions posed in Rawlinson's axis of knowledge, presented in Chapter 4, to interpret my findings of this study to identify the truths and rules of how ID can be spoken about that inform how it is currently understood (190, 227). Identifying perceived truths about ID and the rules of what can be said about ID illuminates the discourses and contexts informing these understandings. Recognition of the truths influencing constructions of ID may aid in understanding the differences between how carers and governmental agencies define ID.

In the historical portion of the literature review of this study, I outlined that Lock understood ID as a variation of a person, an idiot, who *is* permanently without the ability to reason (85, 86).

The American Psychiatric Association developed the diagnosis of ID, within each version of the DSM, that reflected first, the belief that the diagnostic stratification of ID was accurate; and second, that the classified degree of ID severity could predict a person's potential abilities and identify their need for interventions. In my review of current literature, researchers identified participants according to the criteria that a child had acquired a clinical diagnosis. The researchers of the studies that I reviewed explored service navigation barriers most often from the carers' perception of satisfaction with the operations of the system but did not examine how carers understood their children or what needs or interventions that carers prioritized. In this way, ID has been understood as a static essence in that the label of ID is assumed to convey meaning and predict the potential of the diagnosed child.

Within this study, I found discursive regularity, predominantly focussed on impairments, in carer and governmental agencies' understanding of ID. Foucault defined discursive regularities as "order, correlations, positions and functioning" (68)(p38) to the way that an issue is spoken about consistently within a particular social context. This regularity within understandings of ID is indicative of what are believed to be truths about ID and the rules of how ID can be discussed (68). Impairments are made possible by the discursive context in which the carers and governmental agencies' documents shared a belief about this concept of a so-called normally developing child as a true standard reference point that facilitated the distinction of impairments (151)(p62)(244). The carers compared their perception of a "normal" child to their own children and thus identified and described their children as "not normal" according to their own perceptions of their children's impaired abilities to communicate and understand, and dependence on and need for others. Similarly, the governmental agencies' documents detailed operational definitions that identified children according to characteristic categories of IQ, adaptive functioning, and predictability of academic and future independence success based on normative ideals of functioning in these areas. The carers perceived that communication impairments contributed to their children's challenging behaviours, impeded their needs from being met, and prevented their

cognitive abilities from being recognized. However, in the document review of this study, I found that the governmental agencies did not identify communication impairment as a significant characteristic of ID or draw connections between it and other identified characteristics. Deleuze and Guattari's (66) arborescent concept is useful to understand how beliefs about developmental expectations of children have constituted foundational truths of "normal" that function to distinguish impairments. The arborescent concept can be used as a tool to thus trace the origins of truths about normal so that these origins and truths can be critiqued. Foucault's concept of surfaces of emergence, defined as the location where different ways of talking about an issue come from (68)(p41), is useful to explain the role that social norms have in distinguishing ID. Discourses of intellectual and adaptive norms serve as examples of Foucault's (68) surfaces of emergence that facilitate the naming and description of intellectual and adaptive functioning impairments as abnormalities of ID. ID does not exist independently of ideals of normal intellect and adaptive functioning signifiers. Therefore, normal signifiers are assumed truths that facilitate the surfaces of emergence of ID's distinction from "normal." I explored how children with ID are organized and categorized according to discourses that establish ideals of normal using the concept of stratification.

Similar to my interpretation of the truths and conclusions drawn about children with ID by diagnoses within the DSM, children with ID were frequently positioned according to diagnostic labels within the discourses that pervaded the interviews and documents to convey assumed shared understandings, predictions, and meaning about the children and their differences. Deleuze and Guattari's (66) concept of stratification is helpful to explain how social concepts of normal/abnormal and diagnostic labels form boundaries or strata that children with ID are sorted by being divided from children without ID according to their differences and ranked (66). The concept of stratification is useful to articulate how social order is formed within a population. Within this study, children with ID were sorted from children without ID according to how they differed from social constructs of normal/abnormal intellect or adaptive functioning. Ranking categorizes

and establishes hierarchy between and within differences (66). In this study, I identified that ID was categorized according to the diagnostic criteria of adaptive and intellectual functioning. Children with ID were hierarchically ranked within these categories according to their quantified deviation from a normal standard of adaptive or intellectual functioning. To explain, the governmental agencies' definitions of ID and the carers' descriptions quantified the children's degree of ID based on adaptive and intellectual functioning impairment by using terms such as "low" and "high functioning" and "severe." Further, the carers also perceived that their children were ranked at the bottom of the hierarchy of social value. The carers perceived their children were socially devalued when their children were referred to pejoratively or seen as being their diagnosis, and when service providers were resistant to respond to some of their needs. Foucault's concept of grids of specification can be applied to Deleuze and Guattari's concept of ranking to illustrate ID as a taxonomy of hierarchized characteristics of adaptive and intellectual functioning and social position (68).

In the document review, I found that the governmental agencies prioritized adaptive and intellectual diagnostic criteria differently within grids of specification of ID. The operational definitions used by the MEDU, MCYS, and the multi-governmental agencies prioritized the identification of individual adaptive functioning strengths and needs to determine service eligibility. The governmental agencies' prioritization of adaptive functioning abilities aligned with the AAIDD and DSM-5 recommendations to reduce the value placed on IQ scores and increase focus on identifying adaptive functioning ability, needs, and supports (94, 98). Conversely, the community agency providing mental health services, which I introduced in the document review findings, and the MCSS retained IQ scores as a prominent characteristic to "identify" persons with ID and their eligibility for service. The MCSS defended the use of IQ scores by referring to the DSM-5 and AAIDD inclusion of IQ criteria. In this way, although diagnostic organizations were posited as experts and used to legitimate governmental agency definitions of ID, the governmental agencies and some service agencies were the authorities defining ID within individual practice settings.

Foucault's (68) concept of authorities of delimitation is useful to explain how the American Psychiatric Association and AAIDD as well as the individual governmental agencies were positioned and competed as experts to outline "what counts" as a definition of ID (227)(p8).

The significance of the appointment of diagnostic associations and governmental agencies as authorities in defining ID in turn creates understandings of ID and directs how service agencies treat children with ID (68, 227). Indeed, although the interview participants did not discuss IQ scores, the Ontario Select Committee on Developmental Services heard carers report that their children were excluded from services according to IQ cut-offs despite carers perceiving that their children's adaptive functioning needs warranted the services (35).

Reflecting on Foucault's work on objectification, Rabinow proposed that, through the processes of dividing and scientific classification, humans "are given both a social and personal identity" (245)(p8). Deleuze and Guattari's (66) concept of *being*, defined as an arborescent construct of identity, ties the concepts of stratification (through sorting and ranking) and objectification together by articulating how an arborescent schema applies and imposes truth on human beings to "transform [them] into subjects" (72)(p208). To explain, the roots of truth form the concept of being intellectually disabled that necessitates a binary of normal versus not normal intellect and categorizes "different kinds of" ID (68)(p42). Roberts (243) further described how diagnostic labels have been "tied to" a person's "identity" by informing how "others understand that person" (p38). The labels applied to children with ID were often assumed within governmental agency discourse to be accurate descriptions representing *who* the children were and prescribing treatment toward them. The differing governmental agency operational definitions of ID also problematize the arborescent position that a diagnostic label conveys an objective truth about children with ID. These differences reveal a crack in the foundation of truth proclamations made about what does and does not define ID.

The carers simultaneously constructed ID as a form of heterarchical human diversity of difference. Deleuze and Guattari's (66) concept of the rhizome, defined as the infinite and

antifoundational possibilities of the development of truth, is a useful way to theoretically interpret carers' construction of ID as differences. The carers did not differentiate their children from others according to standardized cognitive and adaptive functioning deficits but instead drew comparisons across all children's needs being different from each other and particular to them. Understanding difference as rhizomatic represents a counter-discourse to arborescent understandings of ID. Indeed, disability theorists have suggested that a rhizomatic lens declassifies humans from a normal/abnormal dichotomy. A rhizomatic lens positions people collectively according to the traits of disability, fragility, being "temporarily able bodied" (65)(p169), and mutual dependence as "central to the human condition" (246)(para 6). ID was more often understood by carers within this study according to the disabling social service barriers and limitations that their children experienced. As an example, the carers constructed the ID characteristic of vulnerability in part as a consequence of their child's dependence on the support from service providers who did not understand the child—when providers saw the child as being ID, that is, when they assumed or did not question the child's intentions and potential, and when they imposed normalized ideals of self-care, communication, and understanding on the child. In this way, carers also understood ID through a social model that located societal disabling practices that contributed to their children's vulnerability. Within the literature review, researchers of a few studies explored the disabling effects of service navigational barriers for carers (e.g., employment, finances, stress, negative emotions). For example, Doig et al. (31) described carers seeking services as having to "jump through hoops". As another example, Schleien et al. (124) detailed how parents perceived the unaccommodating attitudes of recreational staff and negative attitudes of other parents towards their children with ID as barriers to their children being included in community recreational activities. In this study, I gained nuanced understanding of how children with ID are understood in part, according to their individual characteristics and needs that also furthered my understanding of how service navigational barriers serve as disabling barriers to children with ID.

In the data analysis of this study, I found that ID was diversely constructed within and between the texts of the interviews and governmental agencies' documents. However, I also identified that the researchers of the included articles of the literature review and the government agencies shared an underlying assumption that carers understood ID consistently with the applied diagnostic labels. An impairment model, focussed on the adaptive and intellectual functioning limitations specified by the ID diagnosis, emerges as the dominant, governing discourse constructing ID. Consequently, the individual differences, challenges, and needs that were not captured within the boundaries of ID diagnoses but that carers perceived were significant characteristics that impacted their children were not acknowledged or prioritized within the service system. However, carers navigated the system with the focus of meeting their children's unique needs. Stated differently, the carers and governmental agencies often understood children with ID very differently, which may have contributed to service navigational challenges because their objectives and goals differed. Governmental agencies, service agencies, and agency specialized personnel were privileged with the authority to identify what criteria and which children were included under the title of ID. The impairment discourse resulted in the child with ID being understood by a diagnostic label, ID, that quantified impairment, predicted future abilities, and prescribed educational placement and supportive services.

### **Implementing Definitions of ID**

In this discussion point, I examine the interview and document themes to identify normative truths and biopower techniques that legitimize governmental agencies' operations and mobilized social agents. I then explore how these truths and techniques develop, implement, and reinforce dominant impairment discourses of ID. Foucault's concept of normalization details how social norms have developed. Foucault (1977) explained that "the norm brings with it a principle of both qualification and correction... [It] is not to exclude and reject... It is always linked to a positive technique of intervention and transformation" (p50). I apply the concept of normalization to thus

clarify the link between believed truths about ID and how society responds at a population and individual level to children with ID (244)(p213).

I used Rawlinson's (200) questions related to the axes of authority and value to flesh out how medicalized impairment-focussed understandings of ID were developed and preserved, as well as how they were used to justify how understandings and treatment of children with ID. I utilized Foucault's theories of the repressive hypothesis (72) and biopolitical technologies of power (including morbidity, health promotion, illness prevention, education, resources, and statistics) (140, 161) to help me to situate discursive truths and how they have justified governmental agencies' authorities and practices related to children with ID.

Foucault's concept of the repressive hypothesis can be used to explain carer and governmental agencies' "ease of acceptance" (72)(p130) in understanding ID through a medicalized view that promotes an impairment-treatment lens. The governmental agencies' medicalized understanding of ID was considered neutral and objectively true because it was scientifically derived, thus challenging and delegitimizing critiques of it (60). The promoted idea of normal intellect was taken up as a logical and desirable state—a neutral human characteristic that existed independently "outside of power" influences (166)(p46). The positioning of ID as a medical-scientific diagnostic object simultaneously appointed and "extend[ed] the power of experts" (72)(p196). Medical-professional diagnostic associations and Ontario governmental agencies were often provided a "speaker's benefit" (p6) for having expertise in the scientific field of diagnosing and treating children with ID (140). The speaker's benefit privileged diagnostic associations and governmental agencies providing services with "the right to pronounce truth" (60)(p60) in defining the diagnostics, labelling, and boundaries that constitute ID (140). Each governmental agency document then identified and mobilized the human resources of "professionals" and "experts" within service agencies. In the documents, the governmental agencies further outlined regulation of service distribution that first required children to be screened, assessed, and identified with validated diagnoses by appointed professionals.

However, the schools and other service agencies held the speaker's benefit to discount the diagnoses and recommendations of medical professionals when they did not align with the school's or other agency's approach. Carers' relied on professional organizations and governmental agencies to speak the truth regarding diagnosing and labelling ID to facilitate their child's access to services. The carers' reliance supported the functioning of biopolitical technologies of power that regulate the population through policies, education delivery methods, and interventions that promote an idea of normal (72, 161). These biopolitical operations were preserved by carers seeking assessment and diagnoses or labelling. When the provided diagnosis or treatments associated with the diagnosis did not align with the carers' beliefs there was tension, fighting, and resistance to biopolitical operations. In the literature review, I identified that researchers often explored service navigational barriers according to the limitations of access to primary care providers that are knowledgeable about ID, and the limitations within the capacity of service agencies to deliver services. From this study, I thus gained awareness of the role that diagnostic processes and negative carer-provider interactions play as service navigation barriers.

The biopolitical objective of promoting societal well-being and life through regulating a population could be argued to justify the impairment-treatment construct of ID (147). My analysis of the interviews and governmental agencies' documents identified an underlying assumption that ID was in part defined according to predictions of academic achievement and potential for independence. Impairment-centric understandings of ID that signify an individual's deviation from the norm were preserved by truths constructed by statistical normative curve and identified outliers. Norms determined according to a "population mean" and congruent with a particular "sociocultural background" (94) were biopolitical applications of statistics that implicated how children with ID were identified and understood by the American Psychiatric Association, within the DSM-5.

The sparse international and absent national prevalence data about ID is a second biopolitical application of statistics that merits discussion in relation to how ID is understood.

Prevalence data heavily influences how services are planned and distributed (19, 75, 82). Therefore, the paucity of ID prevalence data is relevant to the research problem of service navigational barriers. Canadian disability prevalence data clustered all developmental disabilities into one category that prioritized medical diagnoses, while other disability categories did not prioritize medical diagnoses. To explain, Statistics Canada purported in the 2017 *Survey on Disability* (78) to have used a social model to identify persons with disability according “functional difficulties.” Persons were identified as having a disability, with the exception of a developmental disability, through self-reported difficulties (78). Persons were identified as having a developmental disability if they had been diagnosed by a health-care professional. Persons with developmental disabilities could only speak of their difficulties through validated diagnoses and were not provided the opportunity to self-report. The survey privileged, preserved, and validated that diagnostic labels were comprehensive and truthful in conveying the identity of a person with developmental disability. This national survey thus positioned developmental disabilities to be understood homogeneously and through a medicalized lens.

The lack of population ID morbidity statistical data may represent a biopolitical passive exclusion of children with ID that lessens the obligation to address their needs. Further, the medicalized lens used to determine developmental disability prevalence in Canada illuminates carers’ perceptions that they were excluded from decision making and that standardized services were inadequate and ill-suited to their children’s needs. The governmental agencies further acknowledged service incapacity to address all children with identified needs and waitlists that provided justification of tiered service delivery models. Tiered models represented technologies of power that reinforced a medical model perspective of ID using diagnostic hierarchies to prioritize service needs.

The governmental agencies’ medicalized view of ID maintained focus on improving the child with ID and reinforced the service system, its experts, and standardized services. My analysis of the interviews and the documents revealed an underlying discourse that emphasized

the urgency and importance of early intervention for children with ID. The subtheme of urgency can be interpreted to have reinforced the medical discourse that positioned the child with ID as having impairments that required treatment. Indeed, included in the literature review of this study, the Canadian Task Force on Preventative Health Care (99) and Krauss et al. (28) promoted early intervention for children with developmental disabilities, and in particular, children with autism. In this study, I identified that the factor of time was associated with the “early period” that positioned the child with ID as optimally treatable and dynamic in the early years but implied that the child’s impairments would become static and less receptive to treatment over time. Deleuze and Guattari’s (66) concept of being can be used to interpret the effects of early intervention discourse as contributing to and reinforcing the understanding of ID beyond the early years as a solidification of the child’s identity. I selected the inclusion criteria of carers of children six aged six to 14 to explore how children with ID are understood beyond the early intervention period and because developmental services are reduced beyond the age of six. The discourse of early intervention also introduced hope that the child with ID could be changed within this optimal time. The hope associated with early intervention further reinforced the carers to seek out medical and system experts to assess, diagnose, and treat their children. There was an identified lack of alignment, however, between the identified needs of the children and the supports that were provided that could be interpreted in two ways: In some cases the children received services; however, the carers and the experts disagreed about the identified needs of the child and the supports they required, or the carers critiqued the services for being predetermined and not meeting the individual needs of the child. In other cases the children were denied services to meet their needs that both the carers and the experts agreed upon because their diagnosis had not been prioritized as eligible for the service or there were inadequate resources to provide the service. The processes of the system that impeded carers and their children with ID from using support services were identified within the Select Committee on Developmental Services report; however, the discourse of disabling systems was in part co-opted to instead reinforce and expand the

system. To explain further, the Select Committee reported that persons with ID received insufficient services and ill-suited standardized services, and experienced service eligibilities that prioritized crises. The committee thus recommended that governmental agencies enhance person-directed priorities within flexible services and generally provide “more services, less system” (35)(p4). A multi-governmental agency partnership created a coordinated service planner role in partial response to the Select Committee report. The new role did not increase service capacity, but created a role for a practitioner to assist families to identify goals and develop a single plan of care within the current system. Individual tailoring of service remained bracketed within the predetermined trajectory of service offerings. The focus remained on treating the child and facilitating navigation within the same system without critique or revision of the limitations of the system.

My analysis of the document review of this study found that biopolitical discourse directed the behaviour of the children with ID and their carers and positioned service providers and professionals to identify the needs and service eligibility of children with ID. The governmental agencies’ outlined directives of diagnostic processes and carers’ adherence to them reflected a shared belief that navigational trajectories and accessed services would increase the well-being of children with ID.

The governmental agencies’ documents outlined diagnostic categories that indicated educational programming associated with categories and the target populations for services. The governmental agencies thus used diagnostic categorization to partitioned children according to characteristics perceived as representing them and their service eligibility. Foucault’s discussion of the use of scaffolding in architecture to facilitate hierarchical observation provides a close analogy to how the governmental agencies’ diagnostic categories were used to organize and direct the actions of each child accordingly (165) . Architecture in this sense is the theoretical categorization of service eligibility and while not a physical structure it does reflect Foucault’s point that through segmentation, individuals become more visible and known (165). Foucault

stated that this instrument produced objectification and “partitioning of individual behaviour” (165)(p172). Within the documents, the governmental agencies justified and necessitated the positioning of professionals as “specialized personnel” (165)(p174) assigned the role of assessing, identifying, and making recommendations that distribute children with ID within the service trajectory. The carers discussed the use of safe rooms and “clearing the classroom” of all other students when the child with ID was exhibiting disruptive behaviour, which offers another example of partitioning that contained and controlled the child exhibiting the behaviours. The carers also perceived that they were excluded from decision making with school staff about the use of these measures with their children. Further, the carers perceived that their children’s behaviours communicated their unmet self-care needs and communication limitations. Indeed, authors of disability literature have framed challenging behaviours as contextually functional for the person exhibiting them (247, 248). The carers perceived that school staff did not recognize the needs that the children’s behaviours were communicating. The carers did not report that there were any discussions with school staff about the potential function of the children’s behaviour or critique of the use of safe rooms or classroom isolation. The school staff’s reaction of partitioning a child exhibiting disruptive behaviours can be interpreted as a means of protecting the other children and staff. Additionally, a child with ID could be understood in this context as being their static diagnosis because their behaviour was viewed one dimensionally as “negative” and requiring control. Through this architecture, an expert economy of professionals is constructed to diagnose children with ID within categories that are assumed to encompass their impairments and eligibility for services. In this way, the categorizing discourse within the governmental agencies’ documents preserves the governmental agencies as authorities over children with ID and services distribution. Within the documents, governmental agencies reported that carer input was as an important aspect to consider; however, carers reported that their critique of and disagreement with standardized assessment and treatment to represent their children’s needs were ignored. Further, carers reported that schools rejected medical diagnoses that did not align

with the schools' assessments. Within the literature review, McGrath et al. (118) and Shooshtari et al. (21) found that having a continuous primary care provider improved access to other health and social services for children diagnosed with ID. These researchers, and the researchers of the other studies included in the review did not explore the effects of either the impact of having or not having a diagnosis, or how different diagnoses or different professionals providing the diagnoses effected the service eligibility of children with ID. In this study, I found that diagnostic processes and service eligibilities were barriers to children with ID navigating service systems that had not been previously identified by researchers exploring service navigational barriers.

Through hierarchical observation, children with ID were examined by professionals according to biopolitical regulations outlined in the governmental agencies' documents, and received a normalizing judgement. Foucault (165) theorized that disciplinary power was invisibly carried out by professionals conducting examinations which "imposed" scientific knowledge onto the person under examination (p187). Indeed, carers described the extensive and repetitive examinations and assessments their children underwent and the documents that were generated from this process. Carers created files about their children from the documents provided to them by experts who had diagnosed their children. The carers used the files to make their children recognizable to service agents according to "discipline-specific" (227)(p8) diagnoses and classifications made by the "right doctors" to validate their service requests for their children. Foucault's (165) concept of the case provides an analogy to understand the implications of the carers' use of the file. To explain, Foucault stated that the case "situates [the individual] in a network of writings... in a whole mass of documents that capture and fix them" (p189). The techniques of examination thus reinforced discursive truths about ID that promoted a medical-impairment approach focussed on IQ, and recognized diagnostic categories and classifications. The medicalization of ID necessitated clinical responses from the governmental agencies and assigned professionals to examine children and apply labels that captured the essence of the child with ID (243).

In the analysis of the interviews and governmental agencies' documents, I found that children became visible cases when they crossed the threshold of abnormal according to IQ scores and adaptive functioning and no longer assimilated in normalized environments, particularly the classroom. The relevance of becoming visible is explained through the normalizing judgement and subsequent gratification or punishment that is determined from the examined case. To clarify, Foucault (165) proposed that cases that are the focus of a discipline will become visible through training and normative corrections whereas cases that are not the focus of a discipline may be excluded (p181). The governmental agencies specified normalizing judgement actions to differentiate, rank, and categorize children according to prioritized characteristics and governmental agency-specific target populations (165)(p183). Foucault (165) proposed that normalizing judgement hierarchizes the "good and the bad subjects in relation to one another" whereby the good subjects receive "honorary classification" (p181). I interpreted the integrated interview and document themes to mean that good subjects are children with autism, already accessing other services, and in "early childhood." Foucault described a good subject as an individual believed to be correctable to "conform" to a normal ideal and thus upon whom more corrective efforts will be applied and resources spent (165)(p182). Conversely, carers perceived that children diagnosed with a developmental delay and ID were not recognized or provided adequate services. Children with developmental delay or ID, in Foucault's framework, would be positioned as bad subjects because they are considered less correctable, being further from the normal ideal and thus rejected and excluded from many services. Foucault theorized that the objective of disciplinary power is to create docile subjects that resemble society's idea of a useful, normal person. The disciplinary system at play within these processes allows for all children to be identified according to their deviation from the norm and to be distributed within the corrective system.

The carers and the governmental agencies positioned the children's receipt of adaptive functioning services as a reward. Foucault (165) defined correction as "advancing their progress

by correcting their defects” (p179). In this way, the medicalization of ID and “standards of normal” (60)(p22) maintained focus on the normalization of the individual with ID through provision of correcting services rather than focusing on disabling social practices. The carers justified their compliance with the repetitive and complex process of service navigation and normalizing judgement with the possibility of obtaining corrective services for their children (165)(p182). In the interview findings, I found inconsistencies related to whether a classification of ID was associated with the desired reward of service eligibility or not. The carers reported inconsistent age cut-offs and eligible diagnoses across service agencies that resulted in their child’s ineligibility from services. Indeed, in the document review, I found that the lead community agency providing youth mental health services deemed children with an IQ “below the second percentile” as ineligible for service (email from anonymous source, June 13, 2018; unreferenced<sup>33</sup>). Within the documents, the governmental agencies overall justified service ineligibility criteria with reported mandates, “scope,” “design,” and “focus” of services agencies. Medical professionals and service providers were thus also positioned as powerful social agents over carers and their children because they had the ability/mandate to exclude-punish or include-correct-reward. Exclusion from service eligibility resulted in the disappearance of the child with ID (165)(pp182-183), as the child’s needs were unrecognized within the predetermined governmental agencies’ categories and unmet (according to carers) because the children did not receive services. The carers expressed frustration, sorrow, and a sense of abandonment related to their children’s exclusion from service eligibility because the prominent discourse promoting corrective services positions these services as in the best interest of the child. To be excluded from corrective services can be interpreted as a punishment by not precluding negative outcomes.

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<sup>33</sup> I was provided written permission from this anonymous source to use the email communication with the understanding that the source and organization would not be named. This permission satisfied the University of Ottawa REB requirement of receipt of written permission from the source of communications to allow inclusion of personal communications.

The outcomes of being judged as either good or bad subjects determined service eligibility and directed the art of distribution and control of activity of the children with ID and their carers, given their acquiescence to the direction from professionals (165)(p136). Repeated professional assessments, classifications, and determination of eligibility partitioned children with ID individually within service systems. Foucault (165) proposed that partitioning facilitates “how to locate individuals... and circulates them in a network of relations” (p143, 146). The carers questioned the relevancy and effectiveness of service eligibility criteria to accurately identify children requiring services. Further, through analysis of the interviews and documents, I found that the carers and governmental agencies’ positioned each service sector as having autonomy and control to establish their own, non-transferable eligibility assessments, and privilege in-house professionals over others. The two-dimensional result was a broad hegemony of the health and social service sector over service recipients, and individual governmental agencies and service agency hegemonies that operated in silos.

The developing mental health strategy for the geographic setting of this study, at the time of this thesis, did not address children with ID who experienced mental health challenges. Children with ID were also restricted from community mental health services, and further denied behavioural, educational, and speech services to address needs reportedly acknowledged by service providers because they hadn’t received a recognized label. Foucault’s (165) disciplinary technique of the art of distribution could be used to interpret that children with ID were “assign[ed] a direction” (p. 152) through their partitioned diagnoses or determined eligibility that “obtain[ed] holds upon” (p. 137) their bodies and controlled their activity and movement within the service navigation trajectory.

I interpreted the MEDU categorization of students to inform “identification and placement” decisions as organization and control of the activity of children with ID using Foucault’s concept of the temporal elaboration of the act (165). Foucault (165) defined temporal elaboration of the act as forms of “precision[ed]” “restraint” and “control” of an individual’s movement or behaviour

(p151). The interviews indicate that carers were influenced and later subjugated by pedagogical ideology promoting inclusive education as the prescriptive and expected choice for classroom placement. The carers used politicized terminology when they referred to mainstream education as “integrated” and specialized education as “segregated.” Specialized classroom placement was interpreted as exclusion of a child with ID. Foucault (249) explained that “the way that people act or react is linked to a way of thinking, and of course thinking is related to tradition” (p14). The carers’ initial ideological alignment with inclusive education and subsequent advocacy for their children’s placement in integrated classrooms reflected their docility to adhere to prominent ideology and technologies of the self through advocacy. As I discussed in Chapter 2, the community living movement problematized all contexts that segregated people with ID from people without ID as unacceptable. The residue of this political discourse remained and was located within the words that the participants used to describe classroom placements (e.g., segregated and inclusion) and in the stated goal of the MEDU to prioritize regular classroom placements. When the carers perceived that an inclusive classroom no longer met their child’s needs and requested the school personnel to allow their children be moved to a specialized classroom, the school personnel refused. The school operated as a disciplinary system that sorted and divided students to train them into functional students. The school system was also, however, influenced by the political pressures of inclusion discourse that limited the ability of the school to sort students into classrooms based on their diagnoses and promoted that students be kept together. Thus, inclusion discourse was a barrier to the disciplinary functioning of the school system by curtailing the separation of students. Furthermore, the carers recognized the shortcomings of the school system to deliver education in an inclusive manner that met their children’s needs.

Within the documents, the governmental agencies implemented dominant impairment and inclusion discourses of ID that mobilized diagnostic experts and service agents to determine the eligibility of children with ID, and prescribed how children with ID could move within the system.

## **Functions of Power**

In this third discussion point, I examine the flows of power within interactions between children with ID, their carers, and service providers in the service system; the effects of power on the citizenship of children with ID; and locations for resistance. The implications of how ID is understood are tied in to make explicit the “effects of the discourse within the web of social power relations” (60)(p54).

I applied the lens of the citizenship of children with ID within the current socio-political context to interpret the materializations of the findings of this study. Citizenship is examined according to the subject position of children with ID: rights, duties, and status. The DSM-5 defined children with ID in part according to their “failure” to meet normative “developmental and socio-cultural standards” and “responsibilities” (94). There was tacit societal expectation that carers would submit their children with ID to ongoing assessments, identification, and services that would modify their behaviour and “way of being” (249)(p18) to reflect a normalized citizen (94, 183, 238). The carers altered communication, validated themselves with supporting documents, and responded with a sense of powerlessness and submission to contested decisions made by others to appeal to agency personnel to access services. From analysis of the interview findings, I found that carers perceived that it was their duty to comply with prescribed directions within the service trajectory despite experiencing burdens within it: waitlists, geographic barriers, ill-suited standardized services, conflicts with service providers, and reduced decision-making autonomy. The burden imposed on the child with ID and their family by the service system was not addressed by the governmental agencies within the documents but was repeatedly detailed by carers. In the literature review, some researchers framed the parents’ experience of caring for their children with ID and coordinating and navigating services, and to a lesser extent, the experiences of children with ID not having their needs met as burdens (33, 117, 119, 120). At the time of completion of this thesis, a class-action law suit had accused the Ontario government of being negligent of adults with developmental disabilities eligible for services because of arduous wait

times for services. The negligence of the province will in part be determined according to whether the province breached its duty to provide care (250). The exploration of the duty of the service system to provide care to children with ID and the burden of the system on the child with ID requires further investigation.

A provincial mental health initiative as well as community mental health services, literacy agencies, and a summer program excluded children with ID from their mandates and services either directly or through lack of accommodation. The explicit exclusion of children with ID from services because of their ID illustrates the deprivation of their right not to be discriminated against within the operations of agencies. More specifically, carers perceived their children's right to services and support—provided to children without ID—was not protected and that their children were at risk to experience inequitable resources compared to children without ID.

The carers perceived themselves as deprived of agency to make decisions related to their child's classroom placement, obtainment of needed services, and safe room confinement. Service agency personnel were often provided with the right to make decisions about which services were needed by children with ID, even when the carers did not agree with them. Foucault (154)(p62) cautioned against privileging some speaking positions and actions over others because these settled truths reappoint new hegemonies dominating others. Foucault's concern was highlighted in the previous discussion regarding ideological barriers to carers' choice of classroom placement for their children. The rights of children with ID to have their carers be the primary decision makers related to education was reduced. In this way, inclusion discourse has co-opted the discourse of individual voice and choice. In other words, co-optation of discourse occurs when a prominent discourse adopts a minority discourse, absorbs it, and "subverts" its meaning (251)(p831)(60)(p62). Inclusion discourse emerged from the community living movement that, along with other objectives, was used to "empower individual choices" of persons with ID. Inclusive education was positioned within service agencies and sometimes by carers as the "right" choice for children with ID. The carers reported that school personnel cited that inclusion ideology

precluded carers' requests for specialized classroom placement. In this way, inclusion discourse was used to promote the choice and voice of children with ID, or their primary decision makers, as long as the primary decision maker's choices aligned with school personnel's interpretation of inclusion discourse. My analysis of the interviews and governmental agencies' documents revealed that when inclusion and individual choice discourses competed, inclusion discourse co-opted individual choice discourse by reducing or removing choice and justifying others to dictate what was best for the child.

The needs that were associated with how ID is understood directly relate to the rights afforded to children with ID. For example, the characteristics of vulnerability and the need to be taken care of equated to the child's loss of right of privacy. Carers justified this loss by asserting that prioritization of safety for children with ID meant they required constant supervision and accompaniment. The duty of the child with ID to comply with services and assessments justified carers' perception that their child needed authority. The child with ID was placed under a greater degree of authority and discipline than a child without ID to ensure compliance with commands and programming. In this way, the rights of the child with ID to autonomy and self-determination were reduced or removed.

The societal citizenship granted to children with ID follows from the above discussion of subject positions of rights and duties. The diagnostic categories applied to children with ID predicted, to an extent, the degree to which each child could and would in the future personally, socially, and economically function and participate in society. These measures of social participation and independence draw on the social model of disability while reinforcing constructs and expectations of the ideal citizen.

The formal citizenship of a child with ID is determined broadly by how individuals are sorted within or outside of society according to legal citizenship (173)(p156). Foucault (140) theorized that disciplinary technologies directed the laws of sorting by classifying individuals according to norms. In this way, the formal citizenship of children with ID can be defined according

to the perceived norms, threshold, and hierarchies that contributed to carer and governmental agency understandings of ID. Within the governmental agencies' documents, there was no mention of excluding children with ID from citizen membership within the province or service system. The citizen proclamation in these documents about children with ID related to their classification according to social norms of citizenship. This classification determined if children with ID were inside or outside of disability citizenship and eligible to receive resources. In her work related to citizenship, Capurri (183) illustrated that although Canada does not actively exclude children with ID born into citizenship, it has established a legal directive to restrict the entry of children with ID into the country to become citizens on the grounds that they have no economic potential but rather represent an economic burden to the health and social system. Interestingly, although immigration is restricted to persons with ID, resources are seemingly a right that increases with the severity of ID for born citizens. What does this say about the construct of formal citizenship? From an immigration perspective there is a strong economic component. Within this study, the governmental agencies and carers reported that service agencies had waitlists or were unable to serve all children requiring service because the services were insufficiently funded. The governmental agencies did not respond with an obligation to provide services to children with ID who were determined eligible beyond the resources they had distributed or allotted. Carers and, indirectly, the governmental agencies recognized the inadequate service resources and funding, which suggests that the formal citizenship rights to services of a child with ID do not extend beyond what the governmental agency has provided. The resource distribution allotment is the threshold beyond which economic and service resource limitations exceed the rights of the child with validated needs. Foucault's concept of biopower (72, 140) is useful to understand the extent and limits to which society will "make live" by disciplining a child to modify them into a docile body through the distribution of resource or "let die" by not providing services (147)(p241). Children with ID are "let die" a social death, according to Goffman's definition, by being excluded from relationships with peers, and from receipt of required health and social services, and assistance

with personal care in the classroom (181, 252). These exclusions may lead to losses of accommodated education and interventions for the child with ID that “separate them from the outside world” (181)(p16). Nurses, and other service providers, should explore how determination of service ineligibility may affect the role given and taken up by children with ID within school and society.

Within this study, co-occurring aspects of moral and formal citizenship influenced the treatment of children with ID. Moral citizenship refers to the normatively derived behavioural and participatory expectations of society’s citizens (173). Schinkel stated that ideals of a moral citizen create society by determining “who belongs to it and who is outside of it” (173)(p168). The governmental agencies’ and diagnostic association definitions of ID that assessed functional abilities and carers’ concerns about independence appear to conclude that moral citizenship is determined by participation within society: independence of self-care, social interactions and verbal communication, employment, and capacity to learn. The carers emphasized the negative impact that their child’s impaired or non-normative communication methods had within their social interactions with peers and school staff. Schinkel (173) claimed that “integration equals citizenship.” Children who did not seamlessly assimilate within normative society were marginalized by not being recognized as social citizens because they could not actively participate in a socially prescribed manner (p. 167-168). Capurri (183) proposed that in political-economic discourse there is a class system related to an individual’s reflectiveness of the “good citizen” that distinguishes a “true” citizen from a “citizen-minus” (p4). Being minus, or not a “true” citizen, is reflected in the exclusion of children with ID from social belonging and participation. In this study, I identified many examples where children with ID were excluded and experienced disabling social barriers. Children with ID can thus be understood as holding formal citizenship associated with rights to services and support that are extended only to the threshold of agency capacity. I interpreted the findings of this study to mean that the moral citizenship of children with ID is reduced or removed because children with ID have been differentiated based on social norms

and do not reflect the expected behaviour of moral citizens. Goffman's (185) concept of stigmatization is helpful to explain how children with ID have been marginalized and the effects of this. In this study, I found that children with ID were often reduced to being understood as their diagnosis. This understanding "remove[d] all significant components of their identity" from being recognized (252)(p238). The effect of reducing the child to their diagnosis was that the child with ID was stigmatized because the "attribute" of ID was socially viewed as "an undesired difference" that reduced the child "from a whole and usual person to a tainted, discounted one" (185)(p3). The governmental agencies' and carers' urgency to intervene and treat, and the negative and/or unsupportive response of peers and staff toward the child supported my interpretation that the attribute of ID was undesirable. Within the literature review, I found a dearth of studies in which researchers examined the roll of stigma within service navigation barriers. Pogge et al. (130) speculated that medical professionals may have failed to communicate discharge diagnoses of ID because of the stigma attached to the label. Baker et al. (121) found that Southeast Asian parents of children with ID associated ID with the stigma of being shameful and a reflection of the parents' spiritual mistakes. In this study, I outlined how intellectual and adaptive norms, labels, the diagnostic process, and eligibility criteria based on labels stigmatized children with ID by often making children with ID socially devalued and excluded. Nurses, and other service providers, thus should evaluate the role that stigmatization may play within service user-provider interactions.

I also identified limitations of the productive nature of disciplinary power from the carers' reports that their children with ID were excluded. The goal of disciplinary processes within the health and social system is to reduce the characteristics of children with ID that are perceived to be impairments to become a normal child and productive adult. Children with ID who cannot be made normal, or docile, become excluded from the standardized, disciplinary processes applied to the rest of society's children.

I conclude the discussion of the flows of power constructing ID with an interpretation of resistant discourse and actions. Within the interviews and documents, carers and governmental

agencies broadly constructed ID using an impairment-focussed model that positioned ID as static. Both data sets also had a palpable underlying resistant discourse constructing ID via a blending of the social and rhizomatic difference models that positioned ID as dynamic. These different understandings of ID placed carers, medical professionals, and service providers at odds about the challenges and needs of children with ID. Further, the carers perceived the governmental agencies' definitions of ID placed medical experts and service agents as hegemonic assessors of children with ID and decision makers regarding their service needs. The flows of power within service navigation reinforced dominant impairment discourses of ID that affected the citizenship of children with ID and contributed to tensions within interactions between service agents and carers. In this thesis, my objective was not to promote one approach over another but to examine the power knowledge that currently constructs ID to form nuanced interpretations of how children with ID are treated within the health and social service system. The competing discourses exposed provide insight into governmental agencies' and carers' shared and contrasting constructs of ID. These similarities and competing differences may contribute to the challenges that carers and their children with ID experience when navigating the health and social service system and may help locate areas for collaboration.

### **Limitations of the Study**

The focussed sample of eight carers of children with ID, none of whom were children with ID, was a limitation of this study. This limitation was surmounted by collecting rich interview data that thoroughly addressed the research questions. The results of this study are valid despite this limitation because the objective of the study was to understand how ID is socially constructed, not to capture a phenomenological perspective. I used a Foucauldian discourse analysis approach that situated what was said rather than the speakers themselves in the data (253).

My use of interviews may be interpreted as a study limitation. I used interviews to collect data because no carers matching the inclusion criteria of this study had submitted letters to the

Select Committee on Developmental Services. I believed that submissions to this committee would have been the most relevant archive of transcripts that addressed the research questions. There were no media stories about children with ID from the study setting and health and social service navigation within the setting area of this study either. Some authors have suggested that interviews should not be the primary method of data collection for a Foucauldian discourse analysis because they are “not naturally occurring” (59)(p70) but are solicited and constructed through researcher influence within interactions with participant interactions (188, 202). I surmounted the limitation of researcher influence by planning a diary-interview data collection method. The director of the developmental services centre felt that this would be a burden for participants to complete and recommended the use of solely interviews. I adhered to this recommendation. I reduced my influence in the interviews by using a grand tour, open-ended question to start the semi-structured interviews, and then asking follow-up questions for clarification. The study findings are valid despite the use of interviews because a Foucauldian discourse analysis approach positions the participant and the researcher within the discourse (253). All research findings are influenced by the position and methodological decisions of researchers and thus no position is considered more valid than another (59, 202). Further, although data that have less researcher “interference” are preferred, some authors perceive that most talk is scripted for a purpose and altered by the speaker according to the context, including interviews (202)(p66)(187). Additionally, children with ID and their carers are often a hidden population and service navigation barriers have been described within the research as an emotionally charged issue. Potter (188)(p612) proposed that when working with hidden populations or sensitive issues, the use of interviews in discourse analysis is justifiable.

My position as a mother of a child with ID and disclosure of this position to participants influenced my interactions with them, “set some of the functional context for the answers” (187)(p165), and contributed to the co-constructed meaning and interpretations made in this study (59, 202). I informed participants of my position if they asked but did not share any further personal

information. My disclosure of my position to the participants could have limited the participants' discussion because they may have assumed that I already understood their experience. Alternatively, not disclosing my position to the participants could have limited their discussion because they may have assumed that I could never understand their experience. I perceived that the participants' awareness of my position established their trust in me because the interviews quickly commenced with the participants sharing their experiences and emotions. Many cried. I surmounted the limitation of the influence of position on the overall study by stating my position within Chapter 1 to provide transparency to the reader. The results of this study are still valid because, as already explained, all research is influenced by the position of the researcher.

An aim of a researcher conducting a Foucauldian discourse analysis is to generate nuanced interpretations of societal understanding of a discursive issue to generate debate and discussions about potential areas for change (59). This kind of analysis values diversity in sampling diversity and variation of data to formulate a rich and heterogenic interpretation of the research question, not to establish generalization (9, 59, 60). The variation of the sample of this study was limited in that it did not sample historical texts, despite Foucault's work that established the relevance of genealogical analysis to gain understanding of historical contributions to current understanding and treatment of subjects (60)(p55). I surmounted this limitation by including a general timeline of the emergence of societal identification and treatment of persons with ID in Chapter 2. Further, I thoroughly conducted my analysis of the current context of the research problem and did not include a focussed historical review because of the volume of collected data and the time required to thoroughly analyze it. Indeed, Jager and Maier's (9) writings support the validity of study findings using this focussed approach, as they suggested that genealogy studies of the history, present, and future should be performed individually because of the arduous amount of work involved in each (p51). Moreover, some authors of Foucauldian discourse analysis recommend sample sizes of only a few texts because, as previously discussed, the focus

is on the talk and not the participant and because discourse analysis is understood to be “an extremely labour intensive approach” (187)(p161)(59, 202).

The sample of this study included provincial documents and carer reports because they are important perspectives that contribute to how ID is understood and how understandings influence each other, and they were available and feasible to analyze (59)(p75)(187)(p162). Phillips and Hardy (59) asserted that “researchers should allow different voices to pervade the text, with particular consideration of voices that are normally silenced” (p83). In this study, I adhered to this suggestion by including the perspective of governmental agencies. The researchers of the aggregated studies of the literature review primarily sampled carers and some service agents but did not include the perspective of governmental agencies. The governmental agencies’ guidelines are contextually important to understand service navigational barriers experienced by children with ID because governmental agencies defined ID and directed the distribution of services and service agents. Further, carers from a rural area of Ontario were included because their voices were not heard within the context of Ontario service navigation for children with ID or within the literature review. The variability within and between the perspectives of individual participants and the governmental agency documents achieved theoretical saturation. There was less variation between governmental agencies regarding how ID was defined and understood. I could have enhanced the variability of the sample using broader inclusion sampling that I detail within the implications for research.

### **Implications**

The results of this study have useful implications for students in health and social science programs, for nurses and service providers in primary care and within service delivery agencies, and for administrators in practice settings. In this study, I identified nuanced areas for further research exploration and important considerations for health and social service policy and program reform.

**Implications for education.**

In addition to the hegemonic impairment lens of understanding ID, the carers reported often encountering service providers who did not consider the communication, personal support, or service barriers that disabled their children. Carers also perceived that service providers often lacked capacity to effectively address their children's needs. Academic and nursing educators can support students and nurses to develop capacity to "provide safe, compassionate, competent, and ethical" (254)(p2) care to children with ID and their carers by providing education about the historical treatment of persons with ID to inform understanding of the continuum of definitions of ID and their implications on how persons with ID have been and are treated; implementing learning activities to examine challenges experienced by children with ID and to implement ethical standards; providing clinical experiences that expose students and nurses to persons with ID and enhance student and nurse capacity to effectively communicate and collaborate; supporting students and nurses to reflect on their own understanding of ID; and teaching and leading students and nurses on how to engage in "political action for system change" (254)(p1) where they identify systemic service and health outcome inequities for persons with ID.

**Implications for clinical practice.**

In this study, I found differences between carer and governmental agency definitions of ID and perceptions of impairments and disabling practices. The governmental agencies often defined ID according to a medical model lens that identified children with ID according to measured impaired intellectual and adaptive functioning that in turn informed their service needs. Carers understood ID in three ways: as an impairment, as a unique human difference, and as a consequence of disabling barriers. The hegemonic medical model understanding mobilized service agents in a manner that carers perceived lessened, and at times dismissed, their own speaking position and created tensions between carers and providers. Nurses can integrate awareness of these differences into practice to enhance patient-centred care by reflecting on their

own understanding of ID and that of the agency that they work for; engaging in active listening of children with ID and their carers to understand their goals and identify impairment and social barriers to these goals; collaborating with children with ID and their carers throughout the nursing process; advocating with and for persons with ID for improved dignity, autonomy, and access within the service system; and informing administrators of identifiable practice-setting barriers to patient-centred care.

#### **Implications for administration.**

Nurse administrators can support and promote collaboration and the delivery of patient-centred care to children with ID and their carers by providing nurses professional development opportunities regarding communicating with and providing therapeutic, person-centred care to children with ID and their carers; providing additional resources in recognition that nurse engagement and collaboration with children with ID and their carers may require more time; and advocating for and implementing strategies within the organization to enhance disability literacy and examine organizational practices collaboratively with persons with ID and their families to identify disabling barriers.

#### **Implications for policy.**

In the document review, I identified that governmental agency guidelines and reports informed service eligibility algorithms and populations targeted for service that were often diagnostic focussed or prioritized service provision to those with the highest needs. The carers in turn reported that their children's needs had been validated by professionals but that they did not receive services because they did not meet eligibility criteria and thus their needs were unmet. In other words, the diagnostic and determination of eligibility processes differentiated and classified the children but did not lead to the services that some carers perceived their children required. Policy developers should explore service distribution models that promote health and collaboration with children with ID and their carers in decision making and through person-centred

service models. Further, in their policy work, policy developers should acknowledge and account for the historical and social impact of social determinants on the health of children with ID and their families by working to reduce health outcome disparities for this population compared to children without ID. Additionally, policy developers should develop policies that enhance flexibility in service delivery and target populations by examining benefits and limitations of how direct funding opportunities can be used, while also reducing the limitations of direct funding already provided. In their work, policy developers should promote intersectoral collaboration to improve access and efficiency of distributing limited fiscal, human, and service resources as well as identify the specific duties of the service system in providing services to children with ID, in addition to the duties of the child to demonstrate eligibility. Policy developers should examine and incorporate research that explains how need is quantified, how specific diagnoses may be tied to this implicitly, and the achieved health outcomes of other provinces or countries using these measures. Policy developers should explore value of maintaining an IQ score as part of determining service eligibility.

#### **Implications for research.**

The disciplinary and regulatory processes at play within the health and social service system require that children with ID become (hyper)visible to receive services by being diagnosed and having their diagnosis statistically accounted for, respectively. To satisfy the requirements of the current system and continue to adhere to the status quo, further research is needed to gather prevalence data to adequately plan and distribute financial and service resources to children with ID. The benefit of increasing statistical surveillance of children with ID is that more children may be able to navigate the service system and receive services. The risk of promoting increased statistical surveillance is that the current system, and its limitations, would be reinforced and children would continue to be required to submit to divisive and classifying processes that do not effectively meet their needs. Further research is required to expand knowledge of methods to

improve collaboration and engagement between children with ID and their carers and service providers; develop service allocation algorithms that shift focus toward health promotion while reconciling economic limitations; and explore how ID is understood within nursing discourse. Future recruitment strategies of children with ID and their carers could include distributing study information letters through schools, primary care providers' offices, social media groups, and associations allied with persons with ID. Sampling diversity could be enhanced within future studies that specifically explore the historical contributions to how people with ID are understood and treated and by including children with ID, primary care providers, specialists, and service agents; media stories about service use by children with ID; and community advocacy groups (and their stakeholders) that include or are for persons with ID. Further, some participants reported that they kept files composed of assessments and diagnostic notes about their children. In future studies, researchers could sample these files to explore the talk of professionals and service providers. Researchers could enhance variation of how ID is understood by sampling records, meeting transcripts, media stories, government publications about historical treatment of persons with ID, and artifacts representing actions and materializations (187)(p162). In future studies, researchers could enhance heterogeneity in data collection methods by collecting observational data of interactions between carers of children with ID and service system agents, observing social media carer support groups, and accessing archives (202). Furthermore, researchers could explore and examine disabling barriers within the context that challenging behaviours are exhibited by children with ID as counter-discourse to challenging behaviours generally being perceived as reflective of the child's impairment. In this study, I identified that carers and governmental agencies generally believe that an "inclusive" education provides benefits for children with ID to be better understood by their peers; however, carers also shared many stories of their children's dignity and privacy being reduced because of public incontinence and experiencing bullying. In future research, researchers could explore the interactions and

understandings of children with ID and their peers who share a classroom and the self-perception of children with ID within these settings.

## Chapter 7

### Conclusion

Compared to children without intellectual disability (ID), children with ID are more likely both to experience health issues and challenges navigating health and social services. Research from the US and, to a lesser extent, Canada and Ontario have explored service navigation barriers experienced by children with ID. Within these studies, researchers have problematized the issue of service navigation by identifying commonly experienced barriers and the demographics of people most likely to experience them. Researchers have not problematized the antecedents that contribute to the persistence of navigational barriers but have examined them according to outcomes. Further, within the research literature, researchers have not explored the operating assumptions and understandings held by carers, service agents, and governmental agencies regarding how they define ID and how needs are determined.

I, consequently, reviewed Ontario governmental agencies' documents and performed interviews with carers of children with ID to identify the diverse discourses that formulate current understandings of ID within the context of service navigation (255)(p205). In this thesis, I asked the following: How is ID currently understood by carers of children with ID? What are the social discourse surrounding how children with ID are understood? What are the materializations of how children with ID are currently understood? What is the nature of the service user-provider relationship within the context of children with ID and their carers navigating services? In this study, I employed a Foucauldian discourse analysis to bring together Deleuze and Guattari's theories regarding social ordering and Foucault's theories of biopower and subjectivity. These theories were useful to my exploration of how children with ID were understood, to locate the truths that substantiated these definitions of ID, and to understand how different definitions of ID were experienced by children with ID and their carers within service navigation and within service user-provider interactions.

In this research, I found competing understandings of ID that contributed to services offered and sought for children with ID, interactions between children with ID, their peers, and service providers; and interactions between carers and service providers. ID was chiefly understood as an impairment according to the degree that a child failed to reflect societal “norms” of development. Impairment discourse was supported by scientific knowledge that formed diagnostic criteria and labels. Scientific knowledge about ID situated diagnoses and classifications as truths that formed the starting point from which carers and service agents could interact. The starting point of impairment discourse made it seemingly needless to question or discuss understandings of ID and maintained focus on the limitations of the child rather than the limitations of the service system. The characteristics of intellect, understanding, communication, and independence were measures of normal development. ID was also understood as being outside of normal and the degree of deviation from normal was measured and ranked. Carers perceived that society viewed ID as a negative identity. The impairment discourse contributing to understandings of ID reinforced measures of characteristics of normal development as being scientifically true measures of a person. The impairment discourse simultaneously characterized the essence of the children with ID as incomplete by not achieving social norms of development. Indeed, Foucault purported that Seguin’s nineteenth century concepts of normal childhood development situated ID as “the absence of something” and situated the child with ID as “a particular sort of child... someone who is more or less sunk within a childhood that is normal childhood itself” (244)(p209). Children with ID were thus stigmatized by being socially understood as ID beings. The understanding of ID according to degree of impaired normalcy had implications on the operational assumptions of service agencies regarding the potential, predictability, and needs according to the diagnosis. An impairment understanding of ID thus can be interpreted as facilitating the appointment of governmental agencies, service agencies, and professionals as experts and hegemonic decision makers to assess, diagnose, and treat children with ID or deem them ineligible to access services.

Conversely, but to a lesser extent, ID was understood according to children with ID experiencing disabling barriers, most often within the school setting, which marginalized them. The carers perceived that their children with ID communicated differently and had individual functional abilities and needs. The carers problematized standardized services in general, and more specifically, school programming that privileged normalized modes of communication and expected independence in adaptive skills according to developmental ideals of normal. The carers problematized these service operations for not recognizing and accommodating their children's unique abilities and needs. Frederiksen, Lomborg, and Beedholm (255) summarized Foucault's description of problematization to mean "why and how certain conditions took precedence over something else and how these conditions were experienced as problems" (p204). The impairment discourses that informed understanding of ID took precedence over disabling barrier discourses. The relational tensions found within the service user-provider relations could be attributed to impairment understandings of ID that problematized the child and focused on changing them that conflicted with understandings of ID that problematized the barriers within the service system experienced by children with ID. To explain, Foucault concluded that diverse understandings of a problem inform different beliefs and expectations and are associated with different solutions (245)(p389). Extant literature about service navigational barriers for children with ID is limited to the identification of barriers and does not critique them according to how ID is problematized or the service provider-user relationships regarding how they define ID. Further, researchers of current literature about service navigation barriers have explored the problem according to carers' responses to the barriers but not in relation to understanding the context of barriers. There was subtle discourse, often within the carer interviews, that located ID as one of many infinite human differences and needs. My work contributes to literature exploring barriers to service navigation for children with ID by identifying the different discourses present within carers' and governmental agency perspectives regarding how ID is understood. The diverse understandings of ID can be

located as antecedents to service navigational barriers by identifying the differing expectations, goals, and value applied to children with ID.

In this study, I added nuanced understanding of the relationships between governmental agencies, service providers, and carers through the competing understandings of ID (249)(p15). The governmental agencies' stated intention was to deliver services through agencies collaboratively with carers; however, the carers perceived that service agencies and providers imposed hegemonic-aligning decision-making on children with ID. Through this research, I contributed a rich description of how carers' perceived theirs' and their children's power relations in their experiences navigating service barriers (249, 255). In these findings, I highlighted and explored the political context within which ID was defined as a condition that is understood according to scientific knowledge and experts. The precedence provided scientific knowledge facilitated experts the privilege to make proclamations about the necessity of early interventions, inclusive education, and to determine the child's service needs. There was a palpable struggle between carers and the service system and its agents to determine who 'knows what's best' for the children with ID regarding needed supports. These findings could be of interest to children with ID and their carers, governmental and service agencies, and nursing researchers in understanding the context of how ID is understood and the political matrix within which barriers to service navigation may occur. By understanding that the perspective and objectives of each party within the service provider-consumer relationship may be different, opportunities for nuanced and collaborative discussion should be made available to determine where agreements, differences, and individualized care can be optimized. All parties involved should make efforts to find innovative solutions to service navigational barriers experienced by children with ID within the confines of allocated resources. Further, the agency of children with ID and their carers to collaborate and make decisions with governmental agencies and service agents should be examined and supported.

Lastly, in this study, I found that children with ID were treated according to preconceived beliefs about their diagnosis or label that left the antecedent of their individual challenges and needs unidentified and unmet. These unmet needs perpetuated the child being socially marginalized and stigmatized by peers. Further, carers perceived that their children internalized truths about being abnormal and the lesser value attributed to this and held poor self-images. These findings contribute to understanding how service navigational barriers were perceived by carers to be experienced by children with ID, which has not been explored within extent literature.

The findings of this study can be summarized in six points. (1) Impairment discourse was the dominant discourse constructing understandings of ID and positioned the problem of ID within the child who required treatment. (2) Disabling discourse was a competing discourse that constructed ID positioned focus according service barriers that children with ID experienced. (3) Difference discourse positioned ID as a heterarchical variation of human difference. (4) Impairment discourse that constructed ID was developed within scientific psychiatric knowledge and implemented by governmental agencies that outlined experts and treatment of children with ID. (5) Impairment understandings of ID predict outcomes, prescribed standardized treatments, and appointed hegemony in decision making within services. (6) The impairment, disabling, and difference discourses constructing understandings of ID informed differences in carer, governmental agencies', and service agent understandings, expectations, and ideas for solutions to address ID. These differences contributed to service user-provider relationship conflict about problematizing the child or the service system.

It was not my intention, within this study, to formulate truer claims about what ID is or to employ polemics to eliminate one ideology of ID to appoint another (72, 245). Instead, my purpose for conducting this study was to employ a line of questioning to contribute a nuanced understanding of different "elements of [the] problems" of children with ID experiencing service navigational barriers, from what has previously been explored (245)(p388). My intent was to pose nuanced arguments and interpretations to initiate nuanced debate and critique of a troubling and

persistent problem. I intended that these nuanced arguments and interpretations would also be open for critique (59, 245). The findings of this study have implications on how ID has been identified and experienced as a problem (255).

The key message for children with ID and their carers to take away from this research is that their understanding of what it means to have an ID and their perspective of their own needs and goals are important and should be integrated into individualized service planning and delivery. They should be welcomed to become partners in their own care to the extent of their ability. Similarly, service providers, including nurses, should be cognizant that governmental and service agency definitions of ID may align or differ from those of children with ID and their carers. Further, service providers, including nurses, within agencies employing an impairment understanding of ID should reflect on the degree to which this understanding is used to predict capability and needs of children with ID and to prescribe, in a standardized manner, services. Service providers should take time to explore the concerns, perspectives, and objectives of children with ID and their families to enhance collaborative and client centred planning. Service agencies and providers should also identify where hegemonic decision making by service providers exists and critique the influence this has on families.

## Appendix A

### Literature Review Search Strategy and Flow Chart

The research questions of this study were developed using the PICA formulary. To preface this, 'P' refers to population, 'I' refers to issue, 'C' refers to context, and 'A' refers to approach. The study population is children with intellectual disabilities, between the ages of 6-14. The issue under investigation is the navigational challenges experienced by this population within the health and social systems, in pursuit of addressing health and social needs. The context is within power relationships within outpatient service settings in rural Ontario.

#### **Search Strategy: Literature Review of Current Studies**

The construct of 'service navigation' was the focus of the literature review. The initial step of the review began with a search of primary sources within the bibliographic databases CINAHL, OvidMedline, and PubMed. Limitations included qualifying documents from the year 2000 to 2018, articles in the English language, peer reviewed, and child age category 6-12 years. Initially, children with autism were excluded from the search in order for the researcher to attain an understanding of the current state of literature addressing the research population of children with ID. The initial database searches of CINAHL, OvidMedline, and PubMed included the MeSH terms "intellectual disab\*", "health services- needs and demands", OR "community health services", OR "referral and consultation", OR "continuity of patient care", and "North America". The Pub Med and CINAHL searches retrieved a total of 21 relevant articles; however, 19 were excluded for non-research based approaches, incorrect cataloguing of adult studies, and consideration of people with ID living in group home settings.

A second search of the CINAHL, OvidMedline, and Pub Med databases was conducted with a broadened search, utilizing the MeSH search terms "developmental disabilities" OR "mental retardation" OR "intellectual disability" OR "learning disability", "North America", "community health services" OR "accessibility of health services" OR "referral and consultation" OR "continuity

of patient care” , AND “gatekeepers” OR “health service” OR “navigat\*”. The terms “developmental disability”, “learning disability”, and “mental retardation” were added to ensure that relevant studies utilizing difference terminology to denote ID were isolated and to broaden the search because limited literature was found addressing expressly the population of children with ID. Articles that met the inclusion criteria for the literature review were additionally screened for relevant citations to previously conducted studies that may have fit the search criteria. Via this ancestry approach, three articles were identified as relevant from the previously selected articles from Phelps, Pinter (119) and Nageswaran, Parish (43). A hand search of the journals *Journal of Intellectual and Developmental Disabilities* and *Journal of Intellectual Disabilities* was conducted to determine if saturation of relevant articles had been reached by the previous searches. No additional articles were found. The search strategy is illustrated in the Prisma Flow Diagram (see below).

<p>Database search results (n= 228)</p>	<p>Records identified through other sources (n=3)</p>
<p>Records after duplicates removed (n= 232)</p>	
<p>Records screened for relevance (n= 232)</p>	
<p>Records excluded with reasons (n= 162)</p> <ul style="list-style-type: none"> <li>▪ Not North America</li> <li>▪ Age; adult, infant</li> <li>▪ Autism focus</li> <li>▪ Commentary</li> </ul>	
<p>Full text articles assessed for eligibility (n= 66)</p>	
<p>Full text records excluded with reasons (n= 48)</p> <ul style="list-style-type: none"> <li>▪ Not North America</li> <li>▪ Age; adult, infant</li> <li>▪ Not related</li> <li>▪ Commentary</li> </ul>	
<p>Studies included (n= 18)</p>	



Make your own rules	X	X	X	X	X	X	X	X
Stand up for yourself		X	X	X	X	X		X
Social consequences	X	X	X	X	X	X		X
Self-assessment	X	X				X		X

## Appendix C

### Study Information Letter



Université d'Ottawa  
Faculté des sciences  
de la santé

École des sciences  
infirmières

University of Ottawa  
Faculty of Health  
Sciences

School of Nursing

#### **PARTICIPANTS NEEDED FOR RESEARCH IN HEALTH AND SOCIAL SERVICES FOR CHILDREN WITH INTELLECTUAL DISABILITIES**

We are looking for parents/guardians who have parented a child with intellectual disabilities for at least one year, between the ages of 6-14, to take part in a study about finding and using services for children with intellectual disabilities.

You will be asked to: be interviewed by yourself or with your partner, to talk about what intellectual disability means to you and your experiences seeking services for your child with an intellectual disability.

#### **Your participation would involve:**

- Contacting the researcher to find out more about the study and join if you are interested
- Meeting the researcher at your home or the Developmental Services Centre for a 60-90 minute interview

In appreciation for your time, you will receive your choice of Cornwall bus passes, aquatic centre passes, Walmart gift card, or respite funding valuing a total of \$25.

For more information about this study, or to volunteer for this study, please contact:

Anna Don, RN, PhD (*candidate*)

School of Nursing

## Appendix D

### Case Manager Script

#### Study Information Letter Distribution Information and Instructions

##### Parent/guardian study participation:

**Parents/guardians** of children with intellectual disabilities, between the ages of 6-14, will be invited to participate in a one-on-one interview with the researcher of this study, through a study information letter provided by their Developmental Service Centre case manager. Parents/guardians can either be interviewed individually, with their partner, or two individual interviews with each person in a partner relationship by the researcher.

##### Study Information Letter Distribution Instructions for Developmental Services Centre case managers:

**Case managers** from Developmental Services will distribute the study information letter to clients, either during home visits or when meeting clients in the office.

**Case managers** will determine eligibility of clients from their knowledge of the family. *Please do not review this eligibility with the family, as final eligibility will be determined by the researcher.* To determine eligibility, please consider:

- Is the child between 6-14 years old
- Does the child have an intellectual disability
- Does the child reside with a parent or guardian

Client is ineligible if:

- Child has a physical disability or dual diagnosis. E.g. Intellectual disability and autism

**If the family appears to meet the eligibility criteria, please provide the study information letter, during home or office visits, completing the following steps:**

1. Invite clients to listen to a review the contents of the study information letter, or a reading of the letter in its entirety for clients who may have reading literacy challenges.
2. Direct clients to address any questions or interest to the researcher, whose contact information is at the bottom of the study information letter.
3. Inform clients that Developmental Services is not affiliated with this study and that services provided through this agency will not be influenced by participation/non participation in the study.
4. Explain to clients that Developmental Service Centre employees will have no knowledge of who participates and what they say, **unless**:
  - participants request their case manager be present at time of interview

- participants choose to conduct their interview at the Developmental Service Centre
  - participants choose to discuss their participation with a case manager.
5. Following distribution of the study information letter, Developmental Service Centre case managers will have no further discussion with clients regarding the study.

**The Role of the Researcher:**

- Answer participant questions
- Determine eligibility
- Obtain informed consent
- Determine participant preferred date, time, location of interview
- Determine participant preference for presence of case manager and determine a time suitable with the case manager to schedule a research interview concurrent with a home visit.

**Parents/Guardians may request to the researcher that:**

- Interviews be conducted in their home, with only the researcher present
  - Interviews to be conducted by the researcher, in their home during a home visit with their Developmental Service case manager present for support.
  - Interviews be conducted after hours at the Developmental Service Centre, where a staff person will be present within the building, but not within the interview room.
- Determine participant preference of incentive and provide incentive choice at beginning of interview meeting
  - Conduct interview

## Appendix E

### Pre-Interview Script

Thanks for your interest in this study.

I'm going to ask you some questions about your family to find out if you can be in the study.

1. How old is your child?
2. Does your child have an intellectual disability?
3. Does your child have any other diagnosis or health issues?
4. Are you this child's:
  - Birth parent
  - Adoptive parent
  - Guardian
  - Foster parent
5. Have you been parenting this child for at least one year?
6. Can you speak English in the interview?

The interview will last about one hour to an hour and a half, it could be shorter.

7. **Where** would you like to have the interview?

Will I only interview you, or would you like your partner to be interviewed with you?

8. **When** would you like to book the interview?
9. **What** time would you like?
10. Can I have a contact number that I can reach you in case of appointment changes?

Before starting the interview, you will be given a small gift as thanks for your taking part in this study.

11. Which gift would you like? Your choices are
  - Transit bus passes
  - Aquatic Centre passes
  - \$25 Walmart gift card
  - \$25 cash.

Thank you for your interest in this study. I look forward to meeting you.

## Appendix F

### Interview Guide<sup>34</sup>

**Date:**

**Meeting structure:**

- **Review consent form and obtain consent**
- **Provide participant with their choice of incentive**

**Initiate interview:**

- **Settling in (ice breaking exchange):**
  1. Share info re: study aims
  2. “Thank you for joining this study and sharing your thoughts about what it has been like to try to get help for your child with an intellectual disability. Your story and feelings are important. Feel free to share anything that you feel is important. There are no wrong answers. Your thoughts and feelings matter. You do not have to discuss anything you don’t want to.”
  3. I would like to record our talk so that exactly what you share can be saved and used in this study. If you do not want to have your voice recorded, I will take notes instead. Is it ok if I record?
    - If consent to record is given, initiate recording
    - If no consent, initiate detailed note taking
- **Broad questions (Grand tour questions):**
  1. Can you tell me about the reasons or the important things that you want to share that brought you to participate in this study?
  2. Please tell me about what it has been like finding and getting health and social services for your child? (ie. Getting funding, respite, help for behaviours, dental care, doctors) (Research question 3)  
*Alternative phrasing:* Tell me about the services you want for your child with an intellectual disability? Can you please share your story of how it has gone to get these services for your child?
  3. What do you think people in your family, neighbourhood, or in society in general, think about people with an intellectual disability? (Research question 2 and 3)
  4. Tell me about what you hope or see for your child’s future? (Research question 3)
- **Concluding:**
  1. Is there anything else that you feel is important to talk about?
  2. Are there other parents or guardians of children with ID that you think might like to join in this study? **If yes:** provide participant with study information letter to provide to potential participant
  3. Is there anything that you have just shared that you would like to take back and not have included?

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<sup>34</sup> The structure of the interview guide was adapted from Creswell. 256. 3 ed. Los Angeles: Sage; 2013.p. 165.

4. Thank you for sharing and participating in this study.

## Appendix G

### Structural Guide Questions

#### Structural Analysis<sup>35</sup>

##### Axis of knowledge (closed system of truth)

1. What are the objects and subjects of the discourse?
2. What processes differentiate the objects and subjects of the discourse?
3. What is it that guides this discourse?
4. What regularities can be discerned?
5. What processes produce the physical space, the meaning, and the assumed truths of the discourse?
6. What does the discourse do to the resulting subjects?
7. What grids of specification are there?
8. In the rules for the formation of subjects from objects, what and where do individual differences, deviations, and complaints emerge?
9. How is it specified that these subjects are to be used on pre-existing surfaces, constructed spaces, or bodies?
10. What authorities of delimitation exist?
11. What order governs the appearance, disappearance, replacement and coexistence of the subjects, objects, concepts, styles of statements, and theoretical strategies of the discourse?
12. What are the rules of evidence in the discourse?
13. What order governs the multiplicity and diversity of the subjects, objects, concepts, styles of statements, and theoretical strategies of the discourse?

##### Axis of authority (system of power/knowledge)

1. What are the rules for who is allowed to speak and who is not?
2. How is the discourse preserved, transmitted, and disseminated?
3. What systems are allowed for education, association, and advancement of members of the discourse?
4. How is the right to pronounce truth preserved?
5. What speaking positions are available to people within this discourse?
6. What speaking positions are not allowed?

##### Axis of value or justification (closed system of value)

1. What social agents are mobilized in order to control the deployment of the discourse and how are they trained?
2. How are the technologies of power/knowledge justified by the discourse?

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<sup>35</sup> These questions are directly quoted from Powers. 60. Powers P. The methodology of discourse analysis. Sudbury: Jones and Bartlett Publishers; 2001.p. 56-62

3. How does the discourse justify suppressing other discourses that challenge its dominance in pronouncing truth?
4. What justification is provided for the punishment of participants?
5. What is the justification provided by the discourse for its position as a pronouncer of truth?

### **Power Analysis**

1. In whose interests is the continuation of this discourse?
2. Whose autonomy and responsibility are enhanced by this discourse?
3. Whose autonomy and responsibility are reduced?
4. What dominations are established, perpetuated, and eliminated?
5. What subdiscourses of resistance are present within the discourse?
6. What mechanisms are in place for systemic co-optation of resistance discourses?
7. Whose voice is being heard?
8. Whose voice is being left out?
9. Do people feel constraints against speaking?
10. Are all voices equally informed?
11. What power relations exist between this discourse and others?

## Appendix H

### Structural Code Book

<b>Analytic Focus Question # Code name</b>	<b>Brief Description</b>	<b>Full Description</b>	<b>When to Use</b>
Struct/Knowledge #1-Struct/Know;Objects/subjects	Objects and subjects of discourse	Who are the objects and subjects of the discourse?	Identify the 'objective' objects of the discourse and aspects of the discourse which are constructed by them.
Struct/Knowledge #2-Struct/Know;DifferSubObj	Differentiate subjects and objects	How are subjects and objects differentiated?	Apply this code to concepts representing processes which empirically validate the object of the discourse, and processes which translate this 'objective' knowledge to applying to and creating a subject.
Struct/Knowledge #3-Struct/Know;GuidesDisc	Guides discourse	What guides the discourse? Why was this discourse created in the first place?	Apply this code to concepts referencing contextual influences in the discussion; recommendations, societal influences, professional development requirements, economics, style of statements
Struct/Knowledge #4-Struct/Know;Regularities	Regularities	What regularities can be discerned?	Apply this code to concepts which represent discursive patterns.
Struct/Knowledge #5-Struct/Know;TruthProcess	Processes producing physical space,	What processes produce physical space,	Apply this code to concepts which articulate who are the authorities of

	meaning, truth of discourse	meaning, and truth assumptions of the discourse?	delimitation. These disciplines, agencies, or individuals establish truth assumptions of the discourse, and where, when, and how these truths can be applied through discursive actions.
Struct/Knowledge #6-Struct/Know;ResultingSubject	effects of discourse on resulting subject	What are the effects of the discourse on the resulting subject? How is the discourse organized to produce this effect?	Apply this code to concepts which assign assumptions, treatments, and expectations to the subject. Apply this code to concepts which facilitate and justify these effects on the subject.
Struct/Knowledge #7-Struct/Know;GridsSpec	Grids of specification	What grids of specification are there?	Apply this code to concepts reflecting classification, division; hierarchical organization
Struct/Knowledge #8-Struct/Know;DiffDeviatComplaints	Rules for formation of subjects from objects	Where do individual differences, deviations, complaints emerge in the formation of subjects?	Apply this code to concepts identifying how differences, deviations, and complaints are acknowledged or dealt with.
Struct/Knowledge #9-Struct/Know;Surface,space,bodies	Subjects used on surfaces, spaces, and/or bodies	How are subjects to be used on surfaces, spaces, or bodies?	Apply this code to concepts prescribing expected responses or behaviours from individuals and agencies, how are 'we' supposed to

			treat persons with ID.
Struct/Knowledge #10-Struct/Know;authorDelim	Authorities of delimitation	What authorities of delimitation exist?	Apply this code to concepts identifying social authorities constructing ID discourse.
Struct/Knowledge #11-Struct/Know;GovernsDiscourse	Order governing discourse	What order governs appearance, disappearance, change of how ID is talked about?	Apply this code to concepts which illustrate guiding goals of the discourse, seek for conflicting perspectives.
Struct/Knowledge #12-Struct/Know;RulesEvidence	Rules of evidence	What are the rules of evidence in the discourse? Where is justification information derived from?	Apply this code to concepts which signify criteria applied to discourse which determines its legitimacy and approval.
Struct/Knowledge #13-Struct/Know;GovernsDiscourseDiversity	Order that governs discourse diversity, multiplicity	What order governs the diversity, multiplicity of components of the discourse?	Apply this code to concepts illustrating an order/governing body allowing spectrum of diversity or multiplicity to components of ID discourse.

<b>Analytic focus Question # Code name</b>	<b>Brief Description</b>	<b>Full Description</b>	<b>When To use</b>
Struct/Authority #1-Struct/Auth;RuleSpeak	Rules to speak/not speak	What are the rules of who is allowed to speak, who is not? Who is afforded legitimacy, authority, and how?	Apply this code to concepts noting who has been invited to weigh in on ID discourse, who is not included in panel? What rationale is given for the inclusion of certain positions and exclusion of others?
Struct/Authority #2-Struct/Auth;PreserveDis	Preserve, transmit, disseminate discourse	How is the discourse preserved, transmitted, disseminated?	Apply this code to concepts which identify how the discourse is maintained, shared socially, implemented in practices biopolitically and antamo politically.
Struct/Authority #3- Struct/Auth;DiscMemberAdvance	Advancement of members of the discourse	What systems are allowed for education, association, advancement of members of the discourse?	Apply this code to concepts referencing conferences, courses, certifications, disability studies programs which appoint member to positions of authority and preserve a particular ID discourse.
Struct/Authority #4-Struct/Auht;TruthPreserve	Right to pronounce truth preserved	How is the right to pronounce truth preserved?	Apply this code to concepts which illustrate the support of authorities of the discourse. Concepts reflecting support for certain authority positions or reviews structured around certain pre-existing positions of truth.
Struct/Authority #5-Struct/Auth;AllowedSpeak	Allowed speaking position	What speaking positions are available to	Apply this code to concepts including key words used within this discourse.

		people within this discourse?  What words can be used?	Apply where eligibility criteria to speak are noted. E.g. Must be a physician. Registered professional.
Struct/Authority #6-Struct/Auth;NotAllowedSpeak	Speaking positions not allowed	What speaking positions are not allowed?  What words cannot be used?	Apply this code to concepts discrediting/excluding certain persons from contributing to discourse. E.g. Segregation talk

Question # Code	Brief Description	Full Description	When to use
Struct/Value #1-Struct/Value;SocialAgentsDisc	Mobilization & training of social agents of discourse	Who are social agents that are mobilized to control the application of the discourse? How are they trained?	Apply this code to concepts which illustrate persons who implement the discourse. E.g. Practice evaluations, protests requesting certain things. Training requirements?
Struct/Value #2-Struct/Value;TechPower	Justify technologies of power	How does the discourse justify technologies of power constructed for its purposes?	Apply this code to concepts positioning hegemonic social agents over others to extrapolate the justification of the position of the agent and the subject & concepts relying on validation measures (foundational science). E.g. Powers (2001)(p90-1)
Struct/Value #3- Struct/Value;SuppressChallengeDisc	Justification for suppressing discourses that challenge	How does the discourse justify suppressing discourses that challenge its	Apply this code to concepts which discredit/limit other competing discourses. Attempt to extrapolate details which justify why

	this discourse	dominance in truth proclaiming?	suppressed discourses are less legitimate. Identify favoured ideologies, scientific approaches, disability models. (Powers, p. 92)
Struct/Value #4-Struct/Value;PunishParticip	Justification for participant punishment	What justification is given for punishment of participants?	Apply this code to concepts which outline and justify control and reprimand of participants who do not follow the tenets of the discourse. Ex. Nurses fired who don't dx
Struct/Value #6-Struct/Value;TruthJustification	Discourse justification as truth pronouncer	What is the justification provided by the discourse for its position as a pronouncer of truth?	Apply this code to concepts that provide 'objective' rationale for understanding/action.

Analytic focus Question # Code	Brief Description	Full Description	When to use
Power #1-Power;Interest	Whose interests is the discourse	In whose interest is the continuation of the discourse?	Apply this code to concepts which denote benefit to a person, organization, or department from the prominent ID discourse
Power #2-Power;autonomy!	Autonomy by discourse	Whose autonomy and responsibility are enhanced by the discourse?	Apply this code to concepts which denote that persons have choices and roles.
Power #3-Power;autonomyReduce	Autonomy reduced by discourse	Whose autonomy and responsibility are reduced by the discourse?	Apply this code to concepts which denote reduced choices.

Power #4- Power;hegemonyPres	Established, removed hegemony	What hegemonies are established, perpetuated, eliminated by the discourse?	Apply this code to concepts that illustrate the appointment of persons or groups to decision making positions.
Power #5-Power;SubDisResist	Sub-discourses of resistance	What sub-discourses of resistance are present within the discourse?	Apply this code to concepts illustrating alternative ways of talking about the subject of the discourse (ID)
Power #6-Power;co-optationMethods	Mechanisms for co-optation of resistance discourse	What mechanisms are in place for systematic co-optation of resistance discourses?	Apply this code to concepts which address how resistance discourses are added/addressed by the prevalent discourse. Make note of whether the method is co-opt or incorporating of the resistance discourse to the prevalent discourse.
Power #7-Power;VoiceHeard	Voice is heard	Whose voice is heard in the discourse?	Apply this code to concepts illustrating a group, individuals, or organizations whose voice is heard or present in the discourse.
Power #8- Power;VoiceNotHeard	Voice not heard	Whose voice is not heard in the discourse? (left out)	Apply this code to concepts which leave out a voice expected to be heard but not.
Power #9- Power;SpeakConstraint	Felt constraints to speak	Do individuals feel constraints against speaking?	Apply this code to any concepts representing hesitancy, resistance, shame, fear, ect. to talk about ID and society.
Power #10- Power;RelationB/TDisc	Power relations between discourses	What power relations exist between this discourse and others?	Apply this code to concepts that reflect conflict or collaboration between different perspectives.

# Appendix I

## Ethics Approval

File Number: 1110-14-09

Date (mm/dd/yyyy): 11/19/2014



**Université d'Ottawa**  
Bureau d'éthique et d'intégrité de la recherche

**University of Ottawa**  
Office of Research Ethics and Integrity

### Ethics Approval Notice

#### Health Sciences and Science RFB

#### Principal Investigator / Supervisor / Co-investigator(s) / Student(s)

<u>First Name</u>	<u>Last Name</u>	<u>Affiliation</u>	<u>Role</u>
Patrick	O'Byrne	Health Sciences / Nursing	Supervisor
Anna	Don	Health Sciences / Nursing	Student Researcher

File Number: 1110-14-09

Type of Project: PhD Thesis

Title: Exploring health and social service navigational barriers experienced by children with intellectual disabilities: A Foucauldian discourse analysis

<u>Approval Date (mm/dd/yyyy)</u>	<u>Expiry Date (mm/dd/yyyy)</u>	<u>Approval Type</u>
11/19/2014	11/18/2015	1a

(1a: Approval, 1b: Approval for initial stage only)

#### Special Conditions / Comments:

N/A

This is to confirm that the University of Ottawa Research Ethics Board identified above, which operates in accordance with the Tri-Council Policy Statement (2010) and other applicable laws and regulations in Ontario, has examined and approved the ethics application for the above named research project. Ethics approval is valid for the period indicated above and subject to the conditions listed in the section entitled "Special Conditions / Comments".

During the course of the project, the protocol may not be modified without prior written approval from the REB except when necessary to remove participants from immediate endangerment or when the modification(s) pertain to only administrative or logistical components of the project (e.g., change of telephone number). Investigators must also promptly alert the REB of any changes which increase the risk to participant(s), any changes which considerably affect the conduct of the project, all unanticipated and harmful events that occur, and new information that may negatively affect the conduct of the project and safety of the participant(s). Modifications to the project, including consent and recruitment documentation, should be submitted to the Ethics Office for approval using the "Modification to research project" form available at: <http://www.research.uottawa.ca/ethics/forms.html>.

Please submit an annual report to the Ethics Office four weeks before the above-referenced expiry date to request a renewal of this ethics approval. To close the file, a final report must be submitted. These documents can be found at: <http://www.research.uottawa.ca/ethics/forms.html>.

If you have any questions, please do not hesitate to contact the Ethics Office at extension 5387 or by e-mail at: [ethics@uOttawa.ca](mailto:ethics@uOttawa.ca).



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Université d'Ottawa  
Faculté des sciences  
de la santé

École des sciences  
infirmières

University of Ottawa  
Faculty of Health  
Sciences

School of Nursing

## Appendix J

### Developmental Services Consent Form – English

**Title of the study:** Exploring health and social service navigational barriers experienced by children with intellectual disabilities.

**Researcher:** Anna Don, Thesis supervisor Dr. Patrick O'Byrne  
Department of Nursing  
Faculty of Health Sciences  
University of Ottawa

**Invitation to participate:** I am invited to participate in a study looking at the challenges of findings and getting services for children with intellectual disabilities. Anna Don will be doing the research and Dr. Patrick O'Byrne will be supervising her research work.

**Purpose of the study:** The purpose of this study is to explore the meaning of intellectual disability in our society. We also want to understand how this meaning is a part of how services are planned and given to children with intellectual disabilities. The aim of this study is to gain understanding of how some problems in finding and getting services came about so that future research can try to lessen these problems.

**Participation:** I will be asked to meet with the researcher now to discuss the study, questions I have, and to give my consent to participate in this study. I will then be asked to talk about what intellectual disability means to me, about my experiences trying to get services for my child(ren) with an intellectual disability, and changes to the way services are given that I would like to see. I will talk about these things in an interview with the researcher. This will take between 60-90 minutes. I can have the researcher come to my home, or I can go to a private meeting room at the Developmental Service Centre, in Ontario. If I would like to have my interview at the same time as a home visit with my case manager because I would like to have my case manager with me in the interview, I can ask for this. If my partner and I would like to be interviewed together, I can ask for this. I can share any feelings that are bothering me with the researcher, that happen in the interview, or I can contact her after if I feel upset later. I can also contact my case manager from Developmental Service Centre to talk about these feelings.

**Risks:** I may have heard about this study from my case manager or Relief Counsellor from Developmental Services Centre that provides service to me and/or my child. Some of the problems that I might talk about could be about services provided to me and/or my child from Service Centre.

I have received assurance from the researcher that every effort will be made so that my case manager and other Developmental Service Centre staff will not know if I decide to participate or not in this study or what I talk about. My participation in the study and what I share will be kept confidential if I choose to be interviewed in my home, without anyone else present. My name will be removed from the information I have given in this study. If my words are quoted in the published results of this study, words will be changed so that my identity will not be known. Because of these measures, what I choose to share will not affect the services I and/or my child receive.

If I ask for my case manager to be present during the interview, it has been explained to me that my anonymity will not be protected, and that my case manager will know that I participated. It has also been explained to me that my case manager will know whatever I choose to share if she is present in the interview. I am aware that my confidentiality will not be kept from my case manager if I ask for her presence in the interview. I understand that if I choose to be interviewed in a private office, at the Developmental Service Centre, that a staff member will be in the building. I understand that this means that my participation in the study will not be kept secret if I choose to meet at the centre. What I share in the interview will be kept confidential.

Participating in this study may require me to drive to the Developmental Service Centre, if I ask to be interviewed there, and may take 90 minutes of my time. I am aware that I will receive my choice of bus passes, aquatic centre passes, Walmart gift card, or \$25. I will be given this as thanks for participating and to pay for my transportation to the interview if I choose for it to be outside my house.

If I talk about, or the researcher sees, acts of child abuse or neglect, the researcher has to notify the Children's Aid Society.

In participation, I may talk about my feelings about what intellectual disability means to me, some of the problems my family and/or my child(ren) might have, and any problems I may have had getting help for those issues. Some of these feelings may be hard to talk about and sometimes may be upsetting. It is my right to not answer or talk about anything I don't want to, or to stop participating at any point in the interview. If I need to talk to someone about these feelings I can contact my case manager from Developmental Services. If I decide to stop participating and don't want the researcher to keep any of the information I have already given, I can ask to have it destroyed and not included. It may not be possible to take my information out of this study if I decide after the researcher has removed my identification from my information. The researcher will give me a chance to have any or all that I share in the interview removed at the end of the interview, before I leave. After the interview, I cannot remove what I have talked about from the study because my name will not be attached to the information that I shared.

**Benefits:** By participating in this study, I will be able to talk about my feelings about intellectual disability and my experiences with services for my child with an intellectual disability.

My participation will help to build nursing understanding about what intellectual disability means to parents of children with intellectual disabilities. Understanding of parent's experiences and feelings about how services are planned and given to their child(ren) with intellectual disabilities will also be

gained. This information will help nurses better understand what is important to families with intellectual disabilities and areas that nurses can work to improve services.

**Confidentiality:** I have been assured that everything that I say and do will be kept strictly confidential unless I talk about issues of child abuse or neglect, or the researcher sees child abuse or neglect happening, the researcher is legally required to report this. I know that the contact information that the researcher collects, including my name, phone number, and address will be destroyed after the interview. I know that any details identifying me and my name will be separated and deleted from the information that I share in the interview. I know that the information that I share in the interview will be published, including quotes, at the end of the study and may be presented in conferences. My anonymity will be protected and my identity will never be included within publication or presentations of this study.

**Conservation of data:** Data collected from me, including consent form, written or audio recordings of the interview, and transcribed electronic copies of my interview will be locked in a box for five years at the University of Ottawa. Only the researcher and her thesis supervisor will have key access to the lock box.

**Compensation:** I am aware that a choice between bus passes, aquatic centre passes, Walmart gift card, or respite funding in the amount of \$25 will be provided for my participation in this study. This choice will be provided at the time of the interview. I can stop participating in this study at any time and I will not be required to return this incentive.

**Acceptance:** I, \_\_\_\_\_, agree to participate in the above study conducted by Anna Don of the School of Nursing, Faculty of Health Sciences, from the University of Ottawa, which research is under the supervision of Dr. Patrick O’Byrne.

I, \_\_\_\_\_, AGREE \_\_\_\_ or DISAGREE \_\_\_\_\_ to have my voice recorded during my interview.

If I have any questions or concerns, I may contact the researcher or her supervisor.

If I have questions about the ethical conduct of this study, I can contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5  
Tel:(613)562-5387

Email: [ethics@uottawa.ca](mailto:ethics@uottawa.ca)

There are two copies of the consent form, one of which is mine to keep.

Participant’s signature:

Date:

Researcher’s signature:

Date:

## Developmental Services Consent Form – Française

**Titre de l'étude:** L'exploration des services sociaux et de la santé et les barrières naviguantes expérimentées par les enfants ayant une déficience intellectuelle

**Rechercheuse:** Anna Don, Directeur de Thèse Dr. Patrick O'Byrne  
Département des soins infirmiers  
Faculté des sciences de la santé  
Université d'Ottawa



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Université d'Ottawa  
Faculté des sciences  
de la santé

École des sciences  
infirmières

University of Ottawa  
Faculty of Health  
Sciences

School of Nursing

**Une invitation à participer:** Je suis invité(e) à participer à une étude portant sur les défis à trouver et à recevoir des services pour des enfants ayant une déficience intellectuelle. La recherche sera faite par Anna Don et Dr. Patrick O'Byrne assurera la supervision de l'étude.

**Le but de l'étude:** Le but de cette étude est d'explorer la signification de la déficience intellectuelle dans notre société. Nous voulons également comprendre comment cette signification fait partie de la façon dont les services sont planifiés et répartis aux enfants ayant une déficience intellectuelle. L'objectif de cette étude est de mieux comprendre comment les problèmes à trouver et recevoir des services sont survenus, afin que les recherches futures puissent réduire ceux-ci.

**Participation:** Je serai invité(e) à rencontrer la rechercheuse maintenant afin de discuter de l'étude, poser mes questions et donner mon consentement à participer à cette étude. Ensuite je serai demandé(e) à discuter de ce que la déficience intellectuelle veut dire pour moi, de mes expériences à recevoir des services pour mon (mes) enfant(s) ayant une déficience intellectuelle, ainsi que les changements dans la façon que les services sont répartis ainsi que mes souhaits personnels. Je vais parler de ces enjeux avec la rechercheuse dans une entrevue qui durera environ 60 à 90 minutes. La rechercheuse peut se rendre à mon domicile ou je peux la rencontrer dans une salle au (Developmental Service Centre), et Ontario. Si je désire avoir l'entrevue au même moment que la visite à domicile avec mon gestionnaire de cas, parce que je préfère avoir sa présence lors de l'entrevue, je peux en faire la demande. Si mon partenaire et moi désirons avoir une entrevue ensemble, je peux en faire la demande. Je peux partager tout sentiment de peine avec la rechercheuse, que ce soit lors de l'entrevue ou après celle-ci. Je peux la contacter pour parler de mes sentiments par la suite. Je peux aussi contacter mon gestionnaire de cas de (Developmental Service Centre) pour parler de mes sentiments.

**Risques:** J'ai peut-être entendu parler de cette étude par mon gestionnaire de cas, ou relief conseiller de (Developmental Service Centre), lequel offre des services à moi et/ou mon enfant. Certains des problèmes dont je vais peut-être

discuter peuvent porter sur les services fournis par (Developmental Service Centre) à moi et/ou mon enfant. Je suis rassuré(e) par la chercheuse que tous les efforts seront faits afin que mon gestionnaire de cas et autres membres du (Developmental Service Centre) ne soient pas mis au courant si je décide de participer ou non à l'étude et des sujets discutés. Ma participation à cette étude et ce que je partage seront gardés confidentiels si je choisis d'être interviewé à mon domicile et que personne n'est présent. Mon nom sera enlevé de l'information donnée dans cette étude. Si mes paroles sont citées dans la publication des résultats de l'étude, les mots seront changés afin de garder mon identité confidentielle. En raison de ces mesures, ce que je choisis de partager n'affectera pas les services que je reçois ou que mon enfant reçoit.

Il m'a été expliqué que si je demande que mon gestionnaire de cas soit présent lors de l'entrevue, mon anonymat ne sera pas protégé, et que mon gestionnaire de cas sera au courant que j'ai participé à l'étude. Il m'a aussi été expliqué que mon gestionnaire de cas sera au courant de ce que je choisis de partager si il ou elle est présent(e) lors de l'entrevue. Je suis conscient(e) que ma confidentialité ne sera pas gardée si je choisis d'avoir la présence de mon gestionnaire de cas présent(e) lors de l'entrevue. Je comprends que si je choisis d'être interviewé(e) dans une salle privée de (Developmental Service Centre), qu'il y aura un membre du personnel présent dans l'édifice. Je comprends que ma participation à cette étude ne sera pas gardée secrète si je choisis de passer l'entrevue au bureau. Ce que je dis lors de l'entrevue sera gardé confidentiel. Ma participation à cette étude peut me demander de conduire au bureau (Developmental Service Centre), si je demande de passer l'entrevue sur les lieux et ceci pourrait prendre 90 minutes de mon temps. Je suis conscient(e) que je recevrai soit; des passes d'autobus, des passes au centre aquatique, un certificat-cadeau de Walmart ou 25\$. Ceci me sera remis en guise de remerciement d'avoir participé à l'entrevue et pour défrayer des coûts de déplacement pour passer l'entrevue si je choisis de le faire hors de mon domicile.

Si je parle de, ou que la chercheuse soupçonne des signes d'abus, de maltraitance ou de négligence envers les enfants, la chercheuse doit informer la Société d'aide à l'enfance. En participant, je pourrais parler de mes sentiments quant à ce que la déficience intellectuelle veut dire pour moi, des problèmes que ma famille et/ou mes enfants pourraient avoir ainsi que des problèmes que je pourrais avoir rencontrés afin de recevoir de l'aide sur le sujet. Certains de ces sentiments peuvent être difficiles à aborder et peuvent être bouleversants. C'est mon droit de ne pas répondre ou de discuter des choses auxquelles je ne veux pas parler, ou d'arrêter de participer à l'entrevue n'importe quel moment lors de l'entrevue. Si je ressens le besoin de parler de ces sentiments, je peux contacter mon gestionnaire de cas au (Developmental Service Centre). Si je décide d'arrêter l'entrevue et que je ne veule pas que la chercheuse garde aucune information que j'ai partagée, je peux demander que celle-ci soit détruite et non inclus. Il ne sera pas possible de supprimer mon information de l'étude si je choisis après que la chercheuse ait enlevé l'identité de mon information. La chercheuse me donnera l'opportunité de supprimer une partie ou tout ce que j'ai dit lors de l'entrevue avant mon départ à la fin de l'entrevue. Suite à l'entrevue, je ne pourrai pas supprimer ce que j'ai dit, parce que mon identité ne sera pas rattachée à l'information que j'ai partagée.

**Avantages:** En participant à cette étude, j'aurai l'opportunité de parler de mes sentiments au sujet des déficiences intellectuelles ainsi que mes expériences avec les services pour mon enfant ayant une déficience intellectuelle. Ma participation aidera à la compréhension des soins infirmiers et ce que la déficience intellectuelle veut dire pour des parents d'enfants ayant une déficience intellectuelle. De plus, nous comprendrons mieux les expériences et les sentiments des parents face aux services offerts et donnés à leur enfant ayant une déficience intellectuelle. Cette information aidera les infirmières à mieux comprendre ce qui est important pour les familles avec une personne ayant une déficience intellectuelle, ainsi que les domaines qui restent à travailler afin d'améliorer les services.

**Confidentialité:** On m'a assuré que tout ce que je dis et fais sera gardé strictement confidentiel, sauf si je parle d'abus, de maltraitance ou de négligence envers les enfants. La chercheuse est légalement tenue de signaler à l'Aide à l'enfance, si elle soupçonne ou remarque des signes d'abus, de maltraitance ou de négligence. Je suis conscient(e) que toute information recueillie par la chercheuse, y compris mon nom, mon numéro de téléphone et mon adresse, sera détruite suite à l'entrevue. Je suis conscient(e) que les détails qui identifient ma personne ou mon nom seront séparés et supprimés de l'information partagée pendant l'entrevue. Je suis conscient(e) que l'information que je partage lors de l'entrevue sera publiée, incluant les citations, et qu'à la fin de l'étude, celle-ci pourrait être présentée en conférences. Mon anonymat sera protégé et mon identité ne sera jamais inclus dans les publications ou présentations de cette étude.

**Conservation des données:** Les données qui seront recueillies de moi, incluant mon formulaire de consentement, les enregistrements écrits ou audio de l'entrevue, les copies électroniques transcrites de mon entrevue, seront placées dans une boîte verrouillée pour cinq ans à l'Université d'Ottawa. Seulement la chercheuse et son directeur de thèse auront accès à la clé de la boîte verrouillée.

**Compensation:** Je suis conscient(e) que le choix entre les passes d'autobus les passes au centre aquatique, le certificat-cadeau de Walmart, ou le financement de répit de 25\$ me sera fourni pour ma participation dans cette étude. Ce choix me sera donné au moment où je passe l'entrevue. Je peux arrêter de participer dans cette étude à n'importe quel moment et je ne serai pas requis de retourner cette incitation.

**Acceptation:** Je, \_\_\_\_\_, consens à participer dans l'étude ci-haut, menée par Anna Don de l'École des sciences infirmières, Faculté des sciences de la santé, de l'Université d'Ottawa, laquelle est sous la supervision de Dr. Patrick O'Byrne.

Je, \_\_\_\_\_, CONSENS \_\_\_\_\_ ou NE CONSENS PAS \_\_\_\_\_ à avoir ma voix enregistrée lors de l'entrevue.

Si j'ai des questions ou inquiétudes, je peux contacter la chercheuse ou son superviseur.

Si j'ai des questions de nature éthique pour cette étude, je peux contacter l'Agent de protocole pour l'Éthique de la recherche, Université d'Ottawa, Pavillon Tabaret, 550 Rue Cumberland, Salle 154, Ottawa, ON K1N 6N5

Tel: (613)562-5387

Courriel: ethics@uottawa.ca

Il y a deux copies de ce formulaire de consentement, dont l'une est la mienne à garder.

Signature du participant: \_\_\_\_\_

Date: \_\_\_\_\_

Signature de la chercheuse: \_\_\_\_\_

Date: \_\_\_\_\_

## Special Olympics Consent Form – English

**Title of the study:** Exploring health and social service navigational barriers experienced by children with intellectual disabilities.

**Researcher:** Anna Don, Thesis supervisor Dr. Patrick O’Byrne  
 Department of Nursing  
 Faculty of Health Sciences  
 University of Ottawa



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Université d’Ottawa  
 Faculté des sciences  
 de la santé

École des sciences  
 infirmières

University of Ottawa  
 Faculty of Health  
 Sciences

School of Nursing

**Invitation to participate:** I am invited to participate in a study looking at the challenges finding and getting services for children with intellectual disabilities. Anna Don will be doing the research and Dr. Patrick O’Byrne will be supervising her research work.

**Purpose of the study:** The purpose of this study is to explore the meaning of intellectual disability in our society. We also want to understand how this meaning is a part of how services are planned and given to children with intellectual disabilities. The aim of this study is to gain understanding of how some problems in finding and getting services came about so that future research can try to lessen these problems.

**Participation:** Participation in this study is voluntary. This study is not affiliated with Special Olympics. I will be asked to meet with the researcher now to discuss the study, questions I have, and to give my consent to participate in this study. I will then be asked to talk about what intellectual disability means to me, about my experiences trying to get services for my child(ren) with an intellectual disability, and changes to the way services are given that I would like to see. I will talk about these things in an interview with the researcher. This will take between 60-90 minutes. I can have the researcher come to my home, or I can go to a private meeting room at the Developmental Service Centre, in Ontario. If my partner and I would like to be interviewed together, I can ask for this. I can share any feelings that are bothering me with the researcher, that happen in the interview, or I can contact her after if I feel upset later. I can also contact my case manager from Developmental Service Centre to talk about these feelings.

**Risks.** I may have heard about this study from basketball practice with Special Olympics. Some of the problems that I might talk about could be about services provided to me and/or my child from Special Olympics sports. I have received assurance from the researcher that every effort will be made so that staff and volunteers from Special Olympics will not know if I decide to participate or not in this study or what I talk about. My participation in the study and what I share will be kept confidential if I choose to be interviewed in my home.

My name will be removed from the information I have given in this study. If my words are quoted in the published results of this study, words will be changed so that my identity will not be known. Because of these measures, what I choose to share will not affect the services I and/or my child receive.

I understand that if I choose to be interviewed in a private office, at the Developmental Service Centre, that a staff member will be in the building. I understand that this means that my participation in the study will not be kept secret if I choose to meet at the centre. What I share in the interview will be kept confidential.

Participating in this study may require me to drive to the Developmental Service Centre, if I ask to be interviewed there, and may take 90 minutes of my time. I am aware that I will receive my choice of bus passes, aquatic centre passes, Walmart gift card, or \$25. I will be given this as thanks for participating and to pay for my transportation to the interview if I choose for it to be outside my house.

If I talk about, or the researcher sees, acts of child abuse or neglect, the researcher has to notify the Children's Aid Society.

In participation, I may talk about my feelings about what intellectual disability means to me, some of the problems my family and/or my child(ren) might have, and any problems I may have had getting help for those issues. Some of these feelings may be hard to talk about and sometimes may be upsetting. It is my right to not answer or talk about anything I don't want to, or to stop participating at any point in the interview. If I need to talk to someone about these feelings I can contact my case manager from Developmental Services. If I decide to stop participating and don't want the researcher to keep any of the information I have already given, I can ask to have it destroyed and not included. It may not be possible to take my information out of this study if I decide after the researcher has removed my identification from my information. The researcher will give me a chance to have any or all that I share in the interview removed at the end of the interview, before I leave. After the interview, I cannot remove what I have talked about from the study because my name will not be attached to the information that I shared.

**Benefits:** By participating in this study, I will be able to talk about my feelings about intellectual disability and my experiences with services for my child with an intellectual disability.

My participation will help to build nursing understanding about what intellectual disability means to parents of children with intellectual disabilities. Understanding of parent's experiences and feelings about how services are planned and given to their child(ren) with intellectual disabilities will also be gained. This information will help nurses better understand what is important to families with intellectual disabilities and areas that nurses can work to improve services.

**Confidentiality:** I have been assured that everything that I say and do will be kept strictly confidential unless I talk about issues of child abuse or neglect, or the researcher sees child abuse or neglect happening, the researcher is legally required to report this. I know that the contact information that the researcher collects, including my name, phone number, and address will be destroyed after the interview. I know that any details identifying me and my

name will be separated and deleted from the information that I share in the interview. I know that the information that I share in the interview will be published, including quotes, at the end of the study and may be presented in conferences. My anonymity will be protected and my identity will never be included within publication or presentations of this study.

**Conservation of data:** Data collected from me, including consent form, written or audio recordings of the interview, and transcribed electronic copies of my interview will be locked in a box for five years at the University of Ottawa. Only the researcher and her thesis supervisor will have key access to the lock box.

**Compensation:** I am aware that a choice between bus passes, aquatic centre passes, Walmart gift card, or respite funding in the amount of \$25 will be provided for my participation in this study. This choice will be provided at the time of the interview. I can stop participating in this study at any time and I will not be required to return this incentive.

**Acceptance:** I, \_\_\_\_\_, agree to participate in the above study conducted by Anna Don of the School of Nursing, Faculty of Health Sciences, from the University of Ottawa, which research is under the supervision of Dr. Patrick O'Byrne.

I, \_\_\_\_\_, AGREE \_\_\_\_ or DISAGREE \_\_\_\_\_ to have my voice recorded during my interview.

If I have any questions or concerns, I may contact the researcher or her supervisor.

If I have questions about the ethical conduct of this study, I can contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5

Tel:(613)562-5387

Email: ethics@uottawa.ca

There are two copies of the consent form, one of which is mine to keep.

Participant's signature:

Date:

Researcher's signature:

Date:

## Special Olympics Consent Form – Français

**Titre de l'étude:** L'exploration des services sociaux et de la santé et les barrières naviguantes expérimentées par les enfants ayant une déficience intellectuelle

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**Une invitation à participer:** Je suis invité(e) à participer à une étude portant sur les défis à trouver et à recevoir des services pour des enfants ayant une déficience intellectuelle. La recherche sera faite par Anna Don et Dr. Patrick O'Byrne assurera la supervision de l'étude.

**Le but de l'étude:** Le but de cette étude est d'explorer la signification de la déficience intellectuelle dans notre société. Nous voulons également comprendre comment cette signification fait partie de la façon dont les services sont planifiés et répartis aux enfants ayant une déficience intellectuelle. L'objectif de cette étude est de mieux comprendre comment les problèmes à trouver et recevoir des services sont survenus, afin que les recherches futures puissent réduire ceux-ci.

**Participation:** La participation à cette étude est faite de façon volontaire. Cette étude n'est pas associée aux Olympiques spéciaux. Je serai invité(e) à rencontrer la chercheuse maintenant afin de discuter de l'étude, poser mes questions et donner mon consentement à participer à cette étude. Ensuite je serai demandé(e) à discuter de ce que la déficience intellectuelle veut dire pour moi, de mes expériences à recevoir des services pour mon (mes) enfant(s) ayant une déficience intellectuelle, ainsi que les changements dans la façon que les services sont répartis ainsi que mes souhaits personnels. Je vais parler de ces enjeux avec la chercheuse dans une entrevue qui durera environ 60 à 90 minutes. La chercheuse peut se rendre à mon domicile ou je peux la rencontrer dans une salle au (Developmental Service Centre), à Ontario. Je peux partager tout sentiment de peine avec la chercheuse, que ce soit lors de l'entrevue ou après celle-ci. Je peux la contacter pour parler de mes sentiments par la suite. Je peux aussi contacter mon gestionnaire de cas de (Developmental Service Centre) pour parler de mes sentiments.

**Risques :** J'ai peut-être entendu parler de cette étude aux activités sportives des Olympiques spéciaux de Cornwall. Je suis rassuré(e) par la chercheuse que tous les efforts seront faits afin que les membres de l'équipe et les volontaires de Olympiques spéciaux ne soient pas mis au courant si je décide de participer ou non à l'étude et des sujets discutés.

Ma participation à cette étude et ce que je partage seront gardés confidentiels si je choisis d'être interviewé à mon domicile. Mon nom sera enlevé de l'information donnée dans cette étude. Si mes paroles sont citées dans la publication des résultats de l'étude, les mots seront changés afin de garder mon identité confidentielle. En raison de ces mesures, ce que je choisis de partager n'affectera pas les services que je reçois ou que mon enfant reçoit.

Je suis conscient(e) que ma confidentialité ne sera pas gardée si je choisis d'avoir la présence de mon gestionnaire de cas présent(e) lors de l'entrevue. Je comprends que si je choisis d'être interviewé(e) dans une salle privée de (Developmental Service Centre), qu'il y aura un membre du personnel présent dans l'édifice. Je comprends que ma participation à cette étude ne sera pas gardée secrète si je choisis de passer l'entrevue au bureau. Ce que je dis lors de l'entrevue sera gardé confidentiel. Ma participation à cette étude peut me demander de conduire au bureau (Developmental Service Centre), si je demande de passer l'entrevue sur les lieux et ceci pourrait prendre 90 minutes de mon temps. Je suis conscient(e) que je recevrai soit; des passes d'autobus, des passes au centre aquatique, un certificat-cadeau de Walmart ou 25\$. Ceci me sera remis en guise de remerciement d'avoir participé à l'entrevue et pour défrayer des coûts de déplacement pour passer l'entrevue si je choisis de le faire hors de mon domicile.

Si je parle de, ou que la chercheuse soupçonne des signes d'abus, de maltraitance ou de négligence envers les enfants, la chercheuse doit informer la Société d'aide à l'enfance. En participant, je pourrais parler de mes sentiments quant à ce que la déficience intellectuelle veut dire pour moi, des problèmes que ma famille et/ou mes enfants pourraient avoir ainsi que des problèmes que je pourrais avoir rencontrés afin de recevoir de l'aide sur le sujet. Certains de ces sentiments peuvent être difficiles à aborder et peuvent être bouleversants. C'est mon droit de ne pas répondre ou de discuter des choses auxquelles je ne veux pas parler, ou d'arrêter de participer à l'entrevue n'importe quel moment lors de l'entrevue. Si je ressens le besoin de parler de ces sentiments, je peux contacter mon gestionnaire de cas au (Developmental Service Centre). Si je décide d'arrêter l'entrevue et que je ne veule pas que la chercheuse garde aucune information que j'ai partagée, je peux demander que celle-ci soit détruite et non inclus. Il ne sera pas possible de supprimer mon information de l'étude si je choisis après que la chercheuse ait enlevé l'identité de mon information. La chercheuse me donnera l'opportunité de supprimer une partie ou tout ce que j'ai dit lors de l'entrevue avant mon départ à la fin de l'entrevue. Suite à l'entrevue, je ne pourrai pas supprimer ce que j'ai dit, parce que mon identité ne sera pas rattachée à l'information que j'ai partagée.

**Avantages:** En participant à cette étude, j'aurai l'opportunité de parler de mes sentiments au sujet des déficiences intellectuelles ainsi que mes expériences avec les services pour mon enfant ayant une déficience intellectuelle. Ma participation aidera à la compréhension des soins infirmiers et ce que la déficience intellectuelle veut dire pour des parents d'enfants ayant une déficience intellectuelle. De plus, nous comprendrons mieux les expériences et les sentiments des parents face aux services offerts et donnés à leur enfant ayant une déficience intellectuelle. Cette information aidera les infirmières à mieux comprendre ce qui est important pour les familles avec une personne ayant une déficience intellectuelle, ainsi que les domaines qui restent à travailler afin d'améliorer les services.

**Confidentialité:** On m'a assuré que tout ce que je dis et fais sera gardé strictement confidentiel, sauf si je parle d'abus, de maltraitance ou de négligence envers les enfants. La rechercheuse est légalement tenue de signaler à l'Aide à l'enfance, si elle soupçonne ou remarque des signes d'abus, de maltraitance ou de négligence. Je suis conscient(e) que toute information recueillie par la rechercheuse, y compris mon nom, mon numéro de téléphone et mon adresse, sera détruite suite à l'entrevue. Je suis conscient(e) que les détails qui identifient ma personne ou mon nom seront séparés et supprimés de l'information partagée pendant l'entrevue. Je suis conscient(e) que l'information que je partage lors de l'entrevue sera publiée, incluant les citations, et qu'à la fin de l'étude, celle-ci pourrait être présentée en conférences. Mon anonymat sera protégé et mon identité ne sera jamais inclus dans les publications ou présentations de cette étude.

**Conservation des données:** Les données qui seront recueillies de moi, incluant mon formulaire de consentement, les enregistrements écrits ou audio de l'entrevue, les copies électroniques transcrites de mon entrevue, seront placées dans une boîte verrouillée pour cinq ans à l'Université d'Ottawa. Seulement la rechercheuse et son directeur de thèse auront accès à la clé de la boîte verrouillée.

**Compensation:** Je suis conscient(e) que le choix entre les passes d'autobus, les passes au centre aquatique, le certificat-cadeau de Walmart, ou le financement de répit de 25\$ me sera fourni pour ma participation dans cette étude. Ce choix me sera donné au moment où je passe l'entrevue. Je peux arrêter de participer dans cette étude à n'importe quel moment et je ne serai pas requis de retourner cette incitation.

**Acceptation:** Je, \_\_\_\_\_, consens à participer dans l'étude ci-haut, menée par Anna Don de l'École des sciences infirmières, Faculté des sciences de la santé, de l'Université d'Ottawa, laquelle est sous la supervision de Dr. Patrick O'Byrne.

Je, \_\_\_\_\_, CONSENS \_\_\_\_\_ ou NE CONSENS PAS \_\_\_\_\_ à avoir ma voix enregistrée lors de l'entrevue.

Si j'ai des questions ou inquiétudes, je peux contacter la rechercheuse ou son superviseur.

Si j'ai des questions de nature éthique pour cette étude, je peux contacter l'Agent de protocole pour l'Éthique de la recherche, Université d'Ottawa, Pavillon Tabaret, 550 Rue Cumberland, Salle 154, Ottawa, ON K1N 6N5

Tel: (613)562-5387

Courriel: [ethics@uottawa.ca](mailto:ethics@uottawa.ca)

Il y a deux copies de ce formulaire de consentement, dont l'une est la mienne à garder.

Signature du participant: \_\_\_\_\_ Date: \_\_\_\_\_

Signature de la rechercheuse: \_\_\_\_\_ Date: \_\_\_\_\_

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