

Passports to Adulthood, Strong Families and Good Mothers: A Critical Examination of
Developmental Disability Discourse in Ontario Between 2008-2014

By

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Abstract

This study investigates ways in which motherhood and family are implicated in contemporary policy and practice relating to adults diagnosed with developmental disabilities in Ontario, Canada. In Ontario, recent policy changes emphasize the importance of supporting families and stress inclusion, choice and independence as desirable and attainable outcomes for disabled adults. At the same time, Ontario's provincially regulated developmental services system has been charged by families, journalists and government officials as failing to adequately provide for adults with developmental disabilities and their families, many of whom are said to be in crisis. Conducted from a feminist and disability studies informed, post-structuralist perspective, the current research explores how meanings associated with disability, family and motherhood make contemporary disability related policies and practices possible. More specifically, the current research was undertaken to describe developmental disability discourse in Ontario between 2008-2014, especially as it engages with conceptualizations of motherhood and family. Results from a discourse analysis of policy documents, interviews with eight mothers of adults diagnosed with developmental disabilities and Legislative Assembly of Ontario Select Committee on Developmental Services transcripts indicate that the disabled adult subject embodies discursive flows, tensions and contradictions. Belonging to a category of fixed, medicalized difference from a norm, the disabled adult subject is envisioned as legitimately unable to enact the demands of successful neoliberal citizenship; while simultaneously envisioned as deserving recognition as a unique adult human who should exercise choice and individual potential to approximate normative adulthood and successful neoliberal citizenship.

This tension-laden discourse is made possible by and perpetuates gendered ideals and practices of parenting and a related familialization of care, thereby extending and expanding intensive mothering practices and expectations. At the same time, developmental disability discourse also makes it possible for mothers to draw boundaries around their mothering roles and make demands of the province.

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List of Abbreviations

American Association on Intellectual and Developmental Disabilities (AAIDD)

Application for Developmental Services and Supports (ADSS)

Developmental Services Ontario (DSO)

Fetal Alcohol Spectrum Disorder (FASD)

Legislative Assembly of Ontario Select Committee on Developmental Services (Select Committee)

Ministry of Community and Social Services (MCSS)

Supports Intensity Scale (SIS)

The Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act (2008) (The Social Inclusion Act)

Preface: Notes on Language

This dissertation is about developmental disability, motherhood, family and the relationships between these concepts. As I wrote about these topics, I was aware that the language I used would have consequences, a view driven by recognition that language does not straightforwardly describe reality but rather that language is often debated and always productive. The former insight, that the appropriateness and/ or consequences of specific words, terminology, descriptors and even narratives is debatable, was made especially apparent as I grappled with issues related to disability; throughout this research process, it was impossible to ignore the glaring fact that the language used to describe or categorize the adults currently denoted in policy as “with developmental disabilities” is contentious and often representative of a repressive history and present (Landsman 2009: 11; MCSS 2012-2014a; People First of Canada 2007-2016a; Shildrick 2012: 40; Titchkosky 2001). With regard to the latter insight, which concerns the productive nature of language, this research is conducted from a post-structuralist perspective, which emphasizes how language creates, shapes and defines rather than reflects what may appear to be naturally existing categories or phenomena. Bearing these ideas about language in mind, I begin this work by taking a moment to explain some of the language choices I have made throughout.

First, my focus on mothers necessitates discussion of the meanings of the terms motherhood and mothering. Emphasizing social influences on women’s experiences mothering, in 1977 Adrienne Rich articulated motherhood as a patriarchal institution. The institution of motherhood includes expectations, beliefs and values about women, mothers and mothers’

relationships to their children, all of which impacts mothering practices and evaluations of mothering practices (Green 2010). In the current study, this means that mothering practices, expectations of mothers and statements about mothers are analyzed in reference to intensive mothering ideology, dichotomous myths of good and bad mothers and gendered expectations for care (see Chapter 2 for explanations of these concepts), all of which are part of the socially created institution of motherhood.

Second, in an effort to capture the contradictory discursive field I describe in this project, I use various disability related terms throughout. Accordingly, while always selected purposefully, some of the language invoked throughout this project may variously seem problematic, appropriate or offensive at times. Following the most common practice within the field of critical disability studies, I prefer the use of term disabled (Shildrick 2012: 40), or developmentally disabled to confer the active, social, political processes of disablement that disadvantage adults diagnosed with impairments or disabilities (Morris 2001: 1-5). Similarly reflecting my view that the category disability is socially constituted, I also use the term adults diagnosed with a developmental disability, which emphasizes the role of diagnostic processes in the creation of the construct of disability. That said, a lack of linguistic consensus in the area is highlighted by the fact that many developmental disability-based activists call for the use of a “people first language”, which seeks to emphasize the humanity of people who “happen to have” disabilities (Titchkosky 2001: 129) by using the terms person with a disability. Although critiqued for positioning disability as abnormal, individual and apolitical (ibid), person first language seemed to be accepted as best practice in many of the documents examined for the

current research and was deployed frequently in policy and by parents. Accordingly, I use this language as well, both when reporting on policy or parent statements or when describing the discourse more generally. At other times, other terminology is relevant to the context under discussion. For example, when I discuss the historical constitution of disability I use terms that would now be considered offensive, but that reflect language of the time under discussion.

It is my hope that these language choices do not (re)create problematic visions of disability, but rather highlight the complexity and contradiction inherent to disability discourse and the disability field. I hope that by acknowledging and unpacking this diverse and tangled terrain, we can begin to see the interactions between and the consequences of particular ways of seeing, writing about and talking about disability. On that note, in Chapter 1, I provide a brief overview of my findings related to the content and consequences of developmental disability discourse.

Chapter 1

Introduction

In March 2009, the Ontario government fulfilled its commitment made in 1987 to move from an institution-based system for people with a developmental disability to a community-based service system. Nearly 7,000 adults with a developmental disability in Ontario have successfully transitioned to new homes in the community. Homes have been found that better meet each person's needs based on thorough planning that includes the individuals, their families, facility staff, medical professionals and the community agencies. (Ontario Ministry of Community and Social Services (MCSS) 2012-2014a: n.p.)

[I]ndividuals and families who need developmental services and supports are in crisis... [A]fter struggling to obtain services and enduring waitlists for years, many families feel pushed to the brink of disaster. Only when they are forced into crisis are they able to access desperately needed assistance. When that happens, others are bumped further down the waitlists.... [T]he situation is urgent. We are deeply troubled and alarmed by the range of barriers confronting persons with developmental disabilities (Legislative Assembly of Ontario Select Committee on Developmental Services 2014a: 3)

Within a critical review of developmental disability discourse in Ontario between 2008-2014, especially as it engages with normative conceptualizations of family and motherhood, this dissertation examines a time which has been characterized as embodying both positive change and crisis for adults diagnosed with developmental disabilities and for their families. In 2009 the last Ontario institution for adults with intellectual and developmental disabilities closed and, according to the Ontario Ministry of Community and Social Services (MCSS), “[n]early 7000 adults with a developmental disability... successfully transitioned to new homes in the community” (MCSS 2012-2014a). This transition was preceded by the publication (2008) and followed by the implementation (2011) of *The Services and Supports*

to Promote the Social Inclusion of Persons with Developmental Disabilities Act (2008) (henceforth referred to as *The Social Inclusion Act*), a policy guiding the funding, allocation and delivery of developmental services. According to the MCSS (2012-2014b: n.p.), *The Social Inclusion Act (2008)* was “created to give people with a developmental disability more independence and choice.... Today, people with a developmental disability live in communities across Ontario. With the right services and supports, they can participate fully in community life and feel that they truly belong”.

Although following the 2011 implementation of the *Social Inclusion Act (2008)* policy changes were framed by the MCSS in positive and emancipatory tones stressing choice, inclusion and independence for disabled adults, the Ontario’s Ombudsman received “a steady increase in complaints” (2016: 6) about developmental services. These complaints prompted a November 2012 announcement that the Ombudsman’s office would conduct “a systemic investigation... into how [the MCSS] responds to situations of urgency or crisis involving adults with developmental disabilities, and how it administers the process for coordinating, monitoring, and facilitating access to services for adults with developmental disabilities in situations of crisis” (ibid). Following the investigation, the Ombudsman concluded that many Ontario adults with disabilities and families are served poorly by the provincially funded and regulated developmental services system: “When they reach a crisis point, service gaps often leave [adults with developmental disabilities] and their families without any real choice... Without significant additional reform, many uniquely vulnerable people will continue to be lost in the system and experience harm because of inadequate supports and services” (ibid: 1).

“Frequently... families descend into crisis without stable, dependable, and consistent supports” (ibid: 4). Additionally, in the same timeframe, multiple national press outlets reported on families’ concerns about and struggles with a lack of available, appropriate care, support and housing options for adults diagnosed with developmental disabilities (e.g. Kane 2012; Mosenbraaten 2012a, 2012b; Nelson 2015; Stevens 2015) and, in 2013, the Legislative Assembly of Ontario established a Select Committee on Developmental Services (henceforth referred to as the Select Committee) to observe and make recommendations on the “urgent need for a comprehensive developmental services strategy to address the needs of children, youth and adults in Ontario with an intellectual disability” (Select Committee 2014a: 2). Resulting from their investigations, one of the Select Committee’s conclusions was that “individuals and families who need developmental services and supports are in crisis” (ibid: 3).

Even this cursory review of public discussion about adults diagnosed with developmental disabilities and their families in Ontario reveals a sense that triumphal MCSS pronouncements and predictions have not come to fruition and that the contemporary situation is problematic and therefore worthy of investigation and intervention of some kind. Indeed, in addition to the Ontario Ombudsman (2016) and the Select Committee’s (2014a) recent investigations of Ontario’s developmental service sector and its impact on adults with developmental disabilities and their families, multiple academic studies have been conducted to determine how adults with developmental disabilities (e.g. Lysaght et al. 2017; Martin, Ashworth and Montague 2012; Petner-Arrey, Howell-Moneta and Lysaght 2016) and their parents (e.g. Lunskey et al. 2017; McKenzie et al. 2017; Robinson et al. 2016) are faring in Ontario’s post-institutionalized

context. Often emphasizing that stress or distress can be associated with parenting an adult child with a developmental disability or that disabled adults have historically or are currently at risk for less-than-optimal outcomes, these studies often conclude with recommendations that could contribute to more widespread attainment of desirable outcomes.

Interest in and concern about the Ontario-based situation for adults diagnosed with developmental disabilities and their families similarly drive the research presented in this dissertation. However, I approach this social problem in ways that differ markedly from dominant approaches to understanding developmental disability and family. Much of the above-described research and talk about disabled adults and family includes assumptions that disability is a real category of human difference and that family, or, more specifically, parents, naturally, inevitably and/ or voluntarily occupy a central role in the lives of their adult children. Exemplifying these trends, the MCSS and Select Committee quotes above both seamlessly include the term “family” in their discussion about disabled adults and include a sense that adults diagnosed with developmental disabilities require specialized, disability-specific attention and provisions. Consistent with assumptions about the centrality of family and the difference of disability, Ontario and internationally-conducted studies tend to explain disability or family member outcomes in relation to individual child or parent characteristics, specific aspects of families’ situations or type of available support for adults with disabilities, their parents or their families.

In contrast, I approach the current study equipped with a different lens, through which I ask questions not about individual adult, specific service or family characteristics, but through which I question and interrogate the production, content and effects of the categories developmental disability, family and motherhood. In formulating this line of questioning, I draw insights from post-structuralism, an approach which de-naturalizes and emphasize the effects of categories of human classification and the practices that contribute to the production of these categorizations. Flowing from this view of the human subject, I do not begin this work with the assumption that disability and family are naturally existing classifications, nor do I begin with the assumption that families or parents should naturally play a central role in the lives of disabled adults. I view these oft-held assumptions as the products of social relations rather than as inevitabilities.

To this end, I query and unpack these classifications, the connections between them and the techniques of power that produce them. On a more concrete level, this means that I investigate ways that understandings of disability and family make possible and were made possible by the socio-historical context in which contemporary crises are said to occur. Also drawing on insights made in feminist research on the family, I note that family is not a gender-neutral institution, and that care is a gendered practice (Baker 2005; 2010: 120-126; Lee 2014; Ranson 2005; Fox 2009). Accordingly, I interrogate not only the operation of meanings attributed to family, but of motherhood as well. Taking these ideas together, I do not seek to explain contemporary developmental disability-related “problems” or “successes” in terms of discrete disability, family or service sector variables. Viewing the contemporary disability related

context as circulating in mutually reinforcing relationships with interconnected concepts of disability, family and motherhood, I study and critique the production, content and operation of these concepts. In plainer terms, I seek to understand how meanings associated with disability, family and motherhood make contemporary disability related policy and practices possible. At the same time, I seek to understand how disability related policy and practices give way to certain meanings of disability, family and motherhood.

To this end, I describe disability discourse in Ontario between 2008-2014, especially in its entanglements with family and motherhood. I ask the following specific questions: Who is the disabled adult subject of disability discourse, particularly as deployed in policy? (How) are motherhood and family embroiled in disability discourse? As they negotiate disability discourse, how do mothers (re)produce and resist dominant visions of disability, motherhood, and family? In this way, I am able to respond to questions about the experiences or well-being of adults diagnosed with developmental disabilities and their families, but I do so in a way that does not take family as naturally central to the discussion, and that instead focuses on the operation and effects of the social meaning attached to disability, family and motherhood.

In Chapter Two, I present the concepts that have shaped this work at all stages. I begin by locating developmental disability as a shifting, historically constituted category and I describe modes of thought – such as normalization and the social model – that shape contemporary policy and practice. To understand the operation and impact of these disability specific trends, however, I argue that it is necessary to describe and investigate connections between them, the

political rationalit(ies) in which they are situated and broader trends in community-based care. Accordingly, I describe connections and mutual reinforcement between post-institutional contexts, neoliberalism as an oft-cited prevailing political rationality of the subject (including disabled adults), enhanced private care, family-provided care, gendered parenting and caring practices and an ideology of intensive mothering. I demonstrate that these dominating and interacting logics and practices have the capacity to assign considerable responsibility and blame to families generally and, given ongoing gendered patterns of and expectations for care, to mothers in particular. I end the chapter by arguing that a focus on meaning attributed to disability, family, and motherhood shifts the focus away from mothers, families, and specific services as sources of problems and solutions towards social and culturally based explanations for developmental services sector “crises”.

In Chapter Three, I outline the macro-theoretical approach I take in the current study and describe how this approach informed methodological decisions made throughout. In this chapter, I argue that post-structuralist discourse analysis, drawing from Foucault’s conception of discourse and the subject combined with a feminist focus on women’s talk and experiences, provides theoretical and methodological tools which allow for the in depth, complex, interpretive forms of research and analysis required for the study. Throughout the remainder of the chapter, I explain how this theoretical orientation guides my choice of materials to analyze (policy documents, interviews with mothers, and Select Committee hearing transcripts), interview procedures (in depth, open-ended) and analytical processes (recursive and holistic).

In Chapter Four I present findings pertaining to the question: “Who is the disabled adult subject of disability discourse?” Throughout, I describe the disabled adult subject as embodying discursive flows, tensions and contradictions. Belonging to a category of fixed, medicalized difference from a norm, the disabled adult is envisioned as legitimately unable to enact the demands of successful neoliberal citizenship; while simultaneously envisioned as deserving recognition as a unique adult human who should exercise choice and individual potential to approximate successful neoliberal citizenship. To this end, especially in interaction with policy and service sector practices, disabled adults are required to inhabit a space of categorical difference from the normal human adult, thereby creating and upholding a rigid border demarcating disability/normalcy, while concurrently flexibly moving around and across this border. While always constrained in terms of available subjectivities, disabled adults are nonetheless asked to choose from a limited or imaginary range of available options to come close to, without ever breaking down, the wall that divides disability and normalcy. Support or help with this process is necessary for success but is not guaranteed: as an othered population, disabled adults are deserving of (not naturally or easily attainable) positive outcomes, but, as unique individuals who can and should enact some form of normalcy, are not entitled to any particular outcomes.

Throughout Chapter Five, I link this discursively (re)produced disabled adult to constructs of the family and mothers. Demonstrating how this tension-laden discourse – of disabled adults as medically other/uniquely human and as deserving/but not entitled to normative outcomes - is made possible by and perpetuates gendered ideals and practices of parenting and a related

familialization of care. This chapter advances explanations of connections between the disabled subject and the situations of crisis briefly described at the outset of this chapter. More specifically, I show how characteristics of the discursive disabled adult operate together with an ideology of intensive mothering and complimentary neoliberal logic to compel families generally and mothers specifically to “naturally” participate in intensive mothering practices. Often, these appeals to families, and by proxy mothers, are explicit and readily accepted. At other times, however, the contradictions, gaps and silences inherent to disability discourse require that mothers engage in work extra to explicitly-stated demands, thereby intensifying mothering practices beyond what is easily accepted by or even directly asked of mothers. Consequently, the same fissures that contribute to an intensification of motherhood make it possible for mothers to place discursive boundaries around their mothering roles and to make demands on the state counter to the neoliberal logic woven throughout developmental disability discourse.

In Chapter Six, I summarize these findings that the tensions inherent to disability discourse, which produce the disabled adult as medically other/uniquely human, are made possible by and perpetuate gendered ideals and practices of parenting and a related familialization of care. I then reflect on contributions, limitations and directions for future research stemming from the current study. Given the results of this current research, which demonstrate the usefulness of discourse analysis for unveiling less visible or unintended consequences of service and policy trends, I end by suggesting that future research should interrogate the categories and political

rationalit(ies) invoked and infused in the numerous recent recommendations for changes to the developmental services sector in Ontario.

Chapter 2

Literature Review

In the current study, I aim to describe adult developmental disability discourse in Ontario, especially in its entanglements with motherhood and its effects on mothers of disabled adults. The purpose of this chapter is to contextualize this project historically, culturally and academically. To do so, I begin by historicizing the concept of developmental or intellectual disability to specify disability as a shifting, historically constituted category and to identify ongoing and contemporary trends impacting disability related policy and practice. Next, I situate contemporary disability practices and policies within movements towards neoliberalization and attendant gendered, family provided care. In this section, I explain the ideology of intensive mothering and illustrate its alignment with neoliberal individualizing of responsibility. Finally, I briefly overview and critique contemporary research about adults with disabilities and position the current research in relation to this body of literature. Taken together, the literature reviewed in this chapter points to the relevance of studying disability, family and motherhood together from a perspective that elaborates on the production and operation of the meanings associated with these categories.

Disability as a Historically Constituted Category

Aligned with its roots in late 1960s and early 1970s activism and theorizing, disability studies' perspectives on disability have long involved arguments that disability should be studied as a political and social phenomenon (Linton 2005; Roulstone, Thomas and Watson 2012: 3). Rather than conceptualizing problems associated with disability as intrinsic to individual deficits,

scholars of disability studies have traditionally followed the tenets of the social model of disability, which holds that disabling barriers to participation are the source of oppression for people with impairments (Roulstone et al. 2012: 3-4). Accordingly, disability studies scholarship tends to focus on the social conditions, techniques and practices which constitute disability and the ways in which these understandings, and attendant understandings of normalcy, impact those identifying or identified as disabled. As Linton (2005: 518) articulates, “We prod people to examine how disability as a category was created to serve certain ends and how the category has been institutionalized in social practices and intellectual convention”. Located within this diverse terrain of inquiry, this project begins with the assumption that what is now known as developmental disability is a fluid, contested, historically and socially constituted category. Thus, to highlight strands of thought relevant to ongoing discussions and practices relating to developmental disability, I provide a brief historical overview of this category below.

While the current research project specifically investigates disability in Ontario, disability relevant trends and discourses in Ontario have mirrored those found in other Western jurisdictions, especially the UK and the US (Radford and Park 2002: 3). Further, borders “have real effects on people’s lives, such as access to health care and... penal practices” but are ultimately imaginary constructs (Carey, Ben-Moshe and Chapman 2014: xi). As such, it is possible to “[draw] upon the materiality of the border where useful and leave it aside where it is not” (ibid). Following this line of argument, I use literature from multiple jurisdictions throughout.

Most scholars of the history of intellectual disability have focused on institutionalization and expert knowledge building when charting social understandings of and responses to intellectual disability (Chupik and Wright 2006: 79). The history of disability presented here reflects the bias of much of the historical research available and might therefore give the misleading impression of an overwhelming consent; however, where possible I incorporate information on instances of counter-conduct or the perspectives of families and parents that demonstrate plurality in deviations from official discourse.

The Creation of a Category: Disability, Care and Control.

According to James Trent (1994: 7-10), people who would now be classified as having a developmental or intellectual disability were not systematically grouped or considered a general type prior to the 19th Century. In this “pre-asylum” era, a “local idiot” might be regarded with a sense of “humor, sympathy, benevolence, or even admiration” (ibid: 10), meaning they might be ridiculed, the recipient of Christian charity as a member of the “worthy poor”, or viewed as pure, and connected to nature (Trent 1994: 7-10). In America, “physically able simpletons found no great obstacle in day-to-day living, and obviously disabled idiots received care from various members of what were usually extended families. When a family broke down, idiots unable to care for themselves were placed with neighbors or in almshouses, and more able simpletons... might find themselves in jail” (Trent 1994: 7).

Towards the mid-19th Century, the grouping together of “idiots” in almshouses and jails and the development and application of statistical techniques to gather information about population(s) contributed to the identification of groups of “idiots” (Trent 1994: 7-39).

Consequent concerns about the morality of “idiots” and European evidence that “education in special schools away from corruption, neglect, or over pampering could free idiots from their natural deficiencies and transform them into public citizens” (Trent 1994: 38) preceded the construction of asylums for the temporary residency and education of child “idiots” (Radford and Park 2002: 5; Trent 1994: 7-39).

According to Trent (1994: 60-95), subsequent economic conditions, institutional interest in expansion and sustainability, and limited evidence of educational success resulted in a shift from visions of “idiots” as trainable to visions of “idiots” as in need of protection and as a potential burden to families and danger to society. “Faced with educated ‘simple’ idiots who could not find jobs and multiply disabled-disabled idiots who were burdens to their families and communities, superintendents saw the potential of using one to care for the other while also widening their own professional purview” (ibid: 95). Ideas about the burden and risk posed by all people with disabilities therefore prompted a growth in the number of institutions and the number of people living in institutions, and a concomitant partial shift from local to state responsibility for those considered “idiots”.

In Ontario, the first asylum specialized for “mentally deficient” “patients” did not open until 1876, at which point optimism for education and community re-integration had already passed

(MCSS 2012-2014a; Radford and Park 2002: 6). Suggested by the use of the terminology “patients”, institutional focus was shifting to medicalized identification and care. Physicians and nurses were involved in these institutions and disability increasingly came to be viewed as a medical issue which required medical diagnosis (Bach 2017; Radford and Park 2002: 12; Trent 1994).

The advent and application of intelligence testing and widespread eugenic concerns contributed further changes to understandings of disability (Bach 2017; Davis 2006; Radford and Park 2002: 7; Trent 1994). “The idea that disability was not a status that was conferred but was in fact an individual deficit gained strength in the late 19th century when Binet and Simon developed the first intelligence test” (Bach 2017: 38). Additionally, beginning in the late 19th Century, social Darwinist concerns with the fitness of the nation gained currency. In conjunction with race, gender, and class, disability was central to worries about the health of the nation: “Social Darwinists suggested that too many “unfit” were surviving beyond infancy, resulting in larger numbers of disabled people requiring care” (Radford and Park 2002: 7). Already linked to middle-class assumptions of normalcy (Davis 2006), ties with race and class tightened as immigrants and people living in poverty consistently underperformed on measures of intelligence (Trent 1994). According to Trent (1994: 187), by the 1920’s, those classified ‘mentally deficient’ were considered “at worst... poor, law-breaking, sexually promiscuous, hereditarily tainted lowlifers; at best... they were....silly ‘little morons’”.

Radford and Park (2002: 7) argue that once disability was conceptualized as a threat to national health, the institution was seen as a necessary site of “care and control”. Consideration of families was twofold: on the one hand, institutionalization alleviated responsibility from overburdened family members (ibid: 12); on the other hand, genetic research and theory assigning parents responsibility positioned families as a threat to family members with disabilities and society as a whole (Trent 1994). Thus, a somewhat benevolent sense of collective responsibility circulated concurrently with social Darwinist ideas that justified segregation, sterilization, and limits on marriage for the “unfit” (Carlson 2001: 126-128).

Radford and Park (2002: 6) recognize that even at the height of the “asylum era” most Ontarians who would now be classified as having an intellectual disability did not actually live in an asylum.

It became apparent that the asylum era was marked as much by attitudes as by buildings. Only a small proportion of people diagnosed as “mentally deficient” were institutionalized, but this was due mainly to lack of space and resistance to the level of public spending it would have required. It was widely agreed that, in a perfect society, all such people would be “put away,” and it was often said that those who remained in the community that they “belonged in an asylum”. The asylums created a place for mental deficiency within the social order, and it was widely believed that this place was both proper and beneficial, not only for society, but also for those with disabilities.

However, Chupik and Wright’s (2006) analysis of early 20th Century admission documents to Ontario’s Orillia Centre trouble claims about a largely unquestioned acceptance that institutional segregation represented the rightful place for the “mentally deficient”. Chupik and Wright (ibid) found that the asylum was often used by families of disabled children as a last resort, which was frequently only pursued once pre-existing community-based options had

been exhausted. These findings suggest that the early 20th Century witnessed a generalized consensus that children with disabilities required some form of attention for their deficiencies, but that, counter to medical professionals, families often considered “mental deficiency” curable and that “the asylum... constituted not a dichotomous alternative to ‘the family’, but rather one option of many in an increasingly bureaucratized and complex web of charitable and statutory welfare networks which were interdependent and fluid” (Chupik and Wright 2006: 88).

Exposés, Academics and Advocates: Pressures towards Deinstitutionalization and Community Based Care.

According to most accounts of disability and institutional history, institutions were more popularly and publicly problematized towards the middle of the 20th Century. During the Second World War, the exposé of institutional conditions revealed abuse, neglect and overcrowding (Trent 1994). Around the same time, several American parents publicized accounts of their experiences having a disabled child. These narratives stressed that the birth of a disabled child was not shameful and was not a result of parental genetic or moral deficit. Trent (1994) discusses three influential American parental narratives: two called for institutional reform and improvement, claiming that segregation was best for disabled children, while a celebrity testament claimed that “angels” should remain at home with their families. These narratives inspired parental advocacy; parents who were no longer ashamed could meet and advocate for their children.

In Ontario, some parents advocated for institutional improvements while other academic and parental movements called for social inclusion and community-based care (Radford and Park 2002: 13). At this time, psychologists and university researchers became the new experts on developmental disabilities (Trent 1994). As Radford and Park (2002: 13) contend, “an emerging body of theory, developed in close association with advocacy groups, lent authority to the movement away from institutionalizations”. The normalization principle (Wolfensberger 1972: 28), defined as the “utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible” was influential in a growing acceptance of the idea that people with intellectual disabilities should be able to access the same “normal” opportunities and experiences as those who are non-disabled via community integration (Radford and Park 2002: 14-15). Countering arguments for the continuation of institutionalization based on protective concerns for the safety and well-being of disabled adults (ibid: 15), Perske (1972) advocated for allowing for the “dignity of risk” as opposed to protection and confinement. Beginning in the 1970s, newly formed self-advocacy groups, such as People First, additionally rallied against institutional confinement, based largely on the principle that people with disabilities have a right to be seen as “People First” and participate as general members of the community (Friedman and Beckwith 2014; People First of Ontario 2017).

Aligned with self-advocacy and academic movements stressing rights, deinstitutionalization, and community integration, in the 1970s responsibility for institutions transferred from the Ontario Ministry of Health to the Ontario Ministry of Community and Social Services (Ontario

MCSS 2012-2014a). In 1983, the Ontario government committed to closing all institutions in a movement towards the provision of community-based services.

Since this official commitment, social model and rights-based approaches to disability have grown in influence. In the 1970's, UK based physically disabled activists formed the Union of the Physically Impaired Against Segregation (UPIAS 1976) and developed what has now become known as the highly influential social model of disability (see Barnes 2012: 12-16). Social modelists argue that disability is dominantly understood in medicalized terms and is consequently considered a deficit and an individual problem (Barnes 2012: 12, 21-22; Corker and French 1999: 1-6; Shakespeare 2006: 15-19). The classical social model, on the other hand, differentiates between impairment and disability, locating impairment as a result of bodily (dis)function and disability as a result of oppressive structural and attitudinal barriers (Morris 2001: 2; Shakespeare 2006: 29). According to proponents of the social model, the dependence of people with disabilities has been shaped, not by impairment, but by inaccessible environments and expert-led and paternalistic approaches to care. For proponents of the social model, the "solution" to disability related problems lies in the removal of structural barriers to participation as opposed to medicalized individual interventions.

Similar in some ways to social model approaches, US rights based approaches, such as those that informed the *Americans with Disabilities Act* (1990), draw on identity politics to call for equal treatment (Meekosha 2004). Both approaches position those with disabilities as rights bearing individuals who are entitled to equal treatment and access to the same privileges as

citizens without disabilities (Shakespeare 2006: 10-28). Tenets comprising these modes of thought have been influential in more recent disability related policy developments and changes in the UK and North America. For example, legal and civil rights are among the foundational principles informing *Valuing People*, the UK policy governing services for adults with disabilities (Burton and Kagan 2006: 310). Also, direct payment schemes, available under *Valuing People*, through which individuals are given money to hire their own support workers or assistants, are consistent with disabled activists' calls to end the social dependencies of disabled citizens by not only ending institutionalization, but by facilitating disabled persons' control over their own services and supports (ibid: 307-308; Morris 1991; Shakespeare 139-140).

These trends seem to have influenced recent changes to provincially funded supports for adults diagnosed with developmental disabilities in Ontario as well. In 2009, Ontario finalized its commitment to deinstitutionalization by closing all remaining institutions for adults with developmental disabilities (Ontario MCSS 2012-2014a). Emphasizing inclusion and the supports required to achieve inclusion, in July 2011, the Ontario MCSS implemented the Services and Supports to Promote the *Social Inclusion* of Persons with Developmental Disabilities Act, (2008, emphasis added) as the new legal document directing the provision of services for adults with developmental disabilities (Ontario MCSS 2012-2014b). Evidencing influence of social model thinking, the policy includes a direct payment option and was created with the stated aim of "giv[ing] people with a developmental disability more independence and choice" (ibid).

Despite positively-framed movements away from institutionalization and towards the fulfillment of independence and rights in the community, Chapman, Carey and Ben-Moshe (2014: 17) argue that “closure of large institutions has not led to freedom for all disabled people- nor has it resulted in the radical acceptance of difference among us.” Similarly, in 2002, Radford and Park (2002: 16) remarked that amidst Ontario’s ongoing institutional closures “developmental disability is still too closely associated with poverty, affordable housing seems elusive, downloading and funding cutbacks threaten access to health care and social services and for some the specter of homelessness looms large”. Corroborating these troubling depictions of post-institutional conditions, after conducting investigations into the developmental services sector in Ontario, the Select Committee (2014a: 3) concluded that “individuals and families who need developmental services and supports are in crisis. We heard that after struggling to obtain services and enduring waitlists for years, many families feel pushed to the brink of disaster” and Ontario’s Ombudsman (Dubé 2016: 2) asserted that “those in crisis can find themselves inappropriately housed in a variety of institutional settings from hospitals to jails”. Further, according a recent Statistics Canada report on Developmental Disability (Bizier et al. 2015), most Canadians, aged 15-65 years, with developmental disabilities are not employed (71.8%) and report some level of unmet support needs for everyday activities (72.7%). Additionally, Bizier and colleagues found that the median personal income for developmentally disabled adults was 10,800 dollars, less than a third of the median personal income of those without disabilities.

It is not only adults with developmental disabilities who are said to be struggling in Ontario's post-institutional context, but their families as well; as the Select Committee's (2014a: 3) final report states, it is "individuals and *families*" (emphasis added) who are in crisis. More descriptively, the Select Committee's (2014b: n.p.) interim report includes the statement that,

[A]cross the province, families of people with developmental disabilities are in crisis. Many parents appearing before the Committee broke down in tears as they described their failed efforts to access services and supports, and the toll taken by exhaustion and constant anxiety about what will happen to their developmentally disabled child when they die or are otherwise unable to continue caring for them. The toll on families includes a high frequency of marriage breakdown and stress-related illnesses.... Parents described how their state of constant uncertainty about the future led to feelings of "terror," "panic," and a "paralysis of worry and fear." They emphasized that they love their children, and want to care for them at home, but in the absence of adequate funding and supports, feel overwhelmed.

The sense that the contemporary situation is often difficult for parents is validated in Ontario-based research as well, which often examines parents' experiences of stress or distress (e.g. Lunsky et al. 2015; Lunsky et al. 2017; McKenzie et al. 2017). For example, McKenzie and colleagues (2017) measured parents' reported levels of distress before and after their developmentally disabled adult children finished high school and found that parents expressed higher levels of distress once their child left school.

To understand this situation - involving continued segregation in hospitals or jails, lack of support, low income, experiences of crisis, unemployment and elevated levels of stress – contemporarily occurring alongside officially stated commitments to inclusion, deinstitutionalization and choice, it is necessary to consider contemporary disability policy and practice within the broader socio-political context, as explained below.

Community-Based Care in Context: Neoliberalism, Intensive Mothering and Family Provided Care

The shift to community-based care was not only called for by disability advocates and allied academics, politicians recognizing the cost-cutting effect of deinstitutionalization also pushed for the closure of institutions (Soldatic and Meekosha 2012: 205; Trent 1994: 261). This contradiction of end goals (social inclusion and social justice versus economy) but confluence of means (community-based care) in terms of the state provision of care was not limited to the developmental services sector; similar patterns are evident in mental and physical health sectors in Canada and other Westernized Nations (Braedley 2010: 142; Henderson 2005; Miller and Rose 2008: 202-203). Multiple authors have commented that, while the shift to community based care is often framed in positive terms through appeals to, for example, community building, social inclusion or de-medicalization of care, the policies and practices involved in contemporary community-based care are largely informed or co-opted by what have come to be termed neoliberal rationalities, “designed to get the state out of some kinds of health care provision and reallocate it to markets, households, and communities” (Braedley 2010: 143) (see also Braedley and Luxton 2010; Henderson 2005; Soldatic and Meekosha 2012: 204-205). Accordingly, to better understand the social and political project in which the current “crises” experienced by families that include adult children with disabilities takes place, the nature of neoliberalism is described below.

Neoliberalism as Foucauldian Governance.

The term neoliberalism generally refers to assumptions that state intervention into social issues leads to undesirable social and economic outcomes and to attendant valorizations of the free market, individual choice and individual responsibility (e.g. Braedley and Luxton 2010; Fudge and Cossman 2002; Luxton 2010: 164; Soldatic and Meekosha 2012: 196). As Bockman (2013: 14) explains, “neo- liberalism is grounded in the assumption that governments cannot create economic growth or provide social welfare; rather, by trying to help, governments make the world worse for everyone, including the poor”. Researchers investigating social welfare provisions in Ontario and Canada have argued that since at least the 1990s social policy in these jurisdictions has been guided by neoliberal values or rationalities (e.g. Fudge and Cossman 2002; Brodie 2008; 2010; Little 2011). That said, despite similarities in generalized definitions underscoring research on the pervasiveness or impact of neoliberalism, the concept of neoliberalism been applied to understand contemporary social service contexts in diverse and even incompatible ways (Bockman 2013; Brodie 2010; Larner 2000).

Wendy Larner (2000) argues that neoliberalism has been variously defined as a policy framework, an ideology, and as a form of neo-Foucauldian governance. Larner (ibid) argues that applications of neoliberalism as policy framework have tended to examine outcomes of neoliberal policies, but are over simplistic in their failure to account for how neoliberal regimes shape “programs and subjectivities” (8-9). Approaches to neoliberalism that have emphasized ideology, on the other hand, have largely provided “top down” accounts of the formation of subjectivities and have failed to fully theorize power as productive (ibid: 9-12). Larner believes

that conceptions of neoliberalism as governance are most useful as they provide theoretical space for the consideration of the complexities and contradictions inherent in neoliberal (and all) states (ibid: 12-14). It is this last conceptualization of neoliberalism which I apply in the following research and analysis.

Based on Foucault's (1978: 92-102) conception of power as relational, fluid, and productive, a governmentality perspective holds that the act of governing, "proceeds under, indeed finds its justification in, particular ways of seeing political problems..." (Brodie 2010: 1567). From this lens, specific forms of governance are made possible by the objects of power, including the types of citizens, produced under and immanent to specific political rationalities. According to Miller and Rose (2008: 58), "political rationalities have what one might term an *epistemological* character.... They are articulated in relation to some conception of the nature of objects to be governed – society, the nation, the population, the economy. In particular, they embody some account of the persons over whom government is to be exercised". It is as specific categories, things, and people become thinkable that it becomes possible to govern or act upon them in specific ways (ibid: 15-16; 29-32).

Neoliberalism as a prevailing political rationality has been described by Nikolas Rose (Miller and Rose 2008; Rose 1993, 1996). Miller and Rose (2008: 17) contend that early 20th Century forms of government could be characterized as proceeding "from the social point of view". According to Miller and Rose (ibid: 71-72), post-war welfare states included considerable state intervention in matters of social outcomes: "the State tried to ensure high levels of

employment, economic progress, social security, health and housing through the use of the tax system and investments, through state planning and intervention in the economy, and through the development of an extended and bureaucratically staffed apparatus for social administration". Miller and Rose (ibid) argue that this form of government was made possible by specific conceptions of the citizen, the state, and the economy dominantly circulating at the time. More precisely, post-war states were able to provide some measure of security against the uncertainties of the market (ibid: 206-207) because of related conceptualizations of subjects as social citizens with social rights, of the market as a sometimes volatile and unreliable provider of citizens' well-being, and of the state as the ultimate guarantor of welfare (ibid: 17-18; 203-204).

Beginning in the latter half of the 20th Century, this "social" approach to government came under attack from both the left and the right; conservative demands for reform held that "the increasing levels of taxation and public spending required to sustain social, health, and welfare services, education, and the like were damaging to the health of capitalism" (ibid: 210) while left-leaning critics argued that state controlled attempts to assist the disadvantaged might reproduce inequalities and disadvantage. These, and other critiques, served to delegitimize this "social" form of rule in the latter half of the 20th century. Gradually, the rationality which constituted and was made possible by the "social citizen" and the "state as guarantor" came to be supplanted by "a relatively coherent rationality of government that came to be termed neo-liberalism" (ibid: 211); this rationality involved a general shift in responsibility for well-being from the state to this individual.

This shift in responsibility was made possible by the understanding of the subject prevalent in “advanced liberal” societies. This political subject was no longer social in nature, but was rather autonomous, free and able to make their own choices in the pursuit of their own potential, happiness and well-being (Miller and Rose 2008). The subjects of rule were specified “as active individuals seeking to enterprise themselves to maximize their quality of life through acts of choice” (Miller and Rose 2008: 214). Accordingly, “political reason must now justify and organize itself by arguing over the arrangements that are adequate to the existence of persons as, in their new essence, creatures of freedom, liberty, and autonomy” (ibid). Thus, instead of a state-provided solution to social problems, “the images are now of the enabling state, the facilitating state, the state as animator” of individuals to action (Rose 2009: 63). The role of the state is to help citizens to help themselves, rather than to help citizens access equality in the here and now. For example, health promotion strategies, expert knowledge and input, and private insurance, “enhance[e] the obligations that individuals and families have for monitoring and managing their own health. Every citizen must now become an active partner in the drive for health, accepting their responsibility for securing their own well-being” (Rose 2009: 63). Released from the constraints of the welfare state, active citizens are considered “free” to “choose” and are thus considered accountable for their choices and circumstances.

The language of “free choice”, however, is insidiously misleading in terms of its capacity to elide the conditions in which individual action takes place. As Foucault (1977, 1978) contends, subjectivities, and therefore possibilities for action, are shaped by knowledge building practices

and techniques of power. As Larner (2001: 12) explains, “while neoliberalism may mean less government, it does not follow that there is less governance”. Rather, “contemporary political rationalities rely upon and utilize a range of technologies that shape the civilizing project by shaping and governing the capacities, competencies and wills of the subjects, yet are outside the formal control of ‘public powers’” (Miller and Rose 2008: 214). “Individual” choices and actions are therefore anything but, and are constrained and made possible by the social context in which they are embedded. As Jacques and Radtke argue with regard to choices women can make in terms of marriage, family, children, and career:

Our study suggests that in the case of career and motherhood, the discourse of individual choice may constrain young women by obscuring the tacit socio-political context... the participants positioned themselves as responsible, mature young adults, but also avoided any issues or concerns about gender inequality. In effect, gender equality and male privilege were glossed routinely, and the young women ‘chose’ intensive mothering over a host of alternatives, including not being a mother, being single, not being in a heterosexual relationship, and establishing gender equality in child-rearing. (Jacques and Radtke 2012: 457)

In addition, an emphasis on individual choice promotes individual responsibility and blame. Individuals are held accountable for and are conceived of as having the power to control their current and future well-being (Rose 1996: 12). As Wall (2004: 46) stresses, “the individual is positioned here as free, autonomous, and able to care for him or herself... Greater emphasis is thus placed in this discourse on the ability of individuals to adapt to change, to engage in self-enhancing behaviour, and to manage the risk they pose to themselves and thus reduce their potential burden on society”.

Considered free to choose and care for themselves, individuals are natural targets of intervention and blame for social issues. “It is a governing strategy that demands that people find personal causes and responses... to what are in effect shared social challenges... such as those relating to social reproduction and care” (Brodie 2010: 1590). In other words, social problems are cast as individual problems with individual solutions required. As Brodie argues, neoliberal emphasis on individual responsibility has consequences for those that provide care. In the next sections, the interconnection between neoliberal ideas about individual responsibility, the family, and motherhood will be described.

Neoliberalism and the Family.

The individualized, active neoliberal subject is not only responsible for their own well-being, but is also responsible for the well-being of their family members. Fudge and Cossman (2002: 21) use the term familialization to capture the notion that within neoliberal rationalities formerly or potentially public goods and services relating to care and/ or financial needs are construed as naturally supported and provided for in and by the family (see also Brodie 2010; Luxton 2010). As Luxton (2010: 163) states: “In countries such as Canada... the success of neoliberalism rests on widespread acceptance that individuals and their households must absorb more of the work necessary to ensure the livelihoods and well-being of their members” (Luxton 2010: 163).

Who is the Family of Neoliberal Discourse?

Fudge and Cossman (2002: 21) argue that “form may be less important than function in this strategy. The neoliberal state appears to be less concerned with who a family is (traditional or

non-traditional) than with what a family does (take care of its members)". Certainly, the term "the family" is used and understood differently within and across everyday and policy contexts (Luxton 2005: 31) and research reveals considerable diversity in family forms in Canada (Baker 2010: 4; Eichler 2005; Krull 2011) and elsewhere (Farell et al. 2012; Stacey 1996), suggesting the term "the family" may be misleading in its' insinuation of a consensual, singular meaning (Baker 2010; Beck-Gernshein 2012). Further, as Luxton (2010) shows in her research on neoliberalism and informal care arrangements in Toronto, Ontario, although a sense of obligation for caring might be felt most strongly within the confines of the nuclear family, obligations and informal caring arrangements exist between other kin relations, friends, and neighbours as well.

Nevertheless, multiple feminist and queer theory researchers have argued that the nuclear and/ or heteronormative family, consisting of a heterosexual couple and their biological children, pervade both policy and public imaginations in Westernized nations (Baker 2005, 2010; Eichler 2005; Folgerø 2008; Krull 2011; Luxton 2005: 34; Nelson 2006; Stacey 1996). As Krull and Sempruch (2011: 2) write, "the normative heterosexual family model continues to be the reference point in current mainstream thinking and policy making".

The influence of "the normative heterosexual family model" may be especially strong in relation to child rearing, where neoliberal familialization of care dovetails easily with notions of biological parents as ultimately responsible for their children. Illustrating the latter, Nelson (2006) interviewed white, single, rural mothers and found that, even as they engaged in diverse care and parenting arrangements for their children, the women involved in her study hoped for

and pursued “traditional” (nuclear) family forms, where a mother and father figure would be responsible for raising any children: “In short, the idea of the “traditional” family is a powerful one for these women, even though that family form has failed them (and sometimes disastrously so) in the past” (ibid:794). Similarly, based on interviews with gay and lesbian parents in Norway, Folgerø (2008: 146) concludes that “On the one hand, these families transgress traditional family patterns and challenge normative family values; on the other hand, they partly adopt and reproduce discourses about biological kinship, gender complementary, and family life centered around the co-resident couple”. The notion that parents are and should be responsible for the actions and well-being of their biological children is enshrined in law as well. In Canada, parents are held responsible for their children’s financial well-being, as evident in child poverty alleviation schemes such as child support (Robson 2010). In another exemplification of legal parental responsibility, in Ontario, parents can be held liable for any damages a child inflicts on property (Ontario 2000).

Although the family may be visible in public and political discourse, in neo-liberal contexts family members are often figured in gender-neutral terms, meaning in some cases “mothers” and “fathers” are invisible (Brodie 2008, 2010; Fudge and Cossman 2002; Larner 2001; Little 2011). This invisibility of gender is relatively new to Canadian policy: post-war social welfare and regulations tended to be premised upon, and explicitly encouraging of, a middle-class family consisting of a stay at home mother and a father earning a family wage (Brodie 2010; Little 2011). In contrast, gender does not explicitly bear on the contemporary citizen:

The new "consumer-citizen" is de-gendered. The concept of the male breadwinner has also been eroded, manifest in a more gender-neutral model of the citizen worker. Government agencies and documents now recognize diverse family forms, rather than insisting on a culturally specific nuclear model of the nuclear family, and more often use the gender-neutral term "parents," rather than the gender specific terms "mothers" and "fathers". (Larner 2000: 19)

The erasure of gender from public discourse has been hesitantly interpreted as positive in its consistency with 2nd wave feminist claims for women's rights to autonomous personhood (ibid: 20) but has also been interpreted as failing to recognize gendered expectations which continue to govern women's conduct (Brodie 2008, 2010; Fudge and Cossman 2002).

Care is far from gender neutral, and the privatization or familialization of care does not have gender neutral consequences. In spite of a pervasive gender equality discourse, women's participation in and responsibility for unpaid caring and other domestic work continues to outstrip men's. According to Statistics Canada, Canadian women perform more care work than their male counterparts (Milan, Keown and Urquijo 2011). Although more women participate in the paid workforce currently than historically, gendered labour practices are often exacerbated when couples have children: once they become parents, men tend to work longer hours in paid employment and women tend to perform the majority of childcare and domestic tasks (Baker 2005; 2010: 120-126; Lee 2014; Ranson 2005; Fox 2009). Further, multiple authors have argued that as processes of neoliberalization unfold and private responsibility is enhanced, women tend to take on additional caring duties (Braedley and Luxton 2010: 15; Brodie 2010; Fudge and Cossman 2001).

However, the silencing of gender and the valorization of individual choice may mean that systemic gender-based differences in caring experiences can be understood as individual problems that are the outcomes of men and women's preferences, choices, backgrounds and experiences (Jacques and Radtke 2011). Nonetheless, decisions about care work are not made external to the constraints and pressures of gendered ideals and ideologies. With regard to the care of children, it is widely argued that parenting expectations are guided by an ideology of intensive mothering (Hays 1996), which has been further shown to interact with the tenets of neoliberalism to enhance the obligations experienced by mothers.

Good mothers, Bad mothers and the Ideology of Intensive Mothering.

Approximately two decades ago, Sharon Hays (1996) investigated the consequences of post-War child development and parenting advice on principles, beliefs and expectations guiding contemporary mothering practices and evaluations; as a result of these investigations, Hays classically articulated the term "intensive mothering" to name her observations that North American definitions of "good" mothers dictate that mothers should, and should naturally want to, spend considerable time, money, and mental and emotional energy raising their children. Maternal practices, according to Hays (ibid), are ideally expert driven and child centered. "Bad" mothers, from this perspective, put their needs or wants before those of their child's, and are ultimately responsible for any deficits in their children's outcomes or behaviours. Alignments with a discourse of neoliberalism are obvious: echoing central tenets of neoliberal rationalities, an ideology of intensive mothering emphasizes individualized (maternal) responsibility, risk and control (Wall 2004).

Since the publication of Hays' (1996) classic work on mothering ideals, a host of researchers have built on her observations, arguing that mothering practices and expectations continue to be shaped by ideals of "intensive" (Fox 2009; Romagnoli and Wall 2012; Wall 2005, 2010, 2013), or similar concepts of "total" motherhood (Wolf 2007) or "parental determinism" (Furedi 2014), often in ways that draw upon and coalesce with neoliberalism. For example, Wolf (2007) argues that despite dubious scientific evidence backing claims about the importance of breastfeeding, babies are popularly depicted as "needing" to breastfeed to achieve optimal development. Consequently, mothers who face barriers to breastfeeding (such as participation in paid work) or who choose not to breastfeed are depicted as selfish, problematic or lacking knowledge. In another example, Wall (2010: 255) argues that children's "needs" have proliferated since the 1990's in reference to neuroscientific brain discourse: "The view of childhood embedded in brain development discourse is certainly one of children as highly malleable, as parental projects full of potential, but potential that can only be activated with appropriate and intensive parental inputs". Accordingly, Wall (ibid) found that, informed by neuroscientific brain discourse and neoliberal understandings of responsibility, middle-class Ontario mothers practiced intensive mothering with aims of optimizing their children's intelligence to the extent that mothers reported resultant feelings of exhaustion and stress.

Not only do visions of good motherhood have gendered underpinnings and consequences; race and class are additionally implicated in intensive mothering ideology. The material resources required to enact good motherhood and the white, middle class norms on which good

motherhood is based mean that young, poor and/or racialized mothers are often assumed to be “bad” mothers and/ or the risky subjects of neoliberal discourse, who are likely to require state intervention or surveillance to ensure their child rearing practices do not bring harm to their children (Laureau 2003; Romagnoli and Wall 2012; Hays 2003; Verduzco-Baker 2017; Wolf 2007). Although mothers differing from white, middle class norms by race, age, and/ or class may adhere to the ideology of intensive mothering (Elliott, Powell, and Brenton 2015; Fox 2009; Romagnoli and Wall 2012), the level of resources required to practice intensive mothering may preclude or make it additionally challenging for these mothers to participate in “good” mothering in easily recognizable ways, especially given systemic barriers to “good” outcomes (Fox 2009; Elliot et al. 2015; Verduzco-Baker 2017). Romagnoli and Wall (2012) argue that although young, low income mothers may not internalize intensive mothering ideology, they often felt pressures to enact intensive motherhood to prove they were “good” mothers, capable and able to keep their children. “While for middle-class mothers it defines ‘good’ motherhood, for these mothers it defined their absolute motherhood; whether or not they could even maintain child custody and continue to mother their children” (ibid: 285). Thus, an ideology of intensive motherhood has differential impacts depending on social location.

As Dillaway (2006: 42; 2010) asserts, most research on intensive mothering investigates the experiences of mothers of young children or adolescents. Mandell and Wilson (2011:35), however, argue in their analysis of the literature on mid-life care work that mothers’ relationships and interactions with their children continue to be shaped by an ideology of intensive mothering into children’s adult years. Dillaway (2006), for example, discusses how

menopausal mothers' interactions with their variously aged children were guided by ideals of good motherhood: reinforcing the image of the good mother who puts their children's needs before their own, some mothers did not discuss their symptoms of menopause with their children, adult or otherwise. "Once women are mothers, they are always mothers, and they are always impacted by mothering ideology" (ibid: 51). Further, Mandell and Wilson (2011: 35-37) chronicle how parents continue to assist their adult children, whether parents and children live together: "[h]elp peaks in the child's late twenties and early thirties and falls off after age thirty-five. The proportion of giving and receiving help between parents is not equal until parents are in their seventies and adult children are in their mid-forties" (ibid: 35).

Despite acknowledgement that mothering expectations and practices continue into children's adulthood, the above cited research assumes a relatively normative trajectory for adult children. Although the adult children described in the above research may temporarily boomerang to live back in the family home or may require continued support and assistance, overall, they gain increasing levels of independence. Pressures on parents of adults diagnosed with developmental disabilities, who often experience ongoing dependencies and may be considered perpetually childlike, differ from pressures on parents of adults without disabilities (Todd and Shearn 1996). In some cases, parental responsibility might increase with disabled children's attainment of chronological adulthood because completion of high school often means the end of daily support and scheduled activity. To this end, the impact of mothering ideologies on mothers of adult children diagnosed with developmental disabilities is likely not reflected in the above literature.

Adults with Developmental Disabilities, Family, Parents and Mothers

It appears that limited work on parents, family and adults with developmental disabilities specifically investigates the impact of mothering ideology on policy, practice or experience. As documented with regard to research about mothers and young children with disabilities (Ryan and Runswick Cole 2008), the literature on adults with developmental disabilities and their families, parents or mothers is dominated by studies conducted from more medically or psychologically informed perspectives. To illustrate, recent research considers parents' levels of burden (Lunsky et al. 2017; Robinson et al. 2016), quality of life (Yoong and Koritsas 2012), stress (Hill and Rose 2009) and distress (McKenzie et al. 2017) in relation to individual child or parent characteristics, other responsibilities or available support.

Providing empirical support for the sense that many parents are central in the care and lives of disabled adults and that many parents of adult children diagnosed with intellectual or developmental disabilities experience difficulties in the contemporary service environment, this research expands upon and describes the nature and causes of parent experiences and lends itself to practical interventions and solutions designed to improve families' situations. For example, Robinson and colleagues (2016: 363) suggest that their findings that perceived helpfulness of informal supports is negatively related to parental burden mean that clinicians should focus on bolstering parents' support networks. In another example, Yoong and Koritas (2012: 616) suggest that parents' quality of life would improve with increased access to flexible services, especially residential services. Lunsky and colleagues (2017) write that, based on their findings that compound caregiving is related to increased burden and distress, parents'

additional caregiving roles and responsibilities should be considered and appropriately responded to in assessments of service needs.

From the Foucauldian informed perspective on power briefly outlined above¹, however, these dominant approaches are not suited to interrogating the conditions which make possible or justify available (or unavailable) services, facilitate extensive reliance on parents and inform the meanings and evaluations parents/mothers give to their experiences in the first place. In fact, as it operationalizes the othered status of the disabled family member (Ryan and Runswick-Cole 2008: 200) or aspects of parents' individual situations, psychologically-oriented research can be viewed as premised on and reproductive of conceptions of disability as real human difference and of family as central and integral to the outcomes of disabled adults. Viewed through a post-structuralist lens, it is the content, operation and production of these very categories that should serve as the objects of study; a focus on meanings turns the lens away from assumed categories of difference or naturalized care towards the ways in which the meanings ascribed to these categories impact the provision and evaluation of care.

To this end, a smaller body of UK based research has examined how parents negotiate and are impacted by dominating discourses surrounding developmentally disabled adults (Almack, Clegg and Murphy, 2009; Clegg et al. 2008; Gleeson and Kearns 2001; Murphy, Clegg and Almack 2011; Pilnick et al. 2011). Moving the focus away from parents, adults with disabilities

¹ See Chapter Three for a more detailed description of the post-structuralist theorizations of power I apply in the current research.

or even specific services, this research shows ways in which frequently under-nuanced meanings popularly ascribed to disability create a morally fraught terrain, which parents must negotiate. This research shows how, as they think about and interact with their disabled adult children, parents' ideas and actions are shaped, constrained and evaluated in light of available (and, in many ways, unhelpful) discursive elements pertaining to developmental disability. For example, Almack and colleagues (2009) discuss how emphasis on choice for disabled adults means that parents are often labelled as under or overprotective as they negotiate moral imperatives to privilege choice and protect their vulnerable adult children. In another example, Clegg and colleagues (2008) examine inclusion focused policy and rhetoric, showing how parents often undertake considerable work to facilitate their adult children's inclusion into society. They also point to how competing demands --that parents provide care and foster independence in their children-- mean that parents often feel negatively judged regardless of their actions. Highlighting problematic characteristics and products of disability discourse, this research targets broad reaching but specific and identifiable social forces and conditions which constrain mothers' actions and drive the availability and type of services available as sites for change.

It appears that an even smaller body of work theorizes or expressly examines interactions between conceptualizations of adults diagnosed with developmental disability and motherhood. In a rare example of research which does begin to theorize the two, Pilnick et al. (2011) argue that, in interaction with a discourse of self-determination for adults diagnosed with developmental disabilities, the widespread moral imperative for parents to put their

children's needs before their own meant that one parent in their study described themselves as selfish when making plans based on their own wishes. The relevance of and interconnection between these two categories warrants them as objects worthy of further interrogation in their complexity and interaction. Some research on young children with disabilities and mothers further substantiates this argument: Landsman (2009: 2-47) shows how popularized narratives dictating that mothers can control the outcomes of their pregnancies leads mothers to experience a sense of blame or injustice when they give birth to disabled children. She also shows how mothers, "condemned for their selfishness or admired for their sacrifice" are narratively cast as "bad" or "special" (in short, different) mothers alongside their disabled (non-normative) children (ibid: 89).

Based on the literature reviewed in this chapter, I make four related assertions that inform this project on disability, family, mothers and motherhood. First, family, parents and, especially mothers are integral to community care regimes. Second, concepts of disability, parents and mothers are interrelated and inform one another. Third, the meaning ascribed to these categories justifies, naturalizes and legitimizes the nature and extent of state-provided services, support or intervention. Fourth, these meanings are negotiated by and impact the subjective experiences of those who parent/mother adults diagnosed with developmental disabilities.

Drawing on these post-structuralist and empirically informed insights, my aim here is to describe disability discourse in Ontario between 2008-2014. I ask the following more specific questions: Who is the disabled adult subject of disability discourse, particularly as deployed in

policy? (How) are motherhood and family embroiled in disability discourse? As they negotiate disability discourse, how do mothers (re)produce and resist dominant visions of disability, motherhood, and family? To answer these questions, I conduct a discourse analysis on various materials taken from the time frame in question. This methodological approach and specific methods related decisions are outlined in the following chapter.

Chapter 3

Methodology

As outlined in the previous chapter, the current research focuses on adults with developmental disabilities, mothers and family from a meanings-oriented perspective, thereby breaking with psychological approaches that tend to define the academic field of family and disability.

Accordingly, the theoretical and methodological underpinnings of the current project differ from much of the field as well. Psychological and individualizing approaches to research on disability and the family have been commonly conducted from what can be characterized as a post-positivist perspective (Lincoln, Lynham and Guba 2011). Such research involves the pursuit of knowledge concerning objective reality: of disability, psychological constructs, family composition and so on as explanations for family and disability related outcomes and experiences (e.g. Hill and Rose 2009; Robinson et al. 2016; Yoong and Koritsas 2012). Whether employing surveys and quantitative analysis (e.g. Robinson et al. 2016) or thematically analyzed qualitative interviews (e.g. Yoong and Koritsas 2012), the methodological tools applied in this post-positivist research are useful when researchers investigate individual and family variables as explanations for family and disability related outcomes.

The purpose of the current research however, is to trouble, unpack and explore the effects of the very categories on which post-positivist research is designed. Instead of taking categories and accounts at face value (Holloway and Jefferson 2000: 2-3, 7-12, 56-57; Ringrose 2013: 36, 75-76), the current research seeks to understand how these categories are produced and the messy and complex ways in which mothers are impacted by and negotiate these categories. To

this end, the methodological approach taken in the current study is more closely aligned with methodologies found in more interpretive research in the area. Pilnick et al. (2011), for example, conduct conversation analysis on transcriptions of transition meetings where post-high school plans are made with and for young adults with learning disabilities² in the UK. Using this method, these authors examine how parents and transition workers negotiate a discourse stressing self-determination for adults with disabilities when parents are ultimately responsible for implementing many of the choices their adult children make. In another example, Murphy and colleagues (2011) conduct thematic analysis, specifically examining how parents, paid workers and young people with disabilities construct adulthood as they plan for transitions from high school to post-high school services, schools, work and/ or activities. Unlike less interpretive implementations of thematic analysis, which would focus on uncovering truths about disability, family or the service sector, Murphy and colleagues' (2011) results shed light on the way the meanings ascribed to disability can constrain and enable planning and action; results illustrate how dominant constructions of adulthood can create moral polarities for parents to negotiate, leading the authors to advocate for a nuanced understandings of adulthood and self-determination.

Similarly focused on meanings attributed to disability, the current research is embedded in this in depth, qualitative, interpretive tradition. However, the approach taken here draws the lens of interpretation and analysis wider, to enable analysis of disability discourse more generally,

² Murphy et al. (2011: 64) note that "'Learning disability' is the term most commonly used in the UK for intellectual disability".

including interactions between disability, family and motherhood and the broader discursive field in which decisions and ideas about disability and family are situated. To facilitate this broad reaching, in depth analysis, I adhere to a post-structuralist ontology and epistemology, and conduct a discourse analysis on various materials relating to adults with disabilities and their families in Ontario. Throughout, feminist concerns influence my approach to discourse and more specific methodological decisions. Before explaining methodological procedures, the next section involves description of the theorizations on discourse relevant to the current study.

Post-structuralism, Power, Discourse and Foucault

The current research proceeds from a view of discourse consistent with a Foucauldian post-structuralist ontology and epistemology. Foucault's theorizations on power involve central contentions that, rather than circulating as a top-down repressive force which constrains action, power is relational and productive. Power is not possessed by the powerful and withheld from the oppressed; instead, "power is everywhere; not because it embraces everything, but because it comes from everywhere" (1978: 93). As Shelley Tremain (2005: 4) explains: "power is not something that is exchanged, given, or taken back, but rather is exercised and exists only in action". In addition to this relational, fluid view of power, a Foucauldian perspective holds that power does not simply constrain actions. Contrarily, power relations are productive, making subjects knowable and visible and therefore certain actions and interventions possible or desirable. "We must cease once and for all to describe the effects of power in negative terms: it "excludes", it "represses", it "censors", it "abstracts", it "masks",

it “conceals”. In fact, power produces; it produces reality; it produces domains of objects and rituals of truth. The individual and the knowledge that may be gained of him belong to this production” (Foucault 1977: 194).

Concepts of power/ knowledge, biopower, and governmentality are integral to an understanding of how Foucauldian power operates and how it relates to the current study. Foucault named this modern power biopower, highlighting the notion that power takes life itself as its object and mediates through the body (Foucault 1978: 137). Totalizing and individualizing, this power is “tied to the disciplines of the body... [and] the regulation of populations” (ibid: 145) and “[gives] rise to infinitesimal surveillances, permanent controls, extremely meticulous orderings of space, indeterminate medical or psychological examinations.... comprehensive measures, statistical assessments, and interventions”. What the varied, at times mundane, techniques or technologies of power listed here have in common is reciprocal connection to the human subject: practices such as examinations and statistical assessments contribute to the production of particular subjects – both human beings generally and more specific classifications and identities - the recognition of which makes possible, legitimizes and naturalizes particular responses and interventions. Once techniques of power make it possible for bodies to be defined and recognized as, for example, sexualized, insane, sick, or disabled, associated interventions and actions are made possible, desirable and natural. As suggested by the term power/ knowledge, power and knowledge are thus inextricably and reciprocally linked.

In keeping with a relational conception of power, constraints on or possibilities for action are not only imposed or acted upon by experts or from the state. As Foucault elucidates below, the operation of power is such that the subject becomes “tied to [their] own identity”, a feature of power which has considerable implications for “individual” conduct:

This form of power applies itself to immediate everyday life which categorizes the individual, marks him by his own individuality, attaches him to his own identity, imposes a law of truth on him which he must recognize and which others have to recognize in him. It is a form of power which makes individuals subjects. There are two meanings of the word "subject": subject to someone else by control and dependence; and tied to his own identity by a conscience or self-knowledge. Both meanings suggest a form of power which subjugates and makes subject to. (Foucault 1982: 212)

For the Foucauldian subject, “individual” actions, desires and choices are shaped, enabled and constrained by possibilities tied to available identities or subjectivities. Elaborating on this argument that power makes possible “individual” choices and action, Foucault (ibid: 220) states that the exercise of power

is a total structure of actions brought to bear upon possible actions: It incites, it induces, it seduces, it makes easier or more difficult; in the extreme it constrains or forbids absolutely; it is nevertheless always a way of acting upon an acting subject or acting subjects by virtue of their acting or being capable of action. A set of action upon other actions.

The term governance refers to the point Foucault expresses here, that the operation of power does not necessarily involve coercion or force, but rather the shaping of possibilities for conduct.

Perhaps the equivocal nature of the term conduct is one of the best aids for coming to terms with the specificity of power relations. For to “conduct” is at the same time to “lead” others (according to mechanisms of coercion which are, to varying degrees, strict) and a way of behaving within a more or less open field of possibilities. The exercise of power consists in guiding the possibility of conduct and putting in order the possible outcome. Basically power is less a confrontation between two adversaries or the linking of one to the other than a question of government. (ibid: 220-221)

As relations of power guide possibilities for “individual” actions, it is important to keep in mind that what may be experienced as empowering may in fact be servicing formulations of power which position those with, for example, disabilities, as deviant from a norm.

Discourse and Language.

Discourse and language are connected to all aspects of this Foucauldian conceptualization of power. From a post-structuralist perspective, language is not a neutral medium that can accurately reflect or capture reality; rather, language constitutes reality. As insinuated above in the description of Foucauldian power relations, however, language does not operate independently of other practices or techniques of power and discourse comprises more than just language. Discourse, for Foucault (1972: 47), can be defined as “practices which systematically form the objects of which they speak”. Discourse is not, “simply the surface projection of power mechanisms. Indeed, it is in discourse that power and knowledge are joined together” (Foucault 1978: 100). Put differently, linguistic and non-linguistic practices produce effects of truth, and power relations and discourse cannot be considered separately. As Miller and Rose (2008: 30) assert: “We argue for a view of discourse as a technology of thought, requiring attention to the particular technical devices of writing, listing, numbering, calculating, and computing that render a realm into discourse”. Discourse makes possible and is made possible by other techniques bound up in relations of power/knowledge such as dividing practices, examination practices, confession practices, ordering practices and so on (Foucault 1977; 1978); these types of practices are a part of discourse, producing the objects to

which they refer. At the same time, these types of practices present as possible, logical and even necessary or desirable because of discourse.

Critiques, Applications and Relevance to the Current Research.

These Foucauldian views of language, power, discourse and the subject are relevant to the current research for reasons relating to a commitment to disability studies and feminism. First, a Foucauldian perspective on the subject applies to the current project to the extent that this work begins with the assumption that the disabled subject is not a pre-discursive natural entity available to be known precisely. In other words, persons diagnosed with disabilities are not objects to be studied. Rather, “social problems like mental retardation are in fact social constructions... built from a variety of materials” (Trent 1994: 6). Seen through this lens, instead of discovering true information about disability, scientific and institutional practices have contributed to the creation of the category of disability. It is this denaturalized view of disability I take with me throughout this project.

Second, post-structuralist versions of power and discourse are useful in terms of the feminist concerns underscoring this research. Discourse and post-structuralism draw attention away from individuals as logical sites of intervention, change and explanation towards analysis of complex social forces and relations as shaping experience. Discursively produced and constrained, human subjects are not the authors of their own experiences. Instead, experience and subjectivity are shaped by discourse, and interconnected, local and broad reaching techniques of power and political rationalities. Accordingly, a discursive approach serves as an

antidote to neoliberal emphases on choice, which coalesce easily with ideals of motherhood to readily position mothers as blame-able and responsible for children's outcomes and related research based on disability or family related deficits. Discursive emphasis also discourages simplistic, dichotomous understandings of mothers as either "good" or "bad" as they provide care, but rather as embedded in complex fields of meaning which influence available possibilities for interpretation and action.

To this end, I view the nature of the post-structuralist subject as a strength in the current research, and as compatible with the feminist and disability studies commitments and concerns underlying this research. That said, post-structuralism has been critiqued by both feminist and disability studies scholars. In terms of the latter, Barnes (2012: 22) favours a Marxist approach to the study of disability, arguing that post-modern approaches generally offer a "politically benign focus on culture, language and discourse" at the expense of more pressing matters such as the economy. I, however, am apt to agree with Marian Corker, who writes that a focus on language allows researchers to access complexity in experience and the forces that contribute to experience (1999: 633-634; Corker in Thomas and Corker 2002: 29). Discourse allows a researcher to consider ways in which disability, motherhood and family are tied together, and are in turn linked with techniques of power and wider political rationalities in which they are situated; discourse makes it possible to show complex interrelationships between various realms of knowledge, institutions, settings and understandings of humanity (Corker in Thomas and Corker 2002).

In terms of feminist evaluations of post-structuralist theory, Foucault has been critiqued for conceptualizing subjects who have a limited capacity for agency and resistance. Claudia Malacrida (2003: 47-48) outlines how, for example, Nancy Harstock (1990: 167) argues that Foucault's theorizations on power represent a world, "in which subjects become obliterated or, rather, recreated as passive objects, a world in which passivity or refusal represent the only choices". These concerns about a lack of agency are relevant to the current study because of my feminist-informed interest in exploring women's (mothers') experiences with discourse.

In response to this type of critique, often launched at post-structuralist work, Judith Butler (1999: 182) argues that: "this kind of reasoning falsely presumes (a) agency can only be established through recourse to a prediscursive I, even if that I is found in the midst of a discursive convergence, and (b) that to be constituted by discourse is to be determined by discourse, where determination forecloses the possibility of agency". For Butler, there is no pre-discursive, naturally existing, stable, authentic self on which discursive constraints are imposed. This ontological position, however, actually implies a form of agency. In fact, it is only because we are embedded in a particular discursive field that we are able to imagine a self that exists outside of discourse. "There is no self that is prior to the convergence or who maintains 'integrity' prior to its entrance into this conflicted cultural field. There is only a taking up of the tools where they lie, where the very 'taking up' is enabled by the tool lying there" (ibid: 185). Discourse includes the "tools" that make objects recognizable and actions possible; as such, discourse constrains and governs action, but also includes possibility for action that defies, contradicts, varies, reconfigures and redeploys discourses.

Foucault makes a similar argument with regard to discourse: “Discourse transmits and produces power; it reinforces it, but it also undermines and exposes it, renders it fragile and makes it possible to thwart it” (Foucault 1978: 101). While Foucault claims that power relationships depend on points of resistance, occasionally, “there [are] great radical ruptures, massive binary divisions... But more often one is dealing with mobile and transitory points of resistance, producing cleavages in a society that shift about, fracturing unities and effecting regroupings” (ibid: 96). For example, Foucault (ibid: 101) identifies how nineteenth century practices relating to sexuality resulted in the naming of homosexuality. When homosexuality was recognized in social discourse, it made possible both “a strong advance of social controls into this area of perversity” (ibid: 101) and gave rise to demands that homosexuality be recognized as a legitimate sexuality and positively valued. “There is not, on the one side, a discourse of power, and opposite it, another discourse that runs counter to. Discourses are tactical elements or blocks operating in the fields of force relations” (ibid: 101-102). Thus, within the discourse of sexuality, the creation of the category homosexual made way for social control and sanction at the same time as it made possible a form of resistance to the devaluation of homosexuality as a category. This example illustrates that although resistance may leave the overall discourse (of sexuality in this instance) or strategy of power intact, changes can be made within and because of a specific discourse in the valuation of or responses to particular behaviours or qualities.

Thus, the feminist-post structuralist perspective I take in the current research acknowledges that human subjects participate in power relations in ways that reinforce dominant discourse

but also in ways that include possibilities for (re)interpretation and resistance within discursive formations. Although discourse produces possibilities for truth, these possibilities can be imagined and deployed in various ways and to various ends. The discourse analysis I employ enables analytical attention to broad, institutional practice, as well as more micro-level management of discourse (Malacrida 2003).

Providing empirical evidence for these theoretical understandings of discourse, agency, and resistance, some post-structuralist feminists have researched and emphasized women's or girls' experiences and agency within the discursive field in which they are situated (e.g. Malacrida 2003; Raby and Pomerantz 2015; Wall 2010). These authors have shown how discursive pressures influence available options and subject positions, but how mothers (Malacrida 2003; Wall 2010) or high school students (Raby and Pomerantz 2015) actively negotiate, reinforce and/ or resist dominant discursive elements. For example, in reference to brain development discourse, Wall (2010: 262) states:

[T]he main potential for resistance to the imperatives of brain development discourse... seemed to come from women pushed too far by the demands of work and intensive parenting and supported too little. In questioning, however tentatively, the lack of social legitimacy of their own needs and desires, these mothers were beginning to challenge the discursive opposition of children's needs to mothers' needs that underlies cultural understandings of intensive parenting.

Although their approaches to mothering were heavily influenced by brain development discourse and an associated ideology of intensive mothering, the mothers in Wall's (2010) study nonetheless at times were able to critique this dominant framework, thus articulating a form of resistance.

In sum, the current study takes a discursive approach to researching the adult subject with a developmental disability and their mothers' experiences with disability discourse to enable examination of the complexity of families' experiences, to draw the focus to the cultural context in which families are situated and to de-naturalize and explore the production, content and effects of dominant (and other) understandings of family, adults diagnosed with developmental disability and motherhood. This post-structuralist, discursive approach informed all steps of the research process, which I outline below.

Materials

Texts that illuminate developmental disability discourse as it pertains to adults diagnosed with developmental disabilities, families and mothers and as it effects and is negotiated by mothers in Ontario were selected for analysis. Recently, the developmental services sector and the living conditions and experiences of adults considered to have developmental disabilities in Ontario have been the subject of considerable "buzz" (see Chapters 1 and 6 for summaries of recent discursive proliferation in this area). Accordingly, a wide range of texts were considered for possible inclusion in this analysis. To commit to the in-depth analysis typical of discursive approaches, I realized early on I would have to select a sample of texts from the wide array of available materials related to adults with developmental disabilities in Ontario. In the end, my interest in exploring the effects of discourse as deployed in policy and by mothers means that I have primarily selected documents related to: 1) provincial policy and procedures governing the provision of funding and services for adults diagnosed with developmental disabilities and

2) family members' (mostly mothers') experiences caring and making plans for and with adult family members diagnosed with a developmental disability.

The decision to include both official State documents as well as conversations with and statements from family members (primarily mothers) was driven by a recognition that, although power relations may be particularly dense sites of power relations, power relations are not exercised solely by the state, nor can they be said to originate from the state:

This does not deny the importance of institutions on the establishment of power relations. Instead, I wish to suggest that one must analyze institutions from the standpoint of power relations, rather than vice versa, and that the fundamental point of anchorage of the relationships, even if they are embodied and crystallize in an institution, is to be found outside the institution. (Foucault 1982: 791).

To analyze developmental disability policy from a Foucauldian perspective then, it makes sense to include governmental and non-governmental texts, thereby allowing for determinations of how discourse is deployed in policy and on more micro-levels (i.e. as mothers make sense of and navigate understandings of disability and their particular situations) and how one might play on to the other.

In addition to providing adequate material to develop a snapshot of developmental disability discourse in Ontario (Taylor 2013: 13), official policy related and family member created texts selected in the current study illuminate ways that various discursive elements are deployed in the provincially funded developmental services sector and how the discursive context produces and constrains the experiences and evaluations of family members from families that include

an adult family member diagnosed with an intellectual disability. Specific texts selected for analysis are described below.

The Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008 and Related Documents.

To address research interest relating to discourse generally and discourse as deployed in policy specifically, I analyze policy documents relating to the provision of developmental services to adults diagnosed with a developmental disability in Ontario. Since 2011, the *Social Inclusion Act* (2008) has legally regulated services and associated funding for adults in Ontario. Providing the framework within which publicly funded supports are allocated and delivered, analysis of this policy document and related provincial publications allows me to make claims about the discursive conditions that make particular policies possible and to examine the effects of discourse and techniques or technologies deployed through government regulations and procedures.

To enable a comprehensive examination of the *Social Inclusion Act* (2008) I also analyze *About the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008*, (Ontario Government 2009) (henceforth referred to as *About the Social Inclusion Act*) a plain language guide to the *Social Inclusion Act* (2008) available for download on the MCSS (2012-2014c) website. Additionally, three Ontario regulations exist under the Social Inclusion Act (2008) and are included in the current analysis: *General Regulation* (2008) which provides further definitional clarification of terms used in the *Social Inclusion Act* (2008),

Quality Assurance Measures (2008) for agencies funded under the *Social Inclusion Act* (2008), and *Transition: Deemed Eligibility for Adult Developmental Supports and Services Under the Act* (2008). The plain language guide to quality assurance measures, *A Guide to the Regulation on Quality Assurance Measures* (Ontario Government N.d.³), and *Policy Directives for Service Agencies* (Ontario MCSS N.d.) are also included in analysis.

Application Entities.

The creation of nine Ontario regional application entities, now known as Developmental Services Ontario (DSO's) represents one of the key changes brought forth under the *Social Inclusion Act* (2008) (*Policy Directives for Application Entities*, Ontario MCSS N.d.: ii). Under *Social Inclusion Act*, anyone seeking provincially funded adult developmental services in Ontario must apply through their regional DSO instead of to a specific service or support agency, as was previously the case. DSO's are also intended to determine eligibility for services, assess required levels of support and provide a customer service role, delivering information about services to families and responding to questions and concerns. Justification for the implementation of these application entities includes increased fairness and consistency in application and eligibility procedures (*About the Social Inclusion Act*, Ontario Government 2011: 13). The *Policy*

³ Many of these Government of Ontario documents do not include publication dates. Following the conventions of ASA style, the in-text citations for these documents indicate this lack of publication information with "N.d.". Despite this lack of publication information, however, I want to note that I am confident that these documents are part of and reflective of developmental disability discourse in Ontario during the timeframe under investigation in the current research (2008-2014) for two reasons. First, these documents were all created in reference to and are used in conjunction with the *Social Inclusion Act*, which was published in 2008 and came into effect in 2011. Second, many of these documents include the dates the specific policies or procedures they describe came into effect. All of these dates fall within the timeframe in question. For these reasons, it is clear that these documents were in circulation and used within the years of interest for the current research.

Directives for Application Entities (Ontario MCSS N.d.) document, one of the documents I consider in the course of the current research, presents the official regulations DSO's must follow as they perform these functions.

Relatedly, I also analyze the *Supports Intensity Scale* (SIS) (American Association on Intellectual and Developmental Disabilities (AAIDD) 2004a) as presented in the *Supports Intensity Scale User's Manual Sample* (ibid 2004b) and the *Application for Developmental Services and Supports* (ADSS) (Ontario MCSS 2011), documents used to interview adults with developmental disabilities and/ or their caregivers during the DSO assessment and application process under the SSPSPDDA (2008). More specifically, the SIS (AAIDD 2004a) is used to determine the level of support each applicant requires. The ADSS (Ontario MCSS 2011) is designed with the aim of gathering information about individual applicants to help determine service need and fit.

Passport Program.

Under the *Social Inclusion Act* (2008), adults or their caregivers can apply to receive supports from a community agency funded by the provincial government and/ or they can apply to receive funding themselves to purchase and manage supports or services of their choosing (About the *Social Inclusion Act*, Ontario Government 2009: 12). This latter, direct funding model of service delivery is delivered through the Passport Program. The *Passport Program Guidelines for Adults with a Developmental Disability and Their Caregivers* (Ontario Government N.d.) document, which provides information about the aims of the Passport Program, admissible expenses and the responsibilities and requirement of adults or their caregivers who

receive funding in this manner, is included in the current analysis. I also analyze the document, *Hiring a Support Worker* (Ontario Government 2013), published to provide advice and guidance to persons with disabilities who wish to hire and manage their own support workers.

**Materials from the Legislative Assembly of Ontario Select Committee on
Developmental Services.**

In October 2013, the Legislative Assembly of Ontario appointed a Select Committee on Developmental Services (Select Committee), comprised of a small group of MPPs, to “report to the House its observations and recommendations with respect to the urgent need for a comprehensive developmental services strategy to address the needs of children, youth and adults in Ontario with an intellectual disability” (Select Committee 2014a: 2).

From October 2013 through March 2014, the Select Committee heard from over 140 presenters including people with disabilities and their family members, service providers and ministry staff (Select Committee 2014a: 3). Presenters spoke about their experiences with the developmental services system and their recommendations for sector transformation. The proceedings were transcribed verbatim and made publicly available on the Legislative Assembly of Ontario Website (N.d.). I include these transcripts for analysis in the current research. Because the presentations included in the transcripts were made by a range of presenters, including mothers, with the explicit aim of making claims about the needs of adults with disabilities and how these needs should be met, these Select Committee proceedings provide an opportunity to explore the way developmental disability discourse in Ontario makes claims

about the needs of individuals with disabilities possible, or appear natural, normal or moral, especially as they are related to family and motherhood, and provides an opportunity to examine ways in which mothers navigate the discursive context in which they are embedded.

Interviews.

To further investigate ways in which mothers' experiences are impacted, produced and constrained by disability discourse and ways in which mothers negotiate said discourse, I conducted interviews with family members from families that include a family member diagnosed with a developmental disability. Interviews took place between October 2012 and March 2013, after the implementation of the *Social Inclusion Act (2008)* but before the Select Committee hearings. Reflecting my interest in the interconnectedness of conceptions of disability and motherhood, all family interviews were conducted with mothers. Some interviews took place with mothers alone while other interviews took place with mothers and other family members. More details about the interviews are outlined below.

Interview Participants and Recruitment.

Family members were recruited for participation in the study from a pool of 205 families who were taking part in a larger quantitative study, *Families Seeking Services*, in which researchers were investigating the experiences of parents seeking developmental services for their adult children diagnosed with intellectual or developmental disabilities in Ontario. These parents were also ideally suited to participate in the research here because of my interest in speaking with parents who were navigating the developmental services system as they made plans

concerning care and support for their disabled children. These people were able to reflect on the effects of disability discourse generally and as it is deployed through policy and government funded agencies and services. I conducted one or two interviews with family members from eight families in order to access both breadth and depth in analysis (Goodley et al. 2004; Taylor 2013: 63).

I obtained ethics clearance from the Queen's Health Sciences and Affiliated Teaching Hospitals Research Ethics Board⁴ (see Appendix A for the Research Ethics Approval) before having any contact with participants or potential participants. To begin the recruitment process, during a telephone interview conducted by research assistants as part of the second phase of the *Families Seeking Services* study, parents living no further than a three and half hour drive from Kingston were asked if they would be interested in participating in more in-depth interviews about their experiences with care and support. Of the 57 parents who were asked this question, 50 parents responded "yes". From this pool of 50 families, the *Families Seeking Services* research team chose 20 families to be potentially contacted for participation in the current study. Recognizing the differential effects of discourse across social locations (Foucault 1978: 127; Romagnoli and Wall 2012), families were selected to represent diverse parental and adult child ages, diverse geographical locations (rural, larger city, smaller city), diverse incomes and diverse caring practices and arrangements.

⁴ Researchers affiliated with the Sociology Department at Queen's University typically apply for ethics clearance through the General Research Ethics Board. Because I conducted my interviews as the third stage of a larger study, however, I applied for ethics through the Queen's Health Sciences and Affiliated Teaching Hospitals Research Ethics Board, the board to which applications for the other components of the larger project were submitted.

I contacted eligible families using contact information provided in earlier phases of the *Families Seeking Services* study. Speaking to the parent who took part in the earlier phase of the study, I introduced myself and explained that I was going to be conducting in-depth, face-to-face interviews with family members about their experiences with care and support as the third phase of the *Families Seeking Services* study. When parents indicated they and/or some of their family members were possibly interested in participating, I offered to send more information and consent forms via their preferred method (email or mail). Consent procedures for family members with disabilities included the use of a YouTube video in which I explained the study, consent forms written in language as plain as possible, and a set of five comprehension questions that participants had to answer correctly to demonstrate they understood the nature of their participation in the study. Sending information and consent packages to families allowed all family members to consider whether they were interested in participating before meeting in person. Some families chose to receive information and consent via email while others indicated they would complete consent procedures in person at the first interview. In the latter case, interview time and location were arranged during this initial conversation. This recruitment procedure continued until 8 eligible families agreed to participate. In total, I spoke to 12 families over the phone, four of whom declined the invitation to participate. Two of the parents declined based on time constraints and two of the parents declined based on a fear that information conveyed during an interview might potentially impact eligibility for government funding and services.

Participating families were somewhat diverse in terms of parental age, age of family member with a developmental disability for whom services are requested, location of residence, household income (Table 1) and the diagnosis of the family member with a disability (Table 2). In addition to the information presented in the table, it is worthwhile noting that one family had recently moved to Canada and that three of the mothers interviewed participated in paid employment outside the family home while the other five did not.

Also noteworthy is the fact that although all families were told that family members with disabilities were welcome and encouraged to participate in the study, only one family member with an intellectual disability took part in the interviews. Parents cited communication difficulties and time constraints as reasons why disabled family members could not take part in interviews.

Interview Procedures.

The in-depth interviews were planned and conducted in line with the feminist post-structuralist commitments underscoring this project. In-depth interviews involve “deep” conversations conducted with the aim of facilitating extended talk that is amenable to researching the subjective understandings participants give to particular issues, phenomena, events, or objects (Fontana and Frey 1994: 366; Hesse-Biber and Leavy 2006: 120; Hesse-Biber 2007: 118; Johnson and Rowlands 2012: 101). This in-depth approach matches and supports my interest in understanding the complex and contradictory ways in which mothers and other family

members understand expectations and provisions of care for their adult child diagnosed with an intellectual or developmental disability.

Table 1. *Family Demographics and Family Member Characteristics for Participating Families (n = 8)*

Demographic and Family Member Characteristics	<i>n</i>
<i>Contact Parent's Age (n = 8)</i>	
45 years and younger	1
46-54	3
55-64	2
65 years and older	2
<i>Age of Person with a Disability (n=9)*</i>	
Less than 21 years	3
21-25	2
26-29	3
30 years and older	1
<i>Location of Residence (n=8)</i>	
Small Urban (population < 100000)	1
Large Urban (population ≥ 100000)	5
Rural	2
<i>Annual Household Income</i>	
\$55,000 or less	2
\$55,001 - \$95,000	2
\$95,001 or more	4

*Note: Services were requested for 2 family members with disabilities from one of the participating families

Table 2. Diagnoses of Persons with a Disability for whom Services are Requested (n=9)*

<i>Diagnosis**</i>	<i>n</i>
<i>Disorder/syndrome</i>	
Autism spectrum disorder	3
Down syndrome	1
Cerebral palsy	2
Epilepsy/ Seizure disorder	2
Developmental Disability diagnosis not specified	3
<i>Physical and Sensory impairments</i>	
Mobility impairment/Wheelchair Dependent	2
Hearing Impairment	1
<i>Dual Diagnosis</i>	1

** Note: Diagnoses are not mutually exclusive

I prepared an interview guide to bring to each interview (see Appendix B for the interview guides). I planned to use the interview guide flexibly, as more of a memory aid to help me ensure topics of interest were covered than a protocol to strictly follow:

You're sitting, having a conversation with a person, and part of the artfulness of doing that in-depth interview is to know when to follow-up on what a person is saying in the moment. By the end I want to make sure that all the areas I want to have covered are covered. But you would be missing the whole deal if the only questions you asked were in your guide (David Karp in Hesse-Biber and Leavy 2006: 127)

In line with Karp's assertion that meaningful in-depth interviews are accomplished through attendance and response to the conversation as it unfolds, I was unconcerned with replicating question wording from one interview to another. As Riessman (2008: 25-27) notes, question

wording is often less important than researcher expectations and listening skills in terms of the production of stories.

Approaching interviews with an interest in in-depth accounts and a relatively high degree of openness was in consideration of feminist and post-structuralist research practices and concerns. In terms of the former, willingness to listen to participants' accounts and relinquish control of the flow and content of interviews reflects feminist concerns with the research relationship and with hearing about participants' experiences from their own perspectives (Devault 2004; Karp in Hesse-Biber and Leavy 2006: 127; Hesse-Biber 2007; Hesse-Biber and Leavy 2006: 126-128; Leavy 2007: 158). In terms of the latter, these aforementioned features of the interview and the research relationship are compatible with post-structuralist interests in hearing extended and complex accounts from participants' perspectives rather than through a lens and categorical understandings predetermined by the researcher (Taylor 2013: 63).

From the outset, I planned to conduct two interviews with each family to follow up issues raised in the first interview, ask about ongoing situations and plans families described at the first interview, cover topics of interest not addressed in the first interview and to access depth, complexity and contradiction in personal accounts (Taylor 2013). Conducting a second interview with most participants facilitated extended discussion of issues of interest because of the increased comfort that came with familiarity and the opportunity it provided to extend on earlier accounts or to fill in gaps (Booth and Booth 1998).

As per participants' requests, interviews took place at participants' homes, with the exceptions of a mother who participated over the phone while at work and a mother who participated in an empty room at her son's day program. Most participants took part in two interviews. At the first interview with each participant, I introduced myself, reviewed the purpose – to learn about families' experiences with care and support – and nature – one or two interviews – of the study and gave participants an opportunity to ask questions about the study. This introduction tended to involve informal chitchat, which seemed to enhance rapport and comfort levels for both myself and participating family members (Johnson and Rowlands 2012: 104). Participants who did not complete consent forms prior to this first meeting provided consent at this point. For the one participant who identified as disabled, I orally reviewed the nature of the study and asked five comprehension questions, which the participant was required to answer correctly to indicate they truly understood their potential involvement in the research (Lunsky and Gracey 2009: 90). The participant answered all questions easily. I asked all interview participants for their permission to audio record their interviews. With the exception of one mother and her participating son, all participants agreed to the recordings.

In total, I conducted fourteen interviews with participating mothers. Six mothers participated in two interviews each while two mothers participated in one interview each. As mentioned above, some interviews involved additional family members as well. Altogether, seven interviews were conducted with the mother alone, and seven interviews involved at least one other family member. Other family member participants included the adult sibling of the

disabled family member, the mother's partner (who was the biological parent in all cases but one) and/ or, as previously mentioned, one mother's disabled son.

No two interviews were the same. To encourage extended talk in participants' own words, I began most first interviews with the open-ended question, "Thinking about care and support that you give and receive, tell me about your family". For some participants, this question led quite naturally to other topics or questions included in the interview guide, which I asked in the order and using wording best suited to maintain the "natural" flow of conversation. When relevant, I followed up responses with "probes" (i.e. more specific questions) or with gestures (e.g. nods) or verbal acknowledgement (e.g. "uh-huh" or "yes") that I was listening and interested in hearing more (Hesse-Biber 2007: 126-128). Accordingly, some interviews, and portions of interviews, proceeded in a relatively semi-structured manner.

That said, many participants, who were familiar with and passionate about the issue under investigation, had stories they wanted to share and items they wanted to discuss (Karp in Hesse-Biber and Leavy 2006: 131); during some interviews I did not even ask the initial interview question before the introductory conversation flowed into topics of interest. During large portions of these interviews, participants led me through stories and topics relevant and important to them. My contribution to the conversation involved being an enthusiastic listener (Hesse-Biber and Leavy 2006: 132) who encouraged continuing talk. Several interviews, or sections of interviews, fell somewhere in the middle of these two extremes, and involved some

questions and probes. During lulls or breaks in the conversation, I consulted the interview guide and asked a question.

Interviews also necessarily varied because they involved different configurations of participants. Conducting some interviews with more than one participant was beneficial in terms of developing a more in-depth vision of the workings of developmental disability discourse. Participants tended to challenge one another and elaborate on one another's stories, features of group interviews which have been cited as beneficial in terms of provoking deeper elaboration and discussion and exploring contradictions or points of tension (Hesse-Biber and Leavy 2006: 200-204; Wilkinson 2004: 274-281). I found group conversations resulted in particularly rich material concerning gendered parenting experiences and identities. As family members talked to one another, elaborated on each other's stories, disagreed with one another and responded to each other's comments, gendered identities, knowledges, and expectations tended to be more explicitly highlighted than they were in one on one interviews.

Despite planning for openness and flexibility, I was initially surprised at the degree to which interviews varied from one to the next and the extent to which the flow of conversation was determined by participants. At first, I felt unsure about whether or not I was getting the "right" information or enough information. The variation between interviews could be considered problematic from a post-positivist perspective, where consistency in interview questions is important for the production of rigorous, generalizable results. From a perspective where the interest is not in obtaining generalizable results but is rather on subjective experiences and the

social contexts which shape said experiences, a free-flowing interview style is fitting (Booth and Booth 1998). Further, interviews became quite emotional at times; many participants shared difficult memories or ongoing struggles. What resulted from this process, are rich, detailed interview materials that reflect the perspectives of participants more than my categories and pre-conceived ideas (Fontana and Frey 2003).

Transcription.

Decisions about details to include in transcription were made by referring to the working definition of discourse for this research and my research questions (Devault 2004: 238; Taylor: 2013: 63-64). Reflecting my interest in language, I transcribed verbatim the actual words spoken by participants (Taylor 2013: 63). Because of my interest in the meaning participants ascribed to situations or issues under discussion, I additionally recorded hesitations, laughter and sighs, for example, to enable reflection on emotion and statement meanings (ibid: 63-64). For interviews from the one family who preferred not to be audio-recorded, I took detailed notes by hand throughout interviews. Immediately following the interviews, I typed and expanded on these notes. All participants had the chance to review transcripts and communicate whether they wanted to add, change, or remove anything. No participants expressed a desire to make substantial changes.

Analysis

According to Denzin and Lincoln (2003: 27) "There is, in the final analysis, no difference between writing and fieldwork". With this idea in mind, I began relatively informal and

unsystematic analysis during the interview process. As I transcribed and reflected on recently conducted interviews, I used a notebook to make notes on emerging patterns and initial thoughts, at times relating them to one another and to the relevant theory and literature.

With the exception of these interviews, the materials I analyzed for this dissertation were “found”; I obtained *Social Inclusion Act* policy documents and related materials and Select Committee transcripts online, meaning I was unable to immerse myself in them as they were created. To ensure familiarity with all interview and non-interview documents, I read through all texts – interview transcripts, policy documents, and Select Committee proceedings – before entering the more formal stages of analysis. During this reading stage, I wrote notes in my notebook and in margins to assign names to discursive elements, to note connections between elements, objects produced and the ways objects are produced, contradictions and silences (G. Rose 2012). While I approached all aspects of analysis with an openness to meanings and definitions of disability, motherhood and family (ibid), as I developed ideas about the objects/ subjects produced in disability discourse, I compared emergent findings to existing theory and literature. Here and throughout, the practice of analysis was messy and involved substantial movement and comparison “across” texts and between the parts of a text and more comprehensive findings from all texts:

The process of analyzing discourse data is not linear but exploratory and iterative. In other words, the analyst’s task is not one of straightforwardly ‘translating’ or ‘decoding’ the data one item at a time; rather analysis involves reading and re-reading an entire data set, comparing, noticing, and marking points of interest and returning to them later. (Taylor 2013: 69)

After reading all documents at least once in their entirety, I created, by hand, a “web” (see Appendix C) to visually illustrate, explore, and work with my emerging view of the discourse under investigation. This web depicts connections between various discursive elements, the practices that support and are made possible by them, and ways in which various elements are deployed. Among key ideas represented in this initial web were various contradictory ways in which the disabled subject is produced as both normal and different than normal in disability discourse.

After working through each text once, I realized that policy and interview texts were manageable documents to use in closer readings using more formalized codes, but that the Select Committee transcripts were too numerous and lengthy to formally analyze in their entirety while accessing the depth I was interested in. Therefore, I only formally coded half of the Select Committee transcripts; I ordered transcripts chronologically and flipped a coin to determine whether I would begin with the first or second transcript. Determining that I would begin with the first transcript (October 23), I coded that and every second transcript that followed. While other transcripts were not officially coded, I continued to refer to them throughout analysis, as I moved through and across documents.

To conduct formal analysis, I created two Excel documents: one for parents’ and mothers’ talk and one for policy texts. Within each of these Excel documents, I created tabs, labelled with key discursive elements that emerged in initial read-throughs and web creation (see Appendix D for more information about the labels used for each tab and for an example of text and

commentary included in a tab). For example, each Excel file included tabs for “normal or different than normal”, “family”, “choice”, “inclusion”, and “potential”. As I closely read each document under consideration, I copied and pasted relevant textual excerpts under appropriate tabs, creating new tabs where necessary. In the column beside pasted excerpts, I often wrote notes explaining connections between various excerpts, connections to theory or literature, contradictions within and between excerpts and emerging themes.

As I analyzed each individual text, I moved back and forth between documents to compare ideas that appeared similar or contradictory, to note issues or themes in areas that may have previously escaped my attention or to re-code areas in light of emerging ideas (G. Rose 2012; Taylor 2013). While I did focus on recurring patterns or themes, quantity was not a precursor for the inclusion of an idea, metaphor, narrative, or statement in analysis. As Britzman (2000: 28) notes,

As an interpretive disturbance to the promise of representation, poststructuralists read the absent against the present. Thus, the ethnographic promise of a holistic account is betrayed by the slippage born from the partiality of language of what cannot be said precisely because of what is said, and of the impossible difference within what is said, what is intended, what is signified, what is repressed, what is taken, and what remains.

Because discourse shapes the ease, difficulty, possibility and impossibility of making statements or claims, analysis involved noting what was and was not said or written. Throughout this coding process, I continually made notes in my notebook on developing arguments, ideas, and connections relating to the specific research questions under investigation. I continued this process until I had worked through each text.

Describing the Discourse and Writing

As Denzin and Lincoln note (2003: 27), analysis continues into the writing phase of research. To prepare to write, I considered connections and contradictions between all discursive elements included in the Excel files to develop a central argument. Moving between this formally analyzed material, the interviews or documents which it was drawn from and handwritten notes, I developed the following broad overall argument:

The developmentally disabled adult subject produced in developmental disability policy, policy related documents and dominant developmental disability discourse is fundamentally different from normal adults, but can potentially access normative outcomes and experiences. Developmental disability discourse relies upon, extends and perpetuates dominant gendered images of “the family”. At the same time, however, gaps between dominant discourse as deployed in policy and MCSS documents and mothers’ lived experiences make possible and often explicitly do trouble categories of the disabled adult, neoliberal personhood, and the family and motherhood.

Working from this argument, I wrote up these early findings as draft results/ discussion chapters. As I did so, I continuously drew on texts and codes to extend ideas, noticing contradictions and highlighting messiness.

I sent these initial writings to my supervisor, who commented that they included many important findings, but that they read like an initial description of results and not like a completed text supporting a specific argument. Accordingly, I worked with these findings, texts and coded materials to further analyze and refine my observations and arguments. This ongoing interpretation and re-working of material is typical of qualitative approaches generally, but especially of discourse analysis. According to Gillian Rose (2012: 215),

As this coding and interpretation process proceeds, other issues may start to become important to your interpretation, perhaps issues that had not initially occurred to you.

Unlike content analysis, this does not mean that you have to bait your analytical process and start again with a revised set of categories. Discourse analysis is much more flexible than that. As new questions occur, prompted by one moment of coding, you can return to your materials with different codes in a second —or third or fourth or twentieth— moment of interpretation.

Well into the writing stage I drew connections between previously seemingly disparate findings, re-imagined previously coded material as supporting alternate arguments and investigated new trains of thought by coding or re-coding materials. The more cohesive and analytical arguments resulting from this process are explained and described in the following two chapters.

Chapter 4

Passports to (Neoliberal) Adulthood: Fixed Categories, Individual Flexibility and the Different but Deserving Disabled Adult of Developmental Disability Discourse

The central aim of the current research is to describe developmental disability discourse in Ontario between 2008-2014. Overall, findings developed through the analytical procedures described in the previous chapter suggest that developmental disability discourse (re)produces a categorical boundary between normal and disabled adults, constituting normal and disabled subjects as naturally and fundamentally different from one another. Simultaneously, however, the disabled adult of developmental disability discourse is produced as an individual human who deserves the normative outcomes and experiences their categorization as other explicitly prohibits. In a context of ongoing neoliberalization this means that, as disability discourse (re)enforces a border limiting subjectivities available to both disabled and non-disabled adults, it asks that disabled adults enact individual flexibility to “choose” to move around and through, without ever breaking down, said border. Reliant upon intensive mothering expectations and practices, the tension in this discourse contributes to an extension and expansion of an ideology of intensive mothering. At the same time, however, mothers are able to deploy developmental disability discourse to place limits around their mothering roles and allocate responsibility for disabled adults to the state, thereby troubling neoliberal logic interwoven throughout dominant developmental disability discourse.

This chapter addresses the first of the specific research questions posed in Chapter Two: Who is the disabled adult subject of disability discourse, particularly as deployed in policy? To this end, this chapter includes the first part of the overall argument outlined above: I demonstrate ways in which adults with developmental disabilities are simultaneously and contradictorily (re)produced as distinct-from-normal adult humans yet as inherently human and therefore deserving of age-normative outcomes and experiences. More specifically, I show how disabled adults are somewhat paradoxically produced as failed neoliberal citizens and as potential consumers of choice who deserve to and are capable of flexibly enacting the demands of successful neoliberal citizenship.

I begin the empirical section of this chapter by demonstrating ways in which the adult subject with a developmental disability is (re)produced as different than normal, especially in interaction with provincial policy and in reference to modernist versions of personhood and neoliberal visions of successful citizenship. Next, I demonstrate that, despite (re)producing boundaries between normalcy/ disability, dominant disability discourse simultaneously produces disabled adults as inherently human and therefore as unique individuals whose individuality should be recognized, honoured and responded to. I extend this discussion of individuality to show that, although framed in positive and emancipatory terms, appeals to uniqueness and individuality actually open disabled adults to forms of governance: As unique individuals, disabled adults are compelled to enact (always diminished versions of) successful (flexible and responsible) neoliberal citizenship. In other words, especially in interaction with policy and service sector practices, disabled adults are required to inhabit a space of categorical

difference to the normal human adult, thereby creating and upholding a rigid border demarcating disability/ normalcy, while concurrently enacting individual flexibility to move around and across said border. I end this chapter by briefly discussing some of the implications of these discursive tensions and contradictions and suggesting that these characteristics of the disabled adult subject interact with ideals of family and motherhood, a train of thought I continue in the following chapter.

A New Definition? Ongoing Productions of Disability as Medicalized Difference.

Disability studies scholars working from a range of (often conflicting) perspectives (Barnes 2012; Goodley and Runswick-Cole 2016; Kittay 2011; Shildrick 2012) have consistently agreed that dominant constructions of disability, which position the disabled mind/ body as other to the species norm, are indebted to modernist visions of personhood and/ or medicalized practices performed on/ to disabled bodies and minds. Despite the conceptual shift suggested in the MCSS proclamation that the *Social Inclusion Act* (2008) involves a “new definition of ‘developmental disability’” (*About the Social Inclusion Act* Ontario Government 2009: 10), contemporary developmental disability discourse in Ontario continues to (re)produce disabled adults as medically naturalized members of a coherent category discrete from normative, modernist personhood, thereby drawing familiar boundaries around what it means to be/ to not be a normal, adult human.

Examination of the definition of developmental disability used in the *Social Inclusion Act* (2008) shows ways in which the norm, and the disabled adult as other to the norm are (re)produced in

developmental disability discourse. To be eligible to receive services and supports under the *Social Inclusion Act* (2008), a person must provide evidence that they have a developmental disability as per the following criteria (2008 section 3, subsection 1):

Under the Act and Regulation, a person has a developmental disability if the person has... prescribed significant limitations in cognitive functioning and adaptive functioning and those limitations:

originated before the person reached 18 years of age;

are likely to be life-long in nature; and

affect areas of major life activity, such as personal care, language skills, learning abilities, the capacity to live independently as an adult or any other prescribed activity.

The suggestion that persons with disabilities have “limitations” is only possible in reference to a natural, normal human functioning from which it is possible to deviate, suggesting this definition is premised on the assumption that adults diagnosed with developmental disabilities are fundamentally different than normal adults. This generalized sense that disabled adults differ from normal adults is frequently apparent in mothers’ talk as well: “MJ is not regular, he is very special” (Doreen⁵).

Reflecting the mutual dependence of the concepts of disability and normalcy (Davis 2006), interrogating the nature of disabled adults’ limitations sheds light on the content of both categories. Disability studies scholars have described the persistence of modernist understandings of self, emphasizing autonomy, independence, agency, rationality and control (Goodley and Runswick Cole 2016: 2; Kittay 2011; Shildrick 2012: 32), as underpinning the

⁵ I use pseudonyms when naming participants who participated in interviews.

content of normal personhood and as juxtaposing disabled personhood; where the “normal” adult is autonomous, agentic, rational and in control, the disabled adult is dependent, irrational and risky. In the current research, these complementary visions of personhood appear in discourse. To wit, the *Social Inclusion Act* (2008) definition of disability at least partially relies on, as it perpetuates, a binary whereby the disabled mind/body is dependent and irrational, and the normal adult mind/body is independent and rational. These distinctions are apparent in the assertion that disability related limitations effect “the capacity to live independently as an adult” (*Social Inclusion Act* 2008: Section 3, Subsection 1), a statement which compels readers to imagine a natural (independent) adult state to contrast with a disabled (dependent) adult state. Likewise, the definition provided for “cognitive functioning” connotes diminished rationality in the case of disability: “Cognitive functioning” means a person’s intellectual capacity, including the capacity to reason, organize, plan, make judgments and identify consequences” (ibid: Section 3, Subsection 2).

These differences from the modernist adult are legitimized, naturalized and understood in reference to experts and medicalized understandings of disability as difference. For example, those applying for developmental services must provide “proof” of disability in the form of an assessment conducted by a psychologist or a psychological associate (*Social Inclusion Act* 2008, Section 14, Subsection 3) and services available under the *Social Inclusion Act* (*About the Social Inclusion Act* Ontario Government 2009: 7) include rehabilitation focused interventions provided by “therapeutic allies” (Oliver and Barnes 2012), such as psychologists or social workers. The expert evaluations and interventions necessitated by or provided under the *Social*

Inclusion Act (2008) are indicative and productive of the existence of ongoing, internal, medicalized difference which requires expertise to know and appropriately act upon. Medicalized understandings of disabled adults as different than normal adults are additionally found in mothers' talk about their children. Making medicalized explanations for her son's (irrational) behaviour, and the behaviour of his disabled peers as a group, Sarah asserts "A lot of the[se] kids [with autism] are OCD."

Although naturalized, these dichotomous productions of disability/ normalcy are not inherently natural or inevitable. Gail Landsman (2009: 171-214), for example, argues that mothers of young disabled children tend to accept and use readily available medicalized discourses of disability when their children are first born or diagnosed. Over time, however, they often come to question the conceptual basis of normalcy from which their children are typically considered to deviate. Operating with an expanded definition of normal, these mothers no longer see their children as occupying a space of distance from a norm. Like the mothers involved in Landsman's research, in the current study, all mothers invoked or adhered to an understanding of disability as difference at least some of the time. At the same time, like the parents in Landsman's (ibid) research, parents' descriptions of their children can and do include characterizations which contrast with these dominant discursive themes. For example, Clara describes her daughter in ways that contradict with conceptualizations of developmental or intellectual disability as less than intelligent: "She's a bright cookie, she won't talk to you because she only says a few words, but she looks at you, she examines you...and she's very intelligent". In a similar

example, Geoffrey Shea (January 14 2014⁶) describes his son Yoshci as “bright, cheerful and inquisitive,” and stresses his academic achievements: “he especially enjoyed native studies and parenting in high school, though he struggled with trigonometry and had to retake the course in order to pass.” Stephanie, who frequently refers to her son as autistic, describes her son as being able to “do things” that those who are truly autistic should not be able to do: “[The doctor] said because I can touch him it means he isn’t truly autistic”.

Parents’ narratives at times additionally trouble the efficacy or the importance of expert intervention or treatment. Evoking medicalized understandings of her son, Stephanie compares autism to diabetes - “I think if you have something like [autism] it’s no different than diabetes” -and often discusses the efforts she takes to seek professional assistance or therapy for her son. However, she also discusses ways in which her own, non-expert or evidence based, work with her son proved more effective in teaching him to speak than professional interventions: “And he put his hand in my mouth and he goes ‘stop!’. And so then after that, when we did [speech practice], he’d have his hands in my mouth. It took months... [and] the speech therapist kept thinking it was her. I just laughed...” Like other mothers involved in the study, Stephanie simultaneously contends with discursive elements (re)presenting her son as different in terms set out by medical definitions while, perhaps hesitatingly, questioning the basis of disability as a stable medical category which requires expert intervention. Likewise, in

⁶ To denote a quote taken from the Select Committee transcripts, I include presenters’ first and last names in addition to the date of their presentation.

response to a question about what has helped her son, Sara conveys both that professional assistance was important, and that therapy was in fact not useful at all.

I think... um... it was sensory integration therapy, speech therapy. I'm not sure if any of the therapy money spent helped him or if we just kind of figured it out. I learned sometimes just to back off and let him show me. We moved when he was 3 [years old] and he didn't sleep for 3 months.... it was just awful. And finally, one night out of desperation I just took a pillow and laid against his bedroom door and thought, "go nuts - whatever you need to do". He moved all his furniture... arranged his room exactly like it was at the old house, crawled into bed, and that was it. Because [he is] nonverbal he couldn't tell you. We tried everything, with every therapist... and that's all it was.

Although, in some ways, this passage adheres to a model of disability as difference, it also involves a contention that expert-based intervention and therapy is not necessarily required or effective.

Despite these fluid, complex at times contradictory understandings of disability/ normalcy, the demarcation and enforcement of the boundaries between the normal and the abnormal is emphasized as particularly important under the *Social Inclusion Act* (2008). Affirming and guarding the boundary between eligible (developmentally disabled) and non-eligible (non-developmentally disabled) applicants comprises a significant portion of the role the DSO, newly implemented under the *Social Inclusion Act* (2008), is intended to perform: in the *Policy Directives for Application Entities* document (Ontario MCSS N.d.: 1) confirmation of eligibility is one of five listed types of work DSO's perform and regulations and instruction surrounding eligibility comprise 8 out of the 28 page document (ibid: 7-15). To explain and understand the ongoing importance of boundary marking and the attendant dominance of medicalized, deficit based constructions of disability as difference in the face of assertions or experiences that

trouble this orthodoxy, the next section further examines the discursive threads connecting disability and normalcy; more specifically, the next section examines how the disabled adult is specified as other to the neoliberal citizen for reasons of medicalized difference, a production necessary to justify services in the context of neoliberal rationalities.

Beyond Medicalization and Modernist Personhood: Techniques of Power and Disabled Adults as (Failed) Neoliberal Citizens.

In chapter Two, I presented literature which argues that, contemporarily, neoliberalism circulates as a dominant political rationality and that, within neoliberal political rationalities, citizens are ideally responsible for their health, general well-being and economic security. Accordingly, under neoliberalism, adult citizens are rarely imagined as the legitimate recipients of social services. To illustrate, exemplifying logic that adults should be able to provide for themselves (and their families), since the 1990's Ontario's welfare policy has not considered child care responsibilities a legitimate barrier to the employment of single mothers (Little 2001). As McLaughlin and Goodley (2008: 194) note, in contexts where welfare provision is increasingly conditional, it is necessary to establish recipients of publicly funded social support as other than normal to justify their receipt of social goods. To this end, within contemporary disability discourse, disabled adults are re-presented as embodying a fixed, medicalized difference from the norm which specifically prohibits their enactment of the demands of neoliberal adulthood, thereby justifying their status as legitimate recipients of the services available under the *Social Inclusion Act* (2008).

The SIS as a Technique of Power and the (Re)production of Disabled Adults as (Failed) Neoliberal Citizens.

Within neoliberal rationalities, concerns with human categorization and social service provision relate more to what bodies can do than to what bodies are. Recall that neoliberal citizens are ideally self-actualizing, entrepreneurial, active and responsible individuals (Miller and Rose 2008: 98), or consumer citizens who are able to care for and manage themselves. Taken together, these characteristics are not incompatible with the independent, rational adult of modernist personhood, but do include more focus on activity or conduct. Indeed, Miller and Rose (ibid) argue that, under neoliberalism, “marginalized” subjects have the incapacity to manage themselves and are a threat, and that the focus for experts becomes more superficial, moving from internal characteristics to conduct. In this context, disabled adults are specified as different than normal adults in ways that preclude the enactment of the demands of idealized neoliberal citizenship to justify (limited) state provision for disabled adults while simultaneously justifying the lack of the same or similar provisions for normal adults.

Consistent with trends towards neoliberalization, the definition of disability used in the *Social Inclusion Act* (2008) includes a new focus on conduct: the major change brought to the definition of disability under the *Social Inclusion Act* (2008) is that, where the old definition used only IQ as a determinant of disability, “The new definition of developmental disability is not based strictly on IQ. It also considers how a person handles common demands in life and how independent they are compared to others of a similar age and background” (Ontario MCSS 2012-2014b). By this logic, adults with disabilities are disabled by virtue of their (lack of)

intelligence and rationality and their associated (problematic) social conduct and independence, themes which draw on interconnected neoliberal and modernist versions of personhood.

One especially cogent illustration of the necessity and effects of techniques of power which simultaneously (re)produce disability as different than normal and as potential failed neoliberal citizens can be found with the Supports Intensity Scale (SIS), “the provincially-consistent method to assess the support needs of applicants eligible for Ministry-funded adult developmental services and supports” (*Policy Directives for Application Entities*, Ontario MCSS N.d.: 16). The SIS must be completed by all adults seeking services and/ or another informant who knows them well enough to ascertain “the pattern and intensity of supports necessary for a person to participate in activities linked with normative human functioning” (AAIDD 2017: n.p.). Respondents are required to indicate the frequency, duration, and intensity of support that would be required for the adult diagnosed with a developmental disability to take part in a list of activities related to the areas of: “home living, community living, lifelong learning, employment, health and safety, social activities, and protection and advocacy” (ibid). Examination of specific items under each of these categories reveals that use of the scale produces disabled adults as (potentially) failed neoliberal citizens, who cannot consume “shopping and purchasing good and services” (AAIDD 2004a in AAIDD 2004b: 50), self-manage health “maintaining physical health and fitness” (ibid: 51) “maintaining emotional well- being” (ibid), work “completing work-related tasks with acceptable quality”, protect themselves from risk “protecting self from exploitation” (ibid: 52), manage finances “Manage money” (ibid),

make choices “making choices and decisions” (ibid) or engage in self-actualizing activities “learning and using problem solving strategies” (ibid: 50), without assistance or intervention for reasons presumably associated with their disabled status.

Rather than serving a neutral recording function (Miller and Rose 2008), the scale requires participants to “constitute the individual as effect and object of power, as effect and object of knowledge... [B]y combining hierarchical surveillance and normalizing judgement... assur[ing] the great disciplinary functions of distribution and classification...” (Foucault 1977: 192). By comparing and classifying their children in terms of their distance from idealized neoliberal functioning, parents are swept up in a practice which (re)produces normative human adults as able to care for themselves and as therefore unworthy of publicly provided support and disabled adults as, for reasons of medicalized difference, unable to care for themselves and therefore worthy of support, sometimes in ways that counter their own understandings of their children.

The constitutive effects of this process are evident in the following comments from parents about their experiences with the SIS, which suggest that parents felt a sense of this type of objectification of their child as other to a norm or lacking in reference to the good neoliberal citizen, felt uncomfortable with it and, as a result of their participation in the SIS, at times came to view their child in terms consistent with these productions of and comparisons to normative adult functioning:

We were told to compare Michael to a normal 31-year-old. I'm yet to meet a normal 31-year-old male. I wasn't sure what we were gauging him against, because that's not Michael. Why don't we talk about Michael? Why don't I tell you what we need? Why don't we discuss our situation?... Michael is an individual. Michael's needs are different than the next person's. They're not any greater; they're not any worse. He's Michael, and let's discuss Michael. Let's not compare Michael.... We didn't know how to do this. You're scaling him 1 to 5: Can he bathe, 1 to 5, compared to a normal male? Well, a normal male wouldn't have his mother in the bathroom. How do you gauge that? (Colleen Butler December 18 2013)

Colleen Butler's talk highlights that, as they assign their children numerical scores, parents (at times reluctantly) participate in a process whereby they re-create dichotomous, rigid images of normal and abnormal adult, human functioning. Commenting that the assessment process is "fairly dehumanizing" Kathleen Gifford (January 13 2014) implies recognition that disabled adults are necessarily produced as occupying a space of distance from normative, human functioning. Although the disabled adult constituted through this process may contradict with parents own, more fluid conceptualizations of disability/ normalcy, some parents may come to internalize visions of their children as very different from normal. To this end, Clara remarks that as they participated in the *Social Inclusion Act* (2008) assessment process her and her husband, "realized, 'wow we didn't think she was that bad'".

Rigidity in categorization additionally manifests in terms of exclusion from the category of adult with a developmental disability: as different than normal, those fitting the developmentally disabled category are nonetheless considered to belong to a category of discrete difference from those embodying other signifiers of difference. To illustrate, developmentally disabled adults are considered distinct from older adults who need assistance and medical attention provided in nursing homes. "Teresa should never have been admitted to a nursing home. You

can see in this picture her fellow patients, residents, at the Re kai Centre are in wheelchairs, and Teresa is doing her power walk.” (Ms Franke James January 21 2013). In this excerpt, both adults diagnosed with developmental disability and older adults with physical care needs are positioned as differing from an able-bodied/ minded norm, but these two categories of difference are nonetheless distinct. As such, long term care may be appropriate for older adults with physical health needs, but it is not appropriate for young or middle-aged adults diagnosed with developmental disabilities.

Accordingly, those who do not fit the above described definition of developmental disability are not eligible for services funded under the *Social Inclusion Act* (2008). In attempts to obtain services for their adult children diagnosed in areas not necessarily covered under the *Social Inclusion Act* (2008), parents of adult children who do not fit with *Social Inclusion Act* (2008) eligibility requirements deploy medicalized explanations for their adult children’s behavioural incapacities when they make appeals for increased social support to show both their similarity to disabled adults and their deservingness of services; in other words, parents of children with ineligible diagnoses (re)produce developmental disability as a rigid site of difference from a norm even as they ask for expansion of the category. Presentations made to the Select Committee by parents of adult children who do not currently meet eligibility requirements are a case in point. These presentations involve a call for an expansion of eligibility criteria to cover mental health diagnoses, Autism, Asperger’s Syndrome and Fetal Alcohol Spectrum Disorder (FASD) and involve narrative efforts to claim medical or biological reasons for their children’s inabilities to successfully enact neoliberal citizenship. In other words, to illustrate their

children's deservingness of services and related similarity to developmentally disabled adults, they highlight their children's dependency and the medically or physiologically based deficits which induce this dependency.

Ms. Elspeth Ross (January 17 2014), for example, offers the following about her adult sons with FASD, presenting them as potentially moral recipients of publicly provided support: they are willing to work, but can only do so part time and with assistance due to their intrinsic, medicalized difference from normative human functioning.

FASD is a developmental disability... People talk well and present well and look like everyone else, but they have invisible brain damage.... No two people with FASD are the same, but they are all at risk for school difficulty, mental health issues, difficulties maintaining employment, and addictions. Common challenges are with executive functioning: judging, planning, delaying gratification, consequences, organization, impulsivity and memory. Supports and services and tailored programming make a difference. People with FASD need an "external brain" to help them with daily life. They have many talents and skills, and we build on these to maximize potential.

My sons with FASD are now 34 and 31.... Both graduated from high school and one graduated from college.... Both work part-time in summer in brick and stone with the same long-time boss. They live together in a second house on our property. It is not independence, but interdependence.

One has ODSP support. One has diabetes, type 2, so there are health concerns. We're in constant touch and help them with money management, keeping important documents, filling out forms, understanding time, scheduling and reminding about appointments (that's the external brain), taking them to doctors—yes, I go in with them—and [buy] groceries....

Most affected people have an average IQ, or even higher, and don't qualify for DSO supports; they're considered high-functioning. We can't get by the gatekeeper in Ottawa—Service Coordination—to get programs.... We need the same services as other families in this province with developmental disabilities.

By highlighting the support she provides her sons, and locating the cause of interdependencies or dependencies as based in biological difference, and thus presenting her sons as dependent by no fault of their own, Elspeth Ross makes a case that her sons and others diagnosed with FASD should be eligible to receive developmental services in Ontario. Similar tones are heard in presenters advocating for the inclusion of Autism Spectrum Disorder (ASD) or mental health diagnoses in the DSO eligibility requirement; those with diagnoses that do not fit within DSO eligibility criteria position their children or others with their label as deviating from the independent rational adult ideal, for medical or biological reasons, which in turn limit their capacities to engage in behaviour consistent with neoliberal adult citizenship.

In sum, disability is continuously (re)produced as different than a normal state of humanity, especially in interaction with Ontario policy and the developmental services sector. In interaction with prevailing neoliberal rationalities, it appears necessary to produce disabled adults as fitting narrow, rigid, medicalized categories, which preclude the enactment of successful neoliberal citizenship to justify the provision of social services to this population. The SIS provides an example of ways that distance from normalcy is achieved and required in the context of a neoliberal rationality. In this way, practices surrounding the concept of developmental disability build up and reinforce the border demarcating disability/ normalcy, drawing lines around available subjectivities on either side of the border. Despite landing squarely on the “different” side of disability/ normalcy, also suggested in the SIS is the idea that, with appropriate assistance, disabled adults can and should engage in normative activity, thereby seemingly expanding the boundaries of disabled subjectivity beyond what would have

been historically or is currently “naturally” available to disabled adults. The next section explores contentions that disabled adults are deserving of something more than their categorization as other to the human norm has historically provided.

“Isn’t that what most of us want for ourselves?” Disabled Adults as Deserving Humans

Despite being discursively figured as other to the normal adult human, the adult disabled subject of popular discourse is nonetheless simultaneously imagined as human. For example, the Passport Program, the direct funding model of service delivery available under the *Social Inclusion Act* (2008), was created with the goal of “Help[ing] young *people* make the transition from school to life as an *adult* in the community” (*Passport Program Guidelines for Adults with Developmental Disabilities and their Caregivers*, Ontario N.d.: 3, emphasis added). Further exemplifying this trend, People First language, which seeks to emphasize the humanity of those diagnosed with disabilities by distancing the person (human) from their disability (other than human) (Titchkosky 2001) abounds: “One of my concerns with *people with disabilities*” (Lily).

Disabled Adults as Unique Individuals.

Paradoxically, the humanity disabled adults share with all adults is perhaps most fervently expressed in contentions that disabled adults are unique individuals. This is most succinctly practiced and evidenced through the repeated use of the term “individual” to refer to one or many adults with disabilities (emphases added): “The long and short of it is, for this kind of very vulnerable *individual*” (Sue Irving December 18 2013). “He said right now there is a huge influx of *individuals* between the ages of 18 and 25 years old” (Jane).

Just as the application process for services and supports under the *Social Inclusion Act* (2008) involves techniques of power that constitute adults with developmental disability as different than normal adults, the application process includes techniques of power that produce disabled adults as imbued with a unique, deep psychology. The *Application for Developmental Services and Supports* (ADSS) (Ontario MCSS 2011) document is a case in point. Like the SIS, the ADSS is a questionnaire style document and is part of the “provincially-consistent method to assess the support needs of applicants eligible for Ministry-funded adult developmental services and supports (*Policy Directives for Application Entities*, Ontario MCSS 2014: 16). Meant to be completed in an interview setting with the disabled adult and other respondent(s) who know them well, the ADSS and the SIS are conducted with the stated aim of ascertaining applicants’ priorities and circumstances to facilitate planning on individual and provincial levels (ibid).

As suggested by the biopolitical rationale for conducting the ADSS, the ADSS operates as a technique of power which produces disabled adults as unique individuals who deserve to be acknowledged and recognized as such. Exemplifying this function, the ADSS includes a section titled “Getting to Know You”. Under the Getting to Know You section, applicants are asked to name and expound upon their likes, “Use this section to explore things the individual likes, finds relaxing, feels proud or accomplished about” (Ontario MCSS 2011: 15), dislikes “Explore potential stressors that can lead to anxiety in the life of the individual” (ibid: 16), dreams “Explore the elements of what constitutes a happy future for the individual” (ibid: 17), and goals “Explore areas of interest to the individual over 6-12 months” (ibid). Completing this

section produces the disabled adult as an individual with a deep psychology consisting of individual goals, preferences and desires.

Marked as unique individuals, disabled adults are marked as sharing a central trait with all humans. According to Sampson (1988), when it comes to understanding the self and identity, members of Western, English speaking communities tend to adhere to “self-contained individualism”, a view which entails a clear distinction between self and others. From this perspective, every human is a unique, bounded entity, who exists independently of others. Not only are individual humans self-contained, their interior thoughts, desires and emotions are inherently individual. Rose and Abi-Rached (2013: 221) argue that, over the 20th century, humans have dominantly come to be viewed and to view themselves as unique, psychologized beings with “deep interior mental states” (Rose and Abi-Rached 2013: 223) Within this view of personhood, human autonomy is defined not only in terms of the ability to live independently, but in terms of a possession of unique, coherent and continuous biographies, desires, needs, and interests. This means that, for all people, it is possible and desirable to know and to live authentically in accordance with the authentic, “real” me.

Tied to disabled adults’ inherent humanity, a recognition of disabled adults’ individual uniqueness is thus positively valued. This is especially true given that, as disability advocates and academics have long noted, the experiences of people with disabilities have long been overdetermined by medical professionals, “therapeutic allies”, and other caregivers (Barnes

and Oliver 2012; People First of Canada 2012-2016). Expressing this sentiment, the People First of Canada website includes the statement that,

We see ourselves as self-advocates and full citizens of our country – living equally in the community. We see ourselves as people first, and as people who have taken back control of our lives from families, policy makers and professionals such as support workers, doctors, social workers, and others, who, for far too long, made decisions for us.” (People First of Canada 2012-2016: n.p.).

Accordingly, the moral importance of recognizing the unique individuality of adults with disabilities is embedded in the skill requirements for assessors, the DSO employees who conduct the ADSS and SIS interviews. Ontario MCSS *Policy Directives for Application Entities* (n.d.: 19) stipulate that assessors must possess an “ability to focus the discussion on the support needs and priorities of the individual, and ability to identify nuanced differences between the priorities of the individual and those of other care providers” when conducting ADSS and SIS interviews.

In addition to recognizing disabled adults’ uniqueness and thus inherent humanity, disabled adults’ individual wishes and needs should be appropriately responded to. Results from the ADSS and the SIS are said to be capable of “improv[ing] the quality and responsiveness of Ministry-funded adult developmental services and supports... [by] facilitat[ing] accurate assessments and inform[ing] the development of individual support plans directed by the needs of eligible applicants” (*Policy Directives For Application Entities*, Ontario MCSS n.d.: 16) and, the *Social Inclusion Act* (2008) was implemented with the aim of “be[ing] flexible, so that people’s needs are addressed” and with the recognition that “Adults who have a developmental

disability want more choice and control over their lives.... The new Act will give adults with a developmental disability more independence and choice.” (*About the Social Inclusion Act*, Ontario Government 2009: 3). Accordingly, assertions that disabled adults can and should have their individuality recognized and responded to takes an emancipatory tone, and is presented as a positive and needed development in the developmental services sector. As one parent states, “before it was just, ‘oh you are in crisis. We have to find a home.’ But, they weren’t looking at their needs. What they needed to be happy and live a productive life” (Clara).

Positively-toned linkages between disabled adults as individuals and choice are embodied in the Passport Program, a direct funding model of service delivery available in Ontario under the *Social Inclusion Act* (2008), where “giving” adults with disabilities choices recognizes their unique individuality and inherent personhood:

The transformation of adult developmental services and supports is based on the overarching principle that people who have a developmental disability are members of the community and focuses on independence, dignity and self-determination.

The services and supports funded under Passport are guided by the following principles:

Person-centred/directed – services and supports build on individuals’ strengths and are responsive to their preferences, needs and values.

Choice and Flexibility – individuals identify and participate in activities that are meaningful to them. Direct funding is available to give Passport participants more options in how supports are provided. (*Passport Program Guidelines for Adults with a Developmental Disability and their Caregivers*, Ontario N.d.: 4)

Discursive elements (re)producing disabled adults as unique individuals deserving of choice also coalesce in talk about and services related to person-directed planning, which tends to hold that desirable outcomes will be achieved through planning and choice. To illustrate, despite

considerable limitations on admissible expenses and services available under the *Social Inclusion Act* (2008), “Person Directed Planning” is an available support option:

Under the social inclusion act, adults with disabilities may apply for funding to receive **Person-directed planning services and supports** to help adults with a developmental disability:

- identify their life dreams and goals
- find and use services and supports in their lives to make their plan happen.

(About the Social Inclusion Act, Ontario Government 2009: 7)

Assumptions that adults with disabilities, as unique individuals, can and should identify their individual needs and desires, and that these individual interests can be met by engagement with planning processes, underlie this brief description of planning services and supports.

Taken together, the above evidence suggests a generalized agreement that an emphasis on individuality and related concepts of choice and planning should be embraced. From a Foucauldian perspective, however, a focus on disabled adults’ uniqueness can be viewed as an exercise of power which opens disabled adults to processes of governance rather than more straightforwardly freeing them from a repressive history. Foucault (1977: 193) contends that, compared to past regimes under which individualization was a privilege reserved for the elite,

in a disciplinary regime, individualization is descending: as power becomes more anonymous and more functional, those on whom it is exercised tend to be more strongly individualized; it is exercised by surveillance rather than ceremonies, by observation rather than by commemorative accounts, by comparative measures that have the ‘norm’ as reference rather than genealogies giving ancestors points of reference; by ‘gaps’ rather than by deeds.

In keeping with Foucault's contention that individualization cascades, increasing alongside marginalization, disability discourse evokes a sense that knowing adults with disabilities in all their particularity takes purposeful effort above and beyond efforts necessary with other adults; it appears as though the uniqueness of disabled adults is more highly valued and more overtly considered than the uniqueness of normal adults. This sentiment is captured in the very existence of the SIS and ADSS and in the fact that Person Directed Planning is an available service under the *Social Inclusion Act* (2008).

From this Foucauldian perspective on individualization, the ADSS, the SIS and planning processes operate as technologies of power, "turning of real lives into writing... [and] function[ing] as a procedure of objectification and subjection" (Foucault 1977: 192). Objectified as hyper-individualized, disabled adult subjects embody "correlative elements of power and knowledge" (ibid: 194) and are made amenable to governance and intervention in not only their distance from normalcy, but in their possession of the uniqueness typical of the human species as well. In the Ontario context, this means that even as the disabled adult subject is solidly placed on the "other" side of the disability/normalcy divide, disabled adults are asked to enact some version of the normal, successful neoliberal citizen as they make choices and pursue goals. The operation of the discursive elements productive of these effects is described below.

Flexibly Crossing the Border between Normalcy and Difference: Disabled Adults as (Neoliberal) Responsible, Productive Consumers of Choice.

As discussed above, the *Social Inclusion Act* (2008) purports to flexibly respond to the individual needs and wishes of adults diagnosed with developmental disabilities. That said, dominant developmental disability discourse requires that disabled adults enact flexibly *themselves* to pursue a limited range of (normative) outcomes, experiences and opportunities. Just as disability discourse (re)enforces the boundary demarcating disability/ normalcy, it simultaneously demands that “individual” adults chip away at and approach, without ever fully breaking through, this border.

Flexibly Enacting Normative (Neoliberal) Means and Ends

Alluded to above, the choice and flexibility offered to the unique individuals of developmental disability discourse does not represent unbridled possibility; rather, disabled adults are encouraged and compelled to make choices consistent with the enactment of idealized neoliberal personhood. As such, by engaging with “choice” disabled adults are asked to break out of the constraints of their disability diagnosis to approximate or emulate a version of normalcy, as prescribed by the opposing sides of the disability/ normalcy binary, without ever breaking through or down the barrier that divides disabled from normative subjects. This is true of both the way in which disabled adult subjects ideally access choice and the types of choices disabled adults subject should ideally make.

With regard to the latter, disability discourse includes a sense that disabled adults deserve age normative outcomes. Despite occasional references to a deservingness that explicitly rejects common markers of adulthood, reading in this case, - “He can read. But does [reading] make him happy? No. Does he want to do word searches, and 1000-piece puzzles, and dot to dots every day? Ya.... And he likes to swim once a week. And... skat[e] in the winter... That’s how we are going to fill his day” (Jane) – parents more frequently link adulthood with deservingness of desirable outcomes. The sense that disabled adults deserve outcomes associated with normative adulthood is clearly conveyed in the following quotes: “He is happy, loved, cared for, and his strengths, needs, likes and dislikes are being met in a variety of unique and creative ways. Isn’t that what most of us want for ourselves?” (Cora Nolan January 17 2014). “My daughter is on the list for assisted housing... I think it’s a natural progression, whether you have special needs or not, that you move out of the house” (Jan Hudyma January 14 2014). “Our goals for Kristy are unwavering: to help her to become the best that she can be in her community, with limited stigma; and to live, to the best of her ability, a life that all Ontarians expect and demand” (Sue Irving December 18 2013).

While there is little discursive resistance to the idea that disabled adults deserve “the same thing as the rest of us”, this overwhelming agreement may belie the complexity inherent to the meaning of an “ordinary, typical life”, which differs within and across statements. For example, some of the above discussion contends that meaningful, enjoyable, connected and interdependent lives form at least part of the basis for normative expectations or experiences. However, reflecting observations that meaning and connection tend not to feature in dominant

versions of personhood (Kittay 2011; Clegg et al. 2008), these outcomes coexist with, and are often overshadowed by themes that adults with disabilities deserve to experience independence and productivity. In other words, the disabled adult subject is paradoxically (re)produced as different than normal, and unable to access outcomes and experiences associated with normative (often neoliberal) adulthood, and as a unique individual, deserving and able to access outcomes and experiences associated with normative (often neoliberal) adulthood.

The idea that disabled adults should choose services or supports that allow them to engage in conduct consistent with neoliberal citizenship is even more apparent in policy documents. To illustrate this point, under the *Social Inclusion Act* (2008) generally and the Passport Program specifically, disabled adults can potentially access Community Participation Supports or “Services and supports to assist a person with a developmental disability with social and recreational activities, work activities, volunteer activities and such other services and supports as may be prescribed.” (*Passport Program Guidelines for Adults with a Developmental Disability and their Caregivers*, Ontario Government N.d.: 7). Given that two out of the three examples of possible Community Participation Supports relate to employment related activities, we can see that adults are encouraged to access supports to help them enact the very same activities precluded by their diagnoses: Although positioned as unable to support themselves financially, if disabled adults choose appropriate supports they will be able to enact some version of productivity as either employees or volunteers. As “individuals” with developmental disabilities

make choices, they can and should choose to enact successful neoliberal citizenship as employees and consumers.

The impetus on individual choice in relation to employment is further evidenced by considering the role of related concepts of choice, independence and productivity or employment in accessing inclusion. Curiously, in the official rationale for the need for and benefit of the *Social Inclusion Act* (2008), choice and independence are named as desired outcomes, but social inclusion is not (*About the Social Inclusion Act*, Ontario Government 2009: 3): “The new Act will give adults with a developmental disability more independence and choice”. Rather than representing an editorial oversight, the omission of inclusion from this introduction may in fact reflect the individualized pathways considered best suited to accessing this eponymous outcome (Burton and Kagan 2006). By “choosing” “independence”, for example in the form of employment, disabled adults will be included. Rather than being “given” inclusion, disabled adults are given the tools to flexibly insert themselves in social situations that will presumably contribute to their inclusion. By making the right kinds of choices, disabled adults can be included in their communities.

Exemplifying the link between successful enactment of employment and social inclusion, Allan Mills, an executive for the service provider *Christian Horizons* (December 18 2013), states “When you first meet people, what do you talk about? “Where do you live?” “Where do you work?” For most of the people that we’re serving, “Where do you work?” is not a question that they’re able to answer, but if we can help them with that, that really makes a significant

difference.” Similarly, Sue Irving (December 18 2013) connects her daughter’s community inclusion with her contributions via employment activities “Kristy has re-engaged with the community. She may not be entirely stable all the time, but she’s a contributor. She works at Meals on Wheels and she works at Unionville Home Society. It’s incredible that somebody with such dire needs has the ability to do that, and we strongly advocate that it’s their right”.

Despite her difference, Kristy can be valued as a community member because of her willingness and ability to flexibly engage in the demands of neoliberal adulthood. Further, the pressure to “choose” employment related productivity is strong enough that it can be articulated as human right. Apparent in all of this discussion is the finding that, although they are positioned as individual consumers of choice, disabled adults are not free to choose from a range of unlimited options. Instead, positive choices and/ or encouraged choices are shaped by notions of successful adulthood created and upheld by a disability/ normalcy binary.

That said, it is never expected that disabled adults fully occupy a space of successful neoliberal citizenship and normal adulthood as produced and upheld in the normal/disability distinction. Disabled adults are expected to approximate the demands of neoliberal citizenship, without ever breaking down the binary in question. Illustrating this effect, it seems that no one demands that disabled adults become eligible for well-paying jobs that would enable them to embody the self-sufficiency asked of “normal” neoliberal citizens. Instead, advocates more often ask that disabled adults have access to some form of (often part time, low paying) “productivity”, which would facilitate inclusion and a sense of personal accomplishment in its’ proximity to normative behaviours: “If we can find jobs for folks who are there and wanting to

work, even if it's 20 hours a week at minimum wage, they contribute \$200 to our overall economy. If they're not working for that 20 hours, they're costing somewhere, a program—where if you said it's a 1-to-4 ratio, perhaps they're costing \$200 to support them for that” (Down Syndrome Association of Ontario December 18 2013). As it re(enforces) the wall and the content of either side of the wall of disability/ normalcy, disability discourse makes it possible for disabled adults to approximate but not perfectly emulate the normative, successful neoliberal citizen.

Risk and Responsibility: Choice, Planning and Disabled Adults as Flexible Consumers and Managers.

In addition to making the right kinds of choices, choices that promote independence and productivity, as they make “individual” choices and plans for their futures, disabled adults are positioned as beings who must flexibly navigate risks inherent to their environment in ways that their rigid categorization as different would seemingly preclude. The *Passport Program Guidelines* (Ontario Government N.d.) document reveals that choice interconnects with dominant conceptions of responsible individuals to the effect that adults with disabilities are positioned as beings who can and must manage risk inherent to the practice of choice: “Individuals who manage their own funding and supports are responsible for monitoring the quality of the services being purchased. Complaints or concerns about the quality of supports must be taken up with the service provider, not the Passport Agency” (*Passport Program Guidelines for Adults with a Developmental Disability and their Caregivers*, Ontario Government N.d.: 16). The *Passport Guidelines* document continues on to suggest that this individualized

risk is an unfortunate but necessary aspect of participating in the community as an adult, and suggests measures individuals can take to mitigate any risk:

While developmental services agencies funded by the Ministry of Community and Social Services are regulated and monitored by the Ministry, other agencies and service providers are not. In some cases, mainstream community agencies or private service providers will be regulated by a different level of government, a professional association or a statutory body. Where organizations are not regulated, there may not be an overseeing body that can hear complaints and help resolve problems. Some questions to be asked when selecting a service provider include:...

Are there any conditions related to the provision of the support?

What will my responsibilities be?

Does the service provider have adequate insurance coverage (e.g., in case a support worker is injured while at your home)?

Does the service provider have references?

Do they have a complaints process you understand and feel confident about? (ibid: 16)

Similar themes linking individuality and choice with responsibility for risk management are apparent in the related *Hiring a Support Worker* (Ontario Government 2013: 23) document, which provides information to adults with disabilities about how to hire and manage their own support worker:

The worker you hire may be a stranger. It is very important to protect yourself and your property. Here are some tips that may help you do that: Get a Criminal Record Check and Vulnerable Sector Search before you hire the worker. Your local police department can give you more information about this. Know when abuse or neglect might be happening. Never give your credit card, banking information, PIN numbers and other personal information to your worker. Check your bank and credit card statements each month for strange activity. Check your phone bills to make sure you are not charged for calls you did not make. Keep your medications, valuables, money and personal documents in a safe place. Have a plan in case your worker stops working for you and

make sure you get back any house keys you gave them. If you can't get them back, change your locks.

Although adults with disabilities are different than other adults in many respects, they are, like other adults, individuals who must take responsibility for any risk inherent to their lives as they make choices based on their individual preferences. Rather than the recipients of a flexible system of services, disabled adults must individually and flexibly negotiate the uncertainties of a service context and a broader social context which may not be responsive to their wishes, well-being or needs. They are, in effect, like the participants in corporate training Martin (1997: 351) describes in her treatise on the role of flexibility in wide ranging conceptualizations of success. "These new "whole people" are to be active in their willingness to tolerate risk, danger and the insecurity of being ungrounded... the nature of the person is to shift and to be able, flexibly, to tolerate continuing shifts".

Although the individualized disabled adult is overtly and repeatedly positioned here as a responsible consumer who is required to make good choices to create appropriately desirable lifestyles (Miller and Rose 2008), policy documents include an expectation that disabled adults will at times require assistance as they make choices and navigate risks. To this end, a reliance on family is written into policy documents relating to choice, although often in ways that suggest family involvement is voluntaristic or one of several viable possibilities for support. Suggesting that family members might (want to) help disabled adults make responsible choices, a section entitled "Is this guide for me?" in the *Hiring a Support Worker* document (Ontario Government 2013: 3) asks "Are you a person with a developmental disability in Ontario?... Are

you a friend or family member of someone who wants to hire their own worker? If you answered yes to these questions, this guide may help you or someone you know hire a support worker". This passage not only raises questions about who does or should actually read this document, but similarly raises questions about who does or should actually manage the "individual" risks and responsibilities outlined above: the "individual", the "family" or someone else?

Inadvertently answering this latter question, the *Hiring a Support Worker* document (Ontario Government 2013: 3) communicates that disabled adults themselves might desire family or friend involvement at times because "hiring a worker can be complicated" and requires adherence to various laws and policies. In an excerpt which hesitatingly suggests that "individuals" with disabilities may only be able to responsibly act as managers and consumers with support, the document states that "if you want to hire a worker, you may want to talk to a family member, friend or someone else you trust.... Professionals, such as lawyers and accountants, may also be able to give you advice and help you hire a worker" (ibid: 3). Here, the suggestion that disabled adults might want to hire a "professional" to help them navigate challenges associated with acting as an employer seems to circumvent a requirement that disabled adults rely on family (or friends) for this purpose. That said, the document does imply family involvement might be necessary when it comes to contacting a professional "you could ask a family member or friend to help you find and contact a professional" (ibid: 21) and it is difficult to imagine that assistance communicating with and paying a professional might not also necessitate family involvement. The latter is an especially pertinent issue given that the

budgeting example given in the *Hiring a Support Worker* document (ibid: 7) suggests that an adult hiring a support worker might have access to only 200 dollars per month once recurring expenses, such as food and shelter, are paid⁷. Thus, even when the document includes ideas for support that fall outside the family, family involvement is still implied. To this end, examining the *Hiring a Support Worker* document holistically demonstrates how, when the complexities of individual choice are acknowledged, explicitly individualized risk management expectations are simultaneously tentatively distributed to family and “professionals”. While family, friends and professionals are largely written as *possibly* necessary or desirable in helping “individuals” navigate the complexities of responsabilized management and consumption, in the next chapter I examine in detail how expectations and opportunities for individualized choice and risk management explicitly targeted at disabled adults are often shouldered by families, or more specifically parents or mothers, in practice.

Personal Potential: Self-Actualization as a Path to Successful (Approximate) Neoliberal Adulthood and Inclusion.

As unique, choice-making individuals, disabled adults are additionally governed in a requirement for a degree of embodied rationality, seen as necessary to make (appropriate) choices and to participate in the community in desirable ways. Accordingly, notions of individuality and rationality coalesce to demand that disabled adults pursue self-actualization and to justify behaviour intervention for disabled adults.

⁷ The document also states that disabled adults may need to access Legal Aid to afford a lawyer (ibid: 20). However, no mention is made of programs that could help with the cost of hiring an accountant.

Developmental disability discourse includes a view that not all adults will be able to flexibly make (desirable) choices at all times: when disabled adults' presentations of selves is too far from the border between normal and abnormal, they are ineligible for the types of choice, independence, and therefore inclusion, outlined above. More specifically, it is commonly asserted that a degree of visibly obvious rationality is required for choice and for related outcomes of productivity, inclusion and independence. Highlighting the perception that an expression of rationality is required for choice making, Lily argues that the concept of choice for adults with developmental disabilities should be tempered by realistic expectations that preferences will not necessarily be fulfilled: "but the thing is, you are still working with people with developmental disabilities and some of the things AI wants are just really unreasonable".

While policy documents do not as explicitly limit choice based on rationality, the types of choices available under the policy, involving the application of risk management in the pursuit of inclusion, are deemed inaccessible to disabled adults whose comportment falls too far from the line demarcating disability and normalcy. To illustrate, according to the *Policy Directives for Service Agencies* document (Ontario MCSS N.d.: 10), challenging behaviour is "behaviour that is aggressive or injurious to self or to others or that causes property damage or both and limits the ability of the person with a developmental disability to participate in daily life activities and *in the community* or to *learn new skills* or that is any combination of them..." (emphases added). Presenting as irrational and dangerous, disabled adults with "challenging

behaviour” are (re)presented here as (naturally) limited in the extent to which they can be included in the community.

Some parents view their children’s divergence from normalcy, and consequent limitations on inclusion and choice, as a static, permanent state: “I know my daughter is not employable. I can’t just let her go to Walmart and say, ‘Okay, be a greeter at Walmart.’ Who’s going to watch her?... She doesn’t have the capability to do that—plus the mindset too, with the autism, you know? They’re moderate to severe” (Donna Thompson Jan 17).

Dominant discourse, however, holds that disabled adults are malleable beings, imbued with potential. As Rose and Abi-Rached (2013: 223) articulate in reference to contemporary theories of brain functioning, “this is not a biology of fate or destiny... but a biology that is open to intervention or improvement, malleable and plastic, and for which we have the responsibility to nurture and optimize”. In this context, the self has a “commitment to autonomy and self-fulfillment, the sense of personal responsibility for one’s future” (ibid). Like all adults, disabled adults are flexible beings who can improve themselves with the right intervention and training. In developmental disability discourse, this “improvement” refers to an ability to approximate or enact normative behaviour, as articulated by Jillian Mothersell (January 13 2014), an adult diagnosed with a developmental disability, in her appeals for government funding: “I would like to continue to learn and improve my communication... I would never give up and I hope the Ministry appreciates how hard I try. I will not waste your funding and neither will my friends”.

By harnessing what is viewed as an internal, individual and inherent flexibility to come close to or pass over the line between the normal and the abnormal, disabled adults are able to make appropriate choices and be included. Once again, the *Social Inclusion Act (2008)* does not give flexibility, it demands flexibility. When disabled adults are viewed as self-contained individuals, this impetus for *individual* improvement as a means of enabling social inclusion and, relatedly, appropriate choices appear reasonable. To this end, understandings of disability as difference, understandings of disabled adults as unique individuals and threats to inclusion are invoked throughout the *Policy Directives for Service Agencies* document (Ontario MCSS N.d.: 10) to justify (potentially intrusive) behaviour intervention: “In instances where an adult with a developmental disability has challenging behaviour, it is important that the support the person receives to address his/her behaviour is well-informed, *appropriate to the person’s needs*, and safe, so that the person may *take part in the community* and live *as independently as possible*” (emphases added). The logic in this policy excerpt holds that, as behaviour moves towards the border demarcating normalcy/ disability, disabled adults can enact a version of independence/ neoliberal citizenship and are eligible for inclusion in their communities.

Parents recognize this imperative for their adult children to enact a form of visible rationality and intelligence if they are to be included, and work with their adult children to help them move as close to the line separating disability from normalcy as possible: “Social inclusion has been one of the biggest things from the day Al was born. My focus was on ensuring that his behaviour and the way he carries himself was socially acceptable because I find that’s probably one of the key things” (Lily). Explicitly linking the ability to approximate or enact normative

adulthood, attainment of some version of successful neoliberal citizenship, human and monetary value and employment-based contribution, Mick Kitor (January 14 2014), a father, makes the following argument for enhanced autism therapy funding:

When you invest makes a huge difference... We're not talking about, "Oh, maybe these kids with milder forms of autism won't have to be dependent on the government." They could actually be scientists.... They could contribute, but we choose not to spend on them, not to invest in them. So what do I want for value? I'd like to see government-backed autism therapy loans. Get the therapy earlier, and get more effective treatment. I'd like to see children with milder forms of autism receive the therapy so that they can contribute to society, and there's a lot they have to contribute.

Typifying discursive associations between individual potential, normative comportment, employment and inclusion, this excerpt can be summarized as communicating that through therapeutic intervention, which seeks to normalize thought and behaviour, children with autism will be able to become valuable contributors to society.

The impossibility of valuing and including difference that strays too far from the line of normalcy means that those who defy this discursive logic, that those who commit to therapy and intervention will become normal enough to enact some measure of neoliberal personhood and be included, are ineligible for inclusion:

And people always say "oh inclusion, ya, we don't want to discriminate" But people in society have rules... It wasn't me who said you need to stand in the line at Costco in your little piece of personal space.

... I don't know what's going to happen. This is going to be the last try.... [T]he chief psychologist said if this [intervention] doesn't work, our other option is he's a bubble boy. So he would have to live in a residential that has a day program that gets him some exercise and stuff but he would not, I mean it breaks my heart because we took him everywhere to restaurants and stuff. He could be completely shut down... (Jane)

For some parents, the requirement to move towards normative comportment is more than a matter of finding inclusion via employment or being able to go to a restaurant, it is rather a matter of life and death, as Kristy's mother (Sue Irving December 18 2013) recognizes in her references to Ashley Smith, a 19 year old who died in 2007 while held in federal custody: "We are really afraid and do not wish that... heaven help us, that it might lead Kristy, because she's viewed as a behavioural type, somehow at some point into correctional services, as happened to poor Ashley Smith. Her family will never be the same, and it's our job to stand up for people like that to make sure it never happens again".

Summary

In summary, although disabled adults are (re)produced as belonging squarely on the abnormal side of a normal/ abnormal binary, they are simultaneously required to individually and flexibly move around and across the line that divides disability from normalcy. Davis (2013) contends that, in the flexible age of neoliberalism, identities are no longer imposed; rather, identities are chosen, or consumed. In this context, older hierarchies of normal/ abnormal have been replaced by a newer rubric of diversity, under which difference is celebrated. For Davis (ibid), however, disability will never be valued under this particular conceptualization of diversity because the category of disability continues to rely on dichotomous understandings of normal/ abnormal human functioning. As such, disability is not a chosen, flexible identity; disability is medical, fixed and undesirable. In a context where choice is valued, disability remains unchoose-able.

The findings from this research, however, suggest that developmentally disabled adults are imbued with both the rigidity of this older discourse and the flexibility of this newer discourse of social ordering: although they belong to a fixed (medical, undesirable) category of difference, as unique individuals disabled adults can and should flexibly approximate and emulate normalcy as they chip away at previously closed off subject positions to pursue and choose lifestyles reflecting their own personal preferences. When they are able to do so in ways that approximate normalcy and fit with conceptions of successful neoliberal citizenship, disability may be tolerated in some cases and even valued in others.

That said, the tension immanent to this discourse is not without consequences external to the frequently stated desirable outcomes of choice, inclusion and independence. As I started exploring here, and will continue exploring in the next chapter, the different but flexible adult of disability discourse is not guaranteed any particular services or outcomes and may have experiences that stand in stark contrast to the idealized outcomes of the deserving disabled adult. While this seems to be partially addressed through repeated assertions that disabled adults require assistance or support of some kind as they make choices, plans or participate in the community (as evidenced in the SIS for example), as already mentioned, the *Social Inclusion Act* (2008) governs a discretionary service system. Upon closer inspection, it seems the weight of these discursive inevitabilities and gaps are made possible and rest upon mothers and an attendant familialization of care.

Chapter 5

‘They Say I am a Good Mother’: Intensive and Intensified Mothering in Developmental Disability Discourse

In this chapter, I show ways that the developmental disability discourse I began to describe in the previous chapter is entangled with ideals of intensive mothering and how this discourse impacts and is negotiated by mothers of adults diagnosed with developmental disabilities. In the previous chapter, I described the adult disabled subject of developmental disability discourse as fundamentally, medically different from the normal adult subject in ways that preclude the enactment of idealized neoliberal citizenship. Nonetheless, the disabled adult subject is simultaneously produced as inherently human, and as embodying the unique individuality dominantly considered common to all humans. While commonly (re)presented as having the power to emancipate disabled adults from an oppressive history of control and institutionalization, this humanity and uniqueness make possible particular forms of governance, which require interrogation. Specifically, discursive elements stressing the humanity and individuality of disabled adults encourage disabled adults to flexibly enact the demands of neoliberal adulthood, which their diagnosis and categorization as other simultaneously discursively prohibits. I ended the previous chapter remarking that the tension immanent to this discourse is partially addressed through repeated statements that disabled adults require some form of assistance or support to successfully enact the requirements of neoliberal citizenship. Despite this recognized need for assistance, disabled adults are not entitled or guaranteed any services, supports or outcomes.

In this chapter, I argue that these discursive tensions – of the disabled adult as medically other/ uniquely human and as deserving/ but not entitled to normative outcomes and support - are made possible by gendered ideals and practices of parenting. As I do so, I argue that developmental disability discourse explicitly relies upon and perpetuates an ideology of intensive mothering and an attendant familialization of care. Further to this explicit, often widely accepted, reliance on families and mothers, tensions and contradictions imbued in developmental disability discourse intensify motherhood and mothering practices in ways extra to those explicitly stated in discourse. In other words, the gaps, fissures and contradictions immanent to disability discourse fall squarely on the shoulder of parents in general, and mothers specifically, extending and perpetuating intensive mothering practices and ideology at times in ways beyond what is explicitly demanded or accepted. These same contradictions and tensions however, make it possible for mothers to place discursive boundaries around their mothering roles and to make demands on the state counter to the neoliberal logic woven throughout developmental disability discourse.

Explicit and Naturalized Intensive Mothering and Familialization of Care in Developmental Disability Discourse

A discretionary service system is discursively tenable alongside explicit statements that disabled adults require help, assistance or supports because of a naturalization of and reliance upon intensive mothering and related familialization of care. Consistent with neoliberal movements to community-based care in other areas of social service provision (e.g. Henderson 2005), within developmental disability discourse, the warm, caring, responsible family is envisioned as

the moral and best alternative to institutionalization. In developmental disability discourse circulating in Ontario, family is (re)presented as the best site of care in ways that explicitly draw on both ideals of family as a natural place for community-based care and as the most fiscally responsible means to provide for disabled adults. In other words, moralized visions of family as synonymous with community and inclusion dovetail and are bolstered in interaction with visions of family as the most or only affordable site for care.

Supporting the argument that family is seen as the natural and best site of care in contrast to institutional arrangements, former institutional arrangements are alluded to once in policy documents: The document, *About the Social Inclusion Act* (Ontario Government, 2009: 10), states that the *Social Inclusion Act* (2008) “uses language that talks about services and supports. It also does not use the words ‘facility’ or ‘institution’”. Instead of the undesirable images presumably conjured by mentions of “facility” or “institution”, the term “family” is at times used in conjunction with the term “support” in ways that seemingly place the inclusion and needs of disabled adults most capably and naturally in the hands of the family: one of the principles guiding the Passport Program is “Strong Families and Caregivers – the individual’s family and personal support network is recognized as the primary support for adults with a developmental disability” (*Passport Program Guidelines for Adults with a Developmental Disability and their Caregivers*, Ontario Government N.d.: 4). The superiority of the family home to more formal caring arrangements is heard in parents’ talk as well. Felix, a father I interviewed, states: “Families are keeping their adult children at home. They don’t want to put them in group homes.... Because no group home is never going to meet their child’s needs...

they are happier and more content [at home]”. This argument, that families are a natural vehicle for inclusion, appears to be shared nationally: in response to a survey question asking, “Which of the following plays the most essential role in helping disabled persons participate fully in society?” (Prince 2009: 11) the most frequent response given by the random sample of Canadians completing the survey was, “Families of the person with the disability” (ibid: 12).

Family as a primary site of care is naturalized to the extent that family members’ and other unpaid care providers’ ability to care is unquestioningly used as criteria in determinations of eligibility, type and intensity of services and supports required for disabled adults (ADSS, Ontario MCSS 2011: 37-38; *Policy Directives for Application Entities*, Ontario MCSS N.d.). To illustrate, in the document, *Policy Directives for Applications Entities* (Ontario MCSS N.d.: 23), one of three given examples of reasons disabled adults might require immediate assistance is that, “The unpaid primary caregiver (e.g., family member) is unable to continue providing care that is essential to the health and well-being of the adult”.

Alluded to in the final statement above, which links the unpaid status of family members with their status as the primary source of care, the morality and naturalness associated with notions that disabled adults do the best at home is bolstered in its interconnection with financial arguments for family provided care. While policy may stipulate families as a primary support – seemingly progressive in the face of former institutional or medicalized approaches that may ignore or pathologize families’ voices (Ryan and Runswick Cole 2008) - primary family caregivers cannot be paid under the *Social Inclusion Act* (2008). *Passport Program Guidelines*

for Adults with a Developmental Disability and their Caregivers (Ontario Government N.d.: 6) stipulate that Passport funding may not be used to compensate “Primary caregiver(s) regardless of residence”, which both naturalizes the care families provide and seemingly helps with the policy aim of sustainability, ensuring that the system of support developed through the *Social Inclusion Act* (2008) will “be here for the future” (*About the Social Inclusion Act*, Ontario Government 2009: 3). At times internalizing a view that there is simply not enough public money to support disabled adults without familial assistance, “I have no idea where that money’s going to come from.... I try not to be selfish. Cause... I watch the news and I think, ‘there needs to be help in so many places’” (Jane), parents intertwine comments about family as the best, or natural, and most affordable sites of care. “I would strongly urge the committee to consider better ways of providing more support for families like us who are thinking of making their own residential arrangements for their children, perhaps by direct funding for caregiver costs or as a tax break on all disability-related expenses. Most families want to help their own children” (Helen Leask January 14 2017). Here, economic arguments and a naturalized sensibility that “most families want to help their own children” coalesce to make neoliberal solutions appear sensible and desirable, legitimizing a discretionary developmental services sector.

As such, consistent with a neoliberalization of service provision, much of the support provided to families is support designed for families to help themselves by privately providing for their members through the consumption of services and goods (Luxton 2010; Rose and Abi-Rached 2013; Soldatic and Meekosha 2012), whether it be in the form of Passport funding, designed in

part to “support families and caregivers of an adult with a developmental disability so they can continue in their supportive role” (*Passport Program Guidelines for Adults with a Developmental Disability and their Caregivers* Ontario Government N.d: 3), or through enhanced customer service focus brought in with the DSOs: “The purpose of this policy directive is to ensure that Application Entities provide appropriate information and quality customer service to the public” (*Policy Directives for Application Entities* Ontario MCSS N.d.: 2). Some parents internalize these economic rationalizations and accordingly ask for more information or other services so they can help themselves: “I think they are doing what they can right now with the money, but... they need to give more information to the families...who want to make their own independent program” (Sarah).

Taken together, the policy, interview and presentation excerpts presented here support the argument that family is envisioned as the best place for care, both because of its synonymy with inclusion and community and its place as the most affordable site for care. Below, I elaborate on the former, demonstrating how ideas that family is the best site for care are dependent upon and are strengthened in conjunction with dominant characteristics of the disabled subject and a gendered discourse of intensive mothering.

Mothers Who Know What’s Best and Care the Most: Gender and Intensive Mothering in Disability Discourse.

Although, like much Canadian Social policy (Brodie 2010), the *Social Inclusion Act* (2008) and related documents are officially gender neutral, gendered ideals and patterns of parenting

emerge in closer examination of disability discourse and its effects. Dominating discursive elements contradictorily (re)producing the disabled subject as medically different from the normal human state and as inherently human in the possession of unique needs and desires position the disabled adult as vulnerable and as requiring specialized, attentive care and as requiring intimate, in depth personal knowledge in the pursuit of individually desired outcomes. Entangling and with and strengthening gendered parenting ideals that good mothers do and should know and care the most about their children and their children's outcomes and that they should pursue these outcomes at great personal expense (Hays 1996), these discursive elements justify and demand intensive involvement and input on the part of "good" parents generally and mothers more specifically while legitimizing and naturalizing limited provision of publicly funded services.

Doreen, for example, discusses doing "everything" because of her natural, gendered propensity for knowing what is best for her adult son, in contrast to paid staff, who do not hold the same, parental love for the people with whom they work: "Moms do everything [when their child is a] special needs case.... Who loves you? Who wants what is best for you? They are just service providers. Who really knows what's good for you - your mother and father. We mothers, I don't know if it's a 6th sense, but we know what's best". Similarly, Elaine communicates that paid workers do not care about her son in the same way that she does: There's something about brushing a person's teeth that PSWs don't like.... I stay on top of it... I try and brush his teeth once a week myself and [if they] are that bad I report it.... Well it's hard.... It's very tight, it's awkward, and it takes a little bit of time.... [but] if you care, you will brush them all".

Ideals of parenting/ mothering and the work necessitated by a discretionary service system are mutually reinforcing: the one justifies the other. Below, Cora Nolan (January 17 2014) argues that parents know their children best and care the most because of their caregiving responsibilities, and that their caregiving responsibilities are necessary and justifiable because they know what is best for their children.

Parents and families and individuals with developmental disabilities are the ultimate stakeholder. Professionals and governments come and go. Parents know their child best. They are the experts and ultimately live with the results. Therefore, it stands to reason that every parent wants what is best for their child. Individualized plans must be developed by persons who know the individual well. Encourage families, who best know their family member's need, to develop the plan and attach a budget, with access to the funds to implement it. Otherwise, it's a waste of everyone's time.

Since women generally engage in more caregiving work than men (Baker 2005; 2010: 120-126; Lee 2014; Milan, Keown and Urquijo 2011; Ranson 2005; Fox 2009), these reinforcing ideals and practices can play out on gendered lines: "I try to explain to people that if you as a mother - after being with [your child] 24/7 - don't know everything about him, then you aren't paying attention" (Stephanie).

Which Mother?: Good Mothers and Bad Mothers in the Care of Disabled Adults.

Although mothers, armed with knowledge and love, are deemed to naturally provide high quality care to their children, the risk that "bad" mothers may fail to put their children's needs before their own further shapes policy and governs mothers' actions and rationalizations for the care they provide. At once idealized as the most important carers for disabled adults and regarded with suspicion as potential abusers of funds or resources intended to promote the

wellbeing of their children, parents - who could at any moment purposefully or inadvertently place their own needs or priorities before their adult children's - pose potential threats to the wellbeing and optimal outcomes of disabled adults. This concern is apparent in the fact that DSO assessors are required to have an "ability to focus the discussion on the support needs and priorities of the individual, and ability to identify nuanced differences between the priorities of the individual and those of other care providers" when conducting application package interviews (*Policy Directives for Application Entities*, Ontario MCSS N.d.: 19).

Echoing academic critique (e.g. Pilnick et al. 2011) of a discourse of self-determination, Lily articulates the position in which parents are placed with regard to choice. She points out how parents are expected to enable or implement the choices their adult children make, as parental wishes or concerns are officially considered subservient to those of the child as client. "They won't let you do anything unless they speak with that individual... But in the end, they depend on you as a parent to do everything else. So, it's like this kind of conflicting message: 'You are not important and what you have to say is not important, we have to talk to the client'".

Relying on parents to provide care and support while considering their needs categorically distinct from their children's unique needs means "good" parents will structure their lives around their children's needs and will manage all other aspects of their lives separately from their role as mother to a disabled adult. To this end, Passport funding cannot be used for "indirect respite services and supports (e.g., cleaning, meal preparation, snow removal, care of other family members)" (*Passport Program Guidelines for Adults with a Developmental Disability and Their Caregivers*, Ontario Government N.d.: 11). As Pilnick and colleagues (2011:

319) write, in some situations this juxtaposition of needs means that “greater choice for the young person would mean less choice for other family members, and vice versa”. In this way, the emphasis on choice within developmental disability discourse generally and policy more specifically may actually be based upon, and extend and expand, an ideological contention that the needs of mothers and their children are distinct from one another and that mothers can and should privilege their children’s needs above their own.

This shadow - of the bad mother who would put their own concerns, interests or wants before their adult child’s - looms over mothers to the effect that it can intensify their mothering roles and/or contribute to feelings of guilt. Evidencing effects of the juxtaposition of mother/ child needs, Lily, for example, discusses feeling guilty when her son was not engaged in any programming or activities, despite the fact that she explained his lack of participation in activities as a result of her own paid employment and a lack of appropriate, accessible or available programming: “I was working full time and... you have to drive forever to get to your work. And that was 2 hours of my day, and I have a very busy job. And trying to access information and resources and work full time was very challenging”. Explaining how she felt after she moved to another province so her son could access services, Lily continues, “I don’t feel as guilty... he’s... out all day doing something meaningful and productive”.

Apparent my conversation with Ali, the combination of assumptions that “good” mothers naturally provide for their children and that “bad” mothers exist justifies a need for

government audits of families' finances, makes parents grateful for (often limited and inadequate) support they do receive and legitimizes mothers' roles doing "everything":

We do need receipts... because that's very kind of government to give you fund[ing]... [Y]ou have to spend this fund[ing] [on] your children. Not yourself.... I hear[d] a story about a woman who took money and... put her child in [a] room. [S]he didn't take her... anywhere outside.

I think, 'I'm everything: housekeeper, mother, player, coach, friend, story reader, everything.' You have to do all the roles. But in that main word it's a mother. But... which mother - just a mother, or [a] mother [who] care[s]. [O]ne day the principal of the school said 'we see a lot of moms but they don't do what you do'. (Ali)

Similarly drawing on dichotomous visions of good/ bad mothers, Anne Rahmin (January 17 2014) states that the lived realities of parents with disabled children are such that it is impossible for them to be anything other than "good" moms, an argument she uses to support her claims that families deserve additional flexibility with funding they receive. While this line of thought may seem positive and progressive in the claims that interactions with parents should be non-punitive, it nonetheless continues to legitimize, naturalize and necessitate intensive mothering practices:

The notion that parents of children with autism, particularly those with severe autism that never sleep and bounce at 4 a.m. in the morning, will go wild and spend funding on a drinking binge or at a casino is absurd. We are struggling every day with children who have a severe disability.... Do we sound like the kinds of parents who are likely to abuse the system? What concerns us, in fact, is that so much energy seems to be put into worrying about us abusing the system and so little into the fiscal abuse going on within it by those holding the fiscal purse... From where we stand, the onus is on us, our son's parents, to ensure that he succeeds. To do that, we need to be able to use the fiscal resources that are available as wisely as possible...

This positioning, of the parents of children with autism as "good" parents, both perpetuates an ideologically based belief in "bad" parents, "who are likely to abuse the system", and

naturalizes the intensive work that parents of disabled children take part in “to ensure [their children] succeed”.

In this ideological context, outcomes viewed as less than optimal may only be morally acceptable when mothers have proven themselves to be “good” mothers by “doing everything”, despite the social causes of many of the undesirable outcomes disabled adults could experience. Jane shares that, when it came to finding ways to address her adult son’s unsafe and disruptive behaviour, her family became eligible for significant publicly funded support/ state responsibility only once she had shown that she had exhausted all other options: “We did everything they asked... I had the school coming to the psychiatrist’s appointments...I set up speech people. I did everything [they told us to try].... So Bill’s name went to a service resolution meeting.... [Our worker] said, ‘they’ve done everything we’ve asked’”. In another example, Iman Seifledin (January 17 2014) takes pains to assert that she is a good mother, despite the fact that her son does not live at home.

They say I am a good mother, and I am very involved in my son’s life. I love my son dearly. I have always attended his school meetings, home meetings and medical meetings, to make sure that everyone understood Karim’s needs. He has problems keeping weight on and is extremely thin, so I make him special meals to encourage him to eat. I also hire a support worker, who helps me take Karim out on the weekends.

By stressing the time, money, and emotional efforts she puts into her child’s well being, Iman Seifledin positions herself as a good mother even though her son does not live at home, where, according to the logics of neoliberalism and intensive mothering, he naturally belongs.

To summarize this section, key discursive elements producing disabled adults as medically different than normal but as uniquely individual humans interact with and bolster an ideological expectation for intensive mothering and an attendant familialization of care. Accordingly, the interconnection between these elements governs mothers in their caring roles, shaping both their caring practices and their reflections on their caring practices. It seems that ideas that parents, especially mothers, are ideal and natural providers of support for disabled adults are naturalized to the extent that these connections and statements are often explicit and accepted in policy and talk, where statements such as “most families want to help their own children.” (Helen Leask January 14) legitimate reliance on family care and a discretionary service system. In the following section, I show how developmental disability discourse not only involves explicit statements that parents/ mothers can and should provide for their adult children, but that latent discursive effects additionally contribute to an intensification of mothering practices beyond a degree explicitly stated or as easily accepted.

Latent Discursive Effects and the Intensification of Intensive Mothering

The effects of discourse do not necessarily remain within the bounds of stated, official or individually desired outcomes (Foucault 1978: 99; 100-102). To this end, despite the probably well-intentioned sentiments that, although they are medically different than normal, disabled adults are uniquely human and deserving of normative outcomes, embodiments and experiences, these dominant discursive elements can and do contribute to and occur alongside outcomes counter to the idealized outcomes of disability discourse. As the primary providers of care and support, mothers are therefore frequently left to fill gaps or address concerns in ways

that extend and expand intensive mothering expectations and practices beyond what is officially accepted or stated. Below, I explore ways in which disability discourse contributes to a distance between desirable outcomes/lived experiences for disabled adults. Following these explanations, I present narratives from three mothers, showing how various discursive elements described throughout this project coalesce to extend and expand intensive mothering practices and expectations.

Discursive Gaps and Contradictions.

The intensification of intensive mothering for parents of adults diagnosed with developmental disabilities is inextricable from the considerable discrepancy between idealized outcomes for disabled adults and parents' descriptions of their lived experiences with their children, highlighted in Table 3, below. Choice, inclusion and independence, three explicitly stated policy goals, are listed and described under the column titled "Idealized Outcomes". These categories include considerable overlap with one another and generally encompass the age-normative outcomes disabled adults are dominantly considered to deserve: images and text depicting work, independence from support persons and social interaction in leisure settings suggest that disabled adults can and should enact the flexibility necessary to approximate normative adulthood and display a version of the productivity and independence of the successful neoliberal citizen. Including statements made by parents, the text in the right-hand column is meant to illustrate the extent to which lived experiences can diverge from idealized outcomes. Some of the statements in the right-hand column directly reference idealized outcomes, with parents expressing concerns that disabled adults' experiences fail to align with dominantly

Table 3. Discrepancies Between Idealized Outcomes and Lived Experiences

Idealized Outcomes	Lived Experiences
<p style="text-align: center;">Inclusion</p> <p>The changes in the Act support adults with a developmental disability so that they are included in activities in the community (<i>About the Social Inclusion Act, Ontario 2009: 9</i>).</p> <div style="display: flex; justify-content: space-around;">   </div> <p>Images from <i>About the Social Inclusion Act</i> (ibid: 17, 15).</p>	<p>Al was... at home by himself for many months (Lily).</p> <p>I had caregiver fall asleep on the floor with her... [I]t was like pulling teeth to get them to even take her for a walk (Clara).</p> <p>They don't have friends who talk to them (Ali).</p> <p>MJ works at [a restaurant]. They say it's slow, so they can't give him more hours... Is it actually slow (Doreen)?</p> <p>I never wanted anyone to hurt him, so when I found out people did I was so ashamed I didn't protect him (Stephanie)</p>
<p style="text-align: center;">Choice</p> <p>Adults who have a developmental disability want more choice and control over their lives.... The new Act will give adults with a developmental disability more independence and choice (ibid: 3).</p> <div style="display: flex; justify-content: space-around;">   </div> <p>Images from <i>About the Social Inclusion Act</i> (ibid: 1, 8).</p>	<p>He needs people who will listen.... And he has troubles sequencing.... [U]nless you really... take the time, everything just falls apart (Elaine).</p> <p>Bill has lost freedom.... [Where he lives is] locked (Jane).</p> <p>Group [home] life created... unending anxiety.... Kristy and family had little or no control.... Kristy started constantly aggressing... She became habitually self-injurious and withdrew from... her social routines. She was hospitalized frequently for safety reasons (Jim Irving December 18 2013).</p>
<p style="text-align: center;">Independence</p> <p>They can live independently with the right supports. (ibid: 3)</p> <div style="display: flex; justify-content: space-around;">   </div> <p>Images from <i>About the Social Inclusion Act</i> (ibid: 11, 5)</p>	<p>He's losing skills that we taught him. He's not using a knife and fork. They are cutting... and giving him his food (Jane).</p> <p>He's never independently left the house... I was going to do [that] but we [had] all kinds of catastrophes in the summer, so all my plans went on hold (Stephanie).</p> <p>I know my daughter is not employable. Who's going to watch her (Patti Zimmerman January 14 2014)?</p> <p>MJ was waiting at the mall... A mother with children... didn't move so MJ moved the child with his arm. The mother... said MJ pulled his penis. He ended up in jail (Doreen).</p>

desired outcomes. Some of the statements do not directly reference idealized outcomes, but rather include reference to more fundamental health and safety concerns such as possible incarceration and abuse.

These apparent contradictions, between idealized outcomes and lived experiences, occur not despite disability discourse; rather, these disparate outcomes and experiences are a part of disability discourse and occur because of disability discourse. To elaborate, these outcomes can be understood as effects of a discursive (re)production of disability as a category of undesirable difference and a discursive tendency to gloss over or ignore the challenges or impossibilities of attaining the idealized outcomes depicted in the right-hand column.

Fear and Loathing of Disability.

(Re)productions of disability/ normalcy distinctions contribute to an ongoing de-valuation of disability and characteristics associated with disability. This devaluation becomes apparent in reflection upon ways in which discursive elements stipulating disability/ normalcy operate and are deployed in disability discourse. To summarize the discourse described thus far, while developmentally disabled adults may at times approximate or enact some of the markers of normative adulthood and successful neoliberal citizenship they will, by the very definitions of normal/ abnormal deployed in disability discourse, never be fully encapsulated under constructions of normalcy. The impossibility of fully equating disability with normalcy within contemporary discourse is wrought by the very fact that the category of disability is produced as a state of medicalized anti-normal, which is used to build and uphold the terms of what

counts as normal, as discussed in the previous chapter. Also discussed in the previous chapter, the imagined “success” of disabled adults dominantly refers to and relies on an ability to flexibly enact the type of normalcy and success a medicalized categorization as having a developmental disability explicitly precludes. That is, disabled adults are pervasively considered to deserve independence and productivity, for which disabled adults are required to approximate or enact the independence and rationality associated with normative adulthood.

Considering these elements of disability discourse makes visible how disability is made undesirable in at least two ways. First, as Davis (2013) contends, when disability is produced as a (naturally and biologically) medically other or different human status, normalcy will always be preferred: “Tolerance for variation in the medicalized realm is far less flexible and inclusive than it is in the world of race and gender”. (ibid: 8). For Davis (ibid:7), “most people still want normal blood pressure, cholesterol, and bodily functions”. This means that, as *medically* other to a norm, disabled adults are not only considered to be abnormal; this abnormality is placed in hierarchical relation to the normal side of the disability/ normalcy binary, where normalcy is more desirable than disability.

Evidence and propagation of this hierarchical discursive effect can be found in consideration of the second way that disability discourse makes disability undesirable: Through emphasis on the deservingness of and requirement for disabled adults to enact the demands of normative adulthood and successful neoliberal citizenship. Positioning disabled adults as dependent, irrational and (potentially) failed neoliberal citizens who deserve to, can and should enact

independence and rationality to approximate the embodiment of successful neoliberal citizenship serves to re-value characteristics associated with normative adulthood and de-value characteristics associated with disabled adulthood; as largely unquestioned desired and desirable outcomes, normative traits are held to be unquestionably real, attainable and positive. This argument is not entirely novel: feminist disability studies scholar Eva Kittay (2011) has noted that disability studies' pervasive emphasis on independence as desirable, realistic and normative can be harmful to those who do not attain these ideals. For Kittay (ibid: 53), it is only "when we recognize that dependency is an aspect of what it is to be the sorts of beings we are, we, as a society, can begin to confront our fear and loathing of dependency and with it, of disability".

In the contemporary Ontario context, both the content of the left and right-hand columns of Table 3 can be seen as symptomatic and reproductive of this "fear and loathing" of dependency and disability: idealized versions of independence, inclusion and choice, which emphasize ability to choose and productivity, can only be valued if dependency is de-valued. Similarly, the undesired outcomes listed in the right-hand column, including health and safety concerns and, at the most extreme, suspected abuse, may be made possible when disability is not valued (Morris 1991: 122-127; Strong-Boag 2007). Some of these ideas are elaborated further below.

Glossing over Challenges and Barriers.

Disability discourse also includes consequences for disabled adults in relation to a discursive tendency to gloss over barriers or challenges to accessing "desirable" outcomes. Statements

and images in the left-hand column of Table 3 elide the difficulty that disabled adults may have finding “inclusion” and making real, meaningful choices in environments that include a “fear and loathing” of disability. Burton and Kagan (2006) comment that in UK policy, focus on the generalized community as a source of key outcomes appears to involve romanticization of the locales in which disabled adults reside, which may be more accurately characterized as hostile towards than accepting of disabled adults. Accordingly, finding inclusion – whether it entails paid work, meaningful activities and/ or friends - may be more difficult than policy statements often imply: “it’s hard to find normal people - “normal” - who will spend time with other people and help them come and have a better life” (Stephanie). As discussed in the previous chapter, this seems to be especially true for those who present as falling too far from the border demarcating the boundaries of normalcy, for whom a fear and loathing of disability may justify behaviour modification measures and be associated with incarceration.

The “community” may not be the only place less accepting or amenable to inclusion and other positively-valued outcomes than suggested in official discourse. Kittay (2011) warns that denigration of dependency related difference impedes acceptance or celebration of disability *and* of those that care for people with disabilities. Consistent with this concern, many presentations by workers or organizations that support disabled adults state a need for an increase in developmental service sector wages to enable staff retention and many parents discuss difficulty locating quality staff or services for their children. Highlighting connections between value associated with disability, staff remuneration and quality of care available, Clara (a mother) and Ashley (a sister), for example, speculate that either low pay or the demands of

working with adults with disabilities lead to staff turnover and low staff performance at the group home where their daughter/ sister regularly accesses respite care:

Clara: One thing that bothers me though is you have some nice staff there, you really like them, and you never find out why they [left]...

Ashely: ...[T]hey aren't getting paid that much. Maybe they left to do something better.

Clara: I don't think it's that. I think basically... [the ED] doesn't take any garbage from anybody... [But] I was not happy cause when [the former staff] were there it was beautiful. Now [they] are gone.

Ashley: Well, basically they weren't doing anything.

Clara: ...[M]aybe those two girls were coming in. Tak[ing] their coffee. Sit[ting] there and watch[ing] tv, instead of taking care [of the residents]. Some of these guys at this home. When you see them within the home, some of them have IVs hooked up to them.

Ashley: [But] if you can't handle [it], why are you taking that job?

Thus, even when families have access to privately or publicly funded services, they often report that services do not foster desired outcomes. Some parents' worries refer specifically to idealizations of normative outcomes, while others refer more explicitly to health and safety concerns, including the possibility of abuse, as mentioned in the righthand column of Table 3. Although highly relevant to parents, official discourse, which focuses on choice, inclusion and independence, may imply that these more fundamental concerns, such as access to appropriate housing and health and safety concerns, are taken care of.

Finally, the glossing over of challenges or barriers to idealized outcomes that occurs in dominant discourse extends to understandings of the disabled subject as well. In this regard, *The Social Inclusion Act* (2008) may be similar to UK policy for adults with learning disabilities,

which Burton and Kagan (2006: 305) argue involves “a kind of romanticism about learning disabled people, so that significant impairments and the personal histories that produce human damage, are not so much denied as glossed over”, suggesting little need for significant levels of support. Illustrating this effect in the current project, the images presented in the left-hand column of Table 3 depict adults with disabilities engaging in leisure, work and social activities with little or no visible support. These adults can be read as embodying normative characteristics and displaying normative comportment to the extent that they are able to enact the desirable (normative) outcomes of disability discourse, such as engaging in paid work. Conspicuously absent from these images is recognition of the discursively produced impossibility of universal attainment of normative characteristics and attendant enactment of desirable (normative) roles and inclusion. As previously explored, disabled bodies and minds are used to produce, affirm, reify and assert binary visions of irrational/ rational and dependent/ independent subjects. Produced as dependent, irrational and risky, developmentally disabled adults provide and uphold the (mythical) impression that rational, independent subjects exist. As such, disability discourse belies the fact that rationality and independence are imaginary constructs to begin with (e.g. Kittay 2011). Simultaneously, disability discourse ensures that disabled adults, as categorically and definitionally other-than-normal, will never completely or universally be read as embodying rationality and independence, characteristics understood to be natural preconditions for inclusion and success.

Policy and discourse do include some recognition that some disabled adults will require support to attain desirable outcomes. Further, policy and discourse include recognition that some

disabled adults will require more support than others, in the SIS (AAIDD 2004a in AAIDDb 2004) for example. Nonetheless, this recognition that disabled adults may require support to enact normative comportment to attain (normative) desirable outcomes disappears as in the images depicted in Table 3. In this sense, the images deployed in policy may be more closely aligned with discursive elements stressing the promises of individual potential than discursive elements stressing the necessity of support to achieve the (desirable) outcomes associated with successful neoliberal adulthood. Glossing over the quantity and quality of support at times needed to enact rationality and independence, discursive themes of potential and idealized outcomes may justify a lack of entitlements, may imply that more basic concerns, such as transportation needs and health and safety issues, are irrelevant or taken for granted and may therefore contribute to an intensification of mothering responsibilities in making this near normalcy appear to happen. Some of the ways in which these various discursive threads intertwine to intensify motherhood are discussed below.

Implications of Discursive Gaps and Contradictions.

The gaps, tensions and contradictions inherent to disability discourse mean that, even when parents do not agree with the prescriptive, idealized outcomes enforced in policy and elsewhere (e.g. Clegg et al. 2008), their care work is nonetheless intensified in interaction with this discourse. A lack of appropriate or adequate services, risk of abuse, incarceration or hospitalization and non-inclusive social environments mean that parents not only perform the work required to bridge actual and idealized outcomes, they additionally work to address health and safety concerns. To illustrate complex ways in which expectations for mothering

and family provided care are strengthened, expanded and justified in interaction with disability discourse, I present three mothers' narratives below. Each narrative is meant to highlight the operation and effects of specific discursive elements in the context of a specific mother's life.

The first narrative, Cora Nolan's (January 17 2014) story, centers around choice and planning. In Cora's talk, we can see how discursive elements of unique individuality help justify and depoliticize a lack of quality or appropriate care options: like other mothers involved in this research, Cora seems to interpret a lack of desirable services and supports in light of her son's individual needs and preferences and less in terms of the lack of generally available quality supports or services discussed above. Mothers often state a belief that, while suitable services may exist for others, they do not exist for their children due to diagnosis, needs, personality or interests. In this way, a lack of quality services, a focus on individuality and intensive mothering expectations and practices are mutually reinforcing and justifying: instead of asking for universal access to high quality services, Cora advocates for more individualized funding so that parents can continue providing for their children.

To this end, even when some publicly funded services are available, parents at times choose to care for their adult children themselves because available services do not seem appropriate or of high enough quality. The work involved when caring without formally provided services and/

Cora Nolan's Story

My name is Cora Nolan... Our son, David, who will be 39 years old in March, has a developmental disability, limited speech, numerous medical challenges and needs supervision and support 24/7. When leaving school at 21, the only option offered in our county was a segregated day program that offered traditional supports. We did try this, but David was very unhappy. He did not want to attend, and this caused him frustration, anxiety and regression. It became very apparent that this did not meet his needs.

I just got tired fighting with everybody, and nobody could seem to see what I wanted, so it was just easier to do it myself. We realized that if we wanted him to have a full, interesting and productive life, similar to what you and I experience, then we needed to design a personal plan for him that would meet his needs and lifestyle, based on his needs, interests, strengths and the skills necessary to function and be personally successful to the best of his abilities in his community.

In 2004, we developed a personal plan... and began our quest to acquire funding to support it. We approached ministry personnel in the Kingston area office.... They could see the benefits to David and acknowledged that this was a financially responsible approach to meeting his needs. We did receive some funding that allowed us to implement part of David's plan... [I]t has not been an easy road to travel and there have been many stops, twists, turns and tears along the way. But it is amazing what a difference this approach has made, not only to David, but to our family as well. He is happy, enthusiastic and proud of himself and his accomplishments.

Individual direct funding is not a program, it is a lifestyle that is person-directed. We believe in this approach because it enhances quality of life through individualization for David. It promotes true choice. It respects his rights and encourages flexible opportunities and options. There is a true recognition of respect and dignity, and there is individuality, which ensures a better and more meaningful quality of life now and in the future. Individuals with disabilities have the same wants, needs, rights and expectations as anyone else. Our ultimate goal is to have adequate, annualized dollars to implement and support his entire personalized plan, and include cost-of-living allowance increases, to enable us to pay his support workers a reasonable salary.

In 2010, we built a home with accommodation for David to have his own space within our family home, and he is really enjoying this ownership. It also provides security and stability for his future. We are continuously stressed and worried that David's current funding will be cut or reduced. We go from year to year not knowing what processes or applications will be changed or required. I realize that not everyone or every family wants to take the time to plan, implement and supervise an individual plan for their son or daughter, where you hire your own workers, self-administer funding, do record-keeping and all related paperwork. I acknowledge that it does require a great deal of time, but we consider it investing in David's future.

Note: This story consists of excerpts from Cora Nolan's (January 17 2014) presentation to the Select Committee.

or when choice and planning are invoked are made explicit in parts of Cora's narrative: Cora lists the work she undertakes to implement David's individualized plan, and she discusses funding and building a new home to give her son independence in the form of his "own space".

The second story, Linda Russell's (December 18 2013), further explores parents/ mothers' intensive involvement when parents are responsible for implementing individualized plans or accessing choice. Throughout Linda's talk, connections to an ideology of intensive mothering are apparent. She discusses "making financial sacrifices" and "putting her [daughter's] needs first" in ways that sometimes extend beyond what she views as acceptable. Particularly noteworthy in Linda's narrative are the efforts she and her husband put into ensuring their daughter is able to enact the "productivity" demanded of disabled adults. Elegantly showing the effects of the juxta-positioning of parent/ child needs, caregiving demands mean that Linda Russel does not participate in paid work herself. That said, she devotes some of her time ensuring that her adult daughter is able to participate in volunteer jobs.

While it may be widely accepted that disabled adults require support to flexibly enact the demands of neoliberal personhood, as discussed above, this support is readily downplayed or rendered invisible. To wit, most of the images in the left-hand column of the above table do not depict a support person; disabled adults are instead frequently depicted as working or engaging in leisure activities alone. In contrast, parents' stories highlight the incredible work it can take for disabled adults to successfully enact rationality and associated productivity in the way envisioned in dominant discourse. This productivity, however, is important to many parents; in

Linda Russell

Joanne requires 24-hour supervision and assistance with feeding, toileting and all areas of daily life. We have provided that care for her entire 33 years, and we do not regret that. However, as my husband and I grow older we are physically, mentally, and emotionally tired.... My dream is to see Joanne settled and happy in a safe and stimulating home before a crisis occurs. Most of our friends and family think we choose to continue supporting Joanne at home. They are astounded and horrified that our society has no options available for individuals like Joanne.

We have worked hard to maximize Joanne's capabilities. We have provided her with ongoing therapy.... community experiences and continuing support. Her father and myself take her to and support her at no less than three volunteer jobs. Her work is appreciated, because she has proven herself to be a dedicated worker.... that can be counted on to complete the task at hand.

We have made sacrifices for Joanne: 1) financial, because we gave up a second income so that I could stay at home and care for her, as well as incurring increased costs to support her and 2) physical sacrifices because the stress of caring for her is becoming more difficult by the day.... You may or may not understand how difficult it is to push a wheelchair through snow... [and to] lift it in and out of the trunk of the car.

The relentless daily responsibility is tiring as well. If a worker cancels, if Joanne's bus transportation is cancelled, if the day program is cancelled, whatever my husband and I have scheduled for the day has to be cancelled because her needs come first. My husband and I have to make sure that our activities fit in with the availability of workers who are there to support our daughter. We have no evening activities... Our primary focus is always Joanne. She is the one that takes most of our effort, and she is the one that needs us the most.

We do get... Passport funding..... and we use that to offset the costs of the day support program, and we use it to hire private personal support workers. My husband and I are finding that we're in need of more time off to regroup... so we hire more workers. The money we get from Passport gets spent earlier in the year, and we make up the balance from our finances.

We have done everything we can to improve life for our daughters, including being a strong advocate for Joanne and others like her. However, the reality is we can't do this alone. We simply don't have enough money to support Joanne for the rest of her life. It is important that you understand how desperate we are for assistance, but it is also important that you understand Joanne's intrinsic value as a person in her community. Yes, it is challenging to support Joanne, but it is intensely rewarding to see her success. That is why we have supported her for so many years. That, and because we love her. One thing I really want to get across... is that even though she is an individual with high needs, she can offer things to the community. She's had a volunteer job at the Salvation Army thrift store... ever since she finished school.... There isn't another volunteer who has lasted as long as she has.

Note: This story consists of excerpts from Linda Russell's (December 18 2013) presentation to the Select Committee.

a context where disability is generally devalued, Linda Russell names and describes her daughter's "contributions" to justify her worth as a person and her deservingness of services.

The final narrative, Jane's story, includes more of a focus on inclusion as made possible via potential and the enactment of normalcy. Jane's narrative highlights the substantial time and financial and emotional resources parents/ mothers put into their disabled children's development toward normalcy. As discussed above, the harnessing and activation of individual potential is considered especially important in a context where the enactment of normalcy is often a prerequisite for inclusion or community participation. As also discussed above, however, this strategy will inevitably fail at least some of the time: as different than normal adults, disabled adults are discursively excluded from perfectly emulating the demands of modernist personhood and successful neoliberal citizenship.

As Jane's story highlights, when the strategy of potential does fail, mothers can be left to deal with the emotional and practical implications of these failed promises and of parenting an adult child for whom there exists limited inclusion-oriented options despite the ubiquity of rhetoric glorifying and promising inclusion. Articulating the irony she has witnessed in her experiences as a mother, Jane shares that, despite encountering frequent, generalized pro-inclusion statements, her son was often deemed ineligible for inclusion in even specialized activities due to his non-normative behaviour. Accordingly, this final narrative once again shows how discourse can gloss over the difficulties associated with accessing inclusion and how (failed) promises of potential and inclusion can intensify and complicate mothering experiences.

Jane

Bill was diagnosed in May and we were in [intervention] in June. I look at it as though he's been going to university since he was born. I [was] always ahead of the game. When Bill went to high school, we put him on medication. The self-injurious behaviour had been increasing. Bill's... moving furniture... Now he was hurdling counters at McDonald's. We were going to psychiatrists, we are talking top pediatric psychiatrists. They'd say... "do you think we should give him more meds? OK, here's the script". So, our life became very sheltered. He and I [were stuck] in the house [for many months]. We could not go anywhere. Even to get him in the car, he would sometimes run up the street and move people's planters on their porch.

And people always say "oh, inclusion. Ya we don't want to discriminate". But people in society have rules. I've had people who automatically recognize [he has autism], open the door for me, hold the door... And then there are people who flat out make comments.

And [the City has] camps but they have 3 spots allocated for special needs. Sometimes they've had to ask the parents to pull the kid from the program. While you say its inclusion, you still have a list of 20 rules. You need to be quiet, you need to be standing in a line nicely.

He needs a day program, like a daily activity schedule. Cause if he's in a group home, in a regular group and those other three are going out to... [do] something at Walmart. Bill can't do that.

In October... he just started hitting [himself]. Twenty minutes in, I said, "I am not waiting any longer I am calling 911". EMS gets here. So [the police] came in and my husband said, "what are you going to do?" They said, "put him in handcuffs". So, we had to explain "we know... he seems aggressive, but he's not aggressive to you, he's self-injurious", so my husband said, "I'm not letting you put handcuffs on him". And EMS said, "We can take him, but we are going to handcuff him to a gurney and if he gets really bad we inject him", and it was some med it knocks him out within a second and it has long lasting effects. And we said, "no, we are not letting you do that to our son". So, my husband said, "we are going to have to go sit with you in the back of the police car", and he did.

At this point, [the specialist] says we've got two options here. [We can try this behaviour plan]. [Or] he can live like a bubble boy. His quality of life will deteriorate. Because he can't go out. And all the stuff we've worked, and we've paid thousands of dollars to be able to go to a restaurant. He won't be able to do that. And I cry now because... we have tried so incredibly hard to give Bill, he does everything with us. You know what, you are learning how to skate. We ski, you are skiing.... And now we are being told oh my god this is what his life could be like. Oh my god we are going to sign off on letting them do this [intervention] to our son. Versus living in a bubble.

Boundaries of Parenthood

Thus far I've characterized the Ontario context as one where parents are viewed as ultimately and most appropriately responsible for their children and where desirable outcomes, normative or otherwise, are often challenging to access via social service or more generally available community-based options. Within this context, it can be difficult for parents to articulate that they want to step away from intensive parenting roles or that they want someone other than themselves to care for their children. This seems to most often manifest around placement in residential settings, where adults would live somewhere other than in the family home. Many parents do not mention a need for residential services, preferring their children live with them in their family's home. Expressing concerns about the quality of group homes in comparison to the type of care her son receives when living with her, Doreen states, "the problem with group homes is there is abuse.... MJ's been well taken care of [at home and].... you never know". Speaking about transitioning her son to live in a group home, Colleen Butler (December 18 2013) communicates that she feels like she is abandoning her son, a sentiment made possible when mothers are deemed the best and most appropriate carers for their disabled adult children: "I need to do this, yet my heart feels like I'm abandoning my most vulnerable child" (Colleen Butler December 18 2013).

These parents' discussions about residential arrangements other than the family home invoke discursive elements of family-based care as naturally superior and individualized/ familialized responsibility, tied to conceptions that publicly provided care is low quality or simply not available. Accordingly, disability discourse, in its entanglements with motherhood and family

and observations about publicly provided care, compel mothers to behave in ways consistent with neoliberal demands and familialization of care. As discussed above, many mothers expect to be their children's primary supports, and will ask for information or funding to help themselves in this role.

Although the tensions and contradictions characteristic of disability discourse thus easily interweave with the logics of neoliberalism and intensive mothering ideology to govern mothers' conduct in the provision of and responsibility for family provided care, these same discursive elements create space for resistance to the logics of neoliberalism. Consistent with Foucault's (1978: 100-102) rule of the tactical polyvalence of discourses, which holds that "we must conceive discourse as a series of discontinuous segments whose tactical function is neither uniform nor stable" (ibid: 100), developmental disability discourse and associated conceptualizations of mothers who care the most for their children make it possible for mothers to make demands that question the neoliberal logic that intertwines with developmental disability discourse.

To this end, both discursive strands holding that disabled adults are different than normal and deserving of normative outcomes and experiences make it possible for parents to draw morally acceptable boundaries around their parenting roles while maintaining that they know their children best and care for them the most. To illustrate, some mothers argue that their children would be best supported by someone other than themselves by referring to their children's adult status, the need for friendship and inclusion and their children's wishes. "He doesn't

want to hang out with me, he wants to hang out with his peer group, have his own life and his own activities, he doesn't always want to be hanging out with me" (Lily). "My daughter is on the list for assisted housing, because I'm a firm believer that she's not going to live with me forever. I think it's a natural progression, whether you have special needs or not, that you move out of the house" (Jan Hudyma January 14 2014).

Parents can similarly make claims that they should not be their child's primary support person by invoking the flip side of the discourse, that their children are different than normal. In these cases, parents often state that their adult children's specialized or medical needs extend beyond what a family can reasonably provide. Jane, for example, frequently states that her son requires specialists and experts to ensure his well-being. While she is able to make a moral claim about her son's need for residential services, Jane nonetheless has difficulty saying that her son should live somewhere other than the family home:

Bill provides challenges to us that even in the safest of places, and in the most controlled circumstances, it didn't work. It did not work. And for us to, I mean... of course I was highly emotional... and I just said, "we are trying to bring humour in it". I said, "honestly guys, if Bill came home and was self-injurious what am I supposed to do"? The only thing to do would be to call the hospital or call EMS. (Jane)

The Fragility of Familialized Care.

Fragility created by the application of neoliberal logics and associated intensive reliance on parents additionally makes possible morally acceptable demands for services or supports. As the ultimate guarantors of their adult children's support and well-being, parents' consideration of their own mortality allows them to ask for funding, residential placements or other services.

“I get scared. I was sick recently, and I was frightened to die, because I want to keep alive to fight for my boy” (Patti Zimmerman January 14). Similarly, to back her argument about the importance of accessing and establishing a residential arrangement outside of the family home for her son, Colleen Butler (December 18 2013) states:

As we age, we need to be aware of our own mortality.... Imagine the stress and confusion of living with mom and dad for 30-plus years. All of a sudden, something changes, and you are put in a supported-living home. You do not know the staff or the residents... It’s not good for them to be so reliant on their parents. I’m not going to live forever, and then what happens? I wouldn’t want to be the person to pick up those pieces. Because with Michael, I turn around some days—it’s only him and I in the evening—and he’s right there. Like he’s—boom, I walk into him. But what happens when I’m not there? My husband and my other son are going to have a mess.

Demands on family are also deemed too much when parents believe that other siblings’ well-being is compromised because of the time parents spend caring for their disabled adult child or because they believe their other children would be responsible for their adult children in the event of their own illness, injury or death. In these cases, dictates of responsible motherhood mean that siblings’ well-being creates the basis for morally acceptable demands for services. “Tragically, our son has often accused his mother of only caring about Kristy. We share this private perception as an example of how overwhelmed parents carrying overwhelming responsibilities and risks are seen by extended family members over time” (Jim Irving December 18 2013).

Also illustrating the shortcomings of neoliberal logics, intensive demands on mothers sometimes create situations which are financially, emotionally and/ or physically impossible to for mothers to navigate. Pointing to the challenges associated with being ultimately

responsible and having to advocate for and pursue services, Lily states “I just almost didn’t have it in me any more to even call and try and negotiate services. I don’t know if that makes any sense. You get to a point where you just have too much on your plate and you can’t do one more thing” (Lily). Similarly, Stephanie says, “I gave him the summer to relax and then... we were gonna be going to a day program, but then we had the emergency [with my mother in law] so I put that all off on hold because I can’t split myself that far. There is no way I can get mom up and him and get him over there and pick him up and everything because you never know what’s gonna happen”. Elaine says she had to put her son in long term care because having him at home meant being perpetually tied to the house. She also says, however, “He loved it [being at home]. Why can’t we just keep the parade coming mom?... He knows. He knows we struggle getting him in and out of the van. It’s really hard. And bathing is another issue”.

Critiquing the Imagined Necessity of the Well-Resourced, Nuclear Family.

In an interconnection between the demands of parenting disabled adults in a system without entitlements and the power of gendered, nuclear family forms on imaginings about childrearing (Nelson 2006; Folgerø 2008), many parents argue that well resourced nuclear family forms, often involving a patriarchal provider and a maternal caregiver, are required to meet their adult children’s needs. In other words, the knowledge, financial resources and time often experienced as necessary to provide a good life for disabled adults means that many parents have a hard time imagining successful care arrangements that fall outside the gendered, middle class, nuclear family form. Jane, for example, argues that a lack of entitlements to residential

care entrench gendered patterns of work and care based upon a patriarchal provider and a maternal caregiver.

There is no place for them to go. There is no residential. There is no day program. I said like ok what are they doing? Well they are at home. And their parents can't do anything. They don't have access to family members to care for these young people. They are basically just doing it day by day. Which most likely means the dad works the mom most likely can't have a job because she can't leave the child, right? Or, it's not working or where she works outside the home and the amount of money they pay to have a caregiver exceeds [what she makes at] work. It's crazy, right. And I don't know." (Jane)

Similarly, Clara and Felix articulate that two parents, a patriarchal provider and a maternal caregiver, are required to successfully undertake the financial and caring work required in contemporary caring configurations:

Clara: he takes care of the paperwork I take care of the rest because if it was only one person doing it they would lose it. We do 50/50 here.... Cause one person doing this wouldn't work.

Felix: single families a single mom or dad could not take care of a child like Vanessa. You really need a lot of support.

Clara: But what's gonna happen now he's gonna be working more [to pay for this] van so I'm gonna be doing a lot more in the way of Vanessa's care. [But it isn't tiring] because I'm so used to it.

Felix: It is so tiring. I'm tired all the time (laughing).

While neither Clara and Felix nor Jane whole heartedly embrace the gendered roles they feel are required of them, they did not see any other options. Colleen Butler (December 18 2013) similarly remarks that policy expectations on parents are such that she, as a mother, is (unjustly) unable to participate in paid work. "I was told that funding is not an entitlement, that you are entitled to an education but at age 21 you are not entitled to anything. I still don't understand this statement. Aren't I entitled to be employed, like the next person? Isn't Michael

entitled to a fulfilling life? We need help. We need support”. In fact, some mothers who were unable to provide for their disabled adult children referred to their distance from nuclear family form to explain why they were unable to do so: “He has lived in a group home since he was 11 years old. I am a single parent and have had serious health issues, so I physically was unable to care for Karim at home, and I was faced with no other option but to place him in a group home” (Iman Seifeldin January 17 2017).

Also consistent with the demands of intensive mothering, many mothers seem to believe that knowledge about disability and the developmental service system and financial resources were required to ensure good outcomes for their adult children.

And I work in the social service system so I figure I’m pretty switched on so for me what I always come back to I feel really concerned for those families or parents who are maybe more isolated or not as informed or educated. So, I’m always kind of quite concerned about those people in terms of what’s happening for them....

And that’s what I keep saying. We are really well resourced. We have money, we go bowling, and skiing and do all these things, and I still saw the impact on what was happening to him. I can’t imagine if, and Al doesn’t have real significant behavioural issues, can you imagine having a child with high maintenance [needs] and, you know, finances are stressful and those are some of the things going through my mind. And I’m out working and then I got involved with the Down Syndrome Association, so I knew some of the resources but still knowing about them it was still really difficult to access them because you need that magical government funding. (Lily)

Like Lily, other parents stressed their privilege as members of a well resourced, nuclear family, and often wondered about parents or children who did not have similar advantages. “What if you don’t have money? What if you are a single parent?” (Jane). “I am an involved parent, and because of that I have seen a lot of upsetting things occur in systems over the years. What

about people who have developmental disabilities who do not have families, good advocates, and can't speak for themselves?" (Linda Nilson-Rogers January 17 2014).

Stressing their privilege and their concern for those who do not have similar privilege, these mothers echo academic critiques made of intensive mothering expectations parents of children: intensive mothering requires time and money, resources that working class or poor mothers might not be able to access (Fox 2009; Romagnoli and Wall 2012). Naming and describing this privilege allows mothers to question the apparent lack of equity inherent in the current discretionary service system.

Valuing Disabled Adults and Troubling Neoliberalism.

Alongside their requests for services or commentary upon the scarcity of quality, accessible, appropriate services, some parents take pains to assert that their children are worthy of love, care and support and are not themselves burdensome. Recall Linda Russel's (December 18 2013) statement that she and her husband do not regret the extensive efforts they put into caring for their daughter. Taken into consideration with commentary about wanting to care for their sons or daughters and on the deservingness of their sons or daughters to receive quality outcomes or care, these points of resistance seem to largely place any burden associated with caring on an underfunded, under-resourced developmental services system.

Diverging in perspective from earlier feminist writings on care, which consider caring a burden (e.g. Finch and Groves 1983), ethics of care theorists which valorize and at times

idealize the role of (maternal) carers (e.g. Noddings 1984) (see Shakespeare 2006: 135-152 for an overview and appraisal of feminist and disability studies perspectives on care), or middle-class mothers of young children who have been found to generally take individual responsibility for their children's outcomes (e.g. Wall 2010), some of the mothers in the current study take a stance where they value and desire good outcomes for their disabled children, and where they do want to care for their children, but where they believe that contemporary expectations on parents can be incongruent visions of a good life for their disabled adult children. Thus, discursive elements of difference, adulthood and responsabilized parenthood provide the, perhaps surprising, grounds for critique of the neoliberal logic which is so easily strengthened in interaction with these facets of discourse: parents love their children and want to do what they can for them, but would like to do so in a context where the system or province provides more than they currently do, both for themselves, and for their children. To this end, despite overwhelming neoliberalization of services and internalization of responsibility for their children's well-being, parents are able to make morally acceptable claims for state provision. That is to say, although developmental disability discourse contemporarily justifies and enhances neoliberal (limited) state provisions, the discourse simultaneously includes space for significant, quality state funded and provided services for disabled adults and their families.

Chapter 6

Conclusion

Armed with a general interest in parents and adults diagnosed with developmental disabilities, I began planning this dissertation project in 2010. Since that time, I have witnessed a proliferation of public outcry concerning the troubling status of adults diagnosed with developmental disabilities: over the past 7 years, journalists (e.g. CBC 2014; Kane 2012; Mosenbraaten 2012a, 2012b; Stevens 2015), the Ontario Ombudsman (Dubé 2016), and the Legislative Assembly of Ontario's Select Committee on Developmental Services (2013) investigations and reports have all repeatedly claimed that Ontario's developmental services sector is failing and that families, adults diagnosed with developmental disabilities and the entire system are in crisis. Listening to the public debates as I worked to shape my interests into a specific research project, I found myself increasingly questioning a superficially natural and inextricable part of the conversation and my general area of inquiry: the family. According to public dialogue, it is parents and families who are concerned for their adult children (e.g. Kane 2012, Stevens 2015), who surrender the care of their adult disabled children (e.g. Mosenbraaten), who are in crisis (Select Committee 2014: 3) and who should be supported (Select Committee 2014: 2) and empowered (ibid: 4). Through my developing post-structuralist lens, I came to view these categories as anything but natural and inextricable, but rather as important objects of study in their own rights and in their connection to one another. Thus, when I sat down to write this dissertation, instead of beginning by asking the more conventional questions, "how are families of adults diagnosed with developmental disabilities

doing?” or “why are families of disabled adults in crisis?”, I began by asking: “why are we talking about families?” and “how has family become so central to the problem and discussion of disability?”.

More specifically, I wanted to unpack the very meanings of disability, family and, in recognition of the gendered nature of care, motherhood that make possible and are (re)produced by contemporary practices related to developmental disabilities in Ontario. To use the technical terminology I apply throughout this thesis, I conducted this research with the aim of describing adult developmental disability discourse in Ontario between 2008-2014, especially in its entanglements with motherhood and its effects on mothers of disabled adults. Within this overarching aim, I ask the following questions: Who is the disabled adult subject of disability discourse, particularly as deployed in policy? (How) are motherhood and family embroiled in disability discourse? As they negotiate disability discourse, how do mothers (re)produce and resist dominant visions of disability, motherhood, and family? In this way, I am in some ways able to address the question, “why are families in crisis?”, but I do so in a way that does not assume the family as naturally central to the discussion, and that instead focuses on the operation and effects of the social meaning attached to disability, family, and motherhood.

Overview of Findings

To address these research questions, it was important to first situate the topics of study historically, socially and academically. In chapter Two, I provided a historical overview of shifting categorizations of and responses to developmental disability. As I did so, I noted that

contemporary arrangements and policies for adults diagnosed with developmental disabilities are largely influenced by academic and advocacy calls for integration, human rights and de-institutionalization. Despite the positive tone generally associated with concepts of community integration and inclusion, I highlighted connections between post-institutional contexts, trends toward a neoliberalization of services, a familialization of care and an ideology of intensive mothering, which together, have the capacity to assign considerable responsibility and blame to mothers and families. I then gave a brief overview of the dominant approach to research on families and adults with disabilities, arguing that a focus on the meaning attributed to disability, family, and motherhood shifts the focus away from mothers, families and specific services as sources of problems and solutions towards social and culturally based explanations for developmental sector “crises”.

In chapter Three, I explained the theoretical and methodological approach I use to access the social meanings associated with motherhood, disability, and family. I argued that post-structuralist discourse analysis, drawing from Foucault’s conception of discourse and the subject and a feminist focus on women’s talk and experiences, provides theoretical and methodological tools which allow for the in depth, complex, interpretive forms of research and analysis required to meet the aims of the study.

Findings from this discourse analysis are presented in chapters Four and Five. To understand how motherhood and disability intersect, I had to first address the question, “who is the subject of developmental disability discourse in Ontario?”, the results of which are presented in

Chapter Four. Indebted to both an ongoing, medicalized history and contemporary social model, people first and/ or human rights orientations, the adult of disability discourse is contradictorily (re)produced as medically other to the normal adult human and as a unique human who deserves normative experiences and opportunities. Additional polarization emerges in interaction with widely circulating neoliberal thought: as medically other to a norm, the disabled adult is naturally and legitimately unable to enact the demands of neoliberal citizenship; as a unique human, disabled adults should embrace their human potential and make choices consistent with the requirements of neoliberal citizenship. Thus, although disabled adults are (re)presented as belonging to a fixed category of difference, which prohibits the attainment of idealized neoliberal citizenship, disabled adults are simultaneously (re)presented as able to flexibly move around and across the border demarcating normalcy/ disability to approximate, without ever fully attaining, successful neoliberal citizenship. The tensions immanent to this discourse are partially addressed through repeated statements that disabled adults require some form of assistance or support to reach their potential, engage in (financially) productive activity and make (responsible) choices.

In Chapter Five, I continue to paint a picture of the disabled subject as I explore how these discursive tensions – of the disabled adult as medically other/ uniquely human and as deserving/ but not entitled to normative outcomes and support - are made possible by and serve to perpetuate gendered ideals and practices of parenting and a related familialization of care. As I do so, I show how characteristics of the discursive disabled adult interact with an ideology of intensive mothering and complimentary neoliberal logic, explicitly compelling

families generally and mothers specifically to “naturally” participate in intensive mothering practices. Imbued with common sense, these appeals to motherhood and practices of mothering are in many ways readily digestible and enacted. At times, however, the gaps, fissures and contradictions immanent to disability discourse require that mothers extend their mothering practices beyond what is explicitly asked or easily embraced. For this reason, the same contradictions that contribute to an expansion and intensification of mothering practices make it possible for mothers to place discursive boundaries around their mothering roles and to make demands on the state counter to the neoliberal logic woven throughout developmental disability discourse.

Contributions.

Most significantly, the findings from this research point to ways that constructs of family, adults diagnosed with developmental disabilities and motherhood intertwine and are interconnected in ways that entangle with larger social trends. To the best of my knowledge, this contribution is novel to the field: previous interpretive research concerning adults diagnosed with developmental disabilities and parents has focused on how parents negotiate and are constrained by discursive elements emphasized in disability policy, including self-determination (Pilnick et al. 2011), choice (Almack, Clegg, and Murphy 2009) and inclusion (Clegg et al. 2008). This dissertation extends on this small but complex body of literature by examining how understandings of motherhood and family actually make possible dominant understandings of disabled adulthood and vice-versa. Interrogating how the one category is productive of and

reliant upon the other allows for a more complex understanding of the basis, implementation and consequences of disability trends and policy.

Further to this line of thought, the findings in this research provide a view of some of the unintended and more difficult-to-discern consequences of disability-related trends, practices and policy. For example, while tools, processes, practices and assertions specifying the unique individuality of disabled adults may feel progressive, it is important to heed Foucault's warning about the cascading nature of individualization: while uniqueness may be imparted in an effort to recognize disabled adults' inherent humanity, it additionally opens disabled adults to forms of governance and control. As described in Chapter Four, the uniquely individual adult subjects of disability discourse deserve/ are required to plan and choose in ways consistent with the successful neoliberal citizen, justifying limited formally provided services and implicating disabled adults and parents/ mothers in intensive practices of individual risk management as they hire their own support workers and participate in programs and activities that are not regulated by the Ontario MCSS. Additionally, available choices are always constrained by a sense that normative outcomes (i.e. outcomes consistent with the successful neoliberal citizen) are desirable. By virtue of their individual, deficit-based distance from normalcy, disabled adults will never be able to fully enact the demands of successful neoliberal citizenship; however, disability discourse holds that disabled adults should harness their individual potential to approximate normalcy and enact diminished versions of neoliberal personhood. In other words, while always constrained in terms of available subjectivities, disabled adults are

nonetheless asked to choose from a limited or imaginary range of available options to come close to, without ever breaking down, the wall that divides disability and normalcy.

This dissertation also contributes to the important, yet relatively small field of literature that consciously seeks to position mothers of disabled children as neither victims nor problems (e.g. Landsman 2009; McKeever and Miller 2004; Ryan and Runswick-Cole 2008). The work presented here shows how a discursive approach makes it possible to avoid the traps of glorifying or vilifying mothers. A discursive approach instead enables a more nuanced understanding of mothers of disabled adults as critical social actors, who, despite being discursively adept and aware, are nonetheless constrained by the strands of the complex web of thought, (re)presentation, policy and practices in which they are embedded.

Limitations and Future Directions.

Like all research, this dissertation represents one possible way of examining, interpreting and understanding a specific area of inquiry, meaning there are (many) things this dissertation does not do, and (many) other possible ways of viewing and approaching the topic of interest. One obvious limitation of the current research is that, although I endeavored to conduct interviews with a diversity of families, and I do examine gender and – to a more limited extent – class in my analysis, this work could go much further in terms of intersectionality. Race and culture are areas that have been shown to intersect with disability in ways that need to be interrogated further (Bell 2006; Ben-Moshe and Magaña 2014; Connor 2008; Thomas 2014). To this end, an important next step for research in this area would be to continue the analysis presented in this

dissertation to investigate ways that race, for example, is bound up in discussions and practices concerning disability and family.

Because the interviews I conducted were quite open ended and many of my materials were “found” (i.e. I was not involved in their creation), I was able to capture a broad picture of developmental disability discourse, but I was less well equipped to specifically focus or follow up on some of the specific issues that emerged during analysis. Now that I’ve outlined and connected major threads endemic to disability discourse, a logical next step would be to further and more purposefully explore some of the threads and connections that emerged in this research, especially as they relate to motherhood and family. For example, promises that through planning, choice and activation of individual potential, disabled adults can and will achieve positive (often normative) outcomes appear to provide some mothers with considerable hope. At the same time, findings presented in chapter 5 highlight the discrepancies that often manifest between idealized outcomes and lived experiences. Future research could pick up on these themes of (broken) promises or (dashed) hopes to specifically interrogate the effects of discursive elements of intervention or planning, in ways that consider outcomes more broadly than those that can be measured quantitatively.

More specifically, as discussed above, this current research uniquely contributes to the literature on motherhood and disability by exploring the overlap between discourses of disabled adulthood and intensive motherhood. Future research could additionally flesh out and complicate the discourse presented in this dissertation by specifically and examining ways in

which discourses of neuroscience and brain development converge with discourses of disabled adulthood and intensive mothering. The relevance of this possible path for research is supported by prior research which shows overlap and mutual reinforcement between discourses of neuroscience and motherhood as they pertain to young children. In her research with middle-class mothers of young children, Wall (2010) found that brain development discourse coincided with intensive mothering discourse to the effect that mothers were highly invested and involved in intensive mothering practices, which they carried out with the intent of enhancing their children's intelligence. Landsman's (2009) research about motherhood and young disabled children similarly highlights convergence between discourses of motherhood and neuroscience, but also shows how these discourses overlap with and support ideas and practices relating to disability. The mothers in Landsman's research often told stories about their children "overcoming disability" (ibid: 91-142). Landsman (ibid: 130) found that these "overcoming disability" narratives incorporated and were supported by notions of brain malleability, a mother's hard work, and the success of early intervention strategies (ibid: 130). Accordingly, ideas about motherhood and the human brain, as integrated into narratives of children's progress (away from disability), both gave mothers hope that their children could attain the markers of full personhood and contributed to the (intensive) efforts mothers put into their children's development: "Mothers thus express in their narratives both the boundless hope and ever-present, exhausting burdens inherent in a child's open-ended prognosis" (ibid: 141).

Together with the current research, which reveals previously under-considered interconnections and mutual reinforcements between discourses of disabled adulthood and intensive mothering, Landsman's (2009) work raises questions worthy of exploration in future research on motherhood and disabled adulthood. As I discussed above, participation in professional and early intervention does not necessarily correspond with desired outcomes for disabled adults. How do mothers of adult children diagnosed with disabilities make sense of, question or reinforce the promises of neuroscientific brain development in their reflections on early intervention strategies their children participated in? How are causes of and responsibility for disabled adults' "successes" or "failures" assigned in reference to notions of brain development discourse, which often stresses the importance of parents/ mothers' efforts and inputs and suggests the largely unbridled potential of all children? How are "success" and appropriate pathways to achieve success for disabled adults defined in reference to brain development discourse? Popularized brain development discourse holds that a child's "early years" are especially important in determining future success and outcomes (Wall 2004); do notions of "windows of opportunity" contribute to understandings that disabled adults have "progressed" as far as they possibly can and/ or is the hope provided by ideas about brain plasticity extended to include people of all ages? Alternatively, are ongoing commitments (or lack thereof) to disabled adults' "development" informed by other, competing versions of human learning, potential and development? Exploring these types of issues in future research could further complicate and extend the analysis presented in this dissertation by contributing to an understanding of how brain development discourse continues to influence discourses of disability and motherhood beyond early childhood and into adulthood.

Although this research focused on mothers and motherhood in relation to disability, I originally intended to interview adults diagnosed with developmental disabilities. While I was able to interview one disabled adult alongside his mother, none of my other recruitment attempts were successful. Although difficulties recruiting participants diagnosed with intellectual or developmental disabilities have been well described in academic literature (Nicholson, Coyler, and Cooper 2013), future researchers should endeavour to include adults diagnosed with developmental disabilities in interviews to examine ways in which disabled adults participate in disability discourse as it interweaves with family.

Finally, the mothers who participated in interviews were all on waiting lists for provincially funded services and presenters to the Select Committee were likely dissatisfied with an element of service provision. Because I analyzed talk and text from these mothers, but not from mothers or parents more inclined to report satisfaction with the overall type and level of services available to them, this research could be potentially critiqued for involving a sample that overemphasizes a familialization of care. Conducting interviews with families who report considerable satisfaction with the services available to their adult children may complicate the picture of neoliberalization I painted in this dissertation. On the other hand, findings from such research could confirm findings from this project that parents report feeling grateful in ways that reflect neoliberal, individualizing logic. Either way, future investigations into “success” stories could provide further insight into the operation of developmental disability discourse as it impacts mothers and families.

Concluding Thoughts

In 2014, Helena Jaczek, the Minister of the Ontario MCSS, responded to the Select Committee's final report, stating that:

The report reinforces the concerns our government has also heard and is already taking steps on many fronts to address. This year's provincial Budget includes an investment of \$810 million over the next three years to strengthen and increase the range of government-funded services and supports that people with a developmental disability and their families need (Helena Jaczek in *Comprehensive Government Response to the Select Committee on Developmental Services 2014*).

Similarly, in her 2016 response to the Ontario Ombudsman's report on developmental disability and crisis in Ontario, Janet Menard, the Deputy Minister of the Ontario MCSS, communicates a sense that the provincial government is taking practical measures to make the lives of adults with disabilities and their families better: "We are fully committed to working with your office, individuals and families, and the sector to improve outcomes for individuals diagnosed with developmental disabilities. As such, I am pleased... to report on the real progress we have already made" (in Dubé 2016: n.p.).

Despite these stated commitments and this "real progress", earlier this year a Timmins Ontario family launched a class action lawsuit against the provincial government, raising questions about whether recent outpourings of commitments and recommendations have or will yield actual change for adults diagnosed with developmental disabilities in Ontario:

The statement of claim alleges the teen had access to necessary support through one government department as a child, but that was "arbitrarily and unreasonably" discontinued after her 18th birthday.

It further alleges that she applied for support as an adult through a different department and was placed on a wait list, where she remains more than a year later.

The suit, which is seeking \$110 million in damages, alleges the province breached its duties to Leroux and other adults with developmental disabilities by failing to properly manage the wait lists, forcing her relatives to assume her care. (Loriggio 2017: N.p.)

To this end, one final recommendation for future research would be to analyze recommendations and changes made in the developmental services sector to assess whether proposed or actual changes represent a real shift in discourse, political rationality and/ or responsibility. Results from the current research suggest that, as long disabled adults are (re)produced as different than normal but as deserving normative outcomes alongside beliefs that parents can and should be the ultimate and unique guarantors of their adult children's welfare, "people with developmental disabilities and their families" will remain bound in ways that contribute to limited entitlements and intensive responsibility for individuals, mothers and families.

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⁸ This reference section encompasses all references (academic and otherwise) with the exception of the Government of Ontario documents, Policies and Acts I used as data in the dissertation. For clarity, these Government of Ontario references are presented below in a separate References section.

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⁹ While this item is not published by the Government of Ontario, I included it in this reference section because it is used during the assessment process for provincially funded developmental services.

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Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act: Quality Assurance Measures. 2008. Ontario Regulation 299/10.

Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act: Transition: Deemed Eligibility for Adult Developmental Services and Supports Under the Act. 2008. Ontario Regulation 414/12.

Appendix A: Queen's University Health Sciences and Affiliated Teaching Hospitals Research

Ethics Board Approval



QUEEN'S UNIVERSITY HEALTH SCIENCES & AFFILIATED TEACHING HOSPITALS RESEARCH ETHICS BOARD

August 02, 2012

Mrs. Helene Ouellette-Kuntz
Department of Community Health and Epidemiology
Queen's University

Dear Mrs. Ouellette-Kuntz,

Study Title: Families Seeking Adult Developmental Services: Phase Three - Understanding Innovative Practices

Co-Investigators: Miss R. Saaltink, Dr. Y. Lunsky, Dr. C. Krull

Full Board Meeting Date: June 18, 2012

The members of the Queen's University Health Sciences & Affiliated Teaching Hospitals Research Ethics Board have examined the protocol, telephone script: first contact with families, telephone script: interview booking with families if consent not yet returned, telephone script: interview booking with families if consent returned, telephone script: interview booking with supports, interview guide for family members, interview guide for support persons, letter of introduction for supports (mail), letter of introduction for supports (email), consent questions for participants with intellectual or developmental disabilities, letter of introduction for families, information/consent form for providers of support (July 5, 2012), information/consent form for parents (July 8, 2012), information/consent form for family members (July 5, 2012) for your project (as stated above) and consider it to be ethically acceptable. This approval is valid for one year from the date of the Chair's signature below. Please attend carefully to the following list of ethics requirements you must fulfill over the course of your study:

Reporting of Amendments: If there are any changes to your study (e.g. consent, protocol, study procedures, etc.), you must submit an amendment to the Research Ethics Board for approval

Reporting of Serious Adverse Events: Any unexpected serious adverse event occurring locally must be reported within 2 working days or earlier if required by the study sponsor. All other serious adverse events must be reported within 15 days after becoming aware of the information.

Reporting of Complaints: Any complaints made by participants or persons acting on behalf of participants must be reported to the Research Ethics Board within 7 days of becoming aware of the complaint. **Note:** All documents supplied to participants must have the contact information for the Research Ethics Board.

Annual Renewal: Prior to the expiration of your approval (which is one year from the date of the Chair's signature below), you will be reminded to submit your renewal form along with any new changes or amendments you wish to make to your study. If there have been no major changes to your protocol, your approval may be renewed for another year.

Yours sincerely,

Albert J. Clark

Chair, Research Ethics Board

Study Code: EPID-387-12 Romeo #6007060

Investigators please note that if your trial is registered by the sponsor, you must take responsibility to ensure that the registration information is accurate and complete

Appendix B: Interview Guides for Family Members

First Interview

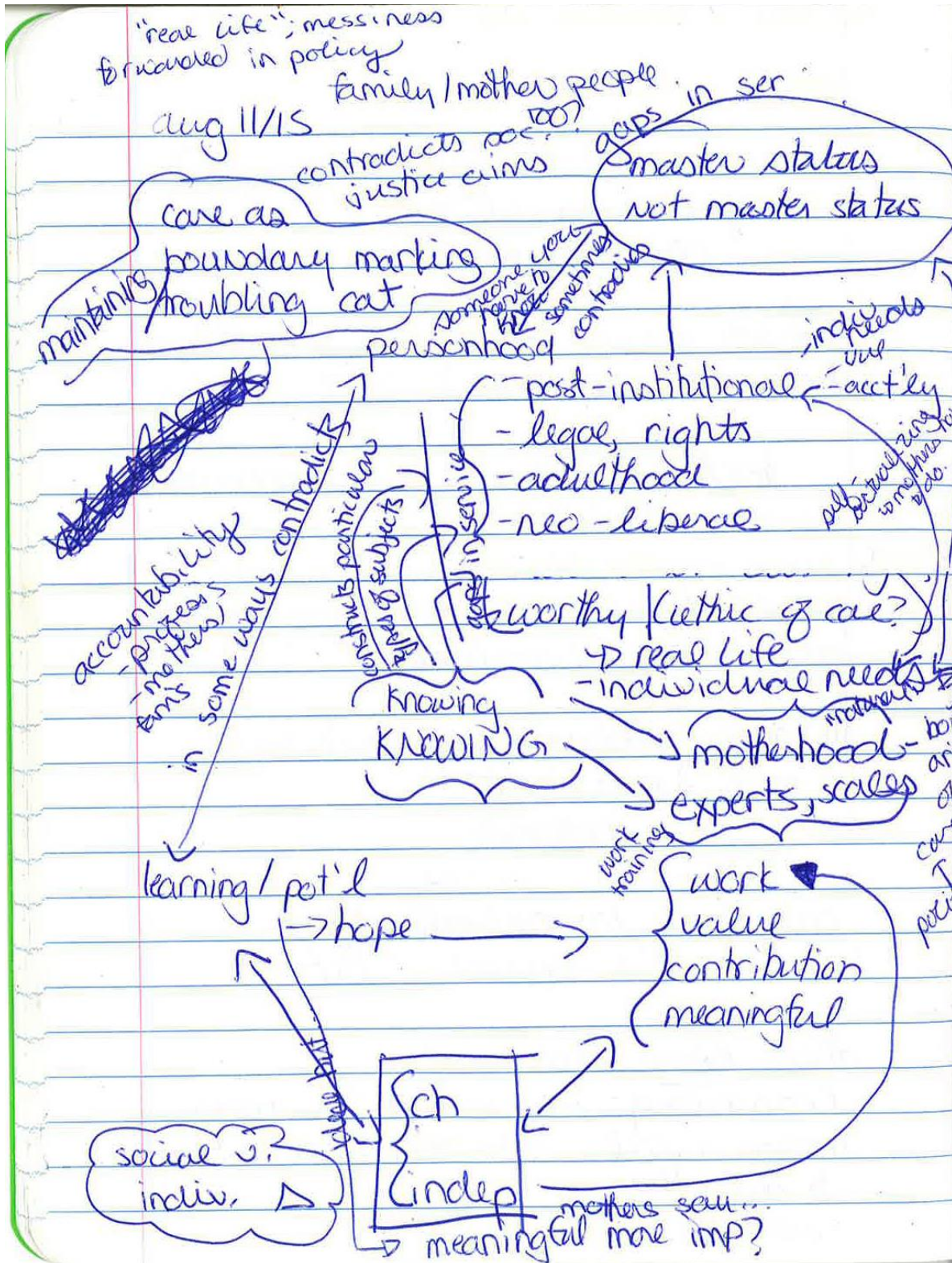
- Thinking about care and support that you give and receive, can you tell me about your family?
- What places, groups, or services are important to you and your family? Why?
- Can you tell me how you started using (name of service)?
- Are there any other people that are important to you or your family?

Second Interview

- Is there anything you would like to add or change to the transcript from the last interview?
- Can you tell me more about (places, groups, services, or providers of support mentioned in previous interview)?
- Can you tell me about the process of applying for developmental services? Why did you apply?
- Is balancing your needs with other family members' needs something you think about? Can you tell me about a time you did this?
- Do you consider yourself a care provider?

- The Ministry of Community and Social Services recently implemented new Developmental Services policy which includes choice, independence and social inclusion as key outcomes for persons with developmental disabilities.
 - Do you think choice is important as a “developmental outcome”? Do any of the supports or services we’ve discussed help increase choice?
 - Do you think independence is importance as a “developmental outcome”? Do any of the supports or services we’ve discussed help increase independence?
 - Do you think social inclusion is important as a “developmental outcome”? Do any of the supports or services we’ve discussed help increase social inclusion?

Appendix C: Web Created During the Analysis Phase



Appendix D: Coding Details

Tab Labels Used in the “Family” Excel Spreadsheets

Advocacy
Boundaries of Parenthood
Choice
Difference Within Category
DSO
Expert Versus Caring
Family
Inclusion
Independence
Individual Needs
Individual Responsibility
Knowing
Normal or Different than Normal
Planning
Potential
Real Life
Something (meaningful) to do
Vulnerable
Work
Value

Tab Labels Used in Excel Spreadsheets for Policy Documents

Boundary Keeping
Customer Service
Choice
Family
Inclusion
Independence
Individual Needs
Individual Responsibility
Money, Value, Work
Normal or Different than Normal
Learning or Potential
Planning
Rights
Vulnerable

Example of the Content in a Tab in the “Family” Excel Document

Tab Label: Potential¹⁰

January 14 – Carrie Groulx	Notes
It’s easy to get them to listen to me or anyone when it comes to problem behaviour, but when it came to consulting on an ABA strategy in order to help her to achieve her goals in her IEP when it came to education, it has been a real challenge.	requires experts, training, and evidence-based practice to teach skills
ABA strategies have been scientifically proven to teach autistic children appropriate behaviour when it comes to their triad of impairment: socialization, communication and behaviour. The Ministry of Education recognizes and requires the use of ABA, but they do not tell the school boards how to spend their money and who to train. ABA strategies are simple and provide a step-by-step instruction on how to teach a specific skill	potential to normalize
January 14 – Mick Kitor	
How much power does a clinical director have over a family? I’ll illustrate with my family. We have invested over \$77,000 in private therapy and a private diagnosis for our son. We raided anything that we had that had value in it: our retirement savings; we borrowed against the equity in our home. Our parents gave us thousands of dollars—they’re retired. It’s really costly to have a kid with autism, if you want to give them the best trajectory possible. The odds that if we have a second child that child will have autism are even greater than the 1 in 77 if you’ve never had a child before. We just don’t have another \$77,000 for private therapy while we wait on the wait-list.	Tons of material about the importance and hope of ABA... parents of kids... compare this to responsible but not trustworthy parents
The decision to make eligibility decisions and discharge decisions should not rest in the same agency that administers the wait-list. That’s like paying the foxes to guard the chicken coop. We need to reverse the burden of	potential and value of intervention

¹⁰ To maintain confidentiality of family members I interviewed, I only included coded text from the Legislative Review Committee Transcripts here.

<p>proof when it comes to eligibility and discharge decisions with regard to the independent review committee. It should be therapy until proven ineffective.</p>	
<p>What did I mean by value? Why did my family spend \$77,000 on private diagnosis and therapy? Well, I'm going to read some quotes from the recent Auditor General's report. I won't go very long. Please excuse the hyperbole; you know how excited accountants can get and how they like to exaggerate—not.</p>	
<p>"Early diagnosis and treatment of autism might reduce the need for more supports and services later on in life." Sounds reasonable to me. You help a child catch up to his peers earlier, and the symptoms are less severe and they can integrate quicker—less cost to the whole system.</p>	
<p>"We estimated that children with autism are diagnosed in Ontario at a median age of a little over three years." They're supposed to be in therapy by then. You can diagnose a kid when they're 18 months old. In Ontario, you can't access services for autism without a diagnosis.</p>	
<p>Another quote: "Children who start IBI before age 4 do better than those who start after age 4." Makes sense. When they're that young, their brains are knowledge sponges, but it starts to fill up, and they absorb information slower and slower as they age, the problem being that the median wait time for children with autism in the three areas that the Auditor General visited was almost four years. It's a little bit of a Catch-22 there.</p>	
<p>Due to the long wait-list for IBI services, children are not typically starting IBI until almost age 7 in Ontario. We know they need to start before age 4. That's three years after the window started to close.</p>	
<p>You wouldn't have to choose between financial ruin and your child's potential.</p>	
<p>To give you an idea of how much three years' difference can make, I did a little a research last night. Apple released the iPhone in June 2007. The share price was \$118. Three years later, they introduced the iPad. The share price was \$228. When would you rather have invested \$114 million? That's how much we invest in our kids each year. As of last night, Apple was trading for \$535 a share. When you invest makes a huge difference.</p>	<p>Investment, value and potential very clearly linked here and in following sections</p>
<p>Despite an outstanding ROI on therapy, according to the Auditor General, the kids who would benefit the most from</p>	

<p>IBI therapy are ineligible. There's scientific research that shows that kids with a milder form of autism have a better outcome with IBI.</p>	
<p>We're not talking about, "Oh, maybe these kids with milder forms of autism won't have to be dependent on the government." They could actually be scientists. They could be engineers. They could be computer scientists. They could be programmers. They could contribute, but we choose not to spend on them, not to invest in them</p>	
<p>So what do I want for value? I'd like to see government-backed autism therapy loans. Get the therapy earlier, and get more effective treatment. I'd like to see children with milder forms of autism receive the therapy so that they can contribute to society, and there's a lot they have to contribute.</p>	
<p>Jack McLaren</p>	
<p>You've done a wonderful job of searching out private sector IBI treatment from people who do an excellent job of delivering it and offer hope for you and your wife, and you find great frustration with the private sector</p>	<p>IBI and hope</p>
<p>January 14 – Rev. Maggie Helwig</p>	<p>Money for potential</p>
<p>My daughter was diagnosed at the age of three and a half. At that time, IBI was only offered up to the age of five, and the waiting list was long enough that we were advised that there was really no point in putting her on the list. She has never received any funded IBI intervention. I know that the age limit has been raised. There may have been some way we could have accessed it later; if there was, nobody ever told us what it might be.</p>	
<p>We have paid for her to have specialized educational help, speech therapy, occupational therapy. We've done that with help from her grandparents, and we're very lucky that we've been able to do that because, really—and I gather this reflects the experience of the previous speaker as well—everything we've been able to access has been in the private sector. We've really never had any funded therapeutic or educational interventions, with the single exception of a few weeks of behavioural intervention focusing on social skills, which she received about a year and a half ago. So that's a few weeks over the course of her entire childhood and adolescence. Everything else has been private sector.</p>	

<p>My daughter wants to be a contributing member of society. She's learning to cook. She goes to work with her father. She works at school to learn basic office skills. She's really doing her best to develop the skills to take her part in society, but there's no structure to help her develop and apply these skills. There's no prospect of appropriate supported housing, maybe not ever—maybe when we die. I don't want my daughter spending her adult years watching television in a nursing home after her parents die, which I know very well is a possibility because I know people it happened to.</p>	<p>wants to contribute - need support to learn skills. Learn skills to work/ contribute.... later says found continuing edu program at George brown themselves... individual responsibility to ensure employable?? LTC mentioned here.</p>
<p>I think clearly the adult system is obviously incredibly poorly resourced. I think maybe people think there is more point in putting resources into the youth system because maybe you can make them be normal and then not have to fund it. But the adult system is hugely, hugely poorly resourced. There just needs to be more resourcing in the system as a whole, but especially for adults with developmental disabilities.</p>	<p>Adult versus child system More value in child... investment</p>
<p>When she's in a specialized environment, where a lot of attention is paid to supporting and developing the ability to interact with other people, that has been something that she would not likely have had anywhere else, and I have seen her behaviour improve tremendously. I have seen her social skills improve tremendously.</p>	<p>Segregation for learning to be "normal"</p>
<p>If that kind of very intensive social skills training could have happened in an environment with neuro-typical children, perhaps that would have been the ideal. But the intensity of the focus and training on behavioural and social skills, I think, is the crucial thing. She interacts with neurotypical people at church and in other parts of her daily life, and—</p>	
<p>Marilyn Leiterman – January 14</p>	
<p>My children are very talented. However, they are not going to be intellects; they're not going to be academics. They are very skilled vocationally. All of them want to be part of society. They want to learn. We need programs in vocations. We need protection factors put in here. Like the lady was speaking about with her child with autism, the same goes with FASD. I do not want a cage for my children. I want help for them. I want programs where we can work together and help them succeed and where all can be part of society and contribute to society.</p>	<p>need programs, need to learn to be part of society and contribute vs cage; individual change (earlier says vulnerable to being bullied)</p>

Geoffrey Shea – January 14	
<p>it seems that our options are bleak. These seem to be the alternatives: If Yoschi continues to live at home with us, and we're resourceful and lucky, we might be able to put together, through various funding supports, enough so that he can have eight hours of attendant care per day, perhaps five days a week. That would be enough support to allow both of his parents to continue to work, but it means that all of our non-working hours will be involved in providing for his care. In this scenario, he will not be able to continue his education, because we live in rural Ontario. His social life and ability to explore the world intellectually will revolve around the interests and abilities of his caregivers. Our capability to contribute to his day-to-day needs will diminish with age and our own physical abilities. His needs will be increasingly demanding throughout our retirement, which will not be very rich, since both of our careers have been impacted</p>	
<p>will have to radically and quickly adjust to some sort of long-term-care facility.</p>	<p>LTC - will not become independent or contribute in this environment</p>
<p>The next alternative that we can imagine is that Yoschi moves to a long-term facility sooner. From what we understand, these range from quasi-independent living facilities, where he might be eligible for three or four hours per day of attendant support, to nursing home-like facilities with greater staff availability but no opportunity for developing or exercising independent skills.</p>	<p>supports for inclusion, meaningful engagement</p>
<p>In these two scenarios, I think we can image this bright, curious, charming young man spending the majority of the rest of his life parked in front of a TV.</p>	
<p>The final scenario that we can imagine for our son is one in which he is provided with attendant support for the entire day, and where he can make life choices based on his interests and abilities. He could then move to a city, where he could continue his education. He could carry on interviewing people so that he can write articles and make documentary films. He could meet people and make friends, perhaps find love, and contribute to society with his many abilities and strengths. This is really the only viable model of support—the one that I just outlined—but it's beyond what almost any family could provide.</p>	<p>available options make it family responsibility for engagement, inclusion, meaningful activity etc. Ask that this be an entitlement because available options do not add up</p>
<p>If the government is going to continue to insist that the</p>	

<p>responsibility for providing services to adults with disabilities falls to aging parents, we're inviting a series of tragic and heartbreaking ends, in many cases.</p>	
<p>Still, we have to acknowledge that the severity of Yoschi's physical needs, combined with his developmental challenges, places him at the far end of the spectrum for any care or support system. But support for these individuals should not be considered optional, provided when and if resources become available. This has to be considered a minimum level of social responsibility.</p>	
<p>Connie Harrison – January 14</p>	
<p>I don't know. I could go on and on and on, but I don't see any magic cure coming down the line for these kids. I just don't. All we can do is make them comfortable and keep them safe and as happy as possible in the community. That's going to require a political will that I haven't seen out there for quite a while. I have not seen that will.</p>	<p>no miracle cure - have to support as are... recognize as a political issue</p>
<p>A lot of people just avoid us like we're the plague and vilify our children, as was done in Barrie last year, calling them monsters. What can I say? It has become a "them and us" kind of attitude, and I don't like it. I'm hoping, whatever this committee comes out with, that they're going to realize that you need a political will, you need to respect people with autism, and you're going to need to put money into paying to see that they are properly looked after.</p>	
<p>My son had an iPad stolen. His belongings are like he's nothing, like he's a nothing person.</p>	
<p>January 17 – FASD</p>	
<p>My son has finished school now, as he is over 21. The implementation of the 21 rule is a little different than you might think, as a parent. It doesn't mean you can go until the day you turn 21. It means that if you turn 21 during the school year, you can't start the school year, so your end date is actually the term before you thought it was.</p>	<p>potential for work</p>
<p>He had a transition plan, which is like a project plan. The goal statement for my son was "to prepare students for entry to the world of work upon graduation from high school, and, as appropriate for each individual, to prepare them for independent living and employment etc."</p>	

<p>The fourth is to ensure the education system treats FASD as what it is: a developmental disability caused by organic brain damage and not as a behavioural problem. Time-limited interventions, such as the section 23 classes, are not sufficient, as these individuals have permanent, organic brain damage.</p>	
<p>December 4 – Dr. Kevin Stoddart</p>	
<p>We also know, though, that social interaction and social understanding continue to present individuals and their families with complex needs despite early intervention and despite excellent intervention in schools. Problems with social interaction may lead to aggressive outbursts in the community, interactions with the legal system and certainly, chronic difficult-to-treat patients in the emergency units of our general hospitals and our mental health in-patient settings.</p>	<p>“problems” despite early intervention</p>
<p>In a recent report that I was lead author on at the Redpath Centre, we found that daily, individuals with autism spectrum disorders are sitting at home, post-high school, with no regular, meaningful daily activities. In that setting, they’re bored. Behaviour problems can occur, and families are faced with caring for their daily needs 24 hours a day, seven days a week.</p>	<p>Compare to excellent outcomes expected via intervention etc.</p>
<p>December 4 – Autism Ontario</p>	
<p>The key things that we’d like to focus on, although there are many issues across the lifespan: Supports and services for autism spectrum disorders are really in-adequate and fragmented and fail to address needs across the lifespan. Secondly, even though there have been some good efforts made—there are some services that are available to some individuals with ASD in our prov-ince—many people with ASD are living in dire circum-stances, and their families often feel desperate in trying to support their children. Early intervention and services for children are critical, and we know it has long-term impacts for their lives, so those are necessary, but as a province, we need to be looking at a wide-ranging per-spective and looking at the needs of older youth and adults with ASD, the time where they spend the majority of their lives.</p>	

<p>In conclusion, you'll see on this very last slide that without accurate numbers, we don't know how many people have ASD, especially in adult years, and we can't plan. Without shared knowledge, we can't learn and in-form our practices. Without an inclusive society, we can-not contribute. The potential of people with ASDs—we've spoken about a lot of the challenges—is phenom-enal. They have much to offer, and we need to provide those supports so that they can be taxpayers and, if not, contributing citizens. It is possible. Without those best practices and supports, we cannot succeed. So help us to see the potential in each person with ASD in the prov-ince.</p>	<p>Potential to become contributors and tax payers</p>
<p>Irvings – December 18</p>	
<p>Behavioral characteristics were visible when Kristy was younger, when she required strong educational intervention techniques to learn and to manage herself. She was fortunate, though, to receive one-to-one educational support throughout her school-age years. When she graduated from the E.C. Drury school in Milton in 2001, Kristy was reasonably functioning. She had basic math skills. She could spell and write. She could read and follow directions, and had a huge social appetite to do her favourite things with her favourite people.</p>	<p>potential, leaning, skills lost with transition to adult services</p>
<p>As a family, we had prepared for her school transition several years prior to support Kristy to move to a group home in Milton where she would be surrounded by her deaf community. All should have been good for the future.</p>	
<p>What happened to her as an adult? After seven years in group home care, Kristy severely diminished for many reasons. Traumatic life events are very long lasting for this class of person. Group life created a cycle of unending anxiety for someone as vulnerable as her. Constant staff turnovers and departures, other clients in crisis, and union chaos and issues meant Kristy and family had little or no control over important aspects of her life. As a result, Kristy started constantly aggressing when approached. She became habitually self-injurious and withdrew from all of her social routines. She was hospitalized frequently for safety reasons. As an example, in 2009, the last fiscal year of her care in the group home, she consumed over \$227,000 in combined MCSS and Ministry of Health funding, which was not inclusive of the previous four months, when Kristy was</p>	

<p>an in-patient at CAMH to detox her from all psychiatric meds.</p>	
<p>After her isolation in a CAMH locked 10-by-8 cell, upon her return to the group home, support workers became afraid of Kristy, so she was left in her room for up to 22 hours per day.</p>	
<p>In March 2010, when Kristy was egregiously discharged on only six days' notice with no transition plan, she was no one we knew. She was traumatized. She had lost all access to all of her friends. She no longer had basic daily life skills. She was not eating—worse yet, ruminating up to 10 times per day—not toileting or communicating; she lacked any manner of self-control, as a caged animal would be. We've often referred to the fact that we're aware that Kristy was willing herself to die at that point.</p>	
<p>Christine was asking us how Kristy is doing, and we're saying that she's in a medical crisis right now. It happens when individuals' meds no longer work for them and they have to be changed, and we've got a lot of experience to understand, when people go into crisis, what's going to happen and what pressures the system is going to put on them. The reality is that when Kristy goes into hospital, it is the common occurrence that hospitals will throw neuroleptic or antipsychotic tranquilizing-type meds in excess at these individuals. They are highly sensitive; in many cases, they're allergic. It causes a cycle where the behaviours increase, the self-injury increases; layer on that that if the caregiving in hospitals isn't supportive enough, it isn't communicated in a way that the person can understand it, then the individual just becomes worse in hospital. So our greatest fear is that she ends up in a long-term hospital stay again.</p>	<p>Talk as though could normalize... in a perfect world.</p>
<p>Of course, hospitals don't want to keep her, so they move her out quickly, and when that happens, well, we've got the experience as well of dealing with the situations that we have when she comes home, so we need CCACs and other third-party agencies to help us for physical and home care supports. That in itself, sadly, is something that tremendously increases our daughter's anxieties and behaviours again, simply because of the random nature by which these people get assigned. They don't always show up on time, their schedules change constantly, and somebody like Kristy, who is very reflective of the autistic community,</p>	

requires a routine that isn't changed. So the reality of the fact that we're dealing with all of this—we're always in threat, when she's in crisis, that our staff are going to leave us. They come at us with concerns over their liability, so we up our insurance and we continue to look for new care workers and try and hold the good ones together so they're not afraid of Kristy.	
Paul Bandiera – December 18	
Very quickly, let's get into a couple of specifics. As I mentioned, with the birth of a child with Down syndrome, we say, "You're in the club," and you're in the club for life.	potential to normalize v you are in the club
Ms. Cheri DiNovo: Thank you very much for your presentation. In my constituency we have a real success story. I can't see from your poster—it's very small—but I think it's one of the folk on your posters: Andreas Prinz—	"success" as normalizing with little or no support
Ms. Cheri DiNovo: —and Marianna, whom I've witnessed because I was their minister all the way through—two individuals with Down syndrome whose parents and community had a circle of support and who were included in all of their community life from the get-go, who are working, are married, live on their own and need very little input from others to assist them in getting by. It truly is a wonderful story. I know we could all benefit from knowing that that's even possible. It would be great to maybe see some other materials on folk like that who have Down syndrome and who are living virtually independent lives.	
Mr. Paul Bandiera: Thank you for that. I think one of the things that we need to do more of is to create a sharing of our success stories. Everyone is different and there is a broad range, but most certainly having those success stories is something that we're all working towards.	
Ms. Cheri DiNovo: Yes, because that would help, I think, in giving us an idea of what success looks like and not just what lack of success looks like.	
December 18 - Alison Galey	
The prohibitive cost of day programs means that many young adults with developmental disabilities are just staying home with aging parents who are exhausted. An educational assistant at Layla's school told me recently that she runs into former students sometimes in the community and sadly	

<p>observes considerable regression in their level of functioning, which she attributes to lack of programming since leaving school, staying at home, sitting in front of a TV, maybe playing video games if you're able, but that's about it. That's what fills their days.</p>	
<p>Kerry's Place – Decmber 18</p>	
<p>Dr. Jo-Ann Reitzel: There is a real need to develop consistent and transparent criteria that would be endorsed by Ontario. What has happened over the years that we have had the Autism Intervention Program has been a series of expert panels. In 2007, I believe, there was a clinical expert panel that recommended that children have a trial of IBI. But from the review of the literature, we knew that IBI was not appropriate for all children. We knew that only a proportion of children responded to it, and yet we really can't identify that at the outset.</p>	<p>ibi works best for high end of spectrum, but apply to low end... this speaks volumes about a desire to normalize</p>
<p>What we need to be able to do is to follow a child's growth and development during the time that they are in IBI and see if it's having that intended effect of actually boosting or accelerating their development. Then what we need is the second expert panel, which was a benchmarks panel, in order to see whether the child is able to achieve those benchmarks and in that way to determine if this treatment is effective. If it's effective and having the intended effect for the child, then the decision would be to continue. If not, the decision would be to discharge, but to discharge, as all my colleagues have been talking about, to the right service for the right child at the right time. That would need this continuum of care.</p>	
<p>Miss Monique Taylor: And with that dis-continuum, what's the transition period? I've been contacted by families who are told, "You have one month left of service and that's it. Your child is done," yet they're feeling that their child has reached these benchmarks, but there are no clear indicators of what that is. So what's the answer to that?</p>	
<p>Dr. Jo-Ann Reitzel: I think one of the answers is in establishing these consistent and transparent criteria for discharging children and being able to educate families about the aim of IBI and that it is effective for some but not for all children with autism. There's a great deal of variability among children with autism. As I'm sure you probably know, IBI really is effective for children with milder symptoms and</p>	

<p>for children who are young. We know that the IBI program right now is dedicated to children who are at the severe end of the spectrum.</p>	
<p>These sorts of disconnects, I think, have been addressed quite nicely in the Auditor General’s report—but asked for re-evaluation of the aims of these autism programs. Really, I feel like we don’t yet have a thorough-enough autism strategy, and if we did, we would be able to see that there is a need for all and that all do deserve interventions, but it’s just not all the same. It’s not like one treatment for all; it’s that we need a continuum and that that will change over time if we can assess those individuals’ needs within their families and the context that they’re living in.</p>	
<p>Provincial Executive Directors Groups, Community Living Ontario – December 18</p>	
<p>Government should invest in children and child development. We believe that earlier and more prudent investment in children’s education, health and social development is likely to reduce dependence on specialized resources later on in adult life. This is so that children can develop a network of relationships, but also friendships and informal supports.</p>	<p>Value in cost saving potential</p>