Problematizing Transition to Adulthood
For Young Disabled People

by

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A thesis submitted in conformity with the requirements
for the degree of Doctor of Philosophy
Dalla Lana School of Public Health

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Abstract

The purpose of this critical qualitative study was to understand how transition to adulthood for young people with developmental disabilities (DD) is constituted as a ‘problem’ in policies and practices across sectors in Ontario and the implications for these young people and their parents. This transition to adulthood has been identified as a policy problem in three provincial government sectors in Ontario, Canada—rehabilitation, education, and developmental services. The problem is predominantly framed as a service transition issue, particularly when young people ‘age out’ of pediatric health services by age 19 and public education by age 21, and seek adult-oriented programs and services. Transition policies have been developed in each sector, shaped by both explicit and implicit understandings of key concepts, such as disability and adulthood. These understandings function to constitute transition as a particular kind of problem, and play a key role in what is considered and proposed to address it, but also what is not considered or potentially neglected or even ignored. What is and is not considered has implications for the health and daily lives of young disabled people and their families. Guided by a problem-questioning approach to policy analysis proposed by Carol Bacchi, I used a
multimethod design, including analysis of policy documents and in-depth interviews with parents, to examine how transition to adulthood is constituted as a problem. My analysis revealed that normative assumptions about ways of being, becoming, and acting as an adult shaped an implied problem of disabled children and their inadequate progression to socially valued adult roles and activities. Policies shaped by these assumptions had both positive (e.g., feelings of self-worth for achieving or approximating socially valued roles and activities) and unintended negative effects (e.g., social exclusion, stress or anxiety when adult roles were not achieved) on young disabled people and their parents. These findings highlight opportunities for rethinking the policy problem in ways that can mitigate unintended harmful consequences on young people with DD and their families and for improving their health and daily life circumstances through healthy public policy and cross-sector coordination.
Acknowledgments

I would like to express sincere appreciation and gratitude to my supervisor Dr. Rebecca Renwick for her mentorship and guidance throughout my PhD journey. Thank you for encouraging me to explore new ideas and ways of thinking, and for guiding my growth as an occupational therapist and researcher. Your advice on both my research and career, and on balancing them both with personal and home life, has been invaluable. I have learned much from you about how to support and nurture students, which I will remember to pay forward as I take on supervisor and mentor roles in my future work.

I would also like to thank Dr. Barbara Gibson and Dr. Cameron Norman, my committee members, for the generous time they provided me in both formal and informal meetings. I always felt I could approach you when I needed clarification about feedback given or reassurance that I was on the right track. Barb—Thank you for advancing my knowledge of critical perspectives and giving me opportunities to hone my skills in applying this knowledge in trainee positions. It turns out that a researcher can delicately balance the worlds of rehabilitation and social theory! Cameron—Thank you for ensuring that a public health perspective was always in mind and for always providing positive encouragement about my progress and productivity. There is still more work to be done to explore systems thinking perspectives on this topic!

I gratefully acknowledge the parents who participated in the interviews for this study. Your stories and insights about planning for your children’s adult lives gave much depth to the research, which would have been completely lost in a policy analysis alone.

I’ve met many trainees and new friends along the way. Spending time with the social theory group, the ‘lab rats’, the virtual critical occupational therapy group, DLSPH students, and public health policy fellows provided a wonderful opportunity to learn from others about navigating academic and research life. A special shout out goes to Dr. Gail Teachman—we pretty much crossed the finish line together! Thanks for your words of encouragement always.
My family has been along for the twists and turns of this PhD ride. Thank you to my parents and both the Hamdani and Davidson clans for supporting my progress and success. I’ve raised two children, a house and a thesis during this trip! My children, Zoe and Graydon, have grown up and gone through their own life stage transitions over the past few years. I am so proud of you both, and look forward to seeing what your adulthood looks like. Words cannot express how grateful I am to my husband Jim Davidson for his encouragement and support, and for taking on extra family administrative duties while I focused on completion. Your pragmatic questions and kind nods helped me to think about better ways to explain what the problem of disability is represented to be and why it matters.
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Chapter 1
Introduction

Transition to adulthood for young disabled people\(^1\) has been identified as a policy problem in three provincial government sectors in Ontario, Canada—the rehabilitation, education, and developmental service sectors. Transition policies and best practices\(^2\) have been developed in each sector, with a particular focus on the issue of transferring young people from childhood to adult-oriented programs and services when they ‘age out’ of pediatric health services at 19 years of age and public education at 21 years of age. The ways in which this issue is characterized as a service transition problem has implications for the courses of action that are proposed in policies, and therefore has implications for the lives and circumstances of the target group, in this case, young disabled people and their families. In this critical qualitative study, I used a multimethod design (e.g., document analysis, in-depth interviews with parents) to examine how transition to adulthood is constituted as a problem in policies and what effects this has on parents of children with DD. Guided by a problem-questioning approach to policy analysis proposed by Carol Bacchi (2009), my analysis revealed that an implied problem of disabled children and their inadequate progressions to socially valued adult roles and activities underpinned the explicit problem of service transitions. Moreover, policies shaped by this implicit understanding of the problem had unintended negative consequences for the health and daily lives of young people with DD and their parents. This thesis critically examines how transition to adulthood is problematized in policies and directs attention to the potential harmful effects on young people with DD and their parents. The findings highlight opportunities to develop supportive, health promoting policies and programs for young disabled people and their families as they experience service and life stage transitions.

\(^1\) I have chosen to use the term ‘disabled people’ rather than ‘people with disabilities’ throughout this thesis. The former is more common in disability studies, usually to signify that it is society that disables people rather than their impairments, and aligns with the critical approach taken in this study. The latter is more common in rehabilitation, education and other fields, usually to reflect the idea of putting the person before his or her disability.

\(^2\) Here, the term ‘best practice’ refers to an intervention that is generally accepted as superior than other options to address a problem, in this case transition. Typically, best practices are informed by research evidence, which, over time, become accepted as self-evident ways to intervene and address a problem. As I discuss later, there are taken-for-granted assumptions about the problem of transition underlying both policies and best practices.
1 Background

Young people with childhood onset disabilities (e.g., cerebral palsy, muscular dystrophy and developmental disabilities) are living longer compared to previous generations due to advances in medical knowledge and management (Sawyer, Drew, Yeo, & Britto, 2007; Wood, Reiss, Ferris, Edwards, & Merrick, 2011). As these young people age beyond child-mandated health, education, and social services, they lack access to services for adults. Government funding for programs and policy supports within and across service sectors have not progressed in stride with medical advances for this population (Wood et al., 2011). Traditionally, childhood disability has fallen under the realm of health care and particularly rehabilitation, which tends to focus on direct interventions for individuals (Barnes, Mercer & Shakespeare, 1999; Oliver, 2009). In contrast, public health tends to focus on broader influences (e.g., policy and system structures) on health from a population perspective (World Health Organization, 1998). From this perspective, transition to adulthood for young people with childhood disabilities can be considered a public health issue for three main reasons: (a) they have complex, diverse health needs that go beyond the medical needs of individuals (Binks, Barden, Burke, & Young, 2007); (b) they lack access to comprehensive, coordinated services because services either do not exist or are fragmented in adulthood (Binks et al., 2007); and (c) they have poor health outcomes, such as increased comorbidity and mortality (Fiorentino et al., 1998; McDonagh, 2000; Ried, 2010; Stevenson, Pharoah, & Stevenson, 1997; Viner, 2008) and poor outcomes related to education, employment, interpersonal relationships and housing (Stewart, Law, Young, et al., 2009). On the latter, a greater understanding of the broad factors that support transitions to adult life for this emerging population is needed (Stewart, Stavness, King, Antle, & Law, 2006). In public health, which generally draws on fundamental aspects of the Ottawa Charter for Health Promotion (World Health Organization, 1986), these broad factors can be conceptualized as social determinants of health. A public health perspective can contribute to understanding the broader social influences on health and well-being of young disabled people as they transition to adult life.

Transition has been described as a complex phenomenon influenced by multiple, diverse factors (Binks et al. 2007; Hamdani, Jetha, & Norman, 2011; Rapley & Davidson, 2010; Reiss & Gibson, 2002; Wang, McGrath & Watts, 2010), including skills and knowledge of self- or shared
management of health at the individual level (Gall, Kingsnorth, & Healy, 2006; Kennedy, Sloman, Douglass, & Sawyer, 2007; Schultz & Liptak 1998), family support at the interpersonal level (Reiss, Gibson & Walker, 2005), training of healthcare providers and coordination between paediatric and adult services at the organizational level (McDonagh, Southwood, & Shaw, 2004; Young, 2007), and resources to support the transition to adulthood at the policy level (King, Baldwin, Currie & Evans, 2006; Reiss & Gibson, 2002; Viner, 2008). Research has focused on identifying these factors and developing policies and best practices at multiple levels to address them. Examples of best practices include transition readiness checklists and self-management programs at the individual level, policies and procedures for transfer to adult services at the organizational level, and formal and informal policies at the system level.

In Ontario, transition policies and best practices have been developed or promoted by several provincial ministries, including the Ministry of Child and Youth Services (MCYS; Ontario MCSS/MCYS, 2011), the Ministry of Education (MEDU; Ontario MEDU, 2002), and the Ministry of Community and Social Services (MCSS; Ontario MCSS/MCYS, 2011). Formal and informal strategies have been developed by pediatric rehabilitation organizations, which fall under the MCYS and the Ministry of Health and Long-term Care (MOHLTC). These include best practice guidelines reported by the CanChild Centre for Childhood Disability Research (Stewart, Law, Young, et al., 2009) and transition models (Kingsnorth et al., 2011). The Ontario MEDU (2002) published a transition planning resource guide to address implementation of policy for students with exceptional learning needs. The Ontario MCSS oversees the transition of social services and funding supports for disabled children when they become adults. Furthermore, the Ontario MCYS (2011) and MCSS (2011) collaborated to draft a framework that provides guidance for developing protocols focused on transitioning young people with DD to adult developmental services in collaboration with community stakeholders (e.g., regional ministry offices, community agencies, and young people and their families). Adult developmental services refer to services and programs that support the inclusion of adults with DD and their families in a variety of activities (e.g., home, work, social, and recreation activities) in their communities. These services and programs are provided by community agencies with

3 The Ontario government’s acronyms for these ministries are used in my dissertation.
financial assistance from the Ontario MCSS. These provincial efforts resonate with best practices in the literature. However, empirical evidence of their effectiveness have yet to be demonstrated, and descriptions of their conceptual underpinnings are largely assumed in the literature (Freed & Hudson, 2006; McDonagh & Kelly, 2010; Stewart, 2009; While et al., 2004).

How transition to adulthood is conceptualized as a problem has implications for what is proposed to address it, and sets expectations for how young disabled people and their parents conduct themselves. These expectations may have both positive and negative consequences for the health and well-being of this population. For example, transition best practices that promote independence skills and competencies associated with a typical adult life may foster feelings of achievement and positive self-worth, as well as access to social determinants of health (e.g., employment, education) and material resources (e.g., income, housing). However, many young disabled people who cannot achieve independence skills because they continue to rely on caregivers for personal care and assistance throughout their adult lives may experience feelings of low self-worth, exclusion from the adult world, and lack access to material resources that can foster conditions for living a healthy life. Thus, the way in which transition to adulthood is understood as a problem has implications for young disabled people and their parents who provide them with care and support. Taken-for-granted assumptions about disability and adulthood shape particular understandings of what constitutes a successful transition to adulthood. These assumptions function to constitute transition to adulthood as a particular kind of problem, which can be examined to shed light on the potential negative effects on young disabled people and their parents.

2 Research Purpose and Aims

The purpose of this research study is to understand how transition to adulthood for young disabled people is constituted as a problem in policies and practices across sectors in Ontario and the implications for young people with DD and their parents. The way the problem of transition to adulthood is represented plays a key role in what is considered and proposed to address it, but also in what is not considered or is potentially neglected or even ignored. My specific research aims are:
• To identify and interrogate taken-for-granted assumptions about disability and adulthood that shape how the problem is conceptualized and what is proposed to address it;
• To understand the potential effects of these assumptions on young people with DD and their parents; and
• To identify ways of rethinking the problem that can potentially mitigate negative effects on young disabled people and their parents, with a particular interest in the latter.

My overarching research questions are:

1. What is the ‘problem’ of transition to adulthood for young disabled people represented to be: a) in the policy; and b) by parents of young people with DD?

2. What assumptions underlie these representations of the ‘problem’?

3. How do these problem representations: a) shape policies; and b) shape how parents of young people with DD think about and conduct themselves?

4. What effects on parents are produced by these representations of the ‘problem’?

Answering these questions through my research will provide new insights into the implicit understandings that shape how transition is characterized as a problem and the unintended deleterious effects of policies on young disabled people and their families. These insights can open possibilities for rethinking what constitutes a successful transition to adulthood and highlight opportunities to develop and refine programs and practices that support young people and their families as they experience service and life stage transitions. My rationale for pursuing this research is to improve the health and daily life circumstances of this population by contributing new knowledge that can inform development of supportive, health promoting policies and practices. The findings will contribute to understanding ways to better manage childhood disability over the life course and draw attention to opportunities for healthy public policy, program development, and cross-sector coordination.
3 Key Terminology

For the purpose of my research, ‘policy’ refers to a course of action proposed by a government or an organization, articulated formally or informally in reports, newspapers, or on websites to address an issue or problem (e.g., a health, education, or social problem; Bacchi, 2009). Policies embody proposals for change and expectations for the whole population or particular subgroups to conduct themselves in particular ways (Bacchi, 2009).

At this stage, ‘problem’ refers to what a policy identifies as needing to change or be ‘fixed’. For example, policy on employment programs for disabled people identifies employment for this population as a problem to be changed or addressed. Policies contain explicit and implicit framings of a problem. My research focuses on identifying implied problems by unpacking the discourses and assumptions underpinning the explicit problem.

‘Discourse’ refers to a “group of ideas or patterned ways of thinking which can both be identified in textual and verbal communications and located in wider social structures” (Lupton, 1992, p. 145). Policy is articulated in discourses, which can have a powerful role in creating particular understandings of ‘problems’ (Bacchi, 2004, 2009). In essence, policies are shaped by “how something is put forward (or represented) as a ‘problem’” (Bacchi, 2009, p. xii) or ‘problematization’. I discuss the concept of problematization in Chapter 2.

In this study, I focus particularly on developmental disability. Traditionally, a diagnosis of developmental disability was determined through a psychological assessment of intelligence. However, recent legislation in Ontario provides a broader description of DD that is not based strictly on intelligence. The Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008 describes people with DD as individuals who have

\[ \ldots \text{significant limitations in cognitive functioning and adaptive functioning and those limitations,} \]

a) originated before the person reached 18 years of age;

b) are likely to be lifelong in nature; and
c) 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. (c. 14, s. 3 (1))

I refer to this description of DD as a starting point in this study, but I unpack the notions of ‘development’ and ‘disability’ as my analysis unfolds. It is a broad description that encompasses a variety of conditions, such as autism, brain injury, cerebral palsy, Down syndrome, intellectual disabilities, and spina bifida.

4 Reflecting on My Role As Researcher

In this section I reflect on my roles as a clinician with experiences of developing and implementing transition programs and as a parent, which influenced my research process, including my interest in the topic, my choice of research questions, and how I viewed the data during analysis and interpretation of findings. Self-reflexivity is a common practice in qualitative research. It refers to being honest and authentic about one’s self, research and audience (Tracy, 2010). Being reflexive involves understanding and making explicit my “self-as-an-instrument” information (Tracy 2010, p. 842).

As an occupational therapist working at a large pediatric rehabilitation hospital, I was involved in developing best practices and programs for preparing young disabled people and their families for transferring to services and supports for adults when they turned 18 years old and were no longer eligible for pediatric health services. These best practices included developing the young people’s skills and knowledge for managing their health and health care, linking young people and their families to health, education, and community services and supports, and developing formal discharge and transfer procedures. On a personal level, I thought that the transition programs in which I was involved was succeeding in preparing young people and their families for leaving childhood services and linking them to adult services. However, I sensed that I was not improving their overall health, well-being, and participation in their communities to the extent possible. Specifically, I had a hunch that our transition program was not working well for young people who continued to rely on their parents or other caregivers for personal care, and financial and decision-making support into adult life. I began to question if the transition interventions that I had developed and implemented in a rehabilitation setting actually changed or improved the health and daily lives of young disabled people and their families. I developed
an interest in understanding the broader policy and social contexts that influence the health and well-being of this population. For this reason, I pursued a degree in public health to increase my knowledge about population health and social determinants of health perspectives for conceptualizing and addressing childhood disability.

Through my PhD coursework, I was exposed to critical social theory perspectives for conceptualizing and understanding health issues, which led me to reflect on my personal and professional assumptions about disability and the aims of rehabilitation interventions. In relation to transition to adulthood, the focus of my previous clinical work, I began to question what constitutes a good adult life and whether or not opportunities for this particular kind of life are available and accessible to young people with severe physical and intellectual impairments. These questions shaped my interest in critically examining how disability, adulthood and a successful transition to adulthood are understood in policy and best practice guidelines.

I also struggled with the idea that I could not provide beneficial and useful transition interventions for young disabled people because I had not experienced what it was like to grow up with a disability. I acknowledged an ethical dilemma regarding my role as a clinician. I was considered an ‘expert’ in transition planning, but who was I to position myself as an expert in planning for a good life? Although after working for nearly 20 years in pediatric rehabilitation I could empathize with the challenges disabled children faced, I began to question if I could really know what it was like to live their lives or be “in their shoes.” In addition, my perspective changed when I became a parent. I began to connect more with parent and family perspectives and was more aware of parents’ relationships with their children, as well as their roles in providing nurture, care, and circumstances for a good life as a child, much like any child. I began to think about my own roles and responsibilities as a parent. Like most parents, I assumed that my roles and responsibilities would shift over time as my children aged and became more independent. I became very interested in the idea that parents of disabled children, particularly those with severe and complex disabilities, might think this way too. However, their children would likely continue to rely on them into adulthood. I wondered, how does this arrangement affect the lives of parents as they age themselves? Through this reflection, my interest shifted to understanding the transition experiences of parents of young disabled people. This interest
contributed to shaping my research questions and decisions about the type of analysis that could answer these questions.

5 Thesis Organization

This thesis consists of eight chapters. Chapter 1 introduced the topic of transition to adulthood for young disabled people in Ontario, key terms, and the thesis as a whole. Chapter 2 describes the critical theoretical framework and key concept of problematization that guided my research. In Chapter 3, I review the literature that has shaped dominant understandings of transition to adulthood in Ontario policy and practice and examine key concepts (e.g., disability, generation, development, and citizenship) that are relevant to my analysis. In Chapter 4, I describe the research design and methods that I used to collect, generate and analyze data to answer my research questions. I used a critical qualitative inquiry design to examine three influential policy documents (one each from rehabilitation, education, and developmental services) and parents’ accounts of their experiences of transitioning their children with DD to adult life. Chapters 5, 6 and 7 discuss my findings about how transition is problematized in each of the rehabilitation, education, and developmental service sectors, respectively. I provide a Foreword and Afterword to these three chapters to help pull together the findings as a whole. I conclude with Chapter 8, in which I discuss the implications of the findings, the theoretical and methodological contributions of my study, and future directions for research.
Chapter 2
Critical Theoretical Framework

The critical paradigm, theories, and key concepts discussed in this chapter provide a framework for my research processes and for answering my research questions. From this theoretical approach, I aim to examine how transition to adulthood is problematized, that is, how it is constituted as a particular kind of ‘problem’ in Ontario policies. I discuss this idea further in this chapter as it is the crux of my analysis. I examine how particular understandings of the problem both shape and are shaped by taken-for-granted knowledge that, in turn, shapes policies and how transitions are experienced by young people with DD and their parents. The way a problem is characterized in a policy is important because it directs attention to what should be changed or ‘fixed’ to solve the problem (Bacchi, 2009). Thus, how a policy problem is characterized can significantly influence how the target population, such as young people with DD and their families, come to understand how they should think about and conduct themselves. This is important because how people think they should be or act can have both positive and negative effects on their lives. First, I discuss the critical approach that guided this study. Second, I discuss the critical policy analysis approach proposed by Carol Bacchi (2009) and its theoretical underpinnings, which I used as a lens for my analysis.

1 Critical Approach

All research involves interpretation through the lens of a theoretical paradigm or perspective (e.g., positivism, social constructivism, interpretive or critical perspectives) whether explicitly stated or not (Denzin & Lincoln, 2011). My study draws on a critical paradigm, which I discuss in this section. A paradigm refers to the epistemological, ontological, and methodological premises that shape a researcher’s “beliefs and feelings about the world and how it should be understood and studied” (Denzin & Lincoln, 2011, p. 13). Epistemology refers to what we think we can know about the nature of things (i.e., about ontology); ontology refers to what we believe about the nature things (i.e., the nature of existence); and methodology refers to how we think we can go about finding out about the nature of things (Bacchi, 2009; Denzin & Lincoln, 2011; Green & Thorogood, 2009). Critical approaches to research draw from a range of theories and intellectual traditions (e.g., Marxism, social theory, feminist theory, poststructuralism), each emphasizing particular epistemological and sociopolitical underpinnings. They share similar
interests in fostering social change, making politics visible, and emancipating individuals or
groups who are socially marginalized or disadvantaged (Gibson & Teachman, 2012; Kincheloe,
McLaren, & Steinberg, 2011). In my study, I draw particularly from critical approaches that
focus on examining how sociopolitical conditions (e.g., power relationships between dominant
and nondominant groups, prevailing social and political thought) operate to marginalize or
produce disadvantages for particular individuals or groups in society (Kincheloe et al., 2011). In
general, critical research traditions are explicitly political and aimed at emancipation (Gibson &
Teachman, 2012). The critical approach taken in my study most closely aligns with the
‘postdiscourses’ (e.g., postmodernism, critical feminism, poststructuralism) approach described
by Kincheloe et al. (2011), which are particularly interested in understanding how sociopolitical
forces shape “individuals’ view of themselves and the world” (p. 163).

Critical approaches involve interpretation “combined with a pronounced interest in critically
disputing social realities” (Alvesson & Sköldberg, 2009, p. 144). They seek to make social
values and assumptions, whether hidden or unacknowledged, explicit, particularly in research
aimed at understanding or explaining social phenomena (Eakin, Robertson, Poland, Coburn, &
Edwards, 1996; Green & Thorogood, 2009; Kincheloe et al., 2011). The aim is to unpack the
social, political, and historical conditions that contribute to establishing these assumptions for the
purpose of revealing power relations (Eakin et al., 1996; Gibson, Nixon & Nicholls, 2010;
Kincheloe et al., 2011). Power relations can be described as certain groups having social
dominance or privilege over other groups; for example, nondisabled people over disabled people,
or adults over children. This dominance or privilege may be inadvertent or unrecognized. Power
relations also refers to the dominance of particular ways of thinking about how to be or to act,
which can become privileged over other ways of thinking, thus, operating to marginalize some
groups in society (Njelesani, Teachman, Durocher, Hamdani & Phelan, 2015). For example,
transitions practices guided by notions of normal development may inadvertently marginalize
people who are unable to achieve the tasks and milestones associated with normal progression to
adult life.

A key epistemological premise of the critical approach taken in this study is the rejection of the
prevailing notion of science being ‘value-free’ (Eakin et al., 1996; Green & Thorogood, 2009).
Rather, a critical perspective draws attention to the sociopolitical dimensions (e.g., social values
and assumptions) in research that are often neglected in ‘value-free’ research (Green & Thorogood, 2009). Critical epistemology links real world phenomena and social ideology, such that “knowledge is both socially constructed and influenced by power relations from within society” (Scotland, 2012, p. 13). For example, disability scholars argue that people with impairments are constructed as disabled, thus, they are marginalized in societies that privilege and prefer able bodies (Hammell, 2006; Hughes, 2009). My approach also draws from a social constructionist view, which proposes that taken-for-granted knowledges are not fixed realities; rather, they are products of particular times, places and circumstances (Bacchi, 2009). Since reality is not fixed, it can be changed through human action (Scotland, 2012). In this regard, the critical approach guiding my study seeks to examine taken-for-granted assumptions about disability and adulthood to reveal how they shape knowledge in particular ways that become taken-for-granted as ‘true’ (Eakin et al., 1996). This knowledge shapes particular understandings about the ‘problem’ and what should be done to address it. A critical approach proposes that taken-for-granted assumptions can be destabilized and altered to promote social change or emancipate people who are marginalized based on these forms of knowledge.

The ontological premise of my approach draws on the idea that realities are socially constructed entities that are not fixed, but are changed and moulded within particular social, political, cultural, economic, and historical contexts (Guba & Lincoln, 2005; Scotland, 2012). In addition, critical ontology takes the view that language does more than label objects of thought, but also operates as discourse to produce realities that reflect power relations. For example, disability has different meanings when understood as a medical compared to a social problem. Furthermore, these meanings have implications for how the problem is addressed and how they position disabled people in relation to other people in society.

Critical methodology focuses on questioning social values and assumptions to expose hegemony, social injustice and opportunities for social change and action (Scotland, 2012). In this study, I chose a qualitative methodological approach, guided by a critical perspective, in order to examine the social values and assumptions underpinning how transition to adulthood is constructed as a problem in Ontario policies. My main methods were document analysis of three key policies and in-depth interviews with 13 parents of young people with DD. In Chapter 4, I discuss my research design and methods in more detail. For now, I highlight two key
methodological premises associated with critical paradigms that underpin my study: triple hermeneutics and reflexivity.

### 1.1 Triple Hermeneutics

Critical theory can be seen as a kind of triple hermeneutics, where hermeneutics refers to the art and theory of interpretation (Alvesson & Sköldberg, 2009). First, at a basic level, people interpret themselves, their experiences, and their social realities within social contexts (Alvesson & Sköldberg, 2009). Second, in double hermeneutics, researchers interpret or attempt to understand and develop knowledge about these social realities (Alvesson & Sköldberg, 2009). Finally, in triple hermeneutics, researchers critically interpret the unconscious processes, ideologies, and power relations or privileging of certain interests over others, which are embedded in how a social reality/phenomena is understood (Alvesson & Sköldberg, 2009). A critical lens scrutinizes forms of understanding that have become self-evident or unproblematic, and are generally accepted without question as natural or as common sense. The aim is to reveal how social realities are produced by social, political, and historical conditions that are shaped by power relations or privileging of certain interests over others and to identify how these conditions can be rendered changeable (Alvesson & Sköldberg, 2009). In essence, a critical perspective has an emancipatory interest in destabilizing taken-for-granted knowledge of a social phenomenon, in order to open possibilities for understandings that can improve the social conditions of people who are marginalized or potentially harmed by dominant understandings. My goal in this study was to identify and destabilize taken-for-granted knowledges that shape how transition to adulthood for young people with DD is understood as a problem in provincial policies. I examined how these understandings produce social conditions and effects that may inadvertently function to marginalize these young people from participating in mainstream society as adults, thus, have consequences for them and for their parents’ lives and circumstances.

### 1.2 Reflexivity

Reflexivity is a key premise of a critical perspective. It refers to researchers subjecting their own research assumptions, practices, and processes to the same critical scrutiny deployed in their research (Eakin et al., 1996; Green & Thorogood, 2009). In other words, social-political
assumptions are interwoven into the processes of research and knowledge production, the thought processes and action of the knowledge producer (e.g., the researcher), and the contexts of these processes (Alvesson & Sköldberg, 2009). Reflexive researchers consider the broader sociopolitical contexts of their research in order to unpack taken-for-granted assumptions produced and embedded in these contexts, which may shape their findings in particular ways (Green & Thorogood, 2009). Reflexivity goes beyond reflection (evaluating one’s own research and practice) by adding a critical dimension of questioning the social-political conditions under which knowledge is produced (Kinsella & Whiteford, 2009; Phelan, 2011). It includes examining one’s own values and dispositions that shape one’s research and process (Njelesani et al., 2015). For example, I am embedded as a researcher within the sociopolitical context of Ontario, and also trained and worked in children’s rehabilitation as an occupational therapist in this context. Moreover, my personal history, for example as a woman and a parent, also shaped my research and interpretations. Thus, it can be difficult for me to untangle my values and assumptions from the broader social context without purposefully raising them to consciousness for scrutiny to the extent possible. Therefore, throughout this study, I incorporated analytic strategies (e.g., reflexive memos and questions) to raise my consciousness about personal values and assumptions that potentially influence and/or underpin my analysis and findings.

Triple hermeneutics and reflexivity are analytic strategies that are consistent with the critical methodological approach that I took to interrogate discourses and assumptions throughout my data generation and analysis. They facilitated my process of interpreting the data by making explicit the deeper meanings that underpin transition discourses. Unpacking these discourses and assumptions shed light on the prevailing ways of thinking that shaped how transition to adulthood for young people with DD was constituted as a particular sort of problem in the sociopolitical context of Ontario.

2 Critical Policy Analysis: What’s The Problem Represented to Be?

In this study, I drew on a critical policy analysis approach developed by Carol Bacchi (2009) called ‘What’s the problem represented to be?’ (WPR) as a lens for examining how transition to adulthood for young disabled people was constituted as a problem in three key documents and
the interview accounts of the 13 parents who participated in this study. WPR emphasizes problem-questioning, rather than problem solving. The former aligns with critical methodologies, which interrogate the social discourses and assumptions that shape knowledge to reveal hegemony, social injustice, and opportunities for social change. The latter aligns with conventional public policy analysis, in which the purpose is to solve or ‘fix’ social problems that are assumed to ‘exist’ outside of the policy-making process. A WPR approach takes the position that problems are produced or constructed in particular ways through the policy-making process (Bacchi, 2009). For this study, I focused on the knowledge that shaped understandings of transition to adulthood for young disabled people as a policy problem. Bacchi (2009) states, “policies constitute ‘problems’, meaning that they make a ‘problem’ exist as a particular type of ‘problem’” [emphasis in original] (p. 263). The use of single quotation marks around ‘problem’ serves to highlight the premise in WPR that policies create particular understandings of what the ‘problem’ is, rather than respond to problems that are assumed to exist in the ‘real’ outside of the policy-making process (Bacchi, 2009). Hence, the construction of problems in policies can be contested and debated. WPR focuses on questioning how policy issues are problematized or constituted as a particular kind of ‘problem’. Consistent with critical methodologies, WPR has a particular interest in examining taken-for-granted assumptions that shape how an issue is constructed in particular ways, with potential implications for the people who are the targets of policies shaped by these assumptions.

Policy making is a problematizing activity (Bacchi, 2009). In other words, policy making is a process that involves creating particular understandings of what the ‘problem’ is. Moreover, “since policy proposals specify what needs to change, they are forms of problematization, containing implicit representations of the character and causes of ‘problems’” (Bacchi, 2009, p. 277). In essence, policies are problematizations. The WPR approach proposes that ‘problems’ are constructed by explicit, but also implicit understandings of a policy issue. It aims to make explicit the implied problem(s) in a policy by critically examining taken-for-granted assumptions embedded in problematizations.

By assumptions, Bacchi (2009) refers to background knowledge that is taken-for-granted as given. These assumptions reflect deep-seated social, cultural, and political values that are embedded within representations of the problem. Problem representations are “the implied
‘problems’ in problematizations” (Bacchi, 2009, p. 277). They are the units of analysis in the WPR approach. The main objectives of examining problem representations are to reveal the predominant problematization (i.e., the implied ‘problem’) embedded within a policy, and to identify the potential effects of this problematization on the target population. Bacchi (2009) contends that problem representations “impact unevenly on different groups of people” (p. 18), meaning there are potentially beneficial and harmful effects of problematizations on different groups. A WPR approach is particularly interested in revealing aspects of problematizations that can have harmful effects on certain groups, which may need to be re-considered or rethought. Problematization is a key concept that shaped my approach to this study, including identifying the research questions, analyzing the data, and interpreting the findings. I discuss its theoretical underpinnings in what follows.

2.1 Problematization

Bacchi draws on the works of Paulo Freire (1996) and Foucault (1998) to conceptualize problematization in the WPR approach. Freire introduced the term as a strategy for critically interrogating taken-for-granted ‘truths’ in order to demystify them and raise consciousness of how dominant groups in society utilize them to marginalize subordinate groups (Bacchi, 2012). Similar to Freire, Foucault (1998) used the term problematization to propose that taken-for-granted assumptions in society, and particularly assumptions underpinning expert knowledges in modern societies, need to be questioned. He also suggested it as a method of analysis for shedding light on the thought behind particular forms of rule. In this sense, his proposed analysis process involves examining “how and why certain things (e.g., behaviour, phenomena, processes) become a problem” (Foucault, 1985, p. 115), and how they are shaped as particular objects for thought (Bacchi, 2012; Deacon, 2000). For example, ‘disability’ and ‘adulthood’ are constructed as problems in particular ways within particular sociopolitical circumstances, which become socially accepted as givens. They do not ‘exist’ as objects of thought until they are produced by practices (e.g., policies, regulations, expert discourses) (Bacchi, 2012). This analysis of problematizations has a particular interest in the knowledges through which rule takes place, and “how men govern (themselves and others) by the production of truth” (Foucault, 1991, p. 79). These forms of rule develop to maintain order in populations. There is no suggestion of deliberate manipulation of marginalized groups by dominant groups. Instead,
Foucault suggested that by unpacking problematizations and practices, the thought behind ‘problems’ can be revealed, including the indirect influences (e.g., roles of experts, values, ideologies) that shape how we are governed, and can open possibilities for new ways of thinking about a problem.

Problematization served as a key theoretical construct for examining how transition for young disabled people was constituted as a ‘problem’ of a particular kind in this study. With respect to other theoretical foundations, the WPR approach has been described as a poststructural, Foucault-inspired form of discourse analysis (Bacchi, 2009, 2012). In a WPR approach, discourse is understood as “a group of related statements, signs and practices that creates the object/s and domains it purports to describe, giving those objects and domains status as ‘truth’ or ‘knowledge’. Discourses set limits on what it is possible to say or think about the object/s they create, though they can and do contain tensions and contradictions that open up spaces for challenge and change” (Bacchi, 2009, p. 275). Thus, discourses shape and are shaped by taken-for-granted social knowledge. Bacchi (2009) posits that discourses become powerful mechanisms for ‘making things happen’ because they are widely accepted as forms of ‘truth’. A WPR approach aims to identify and question ‘truths’ or taken-for-granted knowledge in policies, and to examine what they ‘make happen’ with respect to governing the practices and behaviours of target populations. In what follows, I discuss the main intellectual traditions underpinning the WPR approach.

2.2 Theoretical Foundations of WPR

Bacchi (2009) draws on four intellectual traditions that, together, constitute a lens for problem-questioning in WPR, which align with the critical ‘triple hermeneutics’ approach taken in this study. They are social construction theory, poststructuralism, feminist body theory, and governmentality studies. In what follows, I discuss the key elements of these traditions that were significant in shaping the analytic questions in WPR.

2.2.1 Social Construction Theory

WPR draws on the general premise in social construction theory that “knowledge is a human construction” (Bacchi, 2009, p. 33). With regard to policy, a WPR approach proposes that
Governments are active in the creation or production of policy ‘problems’ through the act of policy making. As noted previously, this approach challenges the assumption underpinning rational, problem-solving approaches to policy making that governments react to problems that exist outside of the policy making process. Rather, WPR argues that policy making is a meaning-making activity, which produces particular understandings of ‘problems’. Thus, different and potentially competing social constructions of a ‘problem’ are possible. Bacchi (2009) does not suggest, however, that policy makers and governments intentionally manipulate problem constructions (although this may be so), but rather, they play a significant role in producing and legitimizing particular understandings of ‘problems’ by virtue of their position and status in governing populations. For example, in developing problematizations of disability and the transition to adulthood in policies, the Ontario government creates particular understandings of the ‘problem’ and what should be done about it. These understandings are underpinned by assumptions about disability and adulthood, which are taken-for-granted or accepted as ‘real’ or ‘true’. In my study, a WPR approach assisted me in interrogating the ‘taken-for-grantedness’ of key concepts and categories, such as disability and adulthood, in policies and parents’ accounts. My aim was to reveal the underlying assumptions that shaped the implied meanings of these concepts and categories, and therefore how transition to adulthood was constituted as a ‘problem’.

2.2.2 Poststructuralism

A WPR approach draws on theoretical insights associated with poststructuralism to expand on its examination of socially constructed knowledge. In particular, WPR draws on poststructuralist premises about the instability and variable meanings of concepts and the influence of politics on assigning meaning to these concepts (Bacchi, 2009). From this perspective, WPR examines how knowledge is produced and changes over time and place under different social, political, and historical contexts (Bacchi, 2009). For example, disability has been conceptualized as a medical, social, or civil rights ‘problem’ under specific sociopolitical circumstances and in different times in history. In a WPR analysis, a poststructural lens directs attention to the political influences that shape the meaning of concepts and categories, and how these meanings function to shape and legitimize policy and governing practices (Bacchi, 2009).
WPR also “emphasizes how subjects (subjectivities) are constituted within policies—how policies incite us to feel about ourselves and others in particular ways” (Bacchi, 2009, p. 265). In this regard, WPR draws particularly on poststructural discourse analysis as a lens to examine how subjects are constituted within policies. In this approach, discourse is understood as meaning systems that encompass assumptions, values, and presuppositions (Bacchi, 2009). A WPR analysis examines how policies as discourse make particular subject positions (e.g., ‘disabled’ child, ‘responsible’ parent, ‘active’ citizen) available, which operate to modify how people think about and conduct themselves. The notion of subject positions draws on Foucault’s work on subjectification processes. In general, it refers to the idea that “we become subjects of a particular kind partly through the ways in which policies set up social relationships and our place (position) within them” [emphasis in original] (Bacchi, 2009, p. 16). Thus, policy as discourse functions to set up social relationships, in which some groups of people are set in opposition to other groups (Bacchi, 2009). The ‘setting up of social relationships’ reflects Foucault’s notion of ‘dividing practices’. For example, polices can set up social relationships of ‘disabled children’ versus ‘nondisabled or normal children’, ‘responsible parents’ versus ‘irresponsible parents’, and ‘active citizens’ versus ‘inactive citizen’. These social relationships function to indicate and encourage desired behaviours of the population, and to identify those groups whose behaviours do not follow the majority and need to be addressed. In this study, I focused on the subject positions produced and made available to young adults with DD and their parents in transitions policies. This was of particular interest in assessing the effects produced by representations of the ‘problem’ identified in the policies and parents’ accounts.

2.2.3 Feminist Body Theory

Bacchi (2009) draws on feminist body theory as a lens for examining what she calls the ‘lived effects’ or material consequences of problem representations on individuals’ daily lives. In particular, she focuses on the notion of the ‘lived materiality’ of subjectivity (Beasley & Bacchi, 2007; Pillow, 2003; Pullen & Tyler, 2007). Following Pillow (2003), Bacchi suggests that discourses in policies both shape the target population as particular types of subjects (e.g., men/women, nondisabled/disabled, active/passive) and have a material impact (e.g., financial circumstances, emotional distress) on their daily life experiences. Pillow (2003) emphasizes that ‘bodies’ are an object of interest in public policy for controlling, regulating and shaping in
particular ways. Moreover, bodies are ascribed with social value and meaning, which has implications for the courses of action proposed in a policy and therefore the daily life circumstances of the target group. Bacchi (2009) suggests, however, that many approaches to discourse analysis “tend to neglect the impact of discourses on how people live their lives on a day-to-day basis, and on how nondiscursive factors interact with discourses” (p. 43). In this vein, the WPR approach directs attention to “the shaping influence of nondiscursive factors, such as the differential social location of women and men, on one’s embodied experience” (p. 43). By way of example, Bacchi (2009) suggests that the differential social value and significance ascribed to female and male bodies shape how women and men think about themselves and others, but also shape problem representations in particular ways that can have real life consequences for their day-to-day lives. Thus, discursive elaborations of problem representations function to constitute subjects of particular types that have both sociopolitical ramifications (e.g., some subjects are socially valued, while others are stigmatized) and material consequences (e.g., access to income, housing, education, job training) for the target group. In this study, the WPR approach provided a lens for examining the types of subjects produced by identified problem representations in transition policies and the real life consequences on the health and day-to-day lives of young people with DD and their families.

2.2.4 Governmentality Studies

The WPR approach draws heavily on theoretical ideas associated with Foucault’s notion of governmentality, meaning the forms of thinking that are necessary for particular ways of governing and managing populations to take place (Bacchi, 2009). As an intellectual tradition, governmentality studies examine and reveal the broad patterns of “thought in or behind government” (Bacchi, 2009, p. 265; emphasis in original). Importantly, this thought is not necessarily at a conscious level, but reflects the kinds of thinking associated with particular kinds of government. Foucault was particularly interested in the forms of government that emerged in the late eighteenth century, which focused on managing populations (Bacchi, 2009). Governmentality scholars draw on Foucault’s notion of problematizations, which I discussed
previously, to examine the broad patterns of thought in or behind governance⁴ (Bacchi, 2009). Governmentality studies focuses particularly on the indirect ways that governing techniques and practices take place through agencies and institutions (e.g., hospitals, schools), and the professionals (e.g., clinicians, educators) that work within them to encourage individuals to be responsible for regulating and conducting themselves (Rose, O’Malley, & Valverde, 2006). In this section, I discuss the key theoretical underpinnings of governmentality perspectives that informed development of the WPR methodological approach to policy analysis.

Foucault used the term governmentality in two ways. First, Foucault (1991) referred to governmentality as the broad patterns of thought that shape particular approaches to government. He used the terms *govern-mentalities, modes of governance*, and *rationales of rule* to reflect the ways of thinking that inform government. Governmentality studies aim to explore the thought behind governance. In other words, governmentality scholars explore the rationale or forms of thinking that must be in place for particular ways of governing to take place (Bacchi, 2009, 2012; Ristovski-Slijepcevic, Chapman, & Beagan, 2010; Rose et al., 2006). These rationalities draw on expert knowledges (e.g., knowledge developed in the fields of medicine or education) to shape techniques and practices for governing the everyday lives of people and populations (Dean, 1999). A WPR approach focuses on “the knowledges through which rule takes place, and the influence of experts and professionals on and through these knowledges, rather than examining their direct role as participants in political processes (e.g., as members of lobby groups)” (Bacchi, 2009, p. 26). In this regard, WPR and governmentality studies approaches are particularly interested in the indirect influence of these knowledges on how people are governed. These knowledges shape the rationale, techniques, and procedures for directing human behaviour to achieve the aims and desires of the government, such as governing children, households, or a population (Foucault, 1997).

The second way in which Foucault uses the term governmentality is to refer to the form of rule that emerged with industrialization and a growing urban population in Western Europe in the late

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⁴ In WPR, governance refers broadly to general societal administration or to “an understanding of rule that includes but also extends beyond the state to encompass a wide range of groups, agencies and institutions, including professionals and the social sciences” (Bacchi, 2009, p. 275).
Governmentality studies draw and build on Foucault’s notion of ‘biopower’ (Rose et al., 2006). Foucault (1998) discussed biopower as a mechanism of social control that arose with the emergence of modern nation states in the late eighteenth century. As populations grew and modes of production became increasingly industrialized, new systems of rule were needed to manage and regulate large groups of people living increasingly in dense urban settings (Foucault, 1991). Prior to the formation of modern states, monarchies constituted the predominant system of rule, particularly in medieval Europe. In these feudal systems, a sovereign ruler controlled the majority peasant population by utilizing the threat of death (Foucault, 1979). With the shift to the modern industrialized state, new technologies of power were needed to control and regulate individual subjects and the population as a whole. Rather than the threat of death, modern states deployed techniques of biopower (e.g., expert knowledges, policies), which functioned to control and regulate populations by promoting life and health through mechanisms in which people regulated themselves in relation to an expected standard. Foucault argued that a diffuse power exercised by the state emerged in Western industrialized societies rather than a repressive power possessed by individuals or groups as in feudal societies (Annandale, 1998). Governmentality scholars suggest that ‘government at a distance’ allows for governments to appear to be noninterfering in the ways in which citizens live and choose to live their daily lives. It is a distinct characteristic of government rationalities associated with liberalism or neoliberalism.

3 Neoliberalism

Neoliberal modes of rule have become predominant and socially accepted as the ‘right’ way of thinking, to the extent that it is both pervasive and invisible, in Western industrialized societies. Historically, industrialized societies arose in Western Europe (e.g., Britain, France) and countries descended from them (e.g., United States, Australia, Canada). They are characterized by technology, mass production, urbanization of the population, democratic political systems, and liberal modes of rule (Browne, 2001). Over centuries, several strands of liberalism evolved, including classic liberalism, modern welfare liberalism, and neoliberalism. Classic liberalism refers to the way of thinking that evolved with the breakdown of feudalism in Europe and the shift to free market or capitalist societies alongside the rise of industrialization into the nineteenth century (Browne, 2001; Heywood, 2003). Features of classical liberalism include the
belief in minimal intervention of the state, and only when essential to protecting the rights and freedoms of individuals and maintaining public order. However, over time, social and economic inequalities arose in the population, which were not addressed by this political ideological approach. Increasingly, governments were compelled to intervene to address these inequalities. What evolved was modern welfare liberalism, wherein governments became increasingly responsible for addressing social inequalities by providing access to public education, health care, and social welfare programs. However, political theorists suggest that features of classical liberalism have regained popularity in Western industrialized societies, particularly in times of economic recession, and have been re-coined as ‘neoliberalism’. Hereafter, when I used the terms ‘Western’ or ‘neoliberal’ societies, I refer to the description in this section. Two key assumptions underlying neoliberal ways of thinking are relevant to my analysis: individualism and equality of opportunity.

3.1 Individualism

Individualism is widely acknowledged as a key feature of liberalism and is deeply entrenched in Western societies (Browne, 2001). It is underpinned by assumptions about people as rational, autonomous agents who are distinct from the population and their social, economic, and political contexts (Browne, 2001). In this regard, free market economies emphasize the goals and interests of individuals in pursuing and securing resources for their own survival rather than those of the social whole. Individualism stresses self-reliance and financial independence as foundations for governing the population as a whole and fosters competition between individuals to propagate a free market economy. An emphasis on residential and financial independence has traditionally shaped the aims of a myriad of social policies and practices targeting disabled people in Western societies. The notion of independence as a preferred outcome of policy and practice is reflected in the transition literature, which I discuss in Chapter 3.

3.2 Equality of Opportunity

Equality of opportunity is also a significant feature of the neoliberal thought that underpins Western societies (Browne, 2001). It emphasizes that all individuals ought to have equal access to opportunities to succeed (or fail) in society. In practice, this tenet of liberalism assumes that individuals should have equal access to opportunities to live a ‘good’ life by ‘levelling the
playing field’. A ‘good’ life is judged in relation to population norms for ways of being (e.g., healthy, self-reliant, financially independent) and acting (e.g., working, volunteering, interacting with others, living independently, etc.) in community life and social and economic participation in society.

‘Leveling the playing field’ is generally affiliated with developing the skills and competencies of citizens to foster equal access to opportunities for social and economic participation, which is taken-for-granted as an indicator of a successful life (Browne, 2001). For example, developing skills and knowledge for work through education and training is generally accepted as the ‘proper’ path to a ‘good’ life in Western industrialized societies. Guided by this idea, governments underpinned by neoliberal assumptions promote and emphasize developing the skills and competencies of individuals for work and becoming self-reliant to foster equitable access to full participation in free market economies and a ‘good’ life, rather than distributing collective social and economic resources across the population. Taken-for-granted assumptions about equality of opportunity that underpin liberal modes of rule have shaped numerous public policies for disabled people in Western industrialized societies (Browne, 2001). Notions of equality of opportunity and individualism shaped my lens for analyzing the tacit assumptions underlying problematizations of transition in my data. As described previously, taken-for-granted assumptions that underpin the problematizations in a policy can have significant implications for how a social issue (e.g., transition to adulthood for young disabled people) is understood, what courses of action are proposed to address it, and what effects these courses of action have on the individuals or groups who are the target of the policy.

4 Summary

In this chapter, I described the critical qualitative approach that guided this analysis. This approach aims to question tacit assumptions underpinning the implied problems in transition discourses embedded in policies and best practices and to reveal the sociopolitical conditions that shaped these assumptions. Such tacit assumptions are internalized by individuals, shaping how they view themselves and conduct their lives in a society. Key theoretical principles of critical perspectives emphasize examining; (a) power relations between dominant groups who perpetuate mainstream ways of thinking that may marginalize nondominant groups; and (b) taken-for-
granted assumptions about how people should/should not conduct their lives, devaluing other ways of being and doing.

In addition, I described the WPR approach to policy analysis with its emphasis on interrogating problematizations and taken-for-granted social assumptions about an issue to understand how it is constituted as a particular kind of ‘problem’. Bacchi (2009) suggests that problems are constituted or given shape in the act of problematizing, thus they are represented or framed in particular ways that determine what is considered significant in understanding the ‘problem’, and what is not considered. This does not necessarily imply intentional manipulation of how problems are represented. Rather, the way a problem is represented draws attention to particular understandings or aspects of the ‘problem’, potentially neglecting, ignoring, or drawing attention away from other understandings of the ‘problem’. Prevailing neoliberal notions of individualism and equality of opportunity tend to shape understandings of public policy issues and how to address them in particular ways in Western industrialized societies. Aligning with the critical approach described in this chapter, my analysis focused on questioning, rather than solving, the ‘problem’ of transition to adulthood for young disabled people.
Chapter 3
Review of Relevant Literature and Concepts

In this chapter, I review the literature about transition to adulthood for young disabled people to understand how it has been conceptualized as a problem and what has been proposed to address it. In the first part of the chapter, I review the literature that has shaped dominant conceptualizations of transition to adulthood in policy and practice in Ontario, and Western societies more broadly (e.g., Canada, United States, United Kingdom, Australia). These conceptualizations draw predominantly from the health and rehabilitation literature, which, for the most part, draws on particular understandings of disability.

In the second part of this chapter, I review key concepts of disability, generation (e.g., childhood, adulthood), development, and citizenship that are relevant to understanding how transition is conceptualized as a problem in Western societies. Consistent with the critical approach taken in this study, I draw on the disability studies literature to unpack the taken-for-granted assumptions that shape how these concepts are understood and their implications for shaping transition as a particular kind of ‘problem’.

1 Relevant Transition Literature

A comprehensive search strategy was employed to identify the primary literature, published between 1990 and 2011, that informed current Ontario policy and best practices on transition to adulthood and disability. The portals searched were: CINAHL, Medline, Scopus, Web of Science, Social Sciences Abstracts, PsycInfo, ERIC, and Dissertation Abstracts. A number of subject headings and key search terms gleaned from my coursework were starting points. The search strategy was tailored to suit each portal. In addition, ‘grey’ or unpublished literature was gleaned from reference lists, Google searches, and from my professional networks and settings. In what follows, I review the literature to illuminate how transition to adulthood is predominantly represented as a problem.

Transition research has focused on identifying and addressing individual factors (e.g., improving impairments and developing skills and knowledge for disability management, etc.) and environmental factors (e.g., increasing family support for self-management of youth, improving
organizational procedures for discharge and transfer to adult services, etc.) that influence the process of transitioning from childhood to adulthood for a broad population of young people with chronic conditions and disabilities (Hamdani, Jetha, et al., 2011). Initially, the research literature shaped particular understandings of transition as a service transfer issue at a chronological age when young disabled people are no longer eligible for health, education, and social services mandated for children. However, stakeholders, including young people, families, service providers and researchers, began to recognize that the issue is broader than a ‘baton-pass’ from child to adult services and has highlighted the developmental transition from child to adult life. Transition is constructed as a complex problem, involving service and developmental transitions, influenced by factors at multiple levels (e.g., individual, interpersonal, organizational, and system levels). In what follows, I discuss prominent definitions of transition in the literature, then provide an overview of the multilevel factors that have been identified as influencing transition.

1.1 Defining Transition

Blum, Hirsch, et al. (2002) described health care transition for young people with special health care needs as:

. . . a dynamic, lifelong process that seeks to meet their individual needs as they move from childhood to adulthood. The goal is to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood. (p.1304)

This description has been adopted almost universally in the health care and rehabilitation literatures, but has also served as a reference to inform transition planning frameworks in children and youth services, and community and social services. It suggests that services should promote development, functioning in daily life, and continuous care over the life course for individuals with childhood onset conditions. It conceptualizes the transition to adulthood as a dynamic, lifelong process, rather than an event of transfer from the pediatric to the adult health care system. Several authors support a lifespan approach to childhood disability (Gibson et al., 2009; Kingsnorth et al., 2011; Priestly, 2003; Stewart, 2009).
McDonagh and Kelly (2010) emphasize the need to clarify language and terminology in transition research. They highlight the need to define transition and transfer, and youth, teens, teenagers, young people, and youth because they are used synonymously in the literature (McDonagh & Kelly, 2010). I discuss these groups of terms in what follows.

The term ‘transition’ generally refers to the broader process of moving between the life stages of childhood and adulthood (Blum, Garell, et al., 1993; Callahan, Winitzer, & Keenan, 2001), whereas ‘transfer’ refers to the actual event of leaving or being discharged from childhood services and moving to adult services. Policies and organizational practices in Ontario have generally focused on the latter and what constitutes a successful transfer, at least on the surface, is a coordinated and planned process of linking young disabled people and their families to adult service providers across sectors. In Ontario, young disabled people typically have access to services mandated for children and youth until 18 years of age (MCSS/MCYS, 2011; Young et al., 2009).

With respect to age terminology, a unified definition or description is not evident in the transition literature. Teen, teenager, and sometimes youth can refer to the life stage somewhere between 13 and 18 years of age, prior to discharge from pediatric services. However, youth also appears to be used synonymously with young adults and refers to the stage before full adulthood is achieved (which is not defined). Arnett (2004) proposes that there is a distinct period between the teens and twenties (generally between 18 to 25 years of age) in which prolonged independent role exploration is accepted, usually in Western industrialized societies, called emerging adulthood. McDonagh and Kelly (2010) proposed that this term would be useful to describe many young people with special health care needs because they tend to experience challenges in achieving traditional milestones and tasks of adulthood. However, re-naming this life stage suggests that there are taken-for-granted assumptions about what constitutes childhood, adolescence, and adulthood, which shape implicit understandings of what constitutes a successful transition from childhood to adulthood, to which young disabled people are compared. Thus, both explicit and implicit understandings of a successful transition to adulthood for young disabled people shape how it is constructed as a problem.
1.2 Multilevel Transition Factors

Transition for young people has been described as a complex issue influenced by multiple interacting factors, including health, personal and environmental factors (Gorter, Stewart, & Woodbury-Smith, 2011; Hamdani, Jetha, et al., 2011; Reiss, Gibson, & Walker, 2005). For the most part, the transition literature has focused on identifying barriers and facilitators to a successful transition to adult life, with a particular focus on identifying multilevel factors (e.g., individual, interpersonal, organizational, and system level factors) that influence the transfer process from child to adult services. In what follows, I review this literature with the aim of understanding how transition to adulthood is conceptualized as a problem and what is proposed to address it in policy and practice.

1.2.1 Individual Factors

*Childhood disability and impairments.* Childhood disability is characterized by a diverse array of impairments and associated conditions, including physical, mental, and emotional impairments, which are associated with limitations to engaging in activities (such as eating, dressing, bathing, getting around the home, school, or community), and to participation in school and work (Callahan & Cooper, 2006; Reiss et al., 2005; Simeonsson et al., 2003). Young disabled people may present with limitations in communication, problem solving, learning, mobility, and personal care (Binks et al., 2007). They often have multiple impairments and medical conditions and are involved in complex health care beyond traditional medical interventions for biological and physiological impairments compared to young people with chronic conditions such as diabetes or asthma (Young et al., 2009). For example, many young people with DD have co-occurring cognitive and behavioural disorders that create unique challenges for providing transitional health care (Camfield, Gibson, & Douglass, 2011; Kuhlthau, Warfield, Hurson, Delahaye, & Crossman, 2015). Young people with autism spectrum disorders (ASD) may have multiple conditions (e.g., mental and behavioural health disorders, epilepsy, gastrointestinal problems, anxiety and depression, and respiratory, food, and skin allergies) (Kuhlthau et al., 2015). The literature suggests that this array of impairments and health conditions often requires specialized health care and makes it difficult to transfer young people with DD to adult health
services, in which service providers tend to be unfamiliar with childhood onset conditions and less coordinated.

*Independence and self-management.* The notion of increasing independence for self-management is prevalent in the transition literature. Self-management (i.e., skills and competencies to manage health) to the extent possible is proposed to be the key to a smooth transition (Binks et al., 2007; Gall et al., 2006; Gorter, 2009; Kennedy et al., 2007; Schultz & Liptak, 1998). Examples of self-management tasks include managing medical conditions, navigating the adult health care system and nonmedical services, communicating with adult clinicians, problem solving and decision making, self-advocacy, and maintaining healthy lifestyles that promote well-being and minimize secondary conditions (Binks et al., 2007; McDonagh & Viner, 2006). In general, independence refers to being self-sufficient and less reliant on others, particularly on parents, for personal care and daily life management.

Transition best practices suggest that young people should be encouraged to gradually take over responsibility for managing their health and daily lives to the extent possible. For example, the Canadian Paediatric Society (CPS; 2007) suggests that adolescents should develop “autonomous, independent consumer skills” (CPS, p. 785). The Society of Adolescent Health and Medicine cautions that “adolescents with chronic conditions are at higher risk for unnecessary dependency” (Rosen et al., 2003, p. 309) and dependency should be prevented through practices that enhance autonomy and a sense of personal responsibility. However, Binks et al. (2007) propose that ‘independence’ does not mean ‘without assistance’. They propose that young people can take responsibility for directing and collaborating with others to manage their care. Recent literature generally acknowledges that independent self-management may not possible for all young people and promotes the idea of ‘shared management’ (Gall et al., 2006; Kieckhefer & Trahms, 2000; Stewart, Freeman, et al., 2009). Giarelli, Bernhardt, Mack, and Pyeritz (2008) suggested that responsibility for health management must be transferred from professionals to parents to youth and should consider what, how and when information is transferred. The shared management model, in which there are shared roles and responsibilities among young people, family members or other caregivers, and service providers is suggested as a framework to foster a gradual shift in responsibility from service providers to parents or other caregivers to young people themselves (Kieckhefer & Trahms, 2000). The emphasis on young people learning to
make decisions and to advocate for themselves, with or without the support of others, reflects the relative value placed on independence. An emphasis on independence reflects that dependence is less than ideal. Thus, dependence on others for health and daily life management is implied as problematic for a successful transition to adulthood for young disabled people.

**Developmental readiness.** Schultz and Liptak (1998) identified developmental readiness as a component of a successful transition to adulthood. They proposed that self-determination, self-efficacy, psychological maturity, and motivation are developmental skills and traits that contribute to young people being prepared for roles and behaviours of adult life (Schultz & Liptak, 1998). Other literature suggests that developmental tasks of adolescence include consolidation of self-identity, progressing to independence from parents, and establishing peer relationships and adult relationships (Fiorentino et al., 1998; Wedgwood, Llewellyn, Honey, & Schneider, 2008). Thus, the literature on best practices focuses on promoting the achievement of developmental skills and tasks to facilitate a successful transition to adult life.

Best practices for transition are guided by principles of “normal, healthy development” (Blum, Hirsch, et al., 2002, p. 1304), described as “appropriate for chronological age and developmental attainment” (Rosen et al., 2003, p. 309), and “mirror the young person’s increasing maturity and emerging adulthood” (Blum, Hirsch, et al., 2002, p. 1305). Blum, Hirsch, et al. (2002) described the intended outcome for youth as the optimal “ability to assume adult roles and functioning” (p. 1304). Ideally, young people are expected to progress along a developmental continuum of skills and competencies in preparation for roles and activities associated with adulthood, including managing personal and health care, moving out of the family home, participating in further education or work, and forming intimate relationships (Hamdani, Mistry & Gibson, 2015). Stewart, Law, Rosenbaum, and Willms (2001) suggested that young disabled people face barriers to achieving developmental milestones, such as graduating from high school, finding employment, and experiencing intimate relationships; yet, they express the same dreams and aspirations as their nondisabled peers. On the whole, the aims of transition preparation and planning focus on achieving skills and competencies associated with a normal developmental trajectory, suggesting that young people who do not achieve these skills and competencies face problems in transitioning to adult life.
1.2.2 Interpersonal Factors

Young people are expected to move towards achieving an autonomous adulthood, including a shift in responsibilities for managing health and activities of daily living from family members to the young person. For many young disabled people, this progression is done with the support and involvement of family members. Two key interpersonal factors—shift in responsibility, and extent and quality of family support—will be discussed in this section.

Extent and quality of family support. Many young people with childhood onset disabilities have depended on their parents to be highly involved in managing their health conditions and in coordinating their care, services and supports, and daily lives since they were infants. The extent and quality of family support has been identified as a factor that contributes morbidity in chronic conditions of childhood (Marks, Allegrante, & Lorig, 2005), particularly as young people begin to take on responsibilities for managing their health and daily lives.

Transition best practices generally emphasis that service providers support both young people and their parents to gradually shift responsibilities for these tasks from parents to the young people themselves to the extent possible (Betz, 2007; Gall et al., 2006). Binks et al. (2007) suggested that support and encouragement from family members are associated with gradual development of autonomy and responsibility for disability management. Furthermore, young people’s connectedness to parents and/or other family members is considered a protective factor for healthy behaviours in youth in general (Bernat & Resnick, 2006). Ideally, there is a shift in responsibility from parents as youth progress through appropriate developmental stages to become knowledgeable and capable participants in their own care (Kieckhefer & Trahms, 2000). Wang et al. (2010) identified the need to transfer health information about condition management gradually. The challenge is that parents may resist relinquishing control of disability management and decision making (Binks et al., 2007).

Reasons for parental resistance include protectiveness, lack of confidence in the youth’s ability to manage the condition, and difficulty accepting a less involved role, particularly if the youth’s cognitive capacity for these tasks is difficult to determine (Binks et al., 2007; Patterson & Lanier, 1999; Stewart, Stavness, et al., 2006). Families may also resist the transition to less familiar adult services, particularly if they perceive adult services to be less engaging of family members in
decision making (Binks et al., 2007). Thus, the literature identifies the extent and quality of support provided by parents and other family members to young people as they take on responsibilities for managing their own health and daily lives as a factor influencing a successful transition to adult life.

1.2.3 Organizational Factors

Several organizational and inter-organizational determinants have been identified in the literature as having an influence on the successful transfer from services for children to those for adults.

Transition programs. The literature emphasizes a long period of preparation before transferring youth to adult services (Blum, Garell, et al., 1993; Blum, Hirsch, et al., 2002; Gorter, 2009; Stewart, Stavness, et al., 2006). Several authors recommend that service providers discuss transition to adulthood with young disabled people and their families starting in early adolescence (Gall et al., 2006; Kennedy et al., 2007) or even as early as diagnosis (Binks et al., 2007). This preparation should address the medical health needs of the young person, but also his or her financial, educational, vocational, and other life needs (Binks et al., 2007; Stewart, Stavness, et al., 2006). King et al. (2006) recommended that transition strategies and programs for childhood and youth should focus on skill instruction (i.e. social skills, life skills, leisure skills, and skills underlying self-determination), self-awareness, and planning and goal setting. Stewart, Stavness, et al. (2006) suggested that skill development focus on self-determination, self-advocacy, choice making, and problem solving with a view of transition to adulthood as part of a developmental continuum or life course, while adopting an individualized approach to services and recognizing the young person’s unique strengths and needs, and their relationships with family, peers and community. Gall et al. (2006) suggest a Growing Up Ready approach, where youth gradually take on responsibility for managing childhood disability over the lifespan. The identified need for transition preparation and planning promoted in the literature suggested that young disabled people lack the skills and competencies expected for managing their lives as adults.

Coordinated transfer process. A coordinated process for transitioning between child and adult services is recommended in the literature (Reiss & Gibson, 2002; Wang et al., 2010). Other recommended elements of a coordinated transfer include: a written plan for transition to adult
services (e.g., who will provide services and where) (Reiss & Gibson, 2002); transfer of health and other information from child services to adult services (Binks et al., 2007; Kennedy et al., 2007; Wang et al., 2010; Wolfstadt, Kaufman, Levitin, & Kaufman, 2011); and communication and collaboration between young people and their families, and service providers on both the child and adult sides of the transfer (Binks et al., 2007; Hamdani, Kingsnorth, & Healy, 2006; Rapley & Davidson, 2010; Stewart, Stavness, et al., 2006; Wedgwood et al., 2008). Reiss and Gibson (2002) recommended that transition plans be developed and graduation from pediatric health care be celebrated with ceremonies and certificates of completion, similar to graduation from high school, to signify leaving childhood services and moving on to adult services. They also recommended strategies, such as combined visits and team meetings, to bridge the transfer between child and adult service providers (Reiss & Gibson, 2002). A focus on coordinating the transition from child to adult services through formalized processes directs attention to the service transfer aspects of the problem, but potentially neglects the experiences of shifting social expectations for conducting oneself in particular ways between child and adult services.

**Shift in service culture.** The literature suggests that the culture of pediatric health services tends to be family-centred and holistic, compared to adult services, which tend to be patient-centred and acute care focused (Camfield et al., 2011; Rosenbaum, 2009). Many young disabled people and their families report an unsatisfactory and abrupt change in their service experiences between child and adult services (Binks et al., 2007; Callahan et al., 2001; Young et al., 2009). Binks et al. (2007) suggested that adults with childhood onset disabilities may not receive the services and support they need, and may even feel rejected or disillusioned with adult services. However, the service culture on both sides of the transfer may contribute to inadequate transitions to adulthood. For example, a family-centred approach common to children’s services may hinder the shift in responsibilities for health and daily life management from parents to youth. Several authors suggest that parents have difficulty letting go of their roles and responsibilities to the detriment of their children’s development of self-management skills. On the adult service side, patient-centred, acute care models may be insufficient for addressing the complex and chronic conditions (Barr et al., 2003), particularly lifelong conditions of childhood onset. Several authors proposed that high quality relationships (e.g., rapport, feelings of trust and connectedness) with service providers, regardless of a focus on families or individuals, can have
a significant influence on how the transition to adulthood is experienced by young people and their families (Reiss et al., 2005; Scal & Ireland, 2005).

1.2.4 System Factors

Access to services for adults. Adult-oriented services for young disabled people are generally described as fragmented and less centralized than services for children (Binks et al., 2007; Reiss et al., 2005). In addition, children’s services are often delivered by multidisciplinary teams, rather than by an individual service provider as in adult services. Moreover, adult services may have insufficient resources (i.e., funding, policy support, and trained professionals and teams) to address chronic, lifelong disabilities adequately. In some jurisdictions, services that meet the needs of young disabled adults may not exist or be limited (Stewart, Freeman, et al., 2009). Thus, a lack of access to services is identified as an issue for transitioning to adult life.

Training of service providers. Young people and their families perceive adult service providers to lack training and interest in childhood disability (Binks et al., 2007; Freed & Hudson, 2006; McDonagh, Southwood, et al., 2004; Young, 2007), and therefore problematic. In health care professions, childhood onset conditions are usually taught in the pediatric portions of training, with little emphasis on implications for adolescence and adulthood. McDonagh, Southwood, et al. (2004) suggested that training for pediatric service providers should include skills and knowledge for supporting the development of self/shared management. Although transition planning is a recommended best practice, Lotstein, McPherson, Strickland, and Newacheck (2005) found that only half of the young people with special health care needs in their study had discussed transitioning to adulthood with their service providers. On the adult service side, service providers need more training about developmental conditions (including combinations of physical, cognitive and communication impairments; Binks et al., 2007), and for working with health advocates (e.g., family members, paid and unpaid caregivers) who accompany many young disabled adults to appointments (Wedgwood et al., 2008).

Social participation. Schultz and Liptak (1998) warned that transition to adulthood requires more than interventions focused on changing individuals (e.g., developing skills for independence and self-management); strategies to change social beliefs and attitudes about disabled people and their participation in society are also needed. Stewart, Freeman, et al. (2009) suggested that
future work is needed to understand participation as an outcome, in addition to outcomes for health and the service transfer process. In health and rehabilitation field, participation usually refers to involvement in life situations (World Health Organization, 2001). Rosenbaum and Stewart (2007) proposed a shift away from impairment-focused to participation-enhancing interventions for childhood disability in rehabilitation. Wang et al. (2010) noted that knowledge about macro system influences, which includes ideology and organization of social institutions, is missing in the transition literature. The idea of social participation suggests that the problem of transition goes beyond addressing the issue of transferring between child and adult services. The literature, particularly in rehabilitation, is beginning to examine the concept of participation as it pertains to transition. However, overall, little attention has been paid to the understanding the broader social contexts that shape how transition to adulthood is constructed as a problem.

1.3 Summary

As the literature review has revealed, the predominant literature that has informed transition policy and practice has focused on identifying barriers and facilitators to the process of transferring from child to adult services. Recommendations for best practices have focused on addressing multilevel factors that influence the transition process. However, what constitutes a successful transition is largely assumed and is most closely linked to the idea of establishing a continuity of service and supports between childhood and adulthood. Furthermore, the meaning of key concepts, such as disability and adulthood, are largely taken-for-granted in the dominant literature that has informed how the problem of transition is conceptualized. Yet, their explicit and implicit meanings can contribute significantly to how transition to adulthood is constituted as a problem, and therefore what is proposed to address it. There is another body of literature that draws on critical scholarship to examine and unpack concepts, such as disability, development and adulthood, which can contribute to new and different ways of understanding how transition is problematized compared to the dominant research on this topic. In what follows, I draw on critical scholarship to examine key concepts that are relevant to understanding how transition to adulthood for young disabled people is constituted as a problem. I identified these concepts by engaging with the transition literature to inform clinical interventions in my previous work and to inform my PhD coursework and research. These concepts are disability, generation (e.g., childhood and adulthood), development, and citizenship.
2 Critical Review of Key Concepts

Consistent with the theoretical approach taken in this study, I critically review key concepts of disability, generation, development, and citizenship to understand how transition to adulthood is represented as a problem in the mainstream literature. I propose that these concepts are produced as objects of interest and are given meaning in relation to notions of what constitutes an ‘ideal’ adult citizen in Western societies. These notions are shaped by normative ideas of being, becoming and acting as an adult. The taken-for-granted meanings that underlie these concepts direct attention to particular courses of action in policies and best practices on transition, which can have both positive and negative consequences on the lives of young people with DD and their families.

First, I begin by examining dominant understandings of disability and how they contribute to shaping disability as a particular kind of ‘problem’. I then draw on Lennard Davis’s (2013) work to discuss how disability is constructed as a ‘problem’ in relation to normality. Second, I draw predominantly on Mark Priestley’s (2003) work to discuss childhood and adulthood as generational categories that can only be understood in relation to each other. Third, I build on the discussion by examining dominant understandings of (normal) child development and how they contribute to shaping the ‘problem’ of transition to adulthood in particular ways. Finally, I discuss the notion of citizenship as it pertains to disability and adulthood. Citizenship is conceptualized in a number of ways but the dominant way it is understood (generally associated with achieving particular rights and responsibilities in adult life) is relevant analyzing policies focused on managing the conduct and lives of a particular group of citizens, such as young disabled people.

2.1 Disability

Disability is something—if it actually is anything at all—that is framed in a number of ways with very different implications for our knowledge, policies, and practices. (Williams, 2001, p. 127)

Williams’ quote reflects that disability has been conceptualized from a number of perspectives (e.g., medical, social, civil rights, and economic perspectives), but most importantly, it became
an ‘object’ of thought in the process of being conceptualized, which has informed how it is understood as a ‘problem’ in policy and practice. In what follows, I discuss the prevailing conceptualizations of disability that have shaped how it is constructed as a ‘problem’ in research, public policy, and practice. These conceptualizations include the individual and social models of disability, and the biopsychosocial model that underpins the *International Classification of Functioning, Disability and Health* (ICF; World Health Organization, 2001). These conceptualizations, and particularly the ICF, are prominent in the health and rehabilitation fields, but have also significantly influenced how disability is understood and addressed in other fields, including education and social services. Consistent with the critical approach taken in this study, I then examine the taken-for-granted assumptions about normality and disability underpinning these conceptualizations.

### 2.1.1 Individual Model

Traditionally, conceptualizations of disability stem from what has been called a medical or ‘individual’ model, which focuses on disability as a problem caused by biological impairments (e.g., impairments to the body, its structures and/or physiological processes) at the individual level (Oliver, 2009; Priestley, 2003). This view of disability assumes that individuals are disabled by their impairments (e.g., physical, cognitive, sensory, psychological, and physiological impairments; Oliver, 2009). In its ‘purest’ form, the model’s theoretical underpinnings assume that biological aspects (e.g., body structure or function) of the individual are the foundations of illness and impairment (Hammell, 2006; Oliver, 2009; Twigg, 2006; Williams, 2001), and generally fall under the concern of medicine. In other words, an individual’s impairments are the root causes of disablement, and make it difficult for the individual to function and perform ‘normal’ life activities (e.g., personal care, daily living, work and leisure activities; Hammell, 2006).

Drawing on medical knowledge about the body and its systems, health and rehabilitation professionals identify and compare impairments to normative standards for bodies, structures, and functioning. Deviations from these normative standards are addressed through interventions (e.g., pharmacological treatment, surgery, therapy) focused on minimizing an individual’s impairments and dysfunction and improving his or her abilities to perform socially expected
activities (Barnes, Mercer & Shakespeare, 1999; Oliver, 2009; Swain, French, Barnes & Thomas, 2009). It is largely assumed that achieving or approximating normal activities will enhance an individual’s independence and fulfillment of his or her social roles and obligations, and thus, will enhance quality of life (Hammell, 2006). Thus, the objective of policy and practices shaped by the individual model is to minimize disability by addressing impairments and to foster normal bodies that are able to function in socially expected roles and activities of daily life to the extent possible (Barnes & Mercer, 2003; Hammell, 2006). Over the past 40 years, disability and civil rights activists have challenged the focus on individuals and their impairments as the cause of disability (Barnes et al., 1999; Hughes & Paterson, 1997; Oliver, 2009; Turner 2001). Rather, they have argued that the problem is physical and social barriers to full participation in society for people who have impairments. What arose was a shift in thinking about the ‘problem’ from the individual to the environment, which was described as a ‘social model’ of disability.

2.1.2 Social Model

With a view on civil rights, disability scholars rejected the notion that impairments were problematic, arguing instead that the problem is social exclusion of people with impairments from full participation in society (Hammell, 2006; Hughes, 2009). They reframed disability as a problem of social oppression and exclusion, analogous to already recognized oppressions associated with gender, race, class and sexuality (Thomas, 2012) and argued that people with impairments are labelled as ‘disabled’ by a social system that erects barriers to their participation (Hughes & Paterson, 1997). Both barriers in the built environment, as well as discrimination and prejudice in the social environment, were viewed as disabling (Swain et al., 2009). In other words, people with impairments are disabled by society and its structures (e.g., political infrastructure, and medical, education and social institutions). In essence, the social model focuses on identifying and dismantling the physical and social barriers in the environments in which people with impairments live (Swain et al., 2009).

The social model advanced the idea that people with impairments experience social disadvantages and exclusion in all aspects of life, including education, employment, housing, civil rights, transportation, and accessible built environments (Thomas, 2012). However, critics
argued that the social model focused too narrowly on addressing only physical and social barriers, neglecting to account for the impact of living with impairments and their effects on individuals. Yet, the individual model focused too narrowly on fixing impairments. A tension between individual and social understandings of disability and how it should be addressed arose. Was disability predominantly a medical problem to which the solution should focus on fixing or addressing biological impairments? Or was disability a social problem to which the solution should focus on addressing physical (e.g., built environments) and social (e.g., stigma, discrimination, etc.) barriers that hindered full participation of people with impairments in society? Based on this tension, new conceptualizations arose that incorporated both individual and social causes of disability. The most notable was the biopsychosocial model, which was developed by the World Health Organization (WHO) to inform development of the ICF (World Health Organization, 2001). The rehabilitation field in particular began to acknowledge the interaction of individual and environmental factors as a cause of disability.

2.1.3 ICF Framework

The ICF replaced WHO’s previous framework called the *International Classification of Impairments, Disability and Handicaps* (Hemmingsson & Jonsson, 2005; Imrie, 2004), which was criticized for having too narrow focus on impairment and factors associated with the individual. Disability scholars and activists urged for an increased emphasis on the rights of disabled citizens to participate fully in society (Barnes, Mercer & Shakespeare, 1999; Hemmingsson & Jonsson, 2005; Hurst, 2003; Swain et al., 2009). What evolved was the ICF, which emphasizes the interaction of the body, the person and broader social and environmental factors in determining health and disability (Imrie, 2004).

Elements of both the individual and social models of disability informed the development of the ICF and reflected a shift in how disability was represented as a problem. In the ICF framework, functioning, disability and health are “viewed as outcomes of interactions between health conditions (diseases, disorders, and injuries) and contextual factors” (World Health Organization, 2002, p. 10). Contextual factors include both personal (e.g., age, gender, race, educational level) and environmental (e.g., physical, social and attitudinal environments) factors and their interactions. Disability is described as an ‘umbrella’ term, that “includes impairments,
activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action, while a participation restriction is a problem experienced by an individual in involvement in life situations (World Health Organization, 2001). Thus, disability is constructed as a complex phenomenon, reflecting an interaction between features of a person’s body and features of the society in which he or she lives (World Health Organization, 2001). The intent is to acknowledge that people interact with their environments and that both individual and environmental factors influence a person’s ability to act and participate in society (Hammell, 2006). The ICF has been advanced by prominent organizations, such as WHO, which has shaped policy approaches to disability around the world. The rehabilitation field in particular has largely embraced this classification system, and the biopsychosocial model that underpins it, as a framework to guide policy and practice (Hammell, 2006). However, critical scholars propose that the ICF shapes and perpetuates powerful discourses about disability as a ‘problem’ that should be fixed or overcome by focusing on individual change, rather than embracing disability as a dimension of difference and focusing on sociopolitical change (e.g., changes to social values and beliefs about disability).

In the first half of this chapter, I reviewed the literature that has contributed to prevailing conceptualizations of the transition problem for young disabled people. For the most part, the literature reflected ideas underpinning the ICF framework with respect to identifying individual and environmental factors, and their interactions and influences on the transition process. The core elements of the ICF have been instrumental in shaping how disability has been conceptualized and constructed as a ‘problem’ in policy and practice, including transition policies and best practices, particularly in Western societies. However, critics of the ICF argue that it perpetuates ideas of disability as ‘not normal’ (Imrie, 2004). In other words, disability only ‘exists’ as a ‘problem’ in relation to normality, which is socially valued and idealized. While the ICF shifts understandings of the causes of disability, prevailing assumptions about normal bodies, normal functioning, and normal ways of participating in society persist and function to construct disability (e.g., disabled bodies, dysfunction, and abnormal ways of participating) as an object of thought or ‘problem’ to be addressed, mediated or ‘fixed’ in society (Gibson, 2016). Critical scholars argue that policies and practices shaped by the problem understood in this way
potentially perpetuate the social disadvantage and lack of access to social participation experienced by young disabled people in their daily lives, despite often sincere efforts to do the contrary. In what follows, I draw on the work of Lennard Davis (2013) to discuss how the concept of disability was constructed in relation to constructions of normality with the rise in interest in population statistics in the mid-nineteenth century.

2.1.4 Normality and Disability

Davis (2013) suggests that “to understand the disabled body, one must return to the concept of the norm, the normal body” (p. 1). Rephrasing Davis’ key argument, the ‘problem’ is not disability; the problem is the way ‘normality’ is constructed to create the problem of disability. He proposed that the concept of normality was constructed in conjunction with the development of statistical norms about the features and characteristics of the population in Europe in the nineteenth century. The purpose was to monitor the features and characteristics of individuals and groups in order to develop public policies for governing subgroups and the population as a whole, and managing social and financial resources. What evolved was the concept of the population norm, such that “the majority of the population must or should somehow be part of the norm” (Davis, 2013, p. 3).

Davis distinguishes between understandings of the normative body and the ‘ideal’ body before and after the rise in using population statistics for policy development. Prior to the use of statistical norms, the features and characteristics of the ideal body were unattainable because they were modelled on artists’ interpretations of divine or ‘other-worldly’ bodies reflected in sculptures and paintings of gods and goddesses (Davis, 2013). From this perspective of the ideal body, “all members of the population fall below the ideal” (Davis, 2013, p. 2). In contrast, statistical norms measured and defined the attributes, both physical and moral, of the ‘average man’. This representation of the average man shaped the normative standard to which all individuals were compared and were expected to aspire. Thus, the normative standards for physical and moral attributes of the average man reconfigured notions of the ideal body and became the guidepost for developing policies in health, education and other public services that foster achievement of these standards in the population.
Davis (2013) suggests that statistical norms became population norms, which shaped the characteristics of the ideal citizen and what courses of action should be taken to foster these characteristics in individuals. People whose physical and behavioural characteristics deviated below the statistical norm, such as many people with physical, cognitive, and sensory impairments, could be identified and appropriate policies developed and enacted to prevent or address these deviations in order to maintain the health and well-being of the population as a whole. In so doing, the concept of disability was created in relation to the construction of normality. Disabled people and their impairments came to be viewed as problems to be addressed. Moreover, the dichotomy of normality and disability produced an implicitly understood social hierarchy, in which normality was socially valued and preferred compared to disability. Davis proposed that this dichotomy produces social divisions (e.g., normal/abnormal, ability/disability) that perpetuate the social discrimination and marginalization experienced by people with impairments. Conceptualizations of disability constructed in relation to normality have underpinned policy and practice globally, including the province of Ontario.

In summary, I have examined the concept of disability and the prevailing ways in which it is implicitly understood and represented as a problem, which has relevance for understanding how transition to adulthood for young disabled people is conceptualized as a problem. Both individual and environmental factors are considered in dominant conceptualizations of disability, however, approaches to disability remains focused on individual rather than social change. Moreover, disability is constructed as a problem in relation to notions of normality, which potentially perpetuates ideas about disability as a problem to be addressed or overcome, rather accepting it as a dimension of difference, much like gender or race. Prevailing ideas about disability reflect tacit assumptions about normal ways of being and functioning over the life course held by the dominant (nondisabled) majority in. Mark Priestley (2003) proposes a framework from a life course perspective for understanding disability and social responses to it.

### 2.2 A Life Course Approach to Disability

Priestley (2003) suggests that social interpretations of disability shape policies and practices in particular ways, which have effects on people with impairments at different life stages and transition points. For example, we tend to think about disability in older adulthood as expected
and natural compared disability in childhood and young adulthood. Priestley (2003) proposes a typology for conceptualizing disability that incorporates individual and social models, similar to the ICF, but also sociological perspectives on the cultural and structural dimensions of disability. He aims to conceptualize the complexity of disability as a social phenomenon. He proposes that generation, a concept broader than ‘ages and stages’ ideas of childhood and adulthood, can also be understood in a similar typology.

The concept of generation involves “thinking about the ways in which important generational categories (like childhood, youth, adulthood or old age) are constructed, and how the boundaries or transitions between them are governed through social relations and social institutions” (Priestley, 2003, p. 4). He suggests that a generational perspective can highlight how disability is understood when significant events occur at different points in life, such as the transition from childhood to adulthood. Thus, it is important to examine both disability and generational categories in order to understand how they shape policy and practices across the life course.

Priestley (2003) proposes that the life course is a central organizing principle in modern societies and suggests that disability research should examine “the ways in which disabled lives are understood, organized and governed within societies” (p. 4). A life course view can highlight social understandings of what roles and responsibilities are expected at different ages and life stages and how they shape understandings of disability. For example, adults are expected to develop traits of independence for fulfilling roles and responsibilities associated with employment and daily life management in Western societies, whereas it is acceptable for children to be dependent on their parents until they develop skills and competencies to fulfill these roles and responsibilities themselves. Thus, socially accepted roles and responsibilities at different life stages shape how generational categories, such as childhood and adulthood, are characterized and understood in relation to one another.

Childhood, adolescence, and adulthood are important concepts in themselves and form a social stratification system based on generational relationships, much like gender or class relationships (Priestley, 2003). They are imbued with cultural meaning and structure in relation to one another that can be examined and connected to understandings of disability and transition to adulthood. For example, Priestly (2003) argues that both childhood and disability are subject to social regulation through institutions (such as schools and hospitals) that potentially deny agency,
competence, and civil rights to groups who have not or cannot achieve developmental tasks associated with independent adulthood. This particular kind of adulthood is valorized as the ideal outcome of child development in Western societies, to which all children are compared. Thus, children and their development are produced as objects of interest for governance and intervention in preparing them for socially valued roles and activities of adult life.

2.3 Child Development

Childhood is typically conceptualized from a developmental psychology perspective (Canadian Paediatric Society, 2007; Schultz & Liptak, 1998). The ultimate goal of childhood within this perspective is to move progressively from complete dependence to the highest possible level of independence (American Academy of Pediatrics, 1996). In Western societies, independence is socially valued and preferred and dependence is constructed as an undesirable trait of adulthood. Fraser and Gordon (1994) suggest that dependency has become a key word in the US welfare state, signifying a moral or psychological flaw in an individual. In their historical analysis of the meaning of dependency, they highlight that the meaning shifted between preindustrial and postindustrial times. In preindustrial times, dependency most commonly meant subordination, in which everyone was connected or subordinated to someone else, usually through dependencies between aggregate groups of people (Fraser & Gordon, 1994). In postindustrial times, dependency became increasingly associated with a moral or psychological deficit in individuals who relied on financial assistance in welfare states (Fraser & Gordon, 1994). These individuals were increasingly stigmatized and represented as deficient in moral or psychological character. Dependency in adulthood is implicitly understood as a trait to be avoided, which has shaped the aims of child development towards gradual and eventual independence in Western societies.

Childhood is a category or stage on the road to adulthood (Priestly, 2003), where adolescence is considered a critical transitional period along the road between dependency in childhood and independence in adulthood (Holmbeck, 2002). Several key developmental tasks are associated with adolescence, including identity formation, emotional development, formation of intimate relationships, cognitive development, and accomplishment of formal education goals, community inclusion, and independent living goals (Wood, Reiss, Ferris, Edwards, & Merrick, 2010). In addition, young people with chronic conditions and disabilities are expected to know
about their medical conditions, medications, and equipment, to develop skills to self-manage their health and daily lives, and to become proficient in accessing and using the health and social services. The expectation is that by achieving these developmental tasks, young disabled people will be prepared for adulthood. The idea of ‘developmentally appropriate’ care abounds in child and adolescent health care discourses (Canadian Paediatric Society, 2007; Hamdani, Mistry, et al., 2015; McDonagh & Kelly, 2010).

A developmental framework based on milestones for physical and cognitive norms is generally accepted in policies for disabled children (Priestley, 2003). Prevailing discourses of development assume a normal and expected progression through key tasks and milestones from childhood to adulthood. Key indicators of a ‘successful’ adulthood include independent living, employment, financial self-reliance, and forming intimate relationships. Transition policies based on this view assume that achieving developmental tasks will prepare children for adulthood. That is, a particular kind of adulthood in which independence, productivity (mainly paid work) and contribution to society are valorized. The goals and expected outcomes for normal development are defined by the perceived norms and competencies for adult life (Priestley, 2003). Children are expected to progress along a normal social and developmental trajectory, to the extent possible, on the journey to adulthood.

Critical scholars argue that developmental discourses are used to privilege and normalize particular world views about the proper outcome of development and have introduced the idea of ‘developmentalism’ (Burman, 2012; Walkerdine, 1993). Riggs (2006) describes developmentalism as the “particular logic that surrounds dominant accounts of childhood, wherein children are presumed to follow a relatively proscribed pathway to reach maturity” (p. 58). Normal development is assumed to take a specific form whereby children develop certain skills and attributes that assist them in becoming good moral citizens (Gibson, Teachman, & Hamdani, 2015). A particular kind of adulthood is generally accepted as the right and natural goal of child development, and therefore the proper aim of transition policies. Ideas about an ideal progression towards a particular adulthood, one in which an adult is constructed as an active citizen who contributes to society in valuable ways, are embedded in social policies focused on child development. This way of thinking has good intentions. It aims to minimize deficits and maximize functioning for accessing a good adult life. Critical scholars argue,
however, that classic child development theory constructs children as ‘incomplete adults’ (Priestley, 2003) or ‘adults-in-the-making’ (Burman, 2012; Walkerdine, 1993). Particular skills and competencies associated with employment and independence are valued for adults in Western industrialized societies. Young people who do not or cannot achieve these particular skills and competencies remain as ‘adults-in-the-making’, experiencing exclusion from full citizenship and social participation in adulthood. There has been little examination of the notion of citizenship in the transition literature, although it is relevant to understanding the aim of transition policies. In the following section, I explore the concept of citizenship and its relevance to disability issues.

2.4 Disability and Citizenship

Developmental discourses underpinning transitions policies reflect notions of what roles and behaviours are expected of adults, and by extension what is expected of adults as citizens, in both explicit and implicit terms. In this section, I discuss the concept of citizenship. Much like disability and adulthood, the meaning of citizenship is often taken-for-granted. Yet, particular meanings tend to take hold and shape ideas about how people should behave and live their lives, which has implications for the aims of transition policies and practices.

On the whole, the concept of citizenship incorporates notions of rights, responsibilities, obligations, needs, and actions. It involves the relationship between individuals and the state, and relationships within a state between individuals (Shakespeare & Watson, 2001). Prince (2009) suggested that there are multiple frames of citizenship in the disability studies literature. These include notions of biological citizenship, domestic citizenship, ecological citizenship, gender citizenship, global citizenship, multicultural citizenship, urban citizenship, and ‘full citizenship’ (Prince, 2009). My intention is not to describe all of these particular notions of citizenship in any detail, but to highlight that there are several ways to conceptualize this concept. Albeit, there are generally accepted notions of citizenship interwoven into the politics and policies of Western industrialized societies.

There are two key points that I wish to make. First, citizenship is generally viewed as a force for social inclusion when it is considered to be a right of all people in society (Lister, 1998), but generates thoughts about who is included and who is excluded. Second, each conceptualization
of citizenship is shaped by particular knowledge claims, social discourses and power relations, which are underpinned by particular ideas and values about what citizenship entails. Moreover, each implies particular policy actions and responses for achieving or accomplishing citizenship. Thus, how citizenship is framed can have potential advantages and disadvantages for of nondominant groups, such as young disabled people, that traditionally experience social marginalization. There are, however, generally accepted notions of ‘full’ or ‘active’ citizenship interwoven into the politics and policies of Western industrialized societies, such as Ontario.

‘Full citizenship’ is promoted by the government and by disability advocates alike, and reflects an idealized vision for all people to have full membership in their communities (Prince, 2009). People, and particularly people who are disenfranchised, pursue full citizenship because it is associated with status and entitlements. The idea of full citizenship generally encompasses the idea of ‘active citizenship’, meaning that all citizens have equal opportunity to participate in the political process and to achieve full citizenship by fulfilling their responsibilities, duties, and obligations to the community. At its core, full, active citizenship is assumed to provide access to opportunities for social inclusion and participation in the labour market. Prince (2009) describes the ‘politics of citizenship’, in which marginalized groups, such as people with disabilities, call for both entitlements (e.g., income supports, protected school and employment accommodations) and equal opportunities to fulfill their social obligations (e.g., to attend regular schools, to work, to own property). However, disability scholars argue “the status of rights and duties of citizenship for people with disabilities is differentiated, incomplete, and contested” (Prince, 2009, p. 181). For example, disabled people underrepresented in the work force, in public office, in opportunities to vote in elections, etc. From this perspective, citizenship status has not resulted in full access to social and political participation for disabled people.

The meaning of citizenship is multilayered and somewhat ambiguous because it can mean different things to different people. As a concept, it can be vague, ambiguous, and difficult to define. Its meaning and underlying sociopolitical assumptions can be contested (Lister, 1998). This contestation derives from key ideological views on how society should be, which are rooted in two dialectical political traditions: liberalism, which I discussed in Chapter 2, and civic republicanism (Lister, 1998; Shakespeare & Watson, 2001). Liberalism emphasizes the individual and his or her rights, whereas civic republicanism emphasizes the community and the
political obligations of individuals to that community (Lister, 1998). The former has several strands (e.g., classic liberalism, modern welfare liberalism, and neoliberalism), which share some central tenets, and tends to dominant political ideologies in Western industrialized nations. The latter, often promoted by critical scholars, is often seen as the most viable alternative liberal concepts of citizenship (Kartal, 2002). Lister (1998) suggested that one way to distinguish between the two traditions is that the former conceptualizes citizenship as status (rights to be a citizen) and the latter as practice (to act as a citizen). In theory, these political ideologies are seemingly distinct; however, in practice, these ideologies co-exist in democratic societies with high participation of political parties and people with diverse views. In Ontario, where democratic forms of government are deeply rooted, there are co-existing political ideologies that shape notions of citizenship.

Marshall’s (1964) notion of citizenship, often a starting point in the citizenship literature, is concerned with the civil, political and social (welfare) rights bestowed by the state to individual citizens in alignment with the principle of ‘equality of opportunity’ underpinning liberal ideologies. There are different ‘brands’ of liberal political ideology, but the central tenets are similar: primacy of the individual, equality of opportunity, individual freedom, state neutrality, and free market economies with minimal government interference. Oliver (2009) used Marshall’s ideas to argue that people with disabilities are denied full and active citizenship because they are denied civil rights (e.g., lack access to income distribution), political rights (e.g., lack of access to polling stations, underrepresented in political parties), and social rights (e.g., lack of access to physical and social environments, stigmatization), which pose barriers to working, socializing, and conducting their lives. Shakespeare and Watson (2001) argue that liberal ideologies downplay notions of difference (e.g., disability) and the barriers experienced by people who are different, promoting the idea of a universal, abstract and disembodied individual. Lister argues, however, that dominant accounts of citizenship are not disembodied, but rather, the idealized citizen, to which all citizens are compared, is a white, heterosexual, and nondisabled male. Society creates “an image of an ideal citizenship against which achievement can be measured and towards which aspirations can be directed” (Marshall, 1964, p. 84). From this standpoint, an ideal citizen in Western industrialized societies meets expectations for contributing to the economic and social life of the community. Citizens who deviate from this normative standard
are less valued and inferior (Shakespeare & Watson, 2001). This premise has implications for understanding who ‘counts’ and is socially valued as a citizen in Western societies and for shaping the conduct of individuals in particular ways through policy, such as transition policy.

3 Summary of Chapter

In this chapter, I reviewed the relevant literature and concepts that have contributed to predominant problematizations of transition to adulthood for young disabled people. In the first part of the chapter, I discussed the multilevel factors (e.g., individual, interpersonal, organizational and system level factors) identified in the literature as influencing the transition to adulthood for young disabled people in order to understand the dominant ways in which the problem is understood. For the most part, transition was conceptualized as service transition problem, and the proposed courses of action focused on addressing the individual, interpersonal, and organizational factors that hindered this transition.

In the second part of this chapter, I unpacked key concepts of disability, generation (e.g., childhood, adulthood), development, and citizenship to understand how their explicit and implicit meanings shape how transition for young disabled people is conceptualized as problem. As a group, these concepts shed light on the kind of adult citizen that is valorized in Western industrialized societies. Drawing on critical scholarship, I discussed how normal ways of being, developing and acting shaped notions of the ideal adult citizen—an active citizen who contributes economically and socially to society yet functions independently— to which all people are compared and expected to aspire. This idealized notion of adulthood functions to construct young disabled people as problems in themselves because they do not or cannot achieve the skills and competencies to achieve this end. In my analysis, I will draw on the explicit and implicit understandings of these concepts as a lens for examining how transition is constituted as a problem in Ontario policies and parents’ accounts of their children’s transition experiences.
Chapter 4
Research Design and Methods

In this chapter I describe the multimethod qualitative design that I used to achieve my research purpose and address my research questions described in Chapter 2. Drawing on the critical approach that I described in Chapter 3, my objectives were to examine:

- how transition to adulthood is constituted as a ‘problem’ across policy sectors in Ontario and by parents of young people with DD;
- how assumptions underlying understandings of the ‘problem’ shape policies and the parents’ conduct in particular ways; and
- what effects these assumptions embedded in policies have on parents.

My research aim and questions were refined throughout the research process, which is not unusual due to the flexible and evolving nature of qualitative research design (Green & Thorogood, 2009). As I discussed in Chapter 3, critical research aims to uncover and unpack commonly held values and assumptions and their contributions to producing power relations between dominant and nondominant groups in society (Kincheloe et al., 2011; Willis, 2007), which aligns with my research aim. Although a critical approach to research does not pre-determine the research design or methods used in a study, its theoretical underpinnings are generally associated with qualitative methodologies. Nonetheless, qualitative methodologies and methods were most congruent with my aim of ‘problem-questioning’ in analyzing the transitions policies from a critical perspective.

A critical qualitative methodology aligned with my specific objective of interrogating the taken-for-granted knowledge and concepts that shaped how the issue of transition to adulthood was understood as a particular kind of ‘problem’ in the sociopolitical context of Ontario. Specifically, critical qualitative methodologies provide a way of making explicit the implied meanings and underlying assumptions that shape understandings of a ‘problem’. These implied meanings and assumptions might remain hidden, neglected or ignored through other methodologies, which, as a starting point, assume that particular meanings offer a ‘true’ or ‘correct’ explanation of the ‘problem’. Instead, a critical qualitative methodology aims to reveal implicit understandings of a
‘problem’, which can be critically examined for the potential implications of these understandings for the people who are the focus of a policy. A critical lens guided my selection of methods and procedures for data collection, analysis, and interpretation for achieving my research aim. To address my research questions, I examined three key documents on transitions for young disabled people and in-depth interview accounts of parents of young people with DD over three phases of data generation and analysis. In what follows, I describe the three phases.

1 Overview of Data Generation and Analysis

Data were generated through two main sources: (a) key policy documents reflecting or representing proposed courses of action on transition to adulthood for young disabled people in the rehabilitation, education, and developmental service sectors in Ontario; and (b) in-depth interviews with parents whose children and/or families had received services from these sectors using a phased approach. Phase 1 involved analyzing documents to identify and unpack the problematizations and underlying social assumptions about transition to adulthood that shaped each policy, and their potential effects on parents. The findings of Phase 1 informed development of questions to guide in-depth, semistructured interviews with parents of children with DD. Phase 2 involved analyzing the parents’ interview accounts about their transitions experiences to examine how transition to adulthood was constructed as a ‘problem’, what assumptions were embedded in this problem construction, and what effects on parents were reflected in these accounts. Phase 3 involved examining the similarities and differences in the findings from Phases 1 and 2. In what follows, I describe the specific methods, procedures, and strategies that I implemented to generate and analyze my data.

1.1 Phase 1

Phase 1 involved analysis of key documents that reflected policies on transition to adulthood for young disabled people in the rehabilitation, education, and developmental disability sectors of the government of Ontario. The primary objectives were to examine how transition for this population was constituted as a ‘problem’ within and across the documents, how this understanding of the ‘problem’ shaped particular problem representations and courses of action, and the potential effects on young adults with DD and their parents. My approach to data generation and analysis was guided by the WPR policy analysis tool. I discussed the theoretical
underpinnings of the WPR policy analysis methodology in Chapter 3. In addition, I incorporated additional analytic strategies, such as developing a policy analysis form (see Appendix A) and a visual matrix chart to compare the documents (see Appendix B), writing analytic summaries, and discussing the analysis with my supervisor and committee members, to support a careful and rigorous analysis. In this section, I describe the procedures, methods, and strategies I employed to select and analyze the documents.

The document analysis involved seven main processes:

- Identifying relevant documents
- Selecting the documents for analysis
- Detailed reading of the documents to highlight key and recurring concepts in the text
- Writing notes about initial reflections of the assumptions underpinning these concepts
- Interrogating each document guided by a series of questions largely informed by Bacchi’s (2009) six WPR questions and additional probing questions (described further below)
- Representing and arranging the findings for each WPR question for each document on a matrix chart to compare the findings across the documents
- Preparing a summary of the overall findings about how transition is problematized and about the assumptions and problem representations underlying this problematization
- Discussing the findings in individual meetings with my supervisor, and in group meetings with my supervisor and committee members.

In general, these processes were followed in a relatively sequential manner as noted above. However, it is common in qualitative research for analysis to evolve and proceed iteratively as new insights and findings arise with each procedure (Cresswell, 2007; Green & Thorogood, 2009). My analysis involved a cycle of going back-and-forth between reading and interrogating the documents, writing notes and summaries, and comparing findings across documents. Through this iterative process, new insights and findings arose as my analysis progressed. In the
section that follows, I describe the document selection, analysis procedures, and additional analytic strategies in more detail.

1.1.1 Document Selection

The main data sources for Phase 1 were documents relevant to policy on transition to adulthood for young disabled people from each identified sector, which were published by the government of Ontario or an organization funded by or affiliated with the government (e.g., a health research institution). A WPR approach proposes that government and policy-related documents are ‘practical texts’ or raw data for analysis (Bacchi, 2009). In this approach, policies are considered ‘practical texts’ or ‘prescriptive texts’ “since they tell us what to do” (Bacchi, 2009, p. 34).

Bacchi’s (2009) notion of practical texts builds on Foucault’s suggested method of examining texts to reveal how issues are thought about or problematized and shaped by power relations in society. She proposes that “policies and their accompanying methods of implementation provide points of entry to the problematizations and problem representations that require scrutiny” (Bacchi, 2009, p. 34). For this study, three documents were purposively selected to identify and interrogate the problem representations they contained.

I established inclusion criteria for documents based on the concept of ‘practical texts’ and on my prior knowledge of the types of documents that had shaped the development of transitions programs and interventions in my work as an occupational therapist at a large pediatric rehabilitation hospital in Ontario. These inclusion criteria were:

- Provided specific recommendations for policy or implementing policy (e.g., transition programs, protocols, procedures or best practices);
- Published by a provincial ministry that is responsible for overseeing programs and services related to specific aspects of transitions (e.g., health care transitions, transition planning in education), or an organization with a provincial mandate that is associated with informing or implementing provincially-funded programs and services; and
- Publicly available and accessible (e.g., on a government or organization website).

I selected three documents—one from each provincial sector (e.g., rehabilitation, education, and developmental services)—that I judged to be representative of the generally agreed upon courses
of action for addressing transitions of young disabled people. Each document is described in more detail in the subsequent results chapters, but I provide a brief description here:

1. “Best Journey to Adult Life” for Youth with Disabilities: An Evidence-based Model and Best Practices Guidelines for the Transition to Adulthood for Youth with Disabilities (Stewart, Freeman, et al., 2009). This document was developed by a group of key pediatric rehabilitation stakeholders (e.g., researchers, clinicians, decision-makers, and families) in Ontario under the lead of the CanChild Centre for Childhood Disability Research (an organization focused on research to support practices in provincially-funded children’s rehabilitation treatment centres) as the outcome of a research project. The project was funded by the Ontario MOHLTC and the Ontario Neurotrauma Foundation (ONF) to generate knowledge and make recommendations for a best practice model and guidelines to address the transition from rehabilitation and related services between childhood and adulthood for young disabled people;

2. Transition Planning: A Resource Guide (Ontario MEDU, 2002). This document was developed by the MEDU as a guide to assist educators in implementing the Ministry’s regulations and policies regarding transition planning from school to work, further education, and community living for exceptional students, including disabled students.

3. Provincial Transition Planning Framework: Transition Planning for Young People with Developmental Disabilities (Ontario MCSS/MCYS, 2011). This draft document was developed through a collaboration of MCSS/MCYS. Its purpose was to guide development of protocols for community and social service agencies associated with the Developmental Services branch of MCSS. The focus is on assisting young people with DD and their families in planning for transitions from services mandated and funded for children to those for adults.

Additional documents that were identified during the research process (e.g., during the document analysis or discussed in a parent interview) were considered for inclusion if they met the criteria described above. Over the course of this study, no additional documents that reflected a change

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5 The draft version continues to be the main document guiding courses of action in MCYS and MCSS.
or update to the proposed recommendations or courses of action in the selected documents were identified. However, documents that provided relevant information about the content or context of the selected documents were examined to inform or supplement the analysis (e.g., the definitions of key concepts were described in a corresponding document rather than the selected document).

Documents published by the government or affiliated organizations provide raw data for examining how transition is framed as a policy issue, in particular by interrogating the courses of action that are proposed. Adopting a critical lens to analyze these documents provided insights into taken-for-granted knowledge and social assumptions (e.g., about disability and adulthood) that underlie policy makers’ views of transition as a problem and how it should be addressed (Green & Thorogood, 2009). A potential disadvantage of a publicly available government document is an incomplete ‘picture’ of the problematizing processes that went into constructing the ‘problem’ and proposed solutions because it is the end product of policy making. As described previously, I examined text in related or relevant documents as needed to supplement the data in the selected documents.

1.1.2 Document Analysis

For the analysis, I employed a policy analysis tool called “What’s the Problem Represented to Be?” (WPR; Bacchi, 2009) as my main analytic device. WPR provides a systematic methodology for examining problem representations and the problematizations and taken-for-granted assumptions embedded in public policies. A WPR approach consists of answering six questions, not necessarily in sequence, each going further in analyzing and describing the problematizations inherent in policies (see Policy Analysis Form, in Appendix A). My rationale for using the WPR was that its theoretical underpinnings were consistent with the overarching critical qualitative approach of my research process, which I discussed in Chapter 3. As such, the three policy documents I identified were practical texts that can be viewed as windows into how transition to adulthood is problematized and the taken-for-granted assumptions about disability, adulthood, and citizenship that shape this problematization. WPR aims to use analytic concepts, such as problematizations, assumptions, and effects, with particular interests in power relations
and the implications for how individuals who are the target of policies think about and conduct themselves.

I used the WPR approach as my main analytic device for interrogating the text in each document individually guided by a series of six questions. These questions were:

1. What’s the ‘problem’ represented to be in a specific policy?;
2. What presuppositions or assumptions underlie this representation of the ‘problem’?;
3. How has this representation of the ‘problem’ come about?;
4. What is left unproblematic in this problem representation?, Where are the silences?, Can the ‘problem’ be thought about differently?;
5. What effects are produced by this representation of the ‘problem’?; and
6. How/where has this representation of the ‘problem’ been produced, disseminated and defended, and how could it be questioned, disrupted and replaced? (Bacchi, 2009, p. xii)

Each question digs deeper into identifying and unpacking the implied meanings that shape how a policy issue is constituted. Using the WPR questions as a foundation, I developed a policy analysis form (see Appendix A) to guide my analysis, which included four additional questions:

1. What other questions does this policy analysis raise?
2. How can the concepts of disability, generational categories, and a life course approach based on Priestley (2003) be employed to explain the findings of this document analysis?
3. How can Foucauldian concepts of dividing practices, power, and governmentality be employed to explain the findings of this document analysis?
4. Any other comments or thoughts about this document?

I added these questions to foster further critical analyses of the documents’ texts using theoretical concepts discussed by Mark Priestley and Michel Foucault. As I described in Chapter 3, Priestley’s work provides a framework for examining disability across the life course and across generations (e.g., childhood and adulthood). Regarding Foucault’s concepts of dividing practices, power, and governmentality, Bacchi (2009) draws on these concepts to inform development of the WPR approach. These concepts are consistent with my research aim of
questioning ‘problems’ and taken-for-granted social assumptions (e.g., about disability and adulthood) embedded in dominant discourses about transition to adulthood.

Data were generated about the ‘problem’, underlying assumptions, and potential effects produced by problematizations reflected in the documents and were recorded on the policy analysis form. Each form was used as an analytic report and was discussed in analysis meetings with my supervisor and committee members. Refinements to the analysis were made based on the outcomes of these discussions and were recorded in meeting minutes or notes. Additional strategies, including generating a visual matrix chart and writing analytic memos, were implemented to foster a rigorous analysis.

1.2 Additional Analytic Strategies

1.2.1 Visual Display Matrix

A visual display matrix was created to organize and facilitate comparisons of the findings of each document analysis (Miles & Huberman, 2014; see Appendix B). The matrix displays the names of the three policy sectors across the horizontal columns and the six WPR questions down the vertical rows. This strategy served as a mechanism to distil the findings to the core themes or ideas that were revealed in each document analysis and to facilitate comparisons across key WPR questions and concepts (e.g., problem representations, assumptions, effects, etc.). The matrix helped me to view and synthesize the findings as a whole, and to identify and further interrogate the predominant problem representation(s) across the documents.

1.2.2 Coding Scheme

Key concepts and themes that emerged through the document analysis process were grouped into categories, labelled with a code name, and recorded on a coding scheme (see Appendix C). The key themes and code names were discussed and agreed on with my supervisor during several meetings focused on the document analyses. In addition, we agreed to include some codes (e.g., ‘problem’, ‘effects on youth’, ‘effects on family’) that reflected key concepts underpinning my research questions. The coding scheme provided a list of code names to organize and conceptualize the key themes that emerged from the document data analyses. In addition, it provided an initial framework for coding and analyzing the interview transcript data in Phase 2.
The coding scheme was further refined after my supervisor and I independently reviewed the first three transcripts. We then met to discuss the emerging themes and compare them to the themes identified in the document analyses. Code names were refined and new ones were added in preparation for analyzing the 10 transcripts that followed. The coding scheme provided a lens for comparing the two data sets in Phase 3.

1.2.3 Reflective Memos

As described in Chapter 3, reflexivity is a key characteristic of a critical approach to research (Alvesson & Sköldberg, 2009; Green & Thorogood, 2009). Following the document analysis, I wrote a series of reflective memos to record my thoughts and insights about how my perspectives and assumptions about transition to adulthood influenced the data generated through the WPR approach, but also how the WPR approach had shaped my lens for analyzing the data. For example, I described my initial unease in thinking ‘critical’ meant that problematizations and the taken-for-granted assumptions that shape them, are always ‘negative’ or ‘bad’. In response, I had to ‘check’ or scrutinize my own assumptions and how they influenced the document analysis. This strategy reminded me that the aim of a critical approach is not to assess if a particular way of thinking about a ‘problem’ is ‘wrong’ and another way of thinking is better or ‘right’. Rather, the critical stance to the data allowed me to investigate the benefits and harms of particular ways of thinking and to consider how things might be thought about otherwise to mitigate potential harmful effects of policies. This process of writing reflective memos helped me to think about the potential impact of my biases and predispositions on the data analysis process, which is congruent with a critical approach to research.

1.3 Outcome of Phase 1

The outcome of Phase 1 was an analytic summary that described key findings about the problem representations and underlying assumptions that shaped the proposed courses of action in the documents as a whole. The analysis was refined after discussing the summary with my supervisor and committee members. The analytic summary illuminated how transition to adulthood was constituted as a particular kind of ‘problem’ across the three policy sectors. The findings of Phase 1 informed the refinement of questions, initially developed at the thesis proposal stage, in preparation for in-depth interviews with parents of young people with DD in
Phase 2. After finalizing the interview guide, a protocol for recruiting and interviewing parent participants for the study was submitted to and approved by the University of Toronto Research Ethics Board (REB; see Appendix D for the REB approval letter).

2 Phase 2

My aims in Phase 2 were to examine how parents of young people with DD characterized the ‘problem’ of transition to adulthood, and how their talk reflected implicit understandings of the ‘problem’ that shaped their goals for their children and had effects on how they thought about and conducted themselves. To address these aims, I generated data through in-depth interviews with 13 parents of young people with DD. Guided by a critical approach, I examined interview transcripts, as well as field notes that I wrote following each interview. I incorporated additional strategies (e.g., developing a codebook, writing memos, analysis meetings with supervisor where we discussed various ways to consider the data) to foster a rigorous critical analysis of the parents’ accounts. In this section, I describe the specific procedures, methods, and strategies that I used to generate and analyze data from the parents’ interview accounts of their transitions experiences.

2.1 Participant Selection and Recruitment Procedures

2.1.1 Inclusion Criteria

The main criterion for inclusion in my study was primary caregivers or long-time guardians of a young person with DD. In addition, potential participants were included if they were:

- biological parents, legal guardians or foster parents young person with DD aged 16 to 29;
- eligible for provincial developmental disability services and supports as described in the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008;
- involved or had been involved in planning for their children’s transitions to health/rehabilitation, education, and/or developmental programs and services for adults on behalf of or in collaboration with their child;
• living in the Greater Toronto or Greater Hamilton Area (due to financial resources and time, I allowed for travel by car within a two-hour radius of downtown Toronto to conduct face-to-face interviews); and

• able to communicate in English in an interview setting (I was unable to conduct interviews in another language).

Although legal guardians and foster parents potentially met the inclusion criteria, only parents responded to the recruitment methods employed (recruitment is described in a section that follows).

For the purpose of this study, parents whose children were described as having DD based on the definition in the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008, described in Chapter 1, were included. Based on this broad description, parents of young people with a variety of medical diagnoses (e.g., autism, cerebral palsy, Down syndrome, intellectual disability, behaviour disorders, and spina bifida) potentially met the criteria for inclusion in this study. Potential participants who responded affirmatively to the question, “Is your child/youth eligible for services for persons with developmental disabilities in Ontario?” during a telephone screening interview (described further below) were invited to participate in the study as long as they met the other criteria. In addition, potential participants whose children had physical, mental, progressive, communication or sensory impairments associated with DD were included if they met the other criteria. I chose the age range of 16 to 29 years to encompass the years before and after the government-mandated age in which young people must be discharged from child health care services (18 years of age) and are no longer eligible for public school (21 years of age). There is no specific age range that constitutes transition age youth or young adults, however, the range I selected is consistent with other literature on transition.

2.1.2 Recruitment Strategy

I used multiple strategies to recruit potential participants for my study. This approach is consistent with “locating information-rich key informants or critical cases” (Patton, 2002, p. 237). It involves identifying “cases of interest from sampling people who know people who
know people who know what cases are information rich, that is, good example for study, good interview participants” (Patton, 2002, p. 243). In my study, I enlisted two organizations, Community Living Toronto (CLT) and Family Alliance Ontario (FAO), who were well-situated to access a network of parents who participated in their programs or services and who potentially met my inclusion criteria (Patton, 2002). CLT is a nonprofit organization that provides a range of personalized supports and services to people with an intellectual disability and their families within the developmental disabilities sector. FAO is a nonprofit organization that supports a network of disabled young people and their families and aims to increase opportunities for inclusion in schools and communities. I was familiar with both of these organizations through my work as an occupational therapist in a transition program. In addition to recruitment activities provided by these organizations, I asked participants at the end of their interviews if they had suggestions for other parents or caregivers who might be interested in participating in the study and provided a copy of the Information and Consent Letter (see Appendix E) to give to the potential participant. Thus, my sample ‘snowballed’ or accumulated through these recruitment processes.

2.1.3 Recruitment Procedures

The participants were recruited in three ways once the University’s REB approved my research protocol. First, the CLT research coordinator disseminated the Information and Consent Letter to front-line service providers to provide them with details about the study and to request their assistance in recruiting participants from their programs and services. I also spoke with the CLT research coordinator by telephone to review the inclusion criteria and to express my interest in recruiting as diverse a sample as possible based on age, gender, socioeconomic, and ethnocultural backgrounds that could potentially provide unique perspectives on transition experiences in Ontario. Second, a recruitment advertisement (see Appendix F) was posted on CLT’s and FAO’s websites and distributed to potential participants via their email distribution lists. Third, I asked interview participants if they had suggestions for other parents/caregivers who might be interested in participating in the study as I discussed previously, and perceived as fitting the inclusion criteria as outlined. All potential participants contacted me directly by phone or email (in response to the recruitment advertisement or to an Information and Consent letter they received from CLT or another participant), rather than through a direct referral from one of
the organizations. If these potential participants did not have an Information and Consent letter already, I sent them a copy via email or regular mail.

I called all potential participants by phone to review and explain the study and consent processes. If they were interested in participating in the study, I used a Telephone Screening Tool (see Appendix G) to ask questions to determine if they met the inclusion criteria. If potential participants met the criteria and provided verbal consent to proceed, an interview was set up at a mutually agreed upon time and in a location that was quiet and private. The participants were asked to review and sign the consent form to bring to the interview. All consent forms were stored in a locked filing cabinet in a secure office.

2.1.4 Description of Participants

I set a target of 15 to 20 parents for this study to fall within a general guideline of 12 to 20 participants for qualitative studies that have a relatively homogenous sample (Kuzel, 1999; Patton, 2002). The aim was to generate information-rich ‘practical texts’ in the form of interview transcripts for an in-depth examination of how transitions were experienced and problematized by parents of young people with DD. I was contacted by phone or email by 16 potential participants, however, three of these potential participants did not reply to phone or email messages to set up a time for a telephone screening interview. In the end, 13 parents of young people with DD participated in in-depth interviews for this study.

Table 1 provides an overview of basic demographic data of the participants, including descriptive data about their children with DD. In summary, 12 mothers and one father participated in this study. All lived in the Greater Toronto Area. Their children ranged in age from 17 to 27 years old. Five of the parents had children still in high school at the time of their interviews. The other eight were parents whose children had already finished high school. Of these eight, four of their children participated in day programs, one participated in a supported employment/training program, and two participated in part-time or online college/university courses while also working part-time. All of the children had stayed in school or planned to stay in school until the provincial government-mandated age of 21 years old except two: one child left high school at 19 years old and one child (17 years old) had not yet determined when she would leave high school.
Table 1: Participants’ Demographic Data. *Note:* All names are pseudonyms.

<table>
<thead>
<tr>
<th>Participant Number</th>
<th>Name</th>
<th>Relationship to child</th>
<th>Employment status</th>
<th>Child’s name</th>
<th>Child’s age</th>
<th>Diagnosis</th>
<th>Current activity of youth</th>
<th>Finished high school</th>
<th>Siblings</th>
<th>Lives with parent(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Jane</td>
<td>mother</td>
<td>Writer</td>
<td>Joy</td>
<td>24</td>
<td>Down Syndrome</td>
<td>College courses/Working part-time</td>
<td>Yes</td>
<td>1 brother</td>
<td>Yes</td>
</tr>
<tr>
<td>2</td>
<td>Diane</td>
<td>mother</td>
<td>Teacher</td>
<td>Lucy</td>
<td>20</td>
<td>Autism</td>
<td>High school</td>
<td>No</td>
<td>1 brother</td>
<td>Yes</td>
</tr>
<tr>
<td>3</td>
<td>Debbie</td>
<td>mother</td>
<td>Health care worker</td>
<td>Grace</td>
<td>17</td>
<td>Intellectual Disability (ID)</td>
<td>High school</td>
<td>No</td>
<td>1 sister</td>
<td>Yes</td>
</tr>
<tr>
<td>4</td>
<td>Harriet</td>
<td>mother</td>
<td>Corporate worker</td>
<td>Molly</td>
<td>27</td>
<td>Global Developmental Disability</td>
<td>Day programs</td>
<td>Yes</td>
<td>2 brothers</td>
<td>Yes</td>
</tr>
<tr>
<td>5</td>
<td>Miranda</td>
<td>mother</td>
<td>Health care worker</td>
<td>Susie</td>
<td>21</td>
<td>Down Syndrome</td>
<td>Day programs</td>
<td>Yes</td>
<td>2 sisters</td>
<td>Yes</td>
</tr>
<tr>
<td>6</td>
<td>Linda</td>
<td>mother</td>
<td>Writer</td>
<td>David</td>
<td>19</td>
<td>Pervasive Developmental Disorder</td>
<td>No</td>
<td>1 sister</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Susan</td>
<td>mother</td>
<td>Nurse</td>
<td>Noah</td>
<td>20</td>
<td>Autism</td>
<td>High school</td>
<td>No</td>
<td>1 brother</td>
<td>Yes</td>
</tr>
<tr>
<td>8</td>
<td>Evelyn</td>
<td>mother</td>
<td>Trainer</td>
<td>Christie</td>
<td>27</td>
<td>ID</td>
<td>Supported employment</td>
<td>Yes</td>
<td>2 sisters</td>
<td>No</td>
</tr>
<tr>
<td>9</td>
<td>Sheila</td>
<td>mother</td>
<td>Project Coordinator</td>
<td>Joshua</td>
<td>25</td>
<td>Down syndrome</td>
<td>Day programs</td>
<td>21</td>
<td>2 brothers</td>
<td>Yes</td>
</tr>
<tr>
<td>10</td>
<td>Lesley</td>
<td>mother</td>
<td>Corporate worker</td>
<td>Amy</td>
<td>24</td>
<td>Cerebral Palsy</td>
<td>Day programs</td>
<td>Yes</td>
<td>1 sister</td>
<td>Yes</td>
</tr>
<tr>
<td>11</td>
<td>Daniel</td>
<td>father</td>
<td>Nonprofit worker</td>
<td>Ella</td>
<td>25</td>
<td>Unspecified ID</td>
<td>Day programs</td>
<td>Yes</td>
<td>1 sister</td>
<td>Yes</td>
</tr>
<tr>
<td>12</td>
<td>Cora</td>
<td>mother</td>
<td>Teacher</td>
<td>Amanda</td>
<td>23</td>
<td>Asperger’s Syndrome; Learning Disabilities</td>
<td>College courses/Working part-time</td>
<td>Yes</td>
<td>1 sister</td>
<td>Yes</td>
</tr>
<tr>
<td>13</td>
<td>Eva</td>
<td>mother</td>
<td>Teacher</td>
<td>Abby</td>
<td>19</td>
<td>Autism; heart, lung &amp; immune conditions</td>
<td>High school</td>
<td>No</td>
<td>1 sister</td>
<td>Yes</td>
</tr>
</tbody>
</table>
2.1.5 Data Generation

Data were generated through face-to-face, semistructured, in-depth interviews that I conducted in a location agreed upon with the participant that allowed for a private conversation. In most cases, the interview took place in the participant’s home. In five cases, an alternative location (e.g., meeting room at the University of Toronto, participant’s workplace) was used upon the participant’s request because quiet or privacy was not at home. The interviews were 51 to 120 minutes in length (average length was 75 minutes).

In-depth interviews are commonly used in qualitative health research to elicit rich, detailed accounts from the perspectives of interviewees (Green & Thorogood, 2009). Interviews are conversations that generate data for exploring interviewee’s accounts related to a research topic. An account is a verbal report provided by an interviewee that provides data on what is said and how it is said (Green & Thorogood, 2009). In-depth interviews yielded data about how transitions were experienced by young people with DD and their families from the perspective of parents and how they talked about the ‘problem’ of transition to adulthood. The parents were asked about their general transitions experiences in Ontario, as well as their transitions experiences with pediatric rehabilitation, education, and developmental disability services.

A semistructured interview style resembles a guided conversation “during which the interviewer may be a neutral listener or, on occasion, steer the direction taken by the interview as required to sustain the flow of the conversation” (Carpenter, 2000, p. 25). The interview is not considered a neutral exchange of asking questions and getting answers, but rather an active process that leads to a “contextually bound and mutually created story” (Fontana & Frey, 2005, p. 696). An interview guide (see Appendix H), informed by the findings of the document analysis in Phase 1, and was developed for this study. The guide included a list of topics to be covered, nondirective open-ended questions to stimulate conversation, and probing questions to be used, as needed, to keep the interview on track for addressing the research questions. As the interviewer, I encouraged each participant’s story to unfold according to his or her direction and narrative style, but actively listened to assess how what was said related to the data collection objectives and focused the discussion as appropriate (Hammersley & Atkinson, 1995). The advantage of this style of interview offers opportunities for the parents to potentially share aspects of their
experiences that might not be revealed in more structured interviews. Access to the parents’ rich insights and experiences was extremely valuable for understanding how young people with DD and their families experience multisector transition policies in Ontario and how they constructed transitions as a ‘problem’.

To capture this information-rich data, interviews were audio-recorded and later transcribed verbatim in preparation for analysis. I transcribed four of the interviews and nine were professionally transcribed. In addition, I wrote field notes (for the Interview Field Note Form see Appendix I) immediately following each interview to document my observations and thoughts about the interview process (e.g., the interview location, the interaction between the participant and me), my reflections about the content of the interview in relation to the research questions, and any new concepts or ideas that emerged. In this study, the interview transcripts and field notes were the main sources of data for the parents’ accounts of their transitions experiences.

2.1.6 Data Analysis Procedures

Data collection and analysis are intertwined with each other in qualitative research (Green & Thorogood, 2009; Miles & Huberman, 2014). Data for analysis included the interview transcripts and field notes. These data were analyzed for key themes, which is the most common approach to qualitative data analysis (Green & Thorogood, 2009). It involved categorizing the recurrent or common themes in the content of the data. However, I went further in my analysis by interrogating the data from a critical perspective, guided by the WPR questions. In this section, I describe the data analysis procedures I used to provide rich descriptions about the transitions experiences and problematizations reflected in the parents’ accounts.

The data analysis involved three main procedures:

- Data preparation and management;
- Reading and memoing; and
- Describing, categorizing, and interpreting.

I describe each of these procedures in what follows.
The first step in the analysis process was to prepare the data for analysis. Once the interviews were transcribed verbatim, I began by reading each interview transcript while listening to the recording of it. This step helped to ensure accuracy of the transcript, and provided me with a general sense of the data. I reviewed my interview field notes to further check for accuracy about the content and context of the interview, and re-listened to the audio recording as required. Nonverbal gestures or communication that were missed were added. Since the interviews were transcribed by multiple people (by me and transcription professionals), the system of notation and transcript format were checked for consistency and edits were made as needed (Kowal & O’Connell, 2004). The data were de-identified, organized, coded, and entered into the HyperRESEARCH data management software program to simplify retrieval of data segments.

The second step involved reading and writing memos on the transcripts. The aim of this step was to get a general sense of the data as a whole. It involved intensive and repeated readings of the interview transcripts to immerse myself in the details (Schmidt, 2004) and to get a sense of the interview as a ‘whole’ before ‘breaking it into parts’ (Creswell, 2007). Next, I wrote memos in the margins of the transcripts to document ideas or concepts that struck me as important for answering the research questions (Miles & Huberman, 2014). Finally, I referred to my interview field notes to reflect on how the observations and thoughts about the interview discussion that I had documented related to what I had read in the transcripts. I added memos about these reflections in the margins of the transcript document.

The third step involved describing, cataloguing, and interpreting the transcript data. Emerging thematic categories were identified and described based on my intensive reading of the transcripts. These emerging themes informed refinement and additions of codes in the initial codebook developed at the end of Phase 1. Themes that were identified were incorporated into subsequent data generation. To improve rigour and reliability of this process, my thesis supervisor read three of the transcripts. We then met to discuss and compare the categories that we had each identified and how they were labelled. As a result of this discussion, the coding scheme was further refined. These codes were used to organize and catalogue text segments, which were entered into the HyperRESEARCH data management software program to simplify retrieval of data by codes. Decisions were made about sorting and combining the codes into overarching themes and about what themes were relevant to answering the research questions.
Interpretation involves making sense of the data and describing what was learned (Green & Thorogood, 2009). I examined the data for linkages among the general themes and compared linkages to existing theoretical concepts (Green & Thorogood, 2009). In this study, interpretations were guided by WPR concepts (e.g., problem representations, taken-for-granted assumptions), Priestley’s concepts (e.g., disability, generation, and life course), concepts associated with Foucault’s work (e.g., dividing practices, power, and governmentality), and a critical approach. I wrote analytic memos to document my interpretations of the data. In addition, I met with my supervisor individually and with my committee to explain and discuss my data interpretations of the data. I documented discussions and decisions made about the analysis in meeting minutes.

2.1.7 Outcome of Phase 2

The outcome of Phase 2 was an analytic summary report containing key themes about the ‘problem’ of transition to adulthood and its effects on parents of young adults with DD, which was reviewed with my committee in a meeting then refined based on the discussion.

3 Phase 3

The aim of Phase 3 was to synthesize the findings from Phases 1 and 2 through a comparative analysis. Comparison is a core feature of qualitative analysis (Green & Thorogood, 2009). Comparisons can be made between a number of things, such as within or between cases, or between outcomes, methods, or theories (Miles & Huberman, 2014). For this study, findings about problem representations and underlying assumptions from Phases 1 and 2 were compared to generate new interpretations to contribute to my overall study findings. Findings from the two data sets provided different vantage points for understanding how transition to adulthood for young disabled people is constituted as a particular sort of ‘problem’ across policy sectors in Ontario and the implications of this understanding of the problem for the parents of young
people with DD. This comparative analysis ‘pulled together’ the study findings and generated overall understandings and interpretations of the combined data sets.

The steps for the comparative analysis were as follows:

1. Intensive review of the analytic summaries from Phases 1 and 2;
2. Discussion in a comparative analysis meeting with my supervisor. Questions to guide this discussion included:
   a. What is congruent and incongruent between the findings of the two data sets?
   b. What do the transition policies say collectively about transitions for disabled young people compared to what parents of young people with DD say?
   c. What issues do the parents raise? Are these issues reflected in the documents?
   d. What new theoretical or methodological knowledge have we learned in the process of comparing the findings?
3. Preparation of a visual matrix display of themes that arose from the comparisons;
4. Further refinement of themes developed during analysis of the interview data; and
5. Preparation of a summary report.

The summary report included discussion about new findings arising from the comparative analysis, discussion about the theories and methods used in this study, and implications for future research.

4 Ethical Considerations

Several procedures were used to ensure that ethical research practices were undertaken in conducting this study. Green and Thorogood (2009) suggest that ethical research practice “requires a consideration of responsibilities to research participants, professional and academic colleagues, research sponsors and the wider public” (p. 62). I was required to apply for approval
from the University of Toronto’s Health Sciences REB to conduct the portion of my study involving human participants, that is, my interviews with parents. I did not require REB approval to conduct my analysis of publicly available documents. The REB approval letter is found in Appendix D. In this section, I discuss ethical considerations related to informed consent, privacy and confidentiality, and possible risks and benefits of participating in the study.

4.1 Informed Consent

Informed consent refers to the ethical principle that individuals should participate in a study voluntarily, without being coerced, persuaded or induced ‘against their will’ (Green & Thorogood, 2009). I implemented several procedures to ensure informed consent of the parent participants, including:

- Mailing an Information and Consent Letter (Appendix E) with an addressed return envelope to potential participants who contacted me by phone or email in response to receiving a recruitment flyer from the CLT research coordinator, a service provider, or another participant, or via an email from CLT or FAO.
- Following up with a phone call to potential participants to review information about the study and consent processes described in the letter and to answer any questions. If the potential participant provided verbal consent to proceed, he or she was asked to review and sign the consent form and to return the form in the envelope provided. Once the signed consent form was received by me, the participant was contacted by phone to set up an interview at a mutually agreed upon time and location.
- If a participant’s signed consent form had not been received by mail prior to the interview, I brought a copy of the consent form to the scheduled interview for review and signature before commencing the interview.
- Prior to starting the interviews, I reminded participants that the conversation would be audio-recorded and asked for verbal consent to proceed. During the initial part of the interview, I verbally reviewed the purpose of the study, the consent process and the process for withdrawing from the study (see Appendix H for Interview Guide). The participant was given the opportunity to ask questions and then was asked verbally if he
or she agreed to proceed with the interview. This portion of the consent process was recorded on the digital audio recorder and documented by me on the Interview Field Note Form (Appendix I).

4.2 Privacy and Confidentiality

The ethical principles of privacy and confidentiality refer to the researcher taking every precaution to respect the privacy of the participants and the confidentiality of their personal information (Green & Thorogood, 2009). I upheld these principles through several procedures, including:

- Keeping all signed consent forms, hard-copies of transcripts and any other written materials in a locked filing cabinet in a secure office;
- Reviewing processes for maintaining privacy of information with the professional transcribers and having them sign a confidentiality form when formal policies were not in place their organizations;
- De-identifying all data using pseudonyms for names, organizations, and geographic locations by me following the transcription of interviews. A number code was used to identify transcripts for each participant. The code guide was seen only by me and was locked in a filing cabinet in a secure office; and
- Creating a password for all electronic files on a password protected laptop computer that was kept in a locked cabinet when not in use.

4.3 Possible Risks and Benefits

During the interviews, there were potential psychological/emotional risks, such as anxiety or distress, for participants in discussing their experiences of transition and future planning for their children. Future planning can be emotional and stressful for parents because it is uncertain, ongoing, and long-term. I included time to discuss emotional reactions to interview questions during the interview and was prepared to encourage parents to contact their own professional supports to address psychological/emotional concerns or provide them with information about
appropriate services and supports. In addition, there were potential risks of emotional harm or distress for the children if they were present or nearby and overheard the conversation during the interviews. For this reason, I explained to participants the potential risks and the rationale for a private 1:1 interview in both the Information and Consent Letter (Appendix A) and during the telephone screening (see Appendix C: Telephone Screening Tool). If a parent was concerned about this risk for his or her child, we conducted the interview at a mutually agreed upon time when the child was not home or in a private room in a mutually agreed upon alternate location, such as at the University or the parent’s workplace. There were no major substantive direct benefits to participants from their involvement in this study. However, the parents may have derived benefits from sharing their experiences of transitioning their children to adulthood and speaking about issues of importance to them with a clinician and researcher who is informed and interested in the topic in a forum that had no direct bearing on their access to services. Nonetheless, the analysis stemming from these accounts can contribute to the literature used by policymakers and practitioners to improve policies and access to programs and services, and thereby improve the health and well-being of young disabled people as they transition to adult life.

5 Summary

In this chapter, I described the multimethod qualitative design guided by a critical approach that I used to examine how transition is conceptualized as a problem in policies and by parents. In the three chapters that follow, I discuss the findings of my research.
Foreword to the Findings

In this Foreword, I set the stage for the three chapters that follow, which discuss my findings. These chapters are:

- Chapter 5: Best Practices for Rehabilitation Transitions;
- Chapter 6: Transition Planning in Education; and
- Chapter 7: Transition Planning in Developmental Services.

In each chapter, I focus on one of the three provincial sectors (i.e., rehabilitation, education, and developmental services sectors, respectively) in Ontario that have identified transition to adulthood for young disabled people as a policy ‘problem’. As previously noted, I use single quotation marks around the term ‘problem’ to highlight the WPR proposition that policies give shape to ‘problems’ in particular ways that can be questioned and rethought. In other words, the policy-making process produces particular representations of ‘problems’, which are shaped by take-for-granted assumptions about what needs to change in order to ‘fix’ these ‘problems’. In this study, I examined how transition to adulthood for young disabled people is constituted as a particular sort of problem, that is, how it is ‘problematized’, within and across three provincial sectors, and how the ‘problem’ understood in particular ways shaped policy recommendations and the transition experiences of young people with DD and their families. I was principally interested in examining how implicit understandings of disability and adulthood shaped particular representations of the ‘problem’ in these policies and in the parents’ accounts of their transitions experiences, and the implications for the parents of young people with DD.

Within each chapter, I address my four research questions in relation to the specific sector. As a review, my four research questions are:

1. What is the ‘problem’ of transition to adulthood for young disabled people represented to be: a) in the policy; and b) by parents of young people with DD?
2. What assumptions underlie these representations of the ‘problem’?
3. How do these problem representations: a) shape policies; and b) shape how parents of young people with DD think about and conduct themselves?

4. What effects on parents are produced by these representations of the ‘problem’?

1 Overview of Findings

My analysis revealed that normative discourses and assumptions about disability, development and a ‘proper’ adulthood functioned to constitute the ‘disabled child’ as a ‘problem’ to be addressed in the documents and parents’ accounts. These discourses and assumptions shaped policy recommendations and parenting practices focused on preventing or minimizing disability, and achieving or approximating a normal developmental trajectory to adult roles and activities associated with independence and productivity that are valorized in Western industrialized societies. Transitions policies and parenting practices, underpinned by ideas of ‘fixing’ disability and abnormal development, shaped implicit understandings of the ‘disabled child’ as an object of interest for intervention through rehabilitation, education, and developmental services, which had both beneficial and harmful effects on parents of children with DD.

At the collective level, across the three policy documents and the parents’ accounts, transition to adulthood was predominantly represented to be a service transition problem. For example, each document made recommendations to improve the transition and transfer to adult programs and services when young disabled people are no longer eligible for childhood health and rehabilitation services, and education programs. Most of the recommendations focused on implementing formal transition planning practices, identifying people responsible for creating transitions plans, and assisting young disabled people and their parents to navigate and coordinate transfers between childhood and adult programs and services within and across sectors. Likewise, the parents in this study explicitly identified the transition to adult services as problematic for their children, and suggested that transition planning, service transfer processes, and accessibility of adult programs and services needed to be improved. The ‘problem’ is thus, on the surface, construed as one of transitioning from one set of services to another and the recommendations of policies and the parents oriented to improving the transitions either through more efficient service provision or assisting families to access and navigate services.
While the problem seems to be one of service transition there is a related and less apparent problematization of disability across the policies and parents’ accounts. The policies focus on the transitions of a specific target group; that is, young people with disabilities. Nondisabled young people are not the target population of these policies, which raises a question, what is held problematic about young disabled people and their transitions from childhood to adulthood in these policies? The answer directs attention to the implied problem of disabled children and assumed ‘unsuccessful’ transitions to adult life compared to ‘normal’ children, particularly at the point when they are no longer eligible for government-funded childhood programs and services. The policies imply that disabled children are at risk of unsuccessful transitions to adult roles and activities associated with so called ‘normal’ life course trajectories (e.g., further education, employment, independent living) because their disabilities hinder their development. In essence, these transition policies represent disabled children and their atypical developmental and social trajectories as a problem in themselves, ‘at risk’ of deviating from the typical life trajectories of ‘normal’ citizens and thus in need of intervention. For the most part, the parents’ accounts reflected that they worked towards preventing or minimizing this risk by pursuing as close to a normal progression to adult roles and activities as possible for their children. In this regard, problematizations of the ‘disabled child’ embedded in transition policies were reproduced in the parents’ accounts.

The problem represented as disabled children and their atypical developmental and social trajectories rested on deep-seated assumptions about socially desired ways of being, developing, and acting across the life course that become normalized, and therefore, accepted as ideal. These assumptions are more closely examined in the chapters that follow. For now, however, I propose that these assumptions reflect the high social value placed on particular ways of being (e.g., able-bodied, independent, active) and doing (e.g., developmental progression, working, independent living) shaped in relation to a normal progression from childhood to normal roles and activities of adulthood. These assumptions functioned to shape the aims of these policies and the behaviours of young people with DD and their parents, and therefore, to fulfill the ends or outcomes of governing and managing the population and its resources.

What are these ends or outcomes, broadly speaking? The ideal outcome of policies is young people who achieve, or approximate to the extent possible, a particular kind of adulthood that is
socially valued and preferred in Western industrialized societies, such as Ontario; that is, young people who achieve or approximate a normal adulthood. Ideally, young disabled people become active adult citizens - citizens who live independently and participate in the work force. These deep-seated assumptions about idealized citizens become entrenched in how the ‘problem’ of transition is constituted in policies. Thus, they shape policy proposals in particular ways that have implications for how young disabled people and their parents think about themselves and conduct their lives as my analysis revealed.

After discussing my findings in the three chapters that follow, I provide an Afterword to summarize how transition to adult programs and services for young adults with DD was constituted as a ‘problem’ across the documents and parents’ accounts.
Chapter 5
Best Practices for Rehabilitation Transitions

In this chapter, I examine how transition to adulthood for young disabled people is constituted as a particular sort of ‘problem’ in the rehabilitation sector in Ontario. Data sources included:

- A document called “Best Journey to Adult Life”: An Evidence-based Model and Best Practice Guidelines for the Transition to Adulthood for Youth with Disabilities (hereafter, *BJA*; Stewart, Freeman, et al., 2009), which reflected current recommendations for transitions in the Ontario rehabilitation sector.
- The parents’ interview accounts of their rehabilitation and health care transitions experiences.

First, I describe and examine the *BJA* document to understand how transition to adulthood for young disabled people was constituted as a ‘problem’. Second, I summarize and examine the parents’ accounts of their rehabilitation and health care transitions experiences to understand how the parents characterized the ‘problem’ of transitions compared to the *BJA* document. In both sections, I identify implicit problem representations embedded in *BJA* and the parents’ accounts that produce particular understandings of the ‘problem’. These implicit representations shaped policy recommendations (e.g., proposed courses of action) and influenced the transitions experiences of the parents who participated in this study. Third, I identify and interrogate key concepts, contained in the *BJA* document, of life course approach, interdependence, and active citizenship to reveal underlying assumptions that function to create particular understandings of the ‘problem’ of transitions and how it should be ‘solved’ or ‘fixed’. For each concept, I also examine how these assumptions were reflected in the parents’ accounts and what implications they had for them.

1 Best Journey to Adult Life

1.2 Document Description

The *BJA* document was developed under the leadership of the CanChild Centre for Childhood Disability Research (hereafter CanChild) in response to a call for proposals from the Ontario
MOHLTC and the ONF to conduct a systematic review of best practice models for transition. CanChild (n. d.) is an influential childhood disability research organization focused on supporting policies and practices in children’s rehabilitation treatment centres in Ontario and beyond. A team of childhood disability researchers gathered evidence on best practices and models on the “transition to adulthood across the continuum of rehabilitation services” (p. 6). Evidence included:

- critical reviews of the literature for the years 2000–2007;
- an environmental scan conducted through focus groups across Ontario; and
- individual interviews with key policy and ministry personnel.

An expert panel of stakeholders (e.g., young disabled people, parents, community members, service providers, and researchers) from across the province met twice to review the evidence, and to develop recommendations for best practice guidelines and a model. The panel participated in a consensus exercise to identify best practice guidelines for youth, parents, community members, and service providers, which were categorized under six broad themes:

1. collaborative initiatives and policies across sectors and stakeholders;
2. building capacity of people and communities;
3. the role of a ‘navigator’ within communities;
4. accessible information and resources;
5. education of key stakeholders; and
6. ongoing research and evaluation (p. 5).

Within each theme, the guidelines were further categorized under sub-headings reflecting key phases of the transition process: “preparation, the journey itself, and the landings in the adult world” (p. 5).

The expert panel agreed on a graphic reflecting a journey in a hot air balloon to represent the BJA model. The document states that the model “represents the dynamic and ever-changing developmental process of a young person’s life course, with the transition to adulthood depicted as an important ‘journey’” (p. 5). It also promotes the idea that balloons and journeys to adult life are not the same for everyone and states that:
An individual is always on a journey at different stages of their life course. A life course approach to viewing the transition to adulthood, as well as other transitions during a person’s life, acknowledges that there are many common issues and challenges along the way. An individual builds their capacity to participate in daily community life as they make their own journey. And a life course approach also acknowledges that journeys are not done alone: we all benefit from supports along the way. A supportive environment can provide the tools and resources that an individual needs as they prepare for their transition ‘journey’ and also to make a smooth landing at their destination of choice. (p. 11)

In addition, several values are identified as the foundation of BJA best practices, including person first, family-centred, focus on strengths and needs rather than diagnosis, equity, life course philosophy, supportive environments, interdependence, and “outcomes of participation, contribution and belonging = citizenship” (p. 9). Later in this chapter, I examine key ideas of life course, interdependence, and citizenship to understand how they shape understandings of the problem of transition in particular ways. The concept of supportive environments is particularly relevant to understanding how transition for young disabled people is represented as a problem in BJA and by key stakeholders in the rehabilitation sector in Ontario.

1.3 What Is the ‘Problem’ Represented to Be in BJA?

The BJA document was developed to address the “transition to adulthood for youth with disabilities” (p. 1) and specifically the “transition to adulthood across the continuum of rehabilitation services” (p. 6) in response to a request for proposals from MOHLTC and ONF for systematic reviews of best practice models. These statements suggest that rehabilitation service transitions are problematic for young disabled people during their broader transitions to adulthood. BJA takes the position that “the transition to adulthood is considered to be a critical journey within an individual’s life course, as there are significant changes taking place within the person and the environment” (p. 10). Thus, this statement suggests that factors associated with the young people themselves and their surrounding environments contribute to the ‘problem’ of unsuccessful or inadequate transitions across rehabilitation services and to adult life more broadly. The problem constructed as changes in both the person and the environment reflects dominant ways of thinking about disability and how to address it in the rehabilitation field. These ways of thinking are significantly influenced by the biopsychosocial model of disability that underpins the ICF. As I discussed in Chapter 3, the ICF shifted attention to the interaction of
both personal and environmental factors as causes of disability.

A ‘supportive environment’ is proposed as a key strategy to address the ‘problem’ of preparing for and transitioning to ‘landings’ or destinations in adult life in BJA, which suggests that unsupportive environments are problematic for the transition to adulthood. The idea of unsupportive environments directs attention to factors external to the individual that influence the transition to adulthood, and is reflected in the six best practice themes. Each theme proposes a change to address a specific issue related to the young person’s immediate and broader social contexts. The specific issues are: lack of collaboration among key stakeholders in developing transition-related initiatives and policies; lack of capacity of people and communities; inadequate service navigation; inadequate and inaccessible information and resources; and lack of education, and research and evaluation evidence for transitioning young disabled people to adult life. As a group, these best practice themes direct attention to factors external to the young person that influence the process of transitioning to adult services and supports and to adult life more broadly. In what follows, I discuss two of the best practice themes to illustrate how they reflect dominant conceptualizations of transition as a problem of the interaction of personal and environmental factors. These conceptualizations aim to draw attention away from the individual and his or her impairments as the main or only cause of disability to the environment. Yet, they perpetuate implicit understandings of disability as a problem to be addressed through rehabilitation policy and practice, which potentially has negative consequences for young people (e.g., perpetuates the stigmatization and marginalization of people with impairments).

The best practice theme of “collaborative initiatives and policies” presumably refers to collaborations between families, agencies, ministries and other stakeholders to work together to support young disabled people as they transition. BJA states that:

Collaboration means that a seamless process/journey occurs at all levels from community to agency, from young persons to policy level, working towards the same outcomes. (p. 13)

Although young people are mentioned as part of the collaboration, the focus is not only on changing them, but also on changing policies and the actions of agencies and communities in the environments surrounding them. Thus, this best practice reflects dominant ideas about addressing the interaction of personal and environmental factors to resolve disability issues in the
rehabilitation field. As another example, *BJA* proposes that agencies and governments implement the role of a ‘navigator’ to assist young people in linking to adult services across sectors in their communities. The focus is not on addressing the individual’s impairments, but rather on improving how young people and their families navigate the transition to adult services, thus, addressing the interaction of personal and environmental factors that contribute to the service transition problem. Again, this best practice attends to both personal and environmental factors, reflecting how the explicit problem of transition is shaped by dominant ways of thinking about the causes of disability and how to address them in rehabilitation. However, an implied problem of disability persists and underpins the explicitly expressed problem of transition to adulthood for young disabled people.

Young disabled people are represented as problems in themselves by virtue of developing best practices in rehabilitation to address their transitions. *BJA* specifically identifies “youth with disabilities” (p. 1) as the target population, rather than youth as a whole. Thus, the issue of unsuccessful service transitions for this particular population carries with it an implied ‘problem’ of young disabled people, or more specifically, disabled children, and their unsuccessful or inadequate transitions to adult life compared to the normative societal expectations. An implicit understanding of normal bodies, normal abilities, and normal life course trajectories shaped how these young people were constructed as problems in themselves, that is, as possessors of an inherent set of risks by virtue of their differences that needed to be managed.

An implied binary of normality/disability was embedded in *BJA*, which operated to shape tacit understandings of ‘disabled children’ as problems to be addressed compared to ‘normal children’. As I discussed in Chapter 2, a binary “assumes an A/not-A relationship. That is, what is on one side of the binary is considered to be excluded from the other side” (Bacchi, 2009, p. 7). A hierarchy is implied such that one side is privileged and considered more important or valued than the other side (Bacchi, 2009). In the case of *BJA*, normal ways of being, functioning, and developing as a child were implied as more valued than abnormal or atypical ways of being, functioning and developing. At this point, I note that *BJA* contains ideas about accepting differences based on bodies (e.g., focus on strengths versus diagnoses) and development (e.g., emphasis on nonlinear, life course progressions), indicating a de-emphasis on ‘fixing’ young disabled people themselves compared to traditional medical model approaches to rehabilitation.
Yet, disability remains unquestioned as a problem that should be addressed in BJA. Taken-for-granted assumptions about normal children (e.g., normal bodies and abilities) and a normal progression to adulthood shaped implicit understandings of disabled children and their unsuccessful transitions to adulthood as a specific ‘problem’ that needed to be addressed by policy and practice in rehabilitation.

Later in this chapter, I unpack key concepts of a life course approach, interdependence, and active citizenship in BJA to reveal taken-for-granted assumptions about normality that shape the implicit problem representation of ‘disabled children’. First, however, I turn to the accounts of the parents of young people with DD who participated in this study to examine how they characterized transition to adulthood as a ‘problem’ within the context of rehabilitation services, and health care more broadly.

2 Transitions to Adult Rehabilitation Services: Parent Perspectives

2.1 Description of Parents’ Accounts

For the most part, the 13 parents of young people with DD who were interviewed in this study did not identify transitions from pediatric to adult rehabilitation or health care services as a predominant problem compared to service transitions in other sectors (e.g., the education and developmental services sectors, which I discuss in Chapter 6 and 7, respectively). In general, the parents talked about being prepared for rehabilitation and health care transitions by pediatric health care providers, which had resulted in better links to adult care. They discussed participating in formal transitions programs and interventions in pediatric hospitals in Ontario, which had prepared them for discharge and transfer to primary care (if they did not already have a primary care provider) and adult specialty care (e.g., rehabilitation, cardiology, gynecology, etc.) when their children were between 17 to 19 years of age. The implementation of transition programs in Ontario pediatric hospitals in recent years may have explained these parents’ more positive experiences of health care transitions compared to the findings that I discussed in the literature review in Chapter 3. All 13 parents had established linkages to a family doctor for general health consultations for their children with DD into adulthood. All parents had achieved transitions to adult specialty services for their children with DD, but one whose child had not yet
reached the eligibility limit of 19 years for pediatric health services. This finding suggests that linkages to adult specialty services had been made for these families, which does not reflect the experiences of families in the literature.

2.2 How Do Parents Characterize the ‘Problem’?

Overall, the parents did not identify transitions to adult rehabilitation and or other health care services as the predominant issue in relation to their children’s overall transition to adulthood. The parents described their children as healthy in adolescence compared to early childhood, despite chronic medical conditions, which may explain why they were generally less concerned about rehabilitation and health care transitions. For example, Debbie described her daughter (Grace, 17 years old, developmental disability) as being “in good health” and Linda described her son (David, 19 years old, autism) as “ridiculously healthy.” On the whole, health care involvement for these families had tapered off between childhood and adolescence because the children’s medical conditions (e.g., seizures, cardiac and gastrointestinal conditions) had been stabilized through medical interventions (e.g., pharmaceutical and/or surgical interventions). Several parents indicated that they maintained links with specialty care doctors as needed to monitor medical conditions, albeit with less frequency than previously. However, none of the parents described their children as being recently involved or needing rehabilitative services specifically focused on assessing or addressing developmental disabilities. Thus, unsurprisingly, the parents’ accounts reflected that they were less concerned about their children’s transitions from pediatric to adult rehabilitation services compared to transitions in other sectors.

The parents did, however, spend significant portions of interview time discussing their early experiences with health and rehabilitation services. My purpose in asking parents about their children’s medical diagnoses and involvement with health care was to gather background information and to lead into questions about their health care transitions experiences. Nevertheless, the parents seemed particularly interested in sharing details about their early experiences with the medical system and professionals. As Evelyn stated:

I think that’s important to the story. And then her development has some sense and some order. (about her daughter Christie, 27 years old, DD)

Evelyn’s comment suggested that her early medical experiences played a significant role in
shaping her understanding of her daughter’s “challenges” and atypical developmental trajectory. Her comment reflected the collective experiences of the parents of learning about their children’s disability and development ‘problems’ from medical experts.

The parents’ accounts reflected dominant medical discourses about disability and abnormal development as problems to be fixed in their discussions about their encounters with health care professionals during their children’s early years. All 13 parents described extensive involvement with specialty medical and rehabilitation services, beyond the regular consultations associated with healthy and typically developing children. For example, Miranda compared her daughter’s health care experiences to those of her nondisabled children:

Immediately at birth she needed surgery. And throughout her childhood years she had a lot of illnesses, some of which required brief hospitalizations mostly related to upper respiratory and breathing issues related to inflammation and congestion. Ear infections. So, a lot of the things that our other kids didn’t have. (about her daughter Susie, 21 years old, Down syndrome)

Similar to Miranda’s comment, Eva described her daughter as “medically prodded” by medical professionals in early childhood compared to her nondisabled daughter. All of the parents described extensive involvement with pediatric specialty care during their children’s infant to school-age years, in which they were exposed to medical discourses about impairments (e.g., physical and cognitive impairments) and disabilities (e.g., developmental and social functioning). By and large, the parents described their children’s health and health care experiences as falling outside of the ‘normal’ experiences of nondisabled children. Their accounts conveyed that medical experts had been integral to identifying their children’s impairments and risk of disability and atypical development as ‘problems’ to be minimized or prevented. These discourses played a significant role in shaping how the parents thought about their children, and what they should do to foster a normal developmental progression.

Medical discourses about disability as impairment shaped explicit and implicit messages about the types of bodies and abilities that are socially valued. For example, Evelyn described her first experience of receiving information from medical experts about her daughter’s health status immediately following her birth:
So I was on the table, full term, and he [obstetrician] pulled my first daughter, pulled Lily, and then went in and said, “there’s another one in here.” And that was Christie. And she wasn’t breathing for four minutes and it caused brain damage. With that brain damage we didn’t know the extent. Initially they revived her. People came in and revived her. And they said, “it could be as bad as CP.” They didn’t know the extent. There was quite a bit of damage. (about her daughter Christie, 27 years old, DD)

The phrase “it could be as bad as CP,” meaning cerebral palsy (a permanent physical disability that affects movement and posture), reflects social judgments about the relative value of disabled bodies. Powerful messages about impairments as ‘damage’ and CP as a ‘bad’ and undesirable outcome produced understandings of impairments and disability as ‘problems’ to be repaired, prevented or avoided. Evelyn described pursuing medical and rehabilitative interventions, which reflected that she had internalized messages about minimizing her daughter’s ‘damage’.

In Jane’s account, she described strong emotional reactions to a doctor who identified her newborn daughter as “failure to thrive.” This medical term is generally used to describe an infant’s lack of growth and development compared to normative standards, which suggests a risk of physical and/or cognitive impairments, or even loss of life. Jane stated:

To call something ‘failure to thrive’, to basically be told as a parent, your daughter has a medical condition, which is basically. I don’t know. To me, it was just like the most negative thing ever to hear. Like “what?!” There’s got to be something we can do. (about her daughter Joy, 24 years old, Down syndrome)

Like Evelyn, Jane’s example illustrates that she was exposed to powerful medical discourses about the relative value of her daughter’s impaired body. However, Jane’s account reflected that she resisted medical labels of impairments that devalued her daughter’s life.

In general, the parents’ accounts reflected their exposure to expert medical discourses about normal health and development, which directed their parenting efforts towards minimizing their children’s biological impairments and developmental deficits to the extent possible. Later in this chapter, I examine the normative assumptions about bodies, functioning, and development that underpinned these discourses. For now, I suggest that the parents’ accounts reflected implicit understandings of their children’s impaired bodies and atypical development as ‘problems’ to be ‘fixed’. The parents drew particularly on medical expertise and knowledge to guide their parenting in ways that promoted their children’s health and development, and minimized their
biological and functional deficits to the extent possible. Similar to the BJA document, their accounts reflected an implicit problem representation of ‘disabled children’ and their risk of atypical development.

At this point, I would like to clarify that I do not propose that pursuing normal bodies, growth, and development under the direction of medical expertise is ‘bad’ or inappropriate. In the circumstances of many families in this study, there were very practical reasons, such as ensuring survival and reducing pain or suffering of their children, for seeking medical expertise and advice. However, I suggest that medical discourses played a significant role in shaping an implicit understanding of normality (e.g., normal bodies, normal development, normal childhood) as socially valued and preferred, which shaped the aims of transitions policies and practices in rehabilitation. Left unquestioned, this implicit understanding may unintentionally perpetuate ideas about young disabled people as ‘problems’ to be fixed, producing potential negative effects of feeling devalued or excluded from participating in ‘normal’ roles and activities associated with an ideal progression from childhood to adulthood. With these potential consequences at stake, the parents generally took up powerful medical discourses, without question, to guide their parenting and decision making for managing the impairments associated with their children’s medical conditions. In essence, the parents’ accounts reproduced powerful medical discourses that constituted disability as a ‘problem’ to be prevented and minimized.

In the sections that follow, I examine key concepts in BJA to reveal underlying assumptions that shape how transition to adulthood is constituted as a particular sort of ‘problem’ in rehabilitation. These key concepts include a ‘life course approach’, ‘interdependence’, and ‘active citizenship’. I examine how these assumptions shaped implicit problem representations of ‘disabled children’ in BJA, which were also reflected in the parents’ accounts.

3. Life Course Approach

3.1 Document

A “life course philosophy” (p. 9) was explicitly stated as a core value underpinning the BJA document. The concept of ‘life course’ was not explicitly defined in the document, but reflected the idea that a person takes numerous journeys over his or her lifespan, across “different
developmental stages and transitions” (p.10). Within the life course, transition to adulthood was described as “a critical journey” (p. 10). The concept of ‘life course’ rested on taken-for-granted assumptions about the developmental progression expected, particularly between childhood and adulthood. *BJA* did aim to reformulate traditional views of normal development as a relatively proscribed, linear progression and sequence with achievement of particular tasks and milestones.

For example, *BJA* states:

> Each youth and family is at different stages of the journey: some are still “on the ground” in preparation for the transition to adulthood; others are starting this journey, with the navigator guiding a great deal; others are nearing the end of the journey, when the youth has more control and self-determination; and there are others who have made one or more ‘landings’ in the adult world and are getting ready to take off again on another journey (p. 10).

This statement reflects the idea that developmental progression occurs at different rates and with different ‘landings’ or outcomes, suggesting that there is more than one way to move from childhood to adulthood. Yet, discourses of a normal and expected developmental progression remained evident throughout the text.

Notions of development were found in several sections in *BJA*. For example, the document stated that a ‘landing’ is an “ongoing developmental process and not an outcome endpoint” (p.17) and “different outcomes may occur at different developmental periods across the life course” (p. 18). These statements aimed to reframe dominant assumptions about a linear, sequential progression across life stages occurring within a particular timeline. Instead, the metaphor of a life course ‘journey’ in *BJA* implied that ‘travel’, movement, or progression from one life stage to the next occurs over a series of small journeys and ‘landings’ or stopping points, which is unique to each young person. However, similar to traditional models of normal development, the *BJA* model was underpinned by assumptions about the roles and activities expected at different life stages. Moreover, a life course progression from childhood to adulthood, whether a steady or stop-and-start progression, was accepted as natural and ideal. Thus, taken-for-granted assumptions about progression or change related to the assumed roles and activities of particular age and life stages shaped implicit understandings of the ‘problem’ of disabled children and their unsuccessful transitions to adulthood.

*BJA* also aimed to reframe normative expectations for a typical trajectory to particular roles and
activities in adult life. For example, the document states that:

The goal of transition should not be focused on a series of outcomes such as employment, independent living and hobbies; but rather, active citizenship and involvement in meaningful occupations (p. 20).

The idea of active citizenship and its underlying assumptions is discussed later in this chapter. My point here is to highlight tacit assumptions about socially expected roles and activities across life stages (e.g., student roles in childhood and adolescence, work roles in adulthood), which underpin how the ‘problem’ of unsuccessful transitions for young disabled people is constructed. BJA attempts to shift normative discourses about traditional roles and activities as the ideal or only outcomes of transition to adulthood by suggesting alternative outcomes, such as active citizenship and participation in meaningful occupations. Even though the BJA best practices emphasized alternative outcomes for development and adulthood, they were underpinned by an implicit problem representation of abnormal developmental and social trajectories.

3.2 Parents’ Accounts

The parents in this study reproduced notions of normal development, particularly in their discussions about pursuing medical interventions and rehabilitation therapies during their children’s infant to school-age years.

Several parents discussed how ideas about normal functioning and development had shaped their ideas of ‘proper’ parenting behaviours for raising a child with DD. For example, Linda’s account reflected that dominant discourses about normal childhood development shaped how she thought about herself and her parenting roles and responsibilities:

We had concerns about him. He was late to walk. He still is somewhat low toned, he’s kind of loosey goosey. He was talking but not a lot. He wasn’t hitting all those markers. I guess we were sort of, maybe, incompetent parents or lax parents. You take him to the pediatrician and they say “no everything’s fine.” We took him to the child development clinic, eventually. (about her son David, 19 years old, autism)

Linda described her parenting as ‘incompetent’ or ‘lax’ because she had not recognized and acted upon her son’s delayed achievement of walking compared to developmental norms. Her account reflected that she had internalized messages embedded in developmental discourses about her responsibility as a parent to monitor developmental progression. Taken-for-granted
assumptions about an idealized progression from childhood to adulthood shaped an implicit understanding that her son’s ‘abnormal’ development was a specific ‘problem’ to be assessed and minimized. This representation of the ‘problem’ constituted her son and his unsuccessful transition to adulthood as a ‘problem’, and also functioned to constitute Linda as an incompetent parent compared to ‘competent’ parents who monitor and address their children’s development.

In another example, Eva’s account reflected that she largely reproduced discourses of normal development in her discussions about pursuing therapies for her daughter’s speech and mobility.

We started that very early. She started making progress. A speech therapist came to the house twice a week. She started saying words and very early the therapist said, “she’s going to be able to speak.” So then there was all the other - she never crawled. She had intense therapy to walk and she started walking at 2 years old, but it was with three times a week [name of physical program] therapy. That was very hard. (about her daughter Abby, 19 years old, autism, heart and immune condition)

Eva described the physical therapy as ‘hard’ because her daughter cried and seemed to be in discomfort during the sessions. Although Eva felt distressed about Abby’s emotional reactions during the therapy exercises, she continued with the therapy because she believed it was in Abby’s best interests for talking, walking, and overall development. To alleviate Eva’s own distress, her husband agreed that he would be responsible for the therapy. This example reflected that powerful discourses about normal development shaped Eva’s parenting behaviours, such that she pursued as close to normal development as possible for Abby, despite her parent intuition that the therapy had negative effects on Abby’s emotional and mental health, as well as her own. Eva’s account also exemplified the significant time commitment and effort expected of parents to be responsible for promoting as close to a normal developmental trajectory as possible for their children.

The accounts of Linda and Eva were representative of the parents’ accounts as whole. The parents largely reproduced similar ideas of normal developmental and life course trajectories that underpinned the BJA document, particularly in their discussions about pursuing medical interventions and rehabilitation therapies. Medical and rehabilitation professionals had evaluated their children’s growth and functioning compared to normative standards for development and had identified them as having ‘developmental disabilities’. In other words, these children were identified as having ‘abnormal’ or ‘atypical’ functioning and development determined through
scales and checklists. The parents’ accounts reflected that ‘functioning’ and ‘development’ were produced as objects or ‘problems’ to be fixed through medical and rehabilitation interventions. These normative discourses shaped the parents’ behaviours such that they pursued medical interventions and rehabilitation therapies to normalize their children’s functioning to the extent possible. Through this exposure to medical and rehabilitation discourses, the parents internalized social values about the types of bodies and functioning that are privileged and preferred, and the types of bodies and functioning that should be prevented or fixed. Moreover, they internalized social expectations about their roles and responsibilities for fostering as close to normal development and functioning as possible in their children, which shaped their parenting behaviours in particular ways geared towards this aim. That is, their parenting behaviours were largely shaped by discourses that emphasized developmental disability as a ‘problem’ located within the child that should be fixed, to the extent possible.

4. Interdependence

4.1 Document

The concept of ‘interdependence’ was explicitly stated and emphasized in BJA, as highlighted in this quote:

Collaboration should support the notion of “interdependence” not independence. We need to work together to redefine the concept of independence to focus on individual control, growth and successful journeys. “Interdependence” acknowledges that everyone needs social supports and networks to succeed throughout life stages (p. 17).

In this statement, BJA proposed reframing traditional notions of independence in rehabilitation, which generally encourage young disabled people to develop skills and capacities to perform activities of daily living (e.g., personal self-care, mobility, household and money management, shopping, etc.) on their own, or to the extent possible, as they progress to adult life. By reformulating the notion of independence in a document specifically focused on the transitions of ‘youth with disabilities’, BJA implied that many young people in this target group were unlikely to achieve living independently in adult life and thus this should not be the goal of transition. Instead, BJA suggested that “everyone,” with or without disabilities, relies on social supports and networks to function in daily life regardless of life stage and age. Thus, BJA
proposed that the term ‘interdependence’ was more reflective for the reality of caring relationships and community living arrangements between people and significant others.

BJA acknowledged that achieving full independence might not be possible for some young disabled people during the transition to adulthood, which implied that independence is ordinarily expected and promoted for young adults but proposed that interdependence was a socially acceptable alternative. For example, BJA explained:

Capacity building should focus on building support and mentoring in early years as well as in the teen years, with the understanding that complete “independence” may not be realistic. Move towards the paradigm of “interdependence” which involves active collaboration between youth, families and communities, and promotes healthier self-esteem and advocacy skills in youth. (p. 20).

This quote suggests that the notion of interdependence may be more achievable than independence for some young disabled people. It also suggested that working towards interdependence could assist young people in building their social support networks (e.g., active collaboration) and confidence in influencing action and change in their own lives (e.g., build self-esteem and advocacy skills). Nevertheless BJA also suggested that young people should aim to do things on their own, but with supports. It stated that best practices should:

Begin by building capacity early, so that youth with disabilities can be encouraged to “do it on my own with supports” and recognize the significance of interdependence for the rest of their lives (p. 20).

This quote reflects the significant value placed on being able to conduct one’s life on one’s own in adulthood (e.g., independence), even if doing so involved help from other people (e.g., interdependence). Based on this premise, BJA aimed to formulate interdependence, rather than independence, as the idealized outcome of transitions to adulthood. However, these discussions left silent the real possibility that some young people remain dependent on other people, often their parents, for help and support with daily and community living activities throughout their lives. What exactly is meant by ‘interdependence’ compared with independence (or dependence) is thus obscure.

The use of the concept of interdependence in BJA rested on an implicit understanding that a tension between independence and dependence exists during the transition to adulthood for
young disabled people. As suggested in the quotes above, the meaning of interdependence in BJA reflected the idea that most people live independent lives, but are also dependent on others for assistance and support. This meaning revealed a binary of independence/dependence that underpinned how interdependence was conceptualized in BJA, which also functioned to shape how transition to adulthood was constructed as a ‘problem’. Taken-for-granted assumptions about independence as a socially preferred trait of adulthood shaped an implied ‘problem’ of young disabled people and their ‘dependence’ on others, to which ‘interdependence’ was proposed as a solution.

‘Dependence’ was not discussed as an acceptable alternative to independence or interdependence in the document. Moreover, ‘interdependence’ can be understood to mean reciprocity or mutual dependence, which raises questions about the nature and character of reciprocity or mutuality that are socially acceptable in adulthood and about what forms of ‘dependence’ are problematic and need to be ‘fixed’. The suggestions of ‘do it on my own with supports’ implied that functioning as independently as possible with assistance and support for daily and community living activities is socially acceptable, but functioning dependently (e.g., full dependence on others daily and community living activities) is to be prevented or avoided. Thus, similar to commonly held meanings of independence, the meaning of interdependence in BJA implied that dependence has lower value than independence on a social hierarchy of adult characteristics. Thus, taken-for-granted assumptions about dependency as problematic for functioning in adulthood underpinned the formulation of the concept of interdependence in BJA. However, similar to the concept of independence, these assumptions produced an implicit problem representation of ‘disabled children’ and their risk of ‘dependency’ in adult life.

Along this line of thinking, BJA suggested in subtle and not so subtle ways that parents should continue to be involved in interdependent relationships with their children in adult life, as exemplified in this excerpt:

Parents are the stabilizing force, and have the best interests of their ‘child’ in mind. The capacity of parents to represent their child’s interests in the best way at different stages of the journey is important (p. 21)

Discourses of interdependence set expectations on parents to remain responsible for managing their children’s lives over the life course. Although BJA proposed best practices that fostered
interdependent relationships with significant others in the young person’s community (e.g., extended family, community members, service providers), it was largely assumed that parents would be the key connection during the transition to adulthood, and beyond. As I discuss below, discourses about independence/interdependence/dependence were reproduced and reflected in the parents’ accounts, which had both positive and negative effects on them.

4.2 Parents’ Accounts

The parents described the varying degrees in which their children relied on them for personal care and daily life management. Some parents talked about their children requiring complete assistance for personal care and other daily activities, which indicated the dependent, not mutually interdependent, nature of the parent-child relationship. In these situations, the children had significant physical and cognitive impairments associated with DD. For example, both Diane and Harriet provided more or less full personal care, rather than assistance, to their daughters. As Harriet explained:

Lucy tends to have seizures at night. So in the morning she is very, very sleepy. But I still manage to get her up and get dressed and get her in her chair and get her out the door to the bus. (about her daughter Lucy, 20 years old, autism and seizure disorder)

Harriet’s daughter was dependent on her for both physical and cognitive assistance to get out of bed, dressed, and to the bus, but also to plan and organize all of these tasks. In other cases, the children could manage the physical aspects of their personal care on their own, but needed supervision or assistance to plan and organize these tasks, which reflected the ‘do it on my own with supports’ approach proposed in BJA. For example, Sheila described her son’s level of independence in daily functioning as “medium to high”:

He’s probably medium to high functioning. I can leave him at home with a list of things to do and he’ll do them. So he’s fairly independent at home with personal sort of stuff. He showers himself, he dresses himself. He has a disease [name] where he has to wear pull- ups. He’ll never be able to [go without them]. But he takes care of all that by himself now. Not so much when he was younger, but he’s fairly independent these days. (about her son Joshua, 25 years old, Down syndrome)

Sheila’s quote suggested a form of interdependence in which her son was physically independent for personal care tasks, but cognitively dependent on her to plan and organize these tasks. All of the children relied on their parents for some degree of help (e.g., full or partial assistance),
supervision, or support for physical or cognitive functioning in activities of daily living. The majority of the parents’ accounts reflected that the children were dependent on others, rather than independent, to manage their personal care and activities of daily living. None of the parents described their children as being fully physically and/or cognitively independent in adult life. Discourses of interdependence, referring to BJA’s meaning of the term as being independent for some aspects of daily living and dependent for other aspects, were reflected in some of the parents’ accounts. However, none of the parents’ accounts reflected mutual dependence or reciprocity for personal care and daily life management in the parent-child relationship as the word implied.

The parents in this study also talked about being heavily involved in managing and coordinating their children’s health and health services after 18 years of age, but with less support for care coordination from adult health care providers than they had experienced with pediatric care providers. Although BJA suggested building interdependent relationships beyond the parent-child relationship to support transitions to adult rehabilitation services and adult life, the parents’ accounts largely reflected that they continued to be largely responsible for health management and service coordination, without involvement of service providers or people in the community. All of the parents, except one, appeared to accept this responsibility without question. Sheila’s account stood out because she discussed specific strategies that she used to shift some responsibilities for her son’s health management to his adult health care providers, attempting to draw them into a larger interdependent health care relationship. For example, Sheila described what she said to her son’s adult gastrointestinal specialist during the first visit:

How about I’ll call you? Can you put in the note that I have direct service [direct access without a referral] to you? That I don’t have to go back through my family doctor for a consultation. And could you please on your own stay on top of what seems to be trending or happening with adults of Down syndrome, can you make that part of your things to know. (about her son Joshua, 25 years old, Down syndrome)

Sheila knew that she could not make the doctor do these things, but she had at least articulated her expectations for shared responsibilities in future health care encounters similar to her experiences with pediatric health care providers. Sheila’s account reflected that she questioned ‘how things worked’ and took a proactive role in shaping shared responsibilities for her son’s health and health service management with adult health care providers. Although the concept of
interdependence in BJA aimed to mitigate dominant ideas about independence as an ideal outcome of transitions policies and interventions, it rested on assumed roles of parents as key players in managing the health and well-being of children who remain dependent on others for personal care and support in their adult lives. These assumed roles were generally taken up without question by the parents in this study, however, the account of one parent who resisted this assumption shed light on the potential effects of these expectations on parents. Thus, discourses of interdependence shaped the parents’ conduct in particular ways in relation to fulfilling responsibilities for providing care and support for dependent children, but neglected to account for changing circumstances, particularly in the future when the parent may no longer be able or available to fulfill these responsibilities.

5 Active Citizenship and Involvement in Meaningful Occupations

5.1 Document

BJA suggests that there are multiple ways to progress towards adult life and multiple possible outcomes, aiming to reframe traditional ideas of a fixed developmental trajectory and outcomes in rehabilitation. For example, as discussed previously, BJA stated:

The goal of transition should not be focused on a series of outcomes such as employment, independent living and hobbies; but rather, active citizenship and involvement in meaningful occupations. The capacity for active citizenship needs to be built by all involved in transition (p. 20).

Thus, BJA suggested that transitions outcomes focus on young disabled people being highly involved in activities that are considered useful or worthwhile for adult citizens, but not necessarily traditional outcomes, such as employment, independent living, or recreational activities. ‘Active citizenship’ and ‘meaningful occupations’ were not explicitly described in BJA, rather their meanings were assumed. I unpack these concepts further in the sections that follow.

As I discussed in Chapter 3, citizenship can refer to both a status (a way of being) and a practice (a way of acting). The notion of ‘citizenship’ in BJA produced the idea that citizens have a status that comes with rights, freedoms and protections, but also social expectations for acting and
participating in particular ways as adult citizens. The idea of ‘active citizenship’ rested on assumptions about individualism, and equality of opportunity, which are associated with central tenets of advanced liberal democracies. Together, these assumptions suggested that individuals should have equal access to opportunities (e.g. a level playing field) for full social, economic, and political participation in society. These assumptions shaped implicit understandings of the specific ‘problem’ of unsupportive environments needing to be ‘fixed’ in order to foster successful transitions for young disabled people. Thus, *BJA* best practices underpinned by these assumptions focused on minimizing or removing environmental barriers that hindered a successful transition to participation in socially accepted roles and activities for adults (e.g., independent living, employment, etc.).

While best practices underpinned by taken-for-granted assumptions about individualism and equality of opportunity can foster a successful transition to adult life for young disabled people, they potentially neglect to account for the power relations that function to privilege a particular sort of adult—an adult who acts as an ‘active’ citizens rather than an ‘inactive’ or ‘passive’ citizens. Thus, an implied binary of active/inactive citizens functioned to shape tacit understandings of the type of adult citizen who is preferred and idealized in liberal democracies. That is, the status and practice of active citizenship carried with it expectations for fulfilling particular adult roles, actions and responsibilities, generally but not only associated with participation in the work force, and residential and financial independence. Young disabled people were considered at risk of failing to achieve active citizenship, in other words, at risk of becoming ‘inactive’ citizens, thus, specific best practices were proposed in *BJA* ameliorate this ‘problem’.

‘Meaningful occupations’ was not explicitly described in *BJA*, but likely drew from terminology in the occupational therapy field, as several of the authors had backgrounds in occupational therapy research and practice. In this field, ‘occupation’ refers to groups of activities and tasks of everyday life, including self-care, leisure, and productive activities (Townsend, 1997). ‘Meaningful occupations’ refers to “occupations that are chosen and performed to generate experiences of personal meaning and satisfaction in individuals, groups, or communities” (Townsend, 1997, p. 181). Examples of meaningful occupations in *BJA* included developing social networks, advocating for political changes, and continuing education, postsecondary
education or community workshops, rather than focusing on traditional occupations for transitions goals, such as employment and independent living. However, similar to the binary of active/inactive citizenship, a binary of meaningful/nonmeaningful occupations operated to shape an implied hierarchy of activities that are socially valued and preferred for adult citizens. The examples provided in BJA suggested that high involvement in roles and activities associated with social norms for an idealized adult citizen, to the extent possible, are thought to foster a successful transition to adulthood for young disabled people.

The binaries of meaningful/nonmeaningful occupations and active/inactive citizenship operated to shape implicit understandings of the ways of being and acting that are socially valued and preferred (e.g., highly involved in social and economic activities associated with active membership in the community). This understanding shaped an implicit problem representation of ‘disabled children’ and their unsuccessful progression to socially valued roles and activities that are traditionally associated with adulthood. This implicit problem representation shaped BJA best practices directed towards achieving or approximating an idealized adult citizen—a citizen who actively participates in meaningful community activities, which can have both benefits for young people who can achieve these ends (e.g., status of ideal citizen, feelings of community inclusion), but also potential harms for those who cannot (e.g., status of inactive citizen, feelings of exclusion, further marginalization from the mainstream population) for young disabled people who do not or cannot easily achieve this goal.

5.2 Parents’ Accounts

The parents’ accounts did not specifically discuss citizenship or participation in meaningful activities in relation to their children’s medical and rehabilitation transitions experiences. On one hand, this reflected that families were less involved in this sector during their children’s teenage years. On the other hand, the parents potentially did not associate notions of citizenship and meaningful activities with medical or rehabilitation practices. However, the parents did talk about fostering social inclusion and participation in meaningful activities in relation to their transitions experiences in schools and the developmental services sector, which I discuss in Chapter 6 and Chapter 7, respectively. For now, I suggest that the parents experiences in rehabilitation largely focused on fixing impairments and preventing disability, to the extent
possible, in preparation for accessing participation in roles and activities socially expected of adults.

6 Summary

In this chapter, I examined how transition to adulthood was problematized in the rehabilitation sector in Ontario. In the BJA document, the transition to adult rehabilitation services, and to adulthood more broadly, was predominantly constituted as a ‘problem’ of service transitions and unsupportive environments. This problem representation shaped BJA best practices that emphasized fostering supportive environments for young disabled people during their transitions to adulthood. This problem representation carried with it an implicit understanding that ‘disability’ and ‘atypical life course trajectories’ were problems to be addressed, even if the solutions focused on changing or modifying environments to accommodate for people with impairments, rather than ‘fixing’ the young disabled people themselves.

In contrast, the parents in this study did not discuss rehabilitation or health care transitions as particularly problematic compared to their children’s transitions in the education and developmental services sectors. Rather, they discussed being prepared for and linked to adult service providers through formal transitions programs and procedures that had been implemented in pediatric rehabilitation services. Instead, they discussed their early health care experiences, which focused on identifying and minimizing physical and cognitive impairments and developmental deficits. The parents largely reproduced medical discourses about disability as a ‘problem’ to be fixed by pursuing rehabilitative interventions to address their children’s impairments and atypical developmental trajectories. Their accounts reflected that they had internalized normative assumptions about ways of being and progressing as a child, which shaped their parenting towards fostering normal abilities and development to the extent possible for their children.

The BJA document contained key concepts that operated to shape implicit understandings of the ‘problem’ of transitions. The key concepts were a life course approach, interdependence, and active citizenship. My analysis revealed that these concepts were shaped in relation to notions of normality (e.g., normal ways of being a child and becoming an adult), which operated to produce the idea of an ideal adult citizen. An ideal adult citizen was constructed as an adult who is
independent and actively participates in socially valued roles and activities (e.g., independent living, employment). The notion of an ideal citizen rested on implicit values and assumptions (e.g., individualism, equality of opportunity) underpinning the rationalities of governance that prevail in Western industrialized societies, such as Ontario.

Transitions best practices in rehabilitation, underpinned by implicit assumptions about a preferred adult citizen, can produce both benefits and harms for young people with DD and their parents. For example, best practices focused on changing the environmental factors that hinder the transition to adult services can foster increased opportunities for young disabled people to participate in social roles and activities in their communities. However, tacit assumptions about an ideal adulthood can function to socially exclude or marginalize young disabled people who fail to achieve or approximate normal roles and activities as they progress to the life stage associated with adulthood. Moreover, these implicit assumptions shaped policies and practices that can have negative consequences for the emotional and mental health and well-being of young people with DD and their parents when they are encouraged to work towards and achieve an idealized adulthood, even when this goal is challenging to achieve or not possible.

In the two chapters that follow, I examine how transition to adulthood is problematized in the education and developmental service sectors, respectively.
Chapter 6
Transition Planning in Education

In this chapter, I discuss how transition to adulthood, particularly the transition from high school to work, further education, and community living, is constructed as a ‘problem’ within the education sector in Ontario. I examine the explicit and implied problems underpinning transition planning for ‘exceptional’ students in a key document from Ontario’s MEDU and in the parents’ interview accounts. First, I describe the selected document called Transition Planning: A Resource Guide (Ontario MEDU, 2002) and examine how it constitutes transition to adulthood as a particular sort of ‘problem’. Second, I briefly describe the parents’ accounts of their education experiences and examine how the parents in this study characterized the ‘problem’ of transitions from school to adult life. Third, I examine key concepts of ‘work and further education’ and ‘community living’, which are identified as key outcomes of transition planning in the TPRG document, to make transparent underlying assumptions about disability and adulthood that shape how the ‘problem’ is understood. I also examine how these assumptions are reflected in the parents’ accounts, with a particular focus on their effects on parents of young adults with DD.

1 Transition Planning: A Resource Guide (TPRG)

1.1 Document Description

Transition planning is required of school boards under Identification and Placement of Exceptional Students (1998), Ontario Regulation 181/98 of the Education Act, 1990. The stated objective of the TPRG document is to provide educators (e.g., principals, teachers, guidance counsellors, and educational assistants), students and their families, and others (e.g., nonfamily advocates, community service and health care providers) with detailed examples for implementing education policy related to planning for transitions from school to work, further education and community living for exceptional students. Thus, transition planning is proposed as a solution to address the implied ‘problem’ of unsuccessful or inadequate transitions from school to adult life for this specific population. In what follows, I examine the proposed solution of transition planning by ‘working backwards’ to see how it constitutes the ‘problem’ of
transition to adulthood for exceptional students. I begin by discussing the meaning of the term ‘exceptional students’ in TPRG.

Regulations under the Education Act, 1990 define an exceptional student as “a pupil whose behavioural, communicational, intellectual, physical or multiple exceptionalities are such that he or she is considered to need placement in a special education program by a committee” (Identification and Placement of Exceptional Students, 1998). The committee referred to is an Identification and Placement Review Committee (IPRC; Ontario MEDU, 2016) of the school board, which formally identifies students as having exceptionalities that require specialized education assessments, placements or programming beyond what is provided in the regular or mainstream education program. The list of ‘exceptionalities’ appears to replace terms more commonly used health and medicine, such as ‘impairments’ or ‘disabilities’. There are two references to “invisible disabilities” (p. 22) and “learning disabilities” (p. 22) in the document. Interestingly, ‘gifted’ students, meaning students with advanced intellectual skills that could not be met in a mainstream classroom, could also be identified as exceptional students, but were exempt from requiring formal transition plans. It is exceptional students with disabilities, that is, disabled students, who are the specific target group for transition planning policy. Thus, disabled students were produced as a particular ‘problem’ for mainstream education programs and for planning transitions to post-high school life.

1.2 What Is the Problem Represented to Be in TPRG?

The ‘problem’ in TPRG is represented to be disabled students and their risk of unsuccessful transitions from school to activities expected of all high school graduates. The proposed course of action is coordinated transition planning, which is reflected in the following statement:

The transition from school to work, further education, and community living can be particularly challenging for some exceptional students. The probability of a successful transition is significantly increased when schools work with parents, employers, community agencies, and providers of further education to develop coordinated transition plans for exceptional students (p. 3).

This statement suggests that transitions from school to work, further education, and community living for some exceptional students, meaning disabled students, are not simple or straightforward in the Ontario education system. It implies that transitions to these particular
pursuits following high school have historically been problematic for this specific population. The proposed solution to address this ‘problem’ is for educators to develop coordinated transition plans for these students in collaboration with parents, employers, agencies providing community services, and institutions providing further education and training. The goal of transition planning is to foster successful transitions to post-high school life for disabled students, with a particular focus on work, further education, and community living.

*TPRG* describes transition plans as “the school’s written plan to assist the student in making a successful transition from school to work, further education, and community living [emphasis in original]” (p. 3) and stated that the student’s goals in these three areas “are the starting point for transition planning” (p. 20). These areas are repeated throughout the document, which emphasized their relative value and importance in preparing disabled students for post-high school life when young people are typically considered to ‘come of age’ as an adult. Moreover, the focus specifically on disabled students suggests that transitions in these particular areas are problematic compared to nondisabled students. In essence, disability is implied as a ‘problem’ for successful transitions from school to adult life in *TPRG*.

The ‘problem’ constituted as unsuccessful transitions to work, further education, and community living also suggests that disabled students have not achieved particular skills and competencies to participate in these areas of adult life by the time they leave high school. *TPRG* suggests that transition planning focus on “generic skills that are needed in making the transition to work, further education, and independent living” (p. 26). It proposes that these ‘generic skills’ should be generally taught across the curriculum, thus, they are expected of all students, and included the following (p. 26):

- Self-advocacy skills
- Study skills
- Vocational/job skills
- Employability skills (e.g., dress, punctuality, responsibility)
- Daily living skills for independence
- Interpersonal skills
- Stress-management skills
• Problem-solving/decision-making skills.

This list of skills indicates the types of roles and activities (e.g., self-care and management, employment, and independent living) that all students are expected to achieve upon completing high school in preparation for adult life, whether through mainstream or special education. These skills reflect an implicit understanding about the types of roles and activities that are valued in society and how young adults are expected to conduct themselves (e.g., independently). TPRG suggests that these generic skills “are crucial to all types of learning, and their lack may be judged by the transition team to be a barrier to the achievement of the student’s goals” (p. 26). Hence, these generic skills are identified as foundations for any learning in the Ontario curriculum, whether the student’s goals are oriented towards achieving skills and competencies in specific subject areas (e.g., math, science, geography) in the regular curriculum, or achieving skills and competencies in a modified or alternative curriculum (i.e., special education). Thus, disabled students are identified as problematic because many of them lack generic skills and competencies considered important for transitioning to and participating in expected roles and activities of young adulthood compared to their nondisabled peers.

Later in this chapter, I unpack the key concepts of work, further education, and community living, which were embedded throughout TPRG, to reveal underlying social assumptions about disability and adulthood that shape the implicit problem representation of ‘disabled students’. First, I discuss how the parents in this study characterized the ‘problem’ of their children’s transitions from school to adult life.

2 Transition Planning Experiences in Education of Parents

2.1 Description of Parents’ Accounts

Five of the parents had children still in high school at the time of their interviews. Eight had children who had already finished high school. Of these eight children, four participated in day programs, one participated in a supported employment program, and two participated in part-time or online college/university courses while also working part-time. All of the children had stayed in school or planned to stay in school until the provincial government-mandated age of 21
years, except two: one child left high school at 19 years old and one child (17 years old) had yet determined when she would leave high school.

As described in Chapter 5, all of the parents in this study discussed being highly involved with both health care and education professionals for developmental and psycho-educational assessments because their children had not met normal developmental milestones (e.g., walking, talking, reading, and writing) in their early school years. The psycho-educational assessments provided information about the children’s capacities for learning (e.g. cognitive, language, and memory skills) and academic work (e.g., reading, writing, math) in order to assist with educational programming at school. Through the school IPRC process, all of the children in this study were identified as ‘exceptional’ students, meaning their academic and learning needs could not be met in a regular education classroom.

All of the children in this study were enrolled in modified or alternative education programs, rather than the regular education program. Modified programs included participation in regular classrooms with accommodations and supports (e.g., withdrawal for specialized or remedial instruction, support from educational assistants or technological devices, modified content and/or expectations for classroom work and tests). Alternative education programs included specialized content and instruction, usually focused on generic skills and basic academic work, and a smaller student to teacher ratios. In some cases, students in modified or alternative education programs participated in regular classrooms for part of the school day for specific courses or activities. In other cases, the special education placement was located in a specialized school, separate from the regular education school. Two parents, who had been dissatisfied by the special education programs in the public school system, sent their children to special education programs in private schools. The children in this study were streamed into special education programming early in their school years, thus, their schools were required to prepare Individual Education Plans (IEPs) and transition plans to prepare them for post-high school life. An IEP is an individualized written plan that describes the special education programs and/or services required by a student identified as having exceptional learning needs (Ontario MEDU, 2004).

The parents talked about two main ways in which their children’s schools had prepared them for the transition from school to post-high school life. First, the schools provided the families with
information about services and programs (e.g. day programs, cooperative workshops) for adults with DD to increase their awareness of what was available beyond the education system. Second, the schools developed formal written transition plans in collaboration with the parents and other people involved in assisting the student to achieve his or her goals (e.g., family members, school system personnel, community service and health care providers), as was required in Ontario Regulation 181/98. All of the parents discussed participating in transition planning with their children’s schools. Their accounts indicated that they had placed confidence in the transition planning process for preparing their children for successful transitions to work, further education, and community living. However, the majority of parents conveyed disappointment and frustration with the outcomes of transition planning because they believed the plans and goals had not been actualized. Regardless, the parents’ accounts largely reproduced implicit problem representations of disability, which underpinned the TPRG document, and their children’s failure to achieve skills and competencies expected of students in regular education in preparation for post-high school life.

2.2 How Do Parents Characterize the ‘Problem’ of Transition Planning in Schools?

By and large, the parents characterized the ‘problem’ of unsuccessful transitions from school to post-high school life for their children as a service transition problem, similar to TPRG. Their accounts indicated that they had accepted and pursued the idea of transition planning proposed in TPRG and by their children’s schools as a solution to address this ‘problem’. In addition, they reproduced TPRG discourses about ideal outcomes of a successful transition from school to work, further education, and community living in their accounts. These discourses were reflected in their parenting behaviours and decisions with respect to creating and pursuing these particular transitions goals for their children. They discussed several specific ‘problems’, such as a void in programs and services for young adults with DD, deficient bureaucratic processes and inadequate training of educators, which impeded a successful transition from school to post-high school activities for their children.

All of the parents described challenges in preparing for a ‘void’ of community programs (e.g., social, recreation, life skills development, and work support and training programs) once high
school ended, which created uncertainty about what their children would do and where they would go on a daily basis as young adults. Up until that stage, the children attended public or private school as required by compulsory education laws, and participated in special education programs. For this reason, the majority of parents delayed their children’s transitions out of high school until the age of 21 years, which was the upper age limit of eligibility for publicly funded education in Ontario. For example, Miranda described her reasons for keeping her daughter in public school as long as possible:

She went to school until she was 21 [years old]. There was no way we were going to pull her out early. Because we knew there was a void after high school. At least in high school the learning was ongoing and the socialization was ongoing, and having friends and all that. (about her daughter Susie, 21 year old, Down syndrome)

Like Miranda, all of the parents discussed challenges in navigating the transition from compulsory education programs, usually funded by the Ontario MEDU (unless the child went to private school), to community programs and social services, usually affiliated with the Developmental Services Branch of the Ontario MCSS. Miranda’s quote points to ongoing learning (in special education), socialization, and having friends as primary goals for her daughter’s post-high school life, rather than the goals of work, further education in preparation for work, and independent living that were promoted in TPRG. Regardless, Miranda suggested that her goals were difficult to achieve because there was a lack of community programs and social services for young adults with DD. Like the majority of parents in this study, Miranda identified a lack of community programs and social services as a specific ‘problem’ for their transitioning.

Several parents discussed ‘bureaucracy’ as a specific ‘problem’ that hindered successful transition planning. For example, when Harriet was asked what she would recommend to other families about transition planning, she responded:

What else would I say to families? Just do more in terms of those IEPs. Like really understand what it is. I mean, I’m sounding really cynical here, but I think often it’s just pushing paper and ‘check the box’. (daughter is Molly, 27 years old, global DD)

Harriet described written IEPs, which included transition plans, as “pushing paper.” In other words, transition planning was a bureaucratic practice that had not resulted in actions by the
school towards achieving a successful transition to programs and services for her daughter. She suggested that written transition plans allowed schools to ‘check the box’, or to demonstrate that they had met the policy requirements, but had not led to transition-related learning (e.g., developing skills and competencies to prepare for adult roles and activities) or actions (e.g. transfers from school to programs and services in the DD and community sector). She did not suggest, however, that transition planning was unnecessary or unneeded. Rather, she recommended that parents “do more” to ensure that creating transition plans was not an outcome in itself, but a step towards implementing actions and achieving their children’s transitions goals. Her recommendation reflected her implicit acceptance that her daughter’s transition to adulthood was problematic and it was her responsibility as a parent to ensure that transition plans were not only created, but also implemented. Nevertheless, her account suggested that her daughter’s school had failed to take responsibility and action for supporting a successful transition to adulthood, which she had assumed was a mutual obligation by virtue of collaborating on the creation of a transition plan.

Evelyn specifically described the transition planning processes as “bureaucratic” because creating a plan had not resulted in achieving her daughter’s transition-related learning goals in preparation for leaving the education system. In addition, she identified inadequate training of educators for transition planning, as well as a general lack of interest and support for transition planning in the education system, as specific issues. As Evelyn explained:

The public schools don’t have qualified staffing. Then if it’s not a good school and you go there to complain, it’s a whole huge process. You’re put on that list or that list. Wherever there’s an opening. Do people really take an interest in the individual? No. It’s bureaucratic. And there’s not that interest in the one individual. You don’t like the school, well there’s an opening over there. Is it suitable? Is it better? It’s an opening. So they’re limited in what they can do. You just have to kind of keep motivated in finding the appropriate environment for your kid. You always have to be on top of it. (about her daughter Christie, 27 years old, DD)

In this quote, Evelyn suggests that educators were under-qualified and/or disinterested in planning for the transitions of disabled students. In addition, she suggests that suitable education programs to support achieving her daughter’s transition-related learning goals were limited or inadequate. As a result, Evelyn proposed that parents had to “be on top of it,” suggesting that students with DD were at risk of unsuccessful transitions from school unless their parents took
on significant responsibilities to ensure that transition plans were created and implemented by educators. Her account reflected an implicit understanding that her daughter’s failure to achieve or approximate traditional learning expectations for transitioning from school to young adult life was problematic, which required special education interventions, including creating a transition plan.

Like Harriet, Evelyn’s account reflected that engaging in mandatory transition planning processes had shaped her parenting behaviours towards preventing or minimizing unsuccessful transitions to the adult developmental services sector. These behaviours involved taking on extraordinary responsibilities to ensure transition plans were created in collaboration with educators and to monitor their implementation. However, Evelyn implied that engaging in bureaucratic processes had not changed the attitudes and behaviours of educators in fostering opportunities to develop her daughter’s skills and competencies related to her transitions goals. Thus, practices and expectations for transition planning in schools as outlined in TPRG had not solved the ‘problem’ of an unsuccessful transition from school to community programs and social services for her daughter. Similar to Harriet, Evelyn’s account reflected that her actions reproduced ideas that her daughter’s transition from school was problematic and required intervention compared to nondisabled students in mainstream education programs.

Both Cora and Linda suggested that educators lacked skills and competencies to develop and implement transition plans, which resulted in an unsuccessful transition from school to post-high school life for their children. For example, when Cora was asked how the school had implemented her daughter’s transition plan, she responded:

They didn’t. That did not happen. So that transition piece, if you read her IEP, there is a piece on the IEP that says “transition plans.” Plans were always that she “go to guidance and research colleges and universities.” That was what they would write. Or they would write, “prepare her to learn to make a resume.” So it was just things that, hello, aren’t you doing this for all the kids? Knock, knock, knock. [Laughs]. And it never happened because she didn’t go to guidance, surprise, surprise, and say, “I have special needs, transition for me is difficult. I don’t know what to do.” They did nothing. (about her daughter Amanda, 23 years old, Asperger’s syndrome)

Cora suggested that the transition plan and goals for her daughter were vague and not individualized as proposed in TPRG, but reflected generic goals for any student. She also
suggested the responsibility for achieving these goals was placed on her daughter, despite being identified as a student who needed special education supports in order to learn and achieve transitional goals. Similarly, Linda suggested that educators had resisted creating measurable and achievable transitions goals specific to her son’s learning needs. When Linda was asked what she thought was behind this resistance, she replied:

Because they don’t want to be accountable for it. Because it’s never a failure to teach, it’s always a failure to learn. Bottom line. I’d never in God knows how many years I’ve been doing this in the school system have ever had a teacher say, “I haven’t figured out how to do this. I haven’t figured out a way to help David do this.” It’s always, “David can’t do this,” in his report card. And he can’t do this. There’s nothing to say, “and here’s how we think we might help.” (about her son David, 19 years old, autism)

Linda’s statement, “it’s never a failure to teach, it’s always a failure to learn,” suggests that educators lack skills and competencies to teach disabled students like her son. Regardless, Linda’s account reflected an implied understanding that her son’s skills and competencies did not meet expectations for a traditional transition from school to post-high school life and required intervention.

These parents took up the idea of transition planning as a good practice in education, but were generally disappointed by the process. Parents discussed transition plans as part of a ‘bureaucratic’ process that served to show ‘on paper’ that the school was meeting the requirements of education policies, but, in practice, had not resulted in successful transitions from school to work, further education or training, or community programs as promoted in TPRG. The parents also described making decisions about placing their children in special education programs and discussed the implications for their children’s social inclusion in schools.

An implied ‘problem’ of exclusion was reflected in the parents’ discussions about pursuing integrated or segregated classroom placements for their children. The schools were required to meet the exceptional learning needs of students through appropriate classroom placements and by developing IEPs and transition plans. Integrated or ‘inclusive’ classroom placements referred to those in the mainstream or regular education program, either full or part-time, and with modified learning goals, accommodations and/or supports. Segregated classroom placements referred to special education classrooms that were separate from mainstream classrooms and
with a modified or alternative curriculum. The choice between integrated and segregated classroom placements depended on parents’ education and transition goals for their children, as well as recommendations from the school. Interestingly, parents used the terms ‘integrated’ and ‘inclusive’ interchangeably, and explicitly used the term ‘segregated’. In comparison, the Ontario MEDU (2002) explicitly used only the term ‘integrated’ to describe classroom placement options on its website. The parents’ accounts reflected that notions of inclusion in education programs had a large influence on parents’ decisions about appropriate classroom placements for their children. For some parents, inclusion referred to full integration in a regular classroom, to the extent possible with special education assistance and supports, whereas other parents described ‘segregated’ classrooms as inclusive because their children had a sense of belonging with their peers. Although ‘inclusion’ was described and accomplished in different ways by the parents, their accounts reflected an implicit problem representation of ‘exclusion’, which shaped the parents’ behaviours and decisions towards preventing or minimizing the social and/or academic exclusion of their children.

Several parents were proponents of full integration in regular classrooms, which reflected that they valued opportunities for academic and social inclusion with nondisabled students in a regular classroom. Cora emphasized that “the point of special education is integration.” She proposed that all students should be assisted to the extent necessary to succeed in a regular academic program, which she suggested that her daughter’s school had failed to do. Likewise, Susan insisted on full integration with specialized supports for her son because she believed that he could participate in a regular education program if provided with proper assistance to learn. As she explained:

He’s finishing school in June this year. Because of that whole [cognitive] processing issue I have home schooled at times. Four years he’s been in high school. They have an ASD program, which doesn’t quite—he doesn’t quite fit the norm [for ASD]. They used to say, when he was young, that he’s one of those hard to serve kids mainly because he’s not like total [learning] needs or anything and he’s not Asperger’s. He has some good skills but he takes his time. And so I’ve always kind of insisted on integration, it’s been a big fight with the school. (about her son Noah, 20 years old, autism)

Susan’s account reflected her belief that her son had adequate skills and competencies to succeed in the regular academic curriculum if he was given appropriate accommodations and supports
(e.g., more time to complete school work and additional instruction). Her insistence on integration and reference to a ‘big fight’ with the school also reflected the significant value she placed on her son’s inclusion in mainstream education. Both Susan and Cora pursued access to regular education for their children and argued that the role of education was to accommodate for their children’s exceptional learning needs within regular education settings. Thus, their accounts implied that academic exclusion from mainstream education was an issue underpinning the ‘problem’ of transitioning to post-high school life.

Some parents preferred special education placements, or what they called ‘segregated’ classrooms, because they provided specialized instruction and support for their children’s exceptional learning needs, as well as opportunities for social interaction. For example, Miranda’s daughter was enrolled in a special education class with part-time integration into a regular class. Miranda described this mixed integrated/segregated arrangement as ideal for her daughter because it provided opportunities for an alternative program focused on generic or life skills and for socializing with students in mainstream education. Miranda’s account reflected that she valued opportunities for her daughter to socialize with ‘regular’ or nondisabled students, while at the same time acknowledging that her daughter did not have the skills and competencies to participate in the regular education program. Thus, her account implied that she saw two aspects to inclusion—academic and social inclusion. Since inclusion in the regular academic program was not possible for her daughter, Miranda pursued opportunities for social interaction and inclusion in mainstream classrooms to prevent or minimize the issue of social exclusion to the extent possible.

A few parents reformulated the generally accepted meaning of inclusion in education, which usually referred to full integration into regular classrooms, to emphasize social interaction and a sense of belonging with peers in segregated classrooms. For example, Linda discussed her preference for segregated settings because she was concerned that her son’s exceptional learning needs would be overlooked in a regular classroom setting. In describing her son’s experience in special education, Linda emphasized that a segregated class did not result in social exclusion:

When he went into the school system he was in a diagnostic kindergarten and he’s been in a special ed[ucation] since. We agreed. We did not push for him to be integrated because we felt he would get overlooked and he wouldn’t necessarily learn. This is in
retrospect, that I’ve yet to meet someone on the [autism] spectrum who was integrated for a whole life who has any more social friends than my son does. (about her son David, 19 years old, autism)

Linda’s account reflected that she valued social interaction and a sense of belonging with peers as an indicator of her son’s inclusion in school. She subscribed to the school’s idea that her son needed a segregated class placement (essentially excluding him from mainstream education) to address his exceptional learning needs, but also emphasized that her son experienced social inclusion in this segregated setting. Like Miranda, Linda’s account reflected that she valued both academic and social inclusion, but pursued special education programs rather than integration into a regular academic program to achieve it. Regardless, Linda’s account reflected an implicit understanding that ‘exclusion’—either academic or social exclusion—was a ‘problem’ to be addressed, which guided her decisions about her son’s classroom placements.

Daniel’s account also reflected how he (re)formulated prevailing ideas about inclusion in describing his daughter’s segregated special education placements:

At a very practical level Ella [daughter] was in special ed after grade one onward. The second closest school to us had a segregated program, and it was good. It was a very small school, so the fact that she was in a segregated classroom but in a very small environment was more inclusive. Wasn’t the pure inclusion that many, if not most people advocate, which is 100 percent inclusive in the regular [education stream]. Because of Ella’s good success in experiencing school in a semisegregated environment, I’m not so strident about the full inclusion. (about his daughter Ella, 25 years old, DD)

As he explained further, Ella was “streamed with a population not academically oriented in a segregated high school.” For Daniel, there were very practical reasons for a segregated special education placement for his daughter because her learning goals were not oriented to a regular academic program. Rather they were oriented to basic academics, life skills and socialization. Daniel, recognizing that his views differed from many parents and reiterated how he framed inclusive education for his daughter: “’Cause for her it was an integrated high school. She was part of everything. In the mix of high schools [though], it was sort of a segregated high school.”

Daniel reproduced notions of inclusion, implying its social value and desirability, but reformulated dominant understandings about inclusion as academic participation in a regular academic program with nondisabled children to social participation and a sense of belonging
with disabled peers in special education programs. On the whole, the parents discussed the ways in which they considered inclusion in making decisions about classroom placements, which suggested that exclusion was problematic for their children. The parents’ accounts reflected that they reproduced discourses of integration in TPRG through their talk about inclusion, but also challenged dominant understandings of this discourse by reformulating notions of inclusion and exclusion.

In the sections that follow, I examine the concepts of ‘work and further education’ and ‘community living’ that were contained in TPRG to reveal assumptions about disability and adulthood that contributed to shaping the problem representations in both TPRG and the parents’ accounts.

3 Work and Further Education

3.1 Document

Taken-for-granted assumptions about transitioning to work or further education following high school education shaped how the ‘problem’ of unsuccessful transitions for disabled students was understood in TPRG. These assumptions shaped work as an ideal outcome of transition planning. The significance of work was illustrated in several statements throughout the document. For example, TPRG stated that: “Almost all students will need or wish to engage in productive employment, supported employment, or meaningful volunteer work” (p. 20).

This statement promoted employment or work as preferred goals for transition planning and reflected taken-for-granted ideas about an ideal transition to employment or work for all students in the education system. It also reflected an implied understanding of the types of roles and activities that are socially preferred and expected of young adults following high school. For example, ‘productive’ and ‘meaningful volunteer’ roles and activities related to work were specifically identified, which implied that other roles and activities were implied to be unproductive and nonmeaningful. The latter were not specifically identified, but potentially refer to social and recreation activities, or doing nothing at all. In addition, the categories of ‘productive employment’, ‘supported employment’, and ‘meaningful volunteer work’ implied a hierarchy of the type of work that is socially valued for young adults, with productive
employment positioned in the top or dominant position. In the sections that follow, I unpack the implied meanings of these categories.

The meaning of the term ‘productive employment’ was not specifically defined in TPRG, rather it was assumed. Presumably, it reflected prevailing assumptions in Western industrialized societies about ideal forms of work; that is, work that contributes to the production of goods and/or services and fosters the economic growth and well-being of society. Moreover, ‘productive employment’ reflected taken-for-granted expectations for students to participate in paid work as adults. The emphasis on work was also exemplified in statements about cooperative education. For example, the document stated that cooperative education or other forms of work experience programming “can be a key factor in supporting a successful transition to work” (p. 13) and “are important components of the transitions plans of some exceptional students” (p. 30). Thus, the document highlighted work as an ideal outcome of education and transition planning for many exceptional students. In addition, the document stated that cooperative education placements could provide “a means for students to acquire and demonstrate workplace skills, thereby easing their transition to the work force” (p. 14). This statement reflected dominant discourses in education about entering the work force as the expected trajectory following school, but also illustrated that the ‘problem’ has to do with disabled students themselves. In other words, this statement points to disabled students’ lack of workplace skills as problematic for a successful transition from school to work. Notwithstanding an emphasis on work as an expected transitions goal, the document also recognized that some disabled students might not achieve work skills for traditional paid employment, thus ‘supported employment’ and ‘meaningful volunteer work’ were suggested as less desired alternatives.

‘Supported employment’ was also not specifically defined in the document. It typically refers to employment in which disabled people, usually with intellectual or mental health impairments, are integrated into a regular setting with the support and assistance of a job coach and are paid a competitive wage that may be funded fully or in part by a disability social service agency. In essence, paid employment, even if achieved with support or assistance, was emphasized as a preferred goal of transition planning. The term ‘meaningful volunteer work’ was also not defined in the document, nor to whom the volunteer work should be meaningful, but arguably, it reflected the idea that unpaid or ‘nonmeaningful’ volunteer work was less socially valued than
paid work, but more valued than not working at all. ‘Supported employment’ and ‘meaningful volunteer work’ were subtly suggested as alternatives when ‘productive employment’ was not possible for some students. In this regard, discourses about work in TPRG produced a particular understanding about unsuccessful transitions to the work force of disabled students. That is, they risked becoming unproductive adult citizens who fail to participate in the labour market and rely on government programs for support and assistance, rather than productive adult citizens who contribute to the economic growth of society are financially self-reliant. This problem representation shaped proposed solutions focused on developing the skills of disabled students for paid work to the extent possible, with supported employment or meaningful volunteer work as acceptable, but less preferred alternatives.

The term ‘further education’ was used frequently throughout the TPRG document and was presented as a primary focus of transition planning, particularly when a transition from school to work was not expected for the student. For example, the document suggested that the transition planning team have “an inventory of further-education opportunities” (p. 18) and provide a student with support in applying “to appropriate institutions and programs for further education, and/or to community support programs, in accordance with her or her post-high school goals” (p. 25). The document provided the following definition:

The term further education is used to refer to continuing study (after the student leaves school) in any formal program, including:

• a program at a college of applied arts and technology;
• a university program;
• a private vocational school program;
• an apprenticeship program;
• a school board continuing education program; or
• a government-funded educational or training program such as a literacy or life skills program. (p. 3)

Thus, further education referred to postsecondary education in college or university, or continuing education/training for work, basic academics (e.g., literacy), and life skills, which were promoted as acceptable transitions goals. Even so, an implied hierarchy of types of
education and training was reflected in the document, such that further education (especially ‘higher’ education at college or university) resulting in an eventual transition to work was emphasized over literacy or life skills training.

Further education and training are put forward as specific solutions to unsuccessful transitions in the document. Thus, lack of education and training of disabled students for participating in work and daily community life is represented to be a specific ‘problem’. This implicit problem representation suggested that disabled students fail to achieve skills and competencies for participating in typical roles and activities associated with work and daily living—a ‘problem’ that can be addressed through additional education and training. This solution to the ‘problem’ was underpinned by taken-for-granted ideas about education being an ‘equalizer’ for people who experience disadvantages in accessing and participating in the work force, which were shaped by prevailing discourses about equality of opportunity common to Western industrialized societies like Ontario. From this viewpoint, the ‘problem’ of unsuccessful transitions was predominantly constituted as lack of education and training of disabled students, and more specifically, their lack of skills and competencies for accessing socially valued roles and activities associated with work and independent living upon high school completion.

In TPRG, discourses and assumptions about work and further education as ideal outcomes of high school education shaped implicit understandings of disabled students and their insufficient work skills and competencies as ‘problems’ that should be prevented or ‘fixed’ through proper transition planning oriented towards these outcomes. In the section that follows, I examine how the concepts of work and further education shaped the parents’ accounts of transition planning for their children.

3.2 Parents’ Accounts

The majority of parents discussed further education, in preparation for eventual work, as their main transition goal for their children. Like TPRG, the parents’ accounts reflected that they largely reproduced assumptions about work or working towards work as preferred goals. In particular, several parents talked about pursuing ‘higher’ education through college or university for their children, whereas other parents pursued work training programs through community agencies. I discuss each in turn.
3.2.1 Pursuing Higher Education: “Position Yourself in Society”

Five parents discussed pursuing further education through college or university programs as transition goals for their children. Their accounts reflected that they believed further education, and particularly higher education, would lead to better opportunities for employment with high income and status than high school education. Evelyn described her rationale for pursuing further education as a goal for her daughter Christie:

> It’s always the same route. You graduate from high school and you continue on with education in school to have some training in order to position yourself in our society.

(about her daughter Christie, 27 years old, DD)

Evelyn’s quotation revealed an inherent assumption that the “same route” or typical trajectory from school to further education and training to eventual employment was expected for any student. She did not challenge this assumption in her talk, rather she drew on it to shape transition goals for her daughter. Her account reflected that she had internalized beliefs about further education and training as keys to a successful transition from high school to employment. In practice, these beliefs had shaped Evelyn’s transition planning aims and behaviours, such that she pursued higher education for her daughter to the extent possible in order to better position her socially and financially for adult life.

Cora discussed pursuing a college diploma program for her daughter, but a specific program with an option to transition to a university degree program. As Cora explained:

> If you take six courses it’s a diploma program. If you take ten courses, at the end of the diploma program, you can transfer into the university. So it’s a back door into a university in science. Once she’s finished all the online courses on the diploma, their program is [in] a little town where they have a farm. She could do part of her degree there, then she would go back to {university name} to finish. I think that is actually maybe not do-able, but of all the things, it has some potential. (about her daughter Amanda, 23 years old, Asperger’s syndrome)

Cora’s account reflected that she placed higher value on university than on college education for her daughter, but pursued college education over high school education at a minimum. Like Evelyn, Cora’s goal was to increase her daughter’s potential for higher paid employment by maximizing her skills, knowledge and educational qualifications, even finding a ‘back door’ into
university, which reflected an implicit understanding that higher education provided more social advantages and held more value in the work force.

Susan described college vocational programs as potentially bridging the gap between high school and work for her son who was still in high school and was working towards a certificate of completion, rather than a graduation diploma. Susan explained that college vocational programs focused on work and life skills training, and offered supervised job placements, which she believed could eventually lead to paid work for Noah. Susan described these programs further:

All these programs are supposed to be geared for people with developmental disabilities. So we had applied. This woman’s son got into one and the idea was that they will get this intense sort of support. They’ll be able to find jobs. They’ll be able to decide what they want to do with their life. The one at {college name} is two years and it’s supposed to be really good and gives them a chance to try out different jobs with the idea that they can find a path they will follow more intensely. (about her son Noah, 20 years old, autism).

Susan’s account illuminated that she pursued college vocational programs for her son because they could provide job training and support and opportunities for eventual sustained employment. Her account reproduced discourses in *TPRG* about further education and work as ideal post-high school activities, which shaped her transition planning goals for her son. Although she pursued a college vocational program for her son, he was not accepted into the program because he required too much support in order to participate. Susan discussed her reaction to the college’s rejection of her son’s application:

Yeah, he will need support but I think he will need support initially. One of the things for this co-op [work placement at high school] is that for two weeks he had somebody supporting him and now he’s independent. They are pleased by how he is doing it. He is taking initiative and he’s not just waiting for someone to tell him what to do and he’s happy.

Susan’s account highlighted that even though she pursued further education for Noah, he experienced barriers to accessing college vocational programs. Specifically, Noah required too much assistance and support to participate in the college program, which implied that students needed a certain level of independence to be successful. Thus, Susan’s account revealed an implied problem of her son’s ‘dependence’ for participating in further education. On this point, Susan talked about Noah needing only short-term support to become independent. From her perspective, the implied problem was ‘inadequate supports’ in the college program for meeting
her son’s learning needs. Although Susan’s transition planning behaviours focused on preparing Noah for further education and work, which aligned with ideal goals promoted in *TPRG*, she described several barriers to achieving this goal.

These parents’ accounts reflected that they highly valued further education, and particularly higher education, for their children, which reproduced discourses about gaining skills and competencies for work reflected in the *TPRG* document. They implicitly understood that higher education created advantages (e.g., paid employment, and higher social status and income) that could position their children for socially valued roles and activities of an ideal adult citizen.

### 3.2.2 Pursuing Work Training

Several parents discussed seeking work training programs for their children, reproducing traditional goals of developing skills and competencies for work following compulsory education. These parents did not talk about pursuing higher education (e.g., university or college), likely because their children did not have the academic qualifications to apply to these programs. Their accounts did reflect, however, their valorization of work, or developing skills for work, as preferred transitions goals. In addition, their accounts reflected a preference for job-specific training or cooperative (co-op) work placements (e.g. focused on ‘employability skills’) over day programs (e.g. focused predominantly on social participation and recreation), which reflected the relative social value they placed on roles and activities associated with work, rather than those associated with social interaction and leisure. The accounts of two of the parents illustrate implicit assumptions about work training as a socially accepted activity for young adults, which shaped the parents’ goals for transition planning.

Miranda talked about her daughter having successful experiences in high school cooperative education programs, which had raised her expectations about pursuing further work training as a transitions goal. Her account suggested that her daughter had not achieved the skills and competencies needed to participate in productive or supported employment during her cooperative education work placements in high school. As promoted in *TPRG*, Miranda pursued further work training as a transitions goal. However, Miranda described a lack of work training programs for young adults with DD in her community as a ‘problem’. In response, Miranda, along with several parents in similar circumstances, pooled their own resources (e.g., skills,
knowledge, and finances) to create a community program for their children. As Miranda explained:

None of our young people had really adequate resources after high school to fulfill the vision [work training] that we had for them and that they had for themselves. So, if that had been present we wouldn’t have had to [create a program]. (about her daughter Susie, 21 years old, Down syndrome)

As Miranda’s account portrayed, she had pursued the transition goals of further education and work training that were promoted in TPRG, but found there were inadequate resources and opportunities in the community to support achievement of these goals. Thus, transition planning had shaped goals focused on work and work training for her daughter and set up expectations that these opportunities existed outside of compulsory education. Miranda had internalized beliefs about the value of work, which had shaped her pursuit of opportunities to develop her daughter’s skills and competencies for work, even though the possibility of her daughter’s eventual transition to productive or supported employment was likely not possible. Similar to Miranda, Sheila described pursuing further work training for her son as a transition goal. Like Miranda, her son had positive experiences in a cooperative work experience program in high school, which had shaped his transition goal of further work training. Sheila’s account conveyed that she had taken up expected roles and responsibilities of parents to participate in creating a transition plan, with the expectation that these responsibilities were shared with the school. However, Sheila described the school as fulfilling its obligations of creating a transition plan, but taking limited responsibility for actually implementing the plan. In response, Sheila took on responsibilities to foster a successful transition from school to further work training for her son. For example, Sheila had requested a summary report of the work skills and competencies that her son had learned during his co-op placements from the school. She wished to use this report to assist in planning for her son’s transition to work or further work training. As Sheila explained, the school responded that her request was unusual and did not follow up, prompting Sheila to follow up directly with her son’s work placement supervisors on her own:

I did call a couple of them [work placement supervisors] just to say what I was trying to do. They were happy to talk with me. One of them said, “how come the school didn’t ask me to write it down?” Since then, Joshua has been in a day program. He has about a half a year of doing nothing because I couldn’t sort out what to do. (Joshua 25 years old, Down syndrome)
Sheila’s account conveyed that she perceived the school to have failed in its responsibilities to implement her son’s transition plan and to foster a transition to further work training, even though further education and mutual responsibilities between the school, community, and families were promoted in *TPRG*.

Like Miranda, Sheila’s account revealed a sense of frustration with her transition planning experience, which had prompted extraordinary effort as a parent to foster achievement of work training as a goal for her son. In the end, her son enrolled in a day program, which Sheila described as akin to “doing nothing.” This description of the day program reflected an internalized belief about the high social value placed on working in adulthood, which had shaped her pursuit of this goal to the extent possible in order to prevent the perceived ‘problem’ of her son ‘doing nothing’. Thus, Sheila’s account reflected implicit assumptions about work or work training as ideal roles and activities in young adulthood and ‘doing nothing’ was to be prevented or avoided. These assumptions point to the taken-for-grantedness of work or ‘doing something’ as indicators of proper activities for young adults in Western industrialized societies.

4 Community Living

4.1 Document

As noted previously, a successful transition from school to ‘community living’ was cited as another main goal of transition planning in *TPRG*. What was meant by ‘community living’ was largely taken-for-granted in the document. Yet, there were several references to making transition plans in partnership with local Community Living Associations (CLAs) (associations providing programs and services for people with intellectual disabilities). These references suggested that the implied meaning of community living in *TPRG* was affiliated with CLAs’ uses of the term. As an example, the goal of Community Living Toronto (a regional CLA) is to support individuals with an intellectual disability to search “for accessible and meaningful ways to live in the community. Whether it’s living alone or with a roommate, working in a supported environment, or participating in community activities” (Community Living Toronto, n.d.). In another example, Community Living Ontario (a provincial CLA) “advocates for people who have an intellectual disability to be fully included in all aspects of community life” (Community Living Ontario, n.d., node/1723). Together, these examples suggested that people with DD have
been excluded from their communities because opportunities for living, working, and participation in community activities have been in accessible for them. Hence, social or community exclusion of people with DD was produced as a ‘problem’ in these quotes. Although the concepts of inclusion and exclusion were not explicitly expressed in TPRG, the essence of their meanings was embedded in text related to ‘community living’. Thus, an implicitly accepted binary of inclusion/exclusion, in which inclusion was socially privileged over exclusion, functioned to constitute unsuccessful transitions from school to community living for people with DD as a ‘problem’. This implicit representation of the ‘problem’ shaped the proposed solution of promoting community living as a goal in TPRG. In effect, this problem representation placed the onus of change on people with DD to develop skills and competencies that afforded inclusion in traditional roles and activities of community life, rather than questioning social values and norms about what constituted inclusive community living.

What constituted a successful transition from school to community living was not explicitly described in TPRG, but several statements indicated the ideal characteristics of community living. Presumably, the transition to community living also implies a transition from living with parents to living on one’s own. For example, in several places the term “independent community living” (p. 20), “independent living” (p. 20), and “independent living in the community” (p. 24) was used in the document. In addition, TPRG suggested that transition planning teams review students’ “independent-living choices” (p.11) and develop “daily living skills for independence” (p. 21 and 27). An implicitly understood binary of independence/dependence, which I discussed in detail in Chapter 5, operated to shape an ideal outcome of independence for community living, rather than dependence. Notions of interdependence, a key concept discussed in the BJA document of Chapter 5, were not explicitly discussed in TPRG. Rather, the document implicitly and explicitly promoted independence for participating in social, economic, and recreation activities in the community as a goal for young adults.

As noted previously, a particular set of ‘generic skills’ (e.g., daily living skills for independence, and self-advocacy, interpersonal, stress-management and decision-making skills) was promoted to prepare students for roles and activities of young adulthood. As a group, these skills suggest that community living as an adult citizen ideally involves having skills to manage daily life activities as independently as possible, that is, with as little assistance and support from others as
possible. Hence, the perceived dependence of many disabled students on others for daily living assistance and support was construed as a specific ‘problem’ to be fixed or prevented. The proposed solution of developing generic independent living skills and competencies, to the extent possible, revealed assumptions about self-reliance and individualism as preferred traits of adult citizens in Western societies.

4.2 Parents’ Accounts

Across the accounts were stories in which parents emphasized participating in community activities and programs, rather than participating in work, further education, or ‘independent community living’ (as per the TPRG document). Instead, their transitions goals focused on seeking programs that offered opportunities for social interaction and a sense of belonging. Examples of community programs and activities included social, recreation, life skills, and volunteer activities. They wanted their children to participate in community programs similar to their high school special education programs, but with same age peers, which they believed would foster a sense of social connection and belonging. For example, Linda described her son as having strong connections to a social group at school, which would make it difficult for him to transition from school to a community program with unfamiliar staff and a new peer group:

He’s not going to want to leave school. That’s where his friends are. [School], it’s everything for him. I came to the realization that ‘meaningful day’ stuff is what I would like him to have eventually, but he can’t cope with every day being a little different. So I’m going to have to look at a community support program. Looking at one with people that I already know and can trust and maybe only a couple of days and then he’ll keep doing the [name of charitable organization] thing. But at some point the money runs out. (about her son David, 19 years old, autism)

Linda’s account reflected the importance of friends and social connections in creating “a meaningful day” for her son, which reproduced notions of meaningful ways of living in the community proposed by CLAs. Thus, she valued meaningful social interactions and activities, which shaped her transitions goals for her son, particularly because work and further education programs were not available or accessible to him. Her discussion suggested that a ‘nonmeaningful day’ (as in a lack of social connections) was to be avoided. Linda’s account reflected that she had internalized social expectations for young adults to do meaningful activities, and reformulated prevailing interpretations of ‘meaningful’ activities that were
reflected in *TPRG* (traditionally work, further education, and independent living) to include social activities and ‘being with friends’. Thus, she pursued a transition to community programs that could support social interactions and a sense of belonging with peers, to the extent possible, while being mindful of the eventual financial constraints she faced.

Debbie, whose daughter Grace was still in high school, also discussed the relative importance of social connections and interactions over academics in her transition planning. Debbie explained that high school provided Grace with opportunities to interact with friends and same age peers, in addition to learning basic skills and knowledge:

> The school is kind of out here for me [because academic work is not my specific goal]. It’s a place where she can go every day socialize. She’s happy. They certainly do some basic school work, but it’s more social for her. (about her daughter Grace, 17 years old, DD)

Debbie’s account reflected the significance of socialization as a goal for Grace because traditional academic achievement was not realistic or expected. From Debbie’s perspective, engaging in basic academic work served the purpose of preparing Grace with generic skills (e.g., basic numeracy and literacy skills) for functioning in adult life, but also served to provide Grace with a sense of doing an activity that was socially expected for her age, even if the substantive focus was not typical for someone her age. Debbie suggested that a meaningful day for her daughter focused on socializing with her peers and doing activities that were expected for her age, even if they were modified or done in an alternate way. Debbie’s account reflected that she resisted discourses about productivity and independent living embedded in *TPRG*, and pursued participation in social and recreation activities—activities that were focused on enjoyment and being with others—as transition goals for her daughter. Her account conveyed that she implicitly understood that her daughter would not transition to “normal” roles and activities associated with young adulthood, such as work, further education, and independent living, which shaped her pursuit of community activities that could foster a sense of belonging for her daughter as an adult.

For the most part, parents who did not expect their children to transition from school to work or further education focused on transition to community programs that provided similar social, recreation, and life skills components as their children’s school programs. In brief, social
inclusion and participation in the community, rather than independent community living, was their main goal for transition planning.

5 Summary

In this chapter, I discussed how transition to adulthood for young disabled people was constructed as a particular kind of ‘problem’ in *TPRG* and the parents’ accounts. The focus on transition from high school to work, further education, and community living suggested the relative importance of these outcomes for young adults in post-high school life. Disabled students, identified as having challenges in achieving these outcomes compared to their nondisabled peers, were constituted as problems to be addressed in *TPRG*. The parents proposed several barriers to achieving transition goals for their children, such as a void of post-high school programs, bureaucratic processes, and inadequate training of educators, as being problematic. For the most part, their accounts reflected that they pursued these goals to the extent possible as the proper outcome of school in preparation for adulthood, rather than question them or consider alternative goals.

*TPRG* was aimed at particular goals related to work, further education, and independent community living. The idealized outcome was a student who achieves an independent and productive adulthood. However, many exceptional students are unable to achieve this particular kind of adulthood and continue to depend or rely on others, usually their families, for personal and financial assistance in their daily lives. Regardless, discourses of transition planning in schools promoted work, further education for eventual work, and independent community living as socially valued and preferred activities following high school, which shaped the aims of *TPRG* as well as the aims of the parents’ transition planning. Disabled students and their parents actively pursued idealized goals of further education, work training, and independent community living, to the extent possible, to improve opportunities for social inclusion and economic participation in adulthood within the hierarchy of socially accepted activities that was produced through transition planning discourses.
Chapter 7
Transition Planning in the Developmental Services Sector

In this chapter, I discuss how transition to adulthood is constituted as a particular kind of ‘problem’ in the Developmental Services sector of the Ontario Ministry of Community and Social Services (MCSS) and in parents’ accounts of their transitions experiences in this sector. Developmental Services refers to ministry-funded community and social programs that “support inclusion of adults with a developmental disability and their families” (Ontario MCSS, 2016).

As in the previous two chapters, I examine a key document that proposes courses of action to address the issue of transition to adulthood for young disabled people. In this chapter, I focus on a policy document that was developed specifically to address the transition to programs and services for young adults with DD in the Developmental Services sector. The document selected for analysis was the Provincial Transition Planning Framework: Transition Planning for Young People with Developmental Disabilities (hereafter PTPF), which was developed by the Ontario MCSS in partnership with the Ontario MCYS (Ontario MCSS and MCYS, 2011). First, I describe the document and examine how it constructed transition to adulthood for young people with DD as ‘problem’. Second, I briefly describe the circumstances of the parents in this study in relation to developmental services and programs and how they characterized the ‘problem’ of transitions in this sector. Third, I examine key concepts of social inclusion, and independence contained in PTPF to reveal taken-for-granted social assumptions that shape how the ‘problem’ is understood. I also examine how these assumptions were reflected in the parents’ accounts and their potential effects on young people with DD and their parents.

1 Transition Planning for Young People with DD

1.1 Description of Document

The ‘problem’ of “lack of planning and inadequate transition support” (p. 3) was identified in a 2006 provincial government review of developmental services called Transforming Supports in Ontario for People who have DD through community consultations with people with DD and their families. This review led to the creation of the provincial Services and Supports to Promote the Social Inclusion of Persons with Disabilities Act in 2008, but also the PTPF document, which was developed in 2011. PTPF focused specifically on planning for transitions from
children’s services funded by MCYS to adult developmental services funded by MCSS when young people with DD turn 18 years of age. The purpose of the PTPF document was to provide a framework for formalizing and coordinating transition planning responsibilities among MCSS, MCYS, and affiliated community entities to improve the transition to services and supports offered by regional ministry offices and community service agencies, particularly those services affiliated with Developmental Services Ontario (DSO). Later, in 2013, PTPF was proposed as the framework to provide directions for integrating transition planning across three Ontario Ministries—the MCSS, MCYS, and MEDU. The main objective of PTPF was to develop a framework for regional MCSS offices and their community and social service partners to develop protocols that fostered a “smooth transfer to adult services and a good transition experience” (p. 3) for young adults with DD and their families. The document sets expectations for young people and their families (e.g., to develop a transition plan), regional ministry offices and community service agencies (e.g., to assist young people and families to develop transition plans, to establish transparent transition planning protocols, and to coordinate transition planning with other entities), and, the ministries themselves (e.g., to provide overall policy direction and oversight).

1.2 What Is the ‘Problem’ of Transition to Adulthood Represented to Be?

The specific ‘problem’ of transition to adulthood for young people with DD was predominantly represented to be ‘lack of planning and inadequate transition support’ in PTPF, which is the same problem addressed in the BJA and TPRG documents discussed in the previous chapters. The framework was specifically developed to address this problem, much like the BJA document in rehabilitation and the TPRG document in education. The main policy directive of PTPF was explicitly stated as “supporting successful transition planning for adult developmental services” (p. 9), which suggested that unsuccessful transition planning was assumed to result in unsuccessful or inadequate transitions to adult life for this population. PTPF proposed two main courses of action to address this ‘problem’: 
• developing individual transition plans; and
• developing regional transition planning protocols across ministries, and developmental service agencies.

Developing written transition plans and transition planning protocols were emphasized as the key courses of action to solve the ‘problem’ of inadequate transition planning and support for young people with DD and their families. The explicitly stated purpose of individual transition plans was to: “Help the young person prepare for adulthood and to plan for adult services in a manner that promotes social inclusion, greater self-reliance and as independent a life as possible” (p.9). This statement suggests that the ideal outcome of transition planning is young people who become self-reliant and independent in their adult lives, and who experience social inclusion in their communities. These characteristics—social inclusion, self-reliance, and independence—were assumed to be key outcomes of successful transition planning, and therefore a successful transition to adulthood, reflecting dominant social beliefs about the characteristics of the ‘proper’ or expected aim of adult life.

By identifying the specific target population, *PTPF* specifies the ‘problem’ of unsuccessful transitions to adulthood to ‘young adults with DD’. Guided by the WPR approach, this ‘problem’ can be further questioned - what is held problematic about the transitions of young adults with DD in particular? This ‘problem’ was shaped as a particular sort of ‘problem’ by implicit understandings about social inclusion, self-reliance, and independence as socially valued traits of adulthood rather than reliance on others, dependence, and social exclusion. Thus, young adults with DD, who often rely on others (e.g., for financial support, and personal care and assistance) and are excluded from participating in typical activities of young adulthood (e.g., independent living, working), were constituted as ‘problems’ to be addressed in policy because they require ongoing services and supports from the Developmental Services Branch of MCSS beyond 18 years of age.

Later in this chapter, I examine the deep-seated social assumptions that shaped the key concepts of independence and social inclusion in *PTPF*, thereby shaping how the ‘problem’ of
unsuccessful transition planning was constituted. For now, I suggest that young people with DD were identified in *PTPF* as being at risk of failing to achieve characteristics of an ideal adulthood because they are often dependent, reliant on others, and social excluded in adulthood. Ideal outcomes of social inclusion, self-reliance, and independence in *PTPF* reflected prevailing social assumptions about what constitutes a ‘good’ or ‘proper’ adulthood. These assumptions shaped implicit understandings of the ‘problem’ of unsuccessful transition planning, and transitions to adulthood more broadly, for this population, and how it should be addressed. Before examining these assumptions further, I describe the parents’ circumstances related to developmental services and examine how parents characterized the ‘problem’ of transitions in the developmental services sector in their interview accounts.

2 Transition Planning in Developmental Services: Parents’ Perspectives

2.1 Description of Parents’ Accounts

All of the families had been linked to at least one developmental services agency, but were at different stages of their transition planning. On the whole, parents discussed many challenges in planning for post-high school programs, service, and supports for their children and as noted in Chapter 6, many parents kept their children in high school until the government-mandated age limit of 21 years old. It is important to note that many of these families’ transition planning experiences occurred in the midst of the provincial government’s review of developmental services. Thus, there were ongoing changes to government practices and processes related to transition planning, which may in part explain the significant challenges discussed by parents in accessing and transitioning their children to adult developmental services following high school.

2.2 How Do Parents Characterize the ‘Problem’?

The parents largely characterized the issue of unsuccessful transitions to adult developmental services as a ‘problem’ of unavailable and inaccessible programs and services once their children left high school, rather than a ‘problem’ of inadequate transition planning and support as identified in *PTPF*. All of the parents talked about participating in formal transition planning, however, they described challenges in finding and transitioning their children to programs and
services for adults. These challenges included long waitlists, inconvenient geographic locations, restrictive eligibility criteria, and nonexistent programs and services. For example, Daniel described being involved with DSO service providers to develop a transition plan, but found that programs and services for young adults with DD were not actually available for his daughter. Daniel stated:

There could be papers or documents that say what the [transition planning] policy is and what the programs are, but there is no money for the programs, so they don’t exist. I mean they aren’t actually there. It’s very frustrating as I’ve gotten to know the sector. Everyone is well-meaning. Nobody who is involved in the sector isn’t interested in making things better, making things work. (about his daughter Ella, 25 years old, DD)

Like Daniel, all of the parents in this study adopted the idea that formal transition planning could foster successful transitions to adult developmental services and opportunities to participate in community-based programs and activities (e.g., social and recreation activities, life skills and employment training) as young adults. However, in reality, programs and services that could support these opportunities did not actually exist in the sector, or there were several barriers to accessing them. Thus, the lack of adult developmental services and programs for this population was produced as a specific ‘problem’ in the parents’ accounts.

The parents discussed specific barriers to accessing programs and services. In particular, several parents talked about long waiting lists for community programs, and social services and supports. For example, Diane discussed her experiences of applying to residential and day programs for her daughter:

When we applied to [agency B], she was put on a waiting list for residential services and for day programs. The assessor who came did not plant any seeds of optimism at all. She basically was very realistic. She said to expect to wait 15 years at least for a group home, but since then it seems to grow. I’ve been told 20 years. Lucy was 17 when we applied. The likelihood of getting a funded spot in the day program was like winning the lottery. (about her daughter Lucy, 20 years old, autism and seizure disorder)

Diane’s quote illustrates the experiences of the majority of the families in this study; formal transition planning as promoted in PTPF had not resulted in access to programs and services upon their children’s transitions out of high school because there were long waiting lists. Diane’s account reflected that she had fulfilled her parental roles and responsibilities of transition
planning, and had expected the government to fulfill their roles and responsibilities in providing access to adult developmental services.

Daniel suggested that the ‘problem’ of transition to adulthood for his daughter was an “ill defined” process for transitioning from high school to adult developmental services and programs, as well as a general lack of government-funded programs. He stated:

My experience with the process is it’s ill defined. It’s not really a process. At 21 [years old], school is over and it’s up to the family to figure it out. The pieces that are apparently the process don’t seem terribly supportive in helping families figure out what’s next. So in going through the process to get [individual] funding, that’s about dollars. It’s not about what to use the dollars for. But [transition planning] does not necessarily entail the research to find out what programs are there. Funded spaces, there aren’t any [government] funded spaces. (about his daughter Ella, 25 years old, DD)

Daniel suggested that families were expected to “figure out what’s next,” in other words, take responsibility for finding programs and services, only to find that many programs had limited availability of spots that were subsidized by the government. Linda also suggested that changes in government funding attributed to difficulties in accessing programs and services when her son turned 18 years old and had left high school. Linda discussed the need for transition planning and support across the lifespan, However, she identified the transition from high school to young adulthood as particularly challenging:

We do need transitions [planning and support] from preschool, to school, from elementary to high school, from high school to adult life, from adult life to senior life without having to go through a whole new process. As parents, at the time when you’re most tired, everything stops. Special Services at Home [funding] gets yanked, if you’re lucky enough to get it now at 18, and schools stops. You just enter the wasteland, at the time that you need the supports most, psychologically. (about her son David, 19 years old, autism)

In this quote, Linda highlighted that transitioning out of high school was challenging for her son. Moreover, this quote shed light on the effects on Linda’s physical and mental energy.

Linda also discussed the issue of lack of “entitlements” to programs and services for young adults with DD compared to childhood. By entitlements, Linda referred to government programs that provide disability benefits, special privileges, and/or funds to citizens of a particular group, in this case, adults with DD. She proposed that entitlements had provided her son with access to
public and special education programs and services until 21 years of age and specialized funding until 18 years of age, but similar entitlements did not exist in the adult developmental services sector once her son left school. Linda’s account reflected that she perceived a significant shift in the government’s role in providing programs and services to individuals with DD once her son was no longer categorized as a child by chronological age. Thus, Linda’s account highlighted that there was a significant shift in funding during her son’s transition from childhood to adulthood, which contributed to the ‘problem’ of unavailable programs and services.

The ‘problem’ of a lack of programs and services for young adults with DD discussed by the parents carried with it an implied problem that MCYS and MOE programs and services ended at a particular chronological age (18 years and 21 years, respectively), when typically developing children are expected to move on to roles and activities associated with a ‘normal’ adulthood (e.g., employment, further education, and independent living). The parents’ accounts reflected that they implicitly understood that their children would not transition to these roles and activities. Although the specifics of how parents characterized the problem (e.g., lack of adult programs and services) differed slightly from the identified problem (e.g., inadequate transition planning and support) in *PTPF*, both reflected an implicit understanding that young adults with DD had not achieved the skills and competencies associated with a traditional transition from high school to work, further education, and independent community living as discussed in Chapter 6. Similar to *PTPF*, an underlying problem represented as ‘young adults with DD’ underpinned the explicit problem of transitioning from school to community and social services for adults. In the next sections, I explore these assumptions further by critically examining the meaning of key concepts of ‘social inclusion’, and ‘self-reliance and independence’ stated in *PTPF*.

### 3 Social Inclusion

#### 3.1 Document

Social inclusion was a key concept associated with the outcomes of transition planning in *PTPF*. It is also the key aim of the Social Inclusion Act, which served as a framework for creating the *PTPF* document with a focus on addressing the transition to adult developmental services for young people with DD. The meaning of social inclusion was not described or defined in *PTPF*,...
or in the Social Inclusion Act. Interestingly, in reviewing the Act, I found the term ‘social inclusion’ only once in its title. Although social inclusion was identified as a policy issue in this sector, its meaning was assumed, and therefore left open to interpretation.

In order to reveal the implied meanings underpinning the term ‘social inclusion’, I identified and interrogated the implicit meanings of social inclusion/social exclusion embedded in the *PTPF* document and the Social Inclusion Act to illuminate underlying assumptions. My objective was to understand how tacit assumptions about inclusion/exclusion shaped the ‘problem’ of transition and the proposed policy directions. By promoting social inclusion as a goal for young adults with DD, *PTPF* necessarily positions them as ‘excluded’ while nondisabled or ‘typically developing’ youth are presumed to be ‘included’ in idealized ‘mainstream’ ways of becoming adults. This raises several questions: What characteristics mark some groups as included while others are deemed excluded? What characteristics of young adults with DD make them ‘in need of’ inclusion? The text provides clues to these questions. For example, the document states that regional protocols should provide the young person with “opportunities to actively participate in and contribute to transition planning” (p. 6), and information and support to “develop the skills they will need to function as an adult” (p. 9). These statements suggest that young people are expected to actively (rather than passively) participate in planning and decision making and to develop a certain set of skills associated with a pre-conceived notion of adulthood.

The concept of social inclusion rests on dominant social assumptions about particular ways of being included and participating in communities in adulthood, which tend to privilege ‘normal’ adult roles and activities. Although not explicitly stated, the *PTPF* document suggests that adults are self-reliant and independent. I discuss this framing of adulthood in more depth later in this chapter, but for now, I suggest that neoliberal notions of an independent, active citizen guide understandings of who is/will be ‘included’. It follows then, that young people with DD are identified as being at risk of social exclusion because their presumed characteristics and behaviours (e.g., passive, reliant on others, dependent) do not reflect social norms and expectations for adulthood. Thus, assumptions about the necessity of approximating these norms are implicit in the goal of social inclusion that is embedded in the *PTPF* text. A hierarchical ordering is suggested where dominant groups (i.e., nondisabled young adults) are valued above less dominant groups (i.e., young adults with DD).
My analysis showed that the services and supports listed in the Social Inclusion Act, 2008, and from which PTPF draws as a guide for transition planning, suggest that particular ways of being and participating in community life are thought to promote social inclusion. In this regard, PTPF suggests that transition planning should:

Identify opportunities for progressively increasing the young person’s independence and ability to function in adult settings and for preparing parents or guardians and other family members for changes. The plan may consider and address all the areas of change including, but not limited to, income support, community inclusion, adult services, living arrangements, adult training and supportive employment or voluntary work experience. (p. 9)

Thus, independence and having particular abilities to function in adult settings are identified as characteristics of adulthood that foster social inclusion. The ‘areas of change’ (e.g., income support, community living, housing arrangements, training, and paid or unpaid work) described in this excerpt pointed to the adult settings or domains of life that young adults with DD and their families are encouraged to consider when planning for service transitions between childhood and adulthood. These domains reflected ideas about the settings in which young adults are expected to function independently. They are also associated with the services and supports that qualify for provincial government funding in the Social Inclusion Act.

The Social Inclusion Act provides a specific list of funded services and supports to which young adults with DD and their families can apply through formal government processes. These include services and supports for:

- residential and housing arrangements (e.g., living in ‘host family’ or group homes with varying degrees of support from a service agency);
- activities of daily living services and supports (e.g., making meals, getting dressed, carrying out personal hygiene, managing money, taking public transit, etc.);
- community participation activities (e.g., social, recreational, work, and volunteer activities, etc.);
- caregiver respite (e.g., rest and support for main caregivers of a person with DD);
• professional and specialized services (e.g., psychologist, social worker, speech-language pathologist, etc.); and

• person-directed planning (e.g., identify life dreams and goals, and ways to achieve them).

Virtually every domain of young adults’ lives are reflected in these services and supports, from housing arrangements to participating in activities of daily living, work, and social, recreation, volunteer activities. In a sense, by suggesting these particular activities, PTPF ‘sanctioned’ or ‘approved’ them as preferred activities for promoting social inclusion. These domains draw on taken-for-granted ideas about the roles and activities that constitute a proper adult life, which are largely shaped by notions of independence, and generally accepted ways of functioning and participating in adult settings. Although, provisions are made, at least in theory, for young adults with DD to identify their own “life dreams and goals,” particular ways of being (e.g., independent), and participating (e.g., working, participating in social, recreation, and volunteer activities, etc.) were promoted in PTPF. The domains reflect inherent social values and assumptions about autonomy, individualism, and equal access to opportunities underpinning neoliberal societies. Taken-for-granted assumptions about autonomy and individualism shaped how transition to adulthood was problematized in the PTPF policy directions which focused on promoting independence and as close to normal functioning in adult life as possible. In essence, these assumptions shaped and were shaped by understandings of social inclusion in PTPF.

To summarize, these assumptions shaped implicit understandings of who are idealized adult citizens, what is social inclusion and how it is achieved. They also shaped an implicit problem representation of young adults with DD and their ‘abnormal’ or ‘atypical’ ways of functioning and transitioning as ‘problems’ to be fixed in order to prevent or address their social exclusion. PTPF, shaped by this implicit problem representation, may have inadvertent negative effects on young people with DD who cannot achieve or approximate normative ways of being and acting. Despite positive intentions in PTPF, many young people with DD may remain marginalized in their communities because they fail to achieve social expectations for normal adult functioning, thus, they fail to meet tacit criteria for social inclusion. In effect, the aims of PTPF may inadvertently perpetuate the social exclusion of young adults with DD.
3.2 Parents’ Accounts

In the interview accounts, the parents largely reproduced discourses in *PTPF* about fostering young adults’ social inclusion through transition planning. For the most part, the parents discussed developing transition plans with, or on behalf of, their children as suggested in the policy. In addition, they described pursuing services and supports in the adult developmental services sector that were ‘approved’ by the government in the Social Inclusion Act. Harriet described her experiences of creating a life plan:

> Somebody at [developmental service agency] facilitated that because it was very clear with the larger sector [Developmental Services Branch of MCSS] image of funding going to more individuals than to agencies. So we weren’t gonna do anything without a life plan. That’s the very first price of entry. So in June we did that, you know, started to explore possibilities because we had no idea what she was going to do in September. (about her daughter Molly, 27 years old, global DD)

Harriet’s account demonstrated that she participated in transition planning because it was required (e.g., ‘price of entry’) in order to receive government funds to support her daughter’s participation in community programs and services associated with the adult developmental services sector. Otherwise, there were limited options for programs and services that provided opportunities for social inclusion once her daughter left high school. In other words, Harriet’s account produced an implicit understanding that her daughter was at risk of social exclusion in adulthood once she left the public education system. Harriet’s account reflected that discourses of social inclusion embedded in *PTPF* played a significant role in shaping her behaviours to comply with transition planning requirements and to minimize the potential risk of social exclusion in adulthood.

Discourses of social inclusion in *PTPF* shaped parenting practices in ways that largely involved pursuing the types of services and supports that were funded by the Social Inclusion Act. As described previously, these services and supports included residential, activities of daily living, community participation and caregiver respite services and supports. The parents discussed various ways they created and fostered social participation and inclusion, to the extent possible, for their children by pursuing and accessing government-funded services and supports. Several parents described creating and arranging as close to a full-time program (e.g., the equivalent hours of full-time school programs) as possible by pursuing programs and services for adults
with DD, which reflected the ‘approved’ activities in *PTPF*. However, most programs were part-time, thus, parents often enrolled their children in several part-time programs to create a full-time program. The parents took on responsibilities for managing and maintaining the applications to these programs, for seeking funding, and for arranging transportation to and from these programs. For example, Harriet’s account reflected the extraordinary work and coordination she did to create a program for her daughter. She described creating a day program in collaboration with several other parents that provided opportunities for life skills training (e.g., cooking, participating in community settings) and supported work training because they could not find a pre-existing day program in their community. Harriet described her daughter’s schedule of activities:

So Tuesday, Wednesday, and Thursdays [the life skills program] runs from 11 to 2. Her job coach comes gets her, and they walk over to a little workshop and café where Molly helps. It’s a little workshop for kids and their nannies and all the caregivers. (about her daughter Molly, 27 years old, global DD).

Harriet created a program that reflected ‘approved’ activities in *PTPF* related to activities of daily living, and community participation (i.e., work activities).

Similar to Harriet, Miranda described creating a program of several part-time activities for her daughter:

She goes to [community program 1] two days a week and then she goes to [community program 2] three days a week. These are other things that she’s been involved with: Dancing she does through [community program 1]. She did a volunteer working placement, which has since ended. She used to volunteer at the [retail shop] through [community program 2] and that’s ended. So, three kind of work-related programs. They were all volunteer, of course, but have all ended which is kind of unfortunate. (about her daughter Susie, 21 years old, Down syndrome).

Miranda’s quote reflected that she predominantly pursued a variety of activities, but particularly valued work activities for her daughter. These accounts illustrated how the parents, on the whole, reproduced ideas of fostering social inclusion, or a sense of belonging, by pursuing ‘approved’ activities in the Social Inclusion Act, and therefore *PTPF*. 
Linda discussed creating a ‘meaningful day’ for her son by ‘cobbling together’ a number of programs and activities, which reproduced assumptions about ‘doing’ particular activities to promote social inclusion. When asked how she envisioned her son’s adult life, Linda explained:

I mean what we want would be for him to be have, they call, you know, a meaningful day. A lot of friends they talk. They cobble together something - volunteer work and community. So we would like him to have that. Semi-independent living. He’d need to live with someone partly because he likes to have people around. (about her son David, 19 years old, autism)

Linda’s quotation reflected that she took up many of the discourses in PTPF associated with fostering social inclusion, such as pursuing volunteer work, community living, and semi-independent living, for her son. These discourses mirrored the idea of being involved in ‘meaningful occupations’ to produce ‘active citizens’, which I discussed in Chapter 5. Thus, ‘doing’ particular activities, largely aligned with social expectations for participating in ‘normal’ adult roles and activities, were considered important for fostering social inclusion and active citizenship. Linda’s account, however, reflected that many parents had to ‘do’ extraordinary work to piece together a daily program to achieve social inclusion for her son. In effect, the concept of social inclusion functioned to shape the parents’ conduct in producing as close to an ideal, ‘socially included’ adult as possible.

The parents’ accounts reflected that they reproduced discourses about social inclusion in PTPF and underlying assumptions about fostering a sense of belonging by participating in particular activities and ways of ‘doing’ social inclusion. The parents ‘cobbled together’ what they could from various programs and services to produce as close to an ideal adulthood as possible. For example, they pursued work and life skills training, volunteer work, and social and recreation activities to create a sense of belonging for their children by ‘doing’ activities that reflected typical roles and activities or at least working towards typical roles and activities of adulthood (e.g., work and life skills training). Their accounts reflected that they valorized opportunities for their children to participate in a variety of roles and activities in their communities, which reflected the idea that ‘doing’ activities, particularly as close to ‘normal’ activities as possible, created a sense of belonging in their children. The parents’ accounts reflected that they had internalized implicit understandings of what constitutes social inclusion in adulthood. These implicit understandings shaped the parents’ actions and decisions for pursuing participation in
particular programs and activities to produce an adult that resembles as close to an ideal adult citizen as possible.

4 Independence

4.1 Document

‘Self-reliance’ and ‘independence’ are identified as key aims of transition plans for individuals in *PTPF*. Their meanings are defined, defined, or differentiated; rather, their meanings are taken-for-granted. There are few references to these terms throughout the document and they are used interchangeably. For this reason, I have chosen to focus on the concept of independence in this analysis because it is more commonly used in the transition literature. By identifying the goal of “as independent a life as possible” (p. 9), *PTPF* highlights the relative importance of independence as an indicator of successful transition planning. The notion of independence reflects a trait that is socially valued in adulthood in advanced liberal democracies. In the sections that follow, I discuss the assumptions underpinning the key concept of independence, and how it constitutes transition to adulthood as a particular sort of ‘problem’.

Independence suggests ideas about relying on oneself and managing one’s own life without assistance. In *PTPF*, the focus on independence reflects the social value it is ascribed as a trait of adulthood, implying that depending on others is a less desirable trait. A binary of independence/dependence shaped implicit understandings of the ‘problem’ in *PTPF*. Independence is promoted as an ideal end of transition planning, suggesting that this trait is associated with a ‘good’ adulthood, rather than dependence on others. *PTPF* also suggests that transition planning should increase opportunities for “young people’s independence and ability to function in adult settings” (p. 9). Hence, independence was also linked to expectations for particular abilities and ways of functioning in adult settings. As discussed in the previous section, these abilities and ways of functioning were shaped by social expectations for young adults to participate in ‘normal’ roles and activities in adult settings to the extent possible. Thus, young adults who can function independently in their daily lives and can participate in community activities without the assistance and support of others are implicitly understood to achieve social inclusion. In essence, dependence was produced as a trait to be prevented, avoided, or minimized. This implicit understanding construed young adults with DD, as the targeted group
of *PTPF*, as problematic because they tend to depend on others for personal and financial support into adult life. They are considered at risk of not developing the socially valued traits of independence that is thought to promote opportunities for a successful transition to adulthood and social inclusion in Western societies. *PTPF* directed attention to increasing the skills of young people with DD to take care of themselves and their personal affairs, and to make decisions and provide for themselves to the extent possible. Discourses about independence in *PTPF* suggest that young adults who can manage their own daily lives, without external support from family members or social services, are socially preferred citizens.

### 4.2 Parents’ Accounts

In this study, the parents’ accounts reflected that they took up discourses of self-reliance and independence to the extent possible as goals in planning for and envisioning their children’s adult lives. However, they faced challenges achieving these goals because their children continued to depend on them or other caregivers to manage and conduct their daily lives. Their children’s reliance and dependence varied across types of daily life activities (e.g., personal care, home and money management, and decision making) and to various extents (e.g., from full assistance and supervision to minimal support and guidance). For example, Diane’s daughter depended on her for full personal care assistance, including dressing, showering, and changing diapers, because her daughter was unable to do these activities on her own. In contrast, Harriet described her daughter as “quite independent” for personal care but requiring a personal support worker to assist her in paying attention to tasks during work placements or volunteer work. Evelyn’s daughter managed her own personal care but depended on her mother to manage her finances and to provide support for making broader work and life decisions. Regardless of the extent of assistance and support provided by the parents, their accounts reflected that they pursued independence to the extent possible in their children’s adult lives.

Several parents discussed pursuing opportunities to develop their children’s independent living skills, either through formal programs or informally at home with a family member or personal support worker. Miranda discussed continuing to develop her daughter’s independence for daily life tasks at home and in the community (e.g., cooking, getting up at the right time in the
morning, taking public transportation, etc.) in advance of exploring possible housing options outside of the family home:

I’d really like to build more independence in her before we embark on that journey. I think we’ve got to start expecting her to do more of her stuff here in a familiar environment before we can ever expect her to do that in a new place. So just starting to build more of those little, little things that have to be done every day. (about her daughter Susie, 21 years old, Down syndrome)

Miranda’s comments reflected that she valued and pursued independent living skills as a goal for her daughter, even though her daughter had not achieved these skills while she was enrolled in a high school. Miranda’s account also reflected that she had internalized social expectations of her responsibility as a parent to continue fostering her daughter’s independence upon finishing high school and evaluated her own conduct in this regard.

Similar to Miranda, Linda discussed different opportunities to foster her son’s independence, but also the challenges she experienced in adopting practices to support his independence. For example, she talked about seeking formal programs for her son that could teach him skills for independent living by gradually decreasing support and assistance, but was unable to find a program in which he was eligible to enrol. She also talked about ways that she could foster more independence by teaching her son to take public transit rather than driving him to his programs. Like Miranda, Linda assumed her role as a parent in fostering opportunities to develop independence, however, she also described the challenges in fulfilling this role. For example, she described herself as being ‘overprotective’ of her son. His seizure disorder was not consistently under control for most of his childhood and she suggested she had missed opportunities for developing independence from his family:

We should have been more vigilant when he was younger and one of the day camps he went up to you could stay overnight one night. And we just didn’t do it, so that ship has sailed. But you can’t know what his capabilities are when you’re [with him] within the house. Although we do try to keep him responsible, we are always there to overprotect him so it’s hard to know [what he can do on his own]. (about her son David, 19 years old, autism)

Linda's account highlighted that she inherently valued independence for her son, but her concern about his health and safety meant that she was tentative to foster opportunities away from the family. She suggested that parents need “training on how to build independence and how to get
past the fears.” Linda also discussed the practical challenges of having time to foster David’s progression and to take him to programs. Although Linda valued the idea of her son living an independent life in the community or working towards this as a goal, the time and effort to provide him with training at home or to take him to a formal program posed a practical problem because both she and her husband worked full-time.

The parents’ accounts suggested that they had internalized social assumptions about independence and self-reliance leading to a successful transition to adult life. Their parenting practices focused on decreasing dependence on others to the extent possible. However, for the most part, the parents recognized that their children would not achieve an idealized standard of independence; that is, independence constructed as the ability to take responsibility for personal care, home, community living and money management without the assistance of others. As a result, several parents reformulated the idea of independence in creative ways. For example, Jane recognized that her daughter would always need relationships with people to help her to make decisions. She described these relationships as “co-dependent” relationships, as illustrated in this quote:

I think she’s always going to need people to help her make some decisions and to support her in a lot of areas. I am hoping that she is going to learn quite a few of these [areas] by moving out and gains some independence. I hope that she will gain more close relationships. It’s kind of ironic, but for Joy to become more independent as she gets older, she is also going to have to become more co-dependent with other people. She seems like a teenager to me. (about her daughter Joy, 24 years old, Down syndrome)

Jane’s quotation reflected that she both strived to increase her daughter’s independence and to establish relationships with others who could support her daughter throughout her adult life, because she recognized that the circumstances would inevitably change in the future (e.g., Jane is unable to fulfill these responsibilities for illness or age-related reasons or she passes away). Achieving an ideal independence was not possible, thus, dependence became a practical ‘problem’ should their life circumstances change. In response, Jane reformulated traditional notions of independence and pursued ‘co-dependent’ relationships as the aim of her daughter’s adulthood.

Daniel also reformulated traditional notions of independence in discussing how he envisioned his daughter’s adult life:
What we envision is a supported life independent of us [emphasis added]. We’d still be part of it. It could be, it would be nice to be very close by for the convenience factor. It’s Ella’s community. She knows it, she knows the different parts of the neighbourhood and everything. It’s where she’s grown up. It’s where she’s always lived. (about his daughter Ella, 25 years old, DD)

This quotation illustrates that Daniel recognized that Ella would not achieve independence in the traditional sense of managing and conducting her daily life activities on her own but could manage with supports to live apart from her parents. Like Jane, Daniel discussed the need to plan for other people (e.g., family members, paid caregivers) to provide his daughter with care and support. These parents envisioned being involved in their children’s adult lives, ideally in their local communities, but did not envision being the main providers of daily care and support. On one hand, this solution to the ‘problem’ of dependency was shaped by practical concerns about the future, such as parents aging, passing away, or becoming ill and no longer available or capable of providing their children with care and support. On the other hand, parenting practices that fostered a “life independent of us” and ‘co-dependent’ relationships reproduced typical social trajectories in which children eventually move out of the family home, and parents becoming less involved in their lives. In many ways, the parents’ accounts reflected that they had internalized social beliefs about fostering self-reliance and independence in their children as the proper focus of parenting and they reproduced these ideas in their parenting practices (e.g., pursuing informal or formal opportunities to train for independence) to the extent possible. However, they also resisted prevailing understandings of independence through their pursuit of achievable goals of independence as ‘co-dependence’ or ‘independent of us’.

PTPF and the parents’ accounts reflected that an idealized adulthood was constructed based on prevailing notions of self-reliance and independence in Western industrialized societies, such that parents internalized and accepted these notions as the proper aims of transition planning. Thus, parents’ practices involved fostering these characteristics in their children, to the extent possible, even if they recognized that their children would not achieve the idealized standard. They worked to achieve this standard as closely as possible by seeking formal or informal independence training, but also by reformulating independence to encompass interdependence and reliance on others. However, across PTPF and the parents’ accounts, it was implicitly understood that ‘dependence’ and ‘reliance on others’ were traits to be avoided to the extent
possible in adulthood. The parents’ accounts reflected that they encouraged their children to
develop independence skills through formal programs or informally at home. Achieving
independence served several purposes from the parents’ perspectives: It provided their children
with more opportunities to participate in socially preferred activities (e.g. volunteer or paid
work), provided an indicator of being able to live and make decisions without the support of
parents (aligning with social norms for their life stages), and provided parents with assurance
that their children could live safely as an adult.

5 Summary

In this chapter, I discussed how transition planning and transition to adulthood was constructed
as a problem in the Developmental Services sector in Ontario. *PTPF* addressed the explicit
problem of ‘inadequate transition planning and support’ of MCSS and its regional offices, and
community and social service partners. In addition, *PTPF* aimed to address the lack of
coordination of responsibilities among these entities. Transition planning, with goals focused on
social inclusion and independence, was proposed as a solution to the ‘problem’, which implied
that social exclusion and dependence on others were problems for young adults with DD.
Normative assumptions about the traits (e.g., independent), and roles and activities (working,
participating in social, recreation and volunteer activities) that afforded social inclusion in
adulthood, shaped an implicit problem representation of young adults with DD and their
dependence on others for assistance and support in daily life activities. This implicit problem
representation shaped how the ‘problem’ of unsuccessful transitions from high school to adult
developmental services was framed in *PTPF* and the parents’ accounts. The parents’ accounts
also reflected that they both reproduced and resisted discourses of social inclusion and
independence. For example, the parents generally took up discourses of independence by
pursuing programs and services that could assist their children in developing this trait, but
encountered several barriers to accessing these programs and services. They also resisted these
discourses by reframing their children’s dependence as ‘interdependence’, similar to the
rehabilitation document discussed in Chapter 5, or ‘co-dependency’. On the whole, these key
discourses shaped parenting practices and conduct, particularly in relation to maintaining the
parents’ responsibilities for providing care and support and for creating programs, or activities,
for their children into adulthood. However, these discourses had consequences for the parents’
lives. In particular, responsibilities for providing care and support for their children were in addition to their other responsibilities, such as work. There were also implications for the future when the parents anticipated being unable or unavailable to continue fulfilling these responsibilities, but had no clear plan for who would fulfill them.
Afterword to the Findings

In the three preceding chapters, I examined how transition to adulthood for young disabled people was constructed as a particular sort of ‘problem’ in the rehabilitation, education, and developmental service sectors in Ontario. Across the documents and parents’ accounts, an explicit ‘problem’ of unsuccessful service transitions from childhood to adulthood was identified. The specific causes of this ‘problem’ and how to address them varied across the documents and parents’ accounts. For example, the BJA document focused on unsupportive environments, and the TPRG and PTPF document focused on inadequate transition planning. Parents discussed a void of programs and services for young adults with DD and inefficient bureaucratic processes as barriers to transition. On the whole, the recommendations produced an implicit problem representation of the ‘disabled child’ and their inadequate progression to socially valued roles and activities compared to ‘normal’ children. The parents of children with DD who participated in this study for the most part reproduced this implicit problem representation in their accounts.

Taken as a whole, transition policies constituted the ‘disabled child’ and his or her progression to adulthood as an object of interest for normalization and intervention. The implied problem represented as the ‘disabled child’ shaped a continuum of policies and recommendations across the sectors, which aimed to address the ‘problem’ of disability and development over the life course from childhood to adulthood. In the rehabilitation sector, it was disabled children and their risk of abnormal development and inactive citizenship that were implicitly represented as problematic. In education, it was disabled students and their risk of inadequate academic progression from school to work, further education, and independent community living roles and activities associated with a normal adulthood that were held problematic. In the developmental services sector, young adults with DD and their risk of dependence and social exclusion from participating in social, economic, and political activities of community life were implied as ‘problems’. This continuum of policies was shaped by an implicitly understood ‘problem’ of disabled children whose life course trajectories differed from the ‘normal’ trajectories of their nondisabled peers.
Taken-for-granted assumptions about normality underpinned the documents and parents’ accounts, which shaped implicit understandings of abnormal bodies, abnormal development, and abnormal progressions to roles and activities of adulthood as ‘problems’ to be addressed and ‘fixed’. As I discussed in Chapter 3, disability was produced as an object of thought or particular ‘problem’ in relation to notions of normality. Thus, assumptions about normal ways of being, developing, and acting as an adult citizen shaped the ideal aims of transitions policies and parenting practices focused on young disabled people and their progression to adulthood. Collectively, the policies suggested that ideal outcome of transition planning is a normal progression to particular socially valued roles and activities of adulthood (e.g., work, independent community living, active involvement in community activities). In addition, several implied binaries shaped ideas about the characteristics of a ‘proper’ adulthood that are associated with the prevailing neoliberal values in Western industrialized societies. For example, implicitly understood binaries of independence/dependence underpinned all of the documents, as well as binaries of active/inactive citizens and meaningful/nonmeaningful activities in the rehabilitation document and inclusion/exclusion in the developmental services document. These binaries functioned to constitute the traits and roles of the idealized neoliberal citizen. That is, a citizen who is independent, active, and participates in meaningful activities (e.g., social, economic, and political activities) is socially valued and preferred compared to citizens who do not demonstrate these traits and roles. The notion of an idealized adult citizen operated to shape the aims of policies and the conduct of parents of young people with DD in pursuing these aims.

The implicit problem representation of young disabled people and their inadequate progression to normal adult roles and activities produced a number of effects on parents. For example, the parents had taken up the idea of transition planning to solve this ‘problem’, assuming it was a mutual obligation proposed by and shared with the schools and developmental service agencies. Their accounts reflected that they had internalized expectations about their obligations and responsibilities to foster as close to a normal progression to an independent and active adult citizen as possible. Nevertheless, most of the parents recognized that their children would not achieve idealized outcomes, such as paid employment and independent living, thus, they pursued the ‘next best’ outcomes, such as participation in meaningful activities and social inclusion. However, these parents expressed disappointment and frustration that the schools and
developmental service agencies had not fulfilled their obligations and responsibilities for implementing transition plans and assisting families in achieving their transitions goals. Moreover, these parents took on extraordinary work and responsibilities to create opportunities for social inclusion and meaningful activities, which was no longer provided by schools. Thus, the implicit problem representation of their disabled children as ‘problems’ to be addressed had implications for the parents’ ongoing responsibilities for providing care and support to their disabled children into adult life, even though they would eventually be unable to provide this care and support in the future due to their own aging.

In Chapter 8 I further discuss the implications of these findings for young adults with DD and their parents, but also the implications for transition policy, practice, and research.
Chapter 8
Discussion

The purpose of my research was to understand how transition to adulthood for young disabled people is problematized in Ontario policies and by parents of children with DD. To achieve this purpose, I identified and unpacked taken-for-granted assumptions about disability, development and adulthood in policy-relevant documents and in parents’ interview accounts of their transition experiences. In addition, I examined how these implicit assumptions shaped proposed courses of action and parenting practices, and what effects they had on the lives of young people with DD and their parents.

In this chapter, I begin by discussing my key findings and their linkages to critical scholarship relevant to disabled children. I then discuss the limitations and future directions of my research, the rigour of my study, and the implications of my findings for rethinking how young disabled people’s transitions to adulthood are conceptualized in policy. In particular, I discuss rethinking an emphasis on normality and on individual life course trajectories. In the remainder of the chapter, I discuss the theoretical and methodological contributions of my research to understanding transition and disability. I conclude with a critical reflection.

1 Summary of Findings: The ‘Problem’ of the Disabled Child

Through this research, I found that taken-for-granted assumptions about normal ways of being, becoming, and acting as an adult citizen in Western societies, such as Ontario, functioned to shape implicit understandings of the ‘disabled child’ as an object of interest for intervention in policies across the rehabilitation, education, and developmental services sectors. These assumptions were reproduced in parents’ accounts of transitioning their children with DD to adult services and to adult life more broadly, and shaped their parenting behaviours towards fostering as close to a normal social and developmental trajectory as possible for their children. Policies shaped by problematizations of the ‘disabled child’ had both beneficial and harmful consequences for young people with DD and their parents.
Prevailing notions of a normal social and developmental trajectory shaped how the ‘problem’ of the ‘disabled child’ was conceptualized and addressed in the transition policies and the parents’ accounts. As social categories, both ‘childhood’ and ‘disability’ are constructed in relation to idealized notions of adulthood - an adulthood characterized by prevailing values of independence, productivity, and active citizenship in Western industrialized societies. In these societies, adult citizens who demonstrate these characteristics are socially valued and privileged compared to disabled children who are implicitly understood to be dependent on others for personal support and financial assistance, and unable to participate in the work force. Ideally, children in this study were expected to achieve a progressive series of skills and competencies towards goals of living independently in the community, further education or training, or participation in paid work upon leaving both school and children’s rehabilitation services between 18 and 21 years of age. If these skills and competencies were not achieved, then the young people with DD and their parents were directed to adult developmental services in Ontario.

On the surface, transition policy in adult developmental services appeared to emphasize fostering social participation and inclusion in a variety of roles and activities in adulthood. Markers of socially preferred traits of adulthood included independence, and participation in normal social roles and activities. However, my findings illuminated that these idealized markers continued to be valorized and socially preferred in adult developmental services. Disabled children were configured in policy as un-adults or adults-in-the-making. Essentially, normative ideas about development and adult functioning, enacted in transition policy, operated to exclude young people with DD from participating in mainstream adult roles and activities, perpetuating their marginalized status in society. The parents’ accounts for the most part indicated that parents took up these normative ideas, pursuing roles and activities typically associated with participation and inclusion in adulthood to the extent possible.

Problematisations of the ‘disabled child’ shaped how the parents in this study conducted and thought about themselves and their children. The parents’ accounts reflected that they were exposed to a range of normative discourses about disability, functioning and development over a trajectory of services from childhood to adulthood, which shaped their conduct in particular ways that promoted as close to a normal progression as possible of their children. In general, the
service trajectory began with a focus on health and rehabilitation services in the infant and early childhood years, shifted to focus on special education services in the school-aged years, and then shifted to a focus on community and social services and supports for adults with DD. The parents discussed being involved in a myriad of assessments and interventions focused on addressing their children’s impairments and developmental deficits. Through this involvement with multiple services, parents of ‘exceptional’ children (as described in education policy) became ‘exceptional’ parents—they were expected to take on extraordinary work to foster their children’s progression to an independent adulthood or make alternative arrangements for children who failed to achieve this end. Yet, as these parents took on extended responsibilities beyond those expected of parents of nondisabled children, their access to government-funded services and supports diminished once their children left high school. This while their own personal and financial resources were being stretched and even depleted as they aged themselves.

On the whole, the parents in this study expressed frustration about the lack of access to disability programs, supports, and entitlements once their children left high school, suggesting that the ‘problem’ was one of inadequate service transitions and accessibility. However, their accounts reflected an implied problem; their children had failed to achieve socially valued traits and characteristics of an independent, productive adult citizen by the time they had reached the chronological age that made them ineligible for childhood services. The policies assumed that parents would continue to provide care and support for their adult children with DD, which parents took up without question and continued to engage in planning for their children’s lives in the present and in the future.

Normative assumptions about bodies, development and adult roles and activities, enacted in the policies, can have both beneficial and deleterious effects on the lives and circumstances of young people with DD and their parents. For example, transitions policies shaped by these assumptions informed goals geared towards skills and competencies for working and living as independently as possible in the community, which parents implicitly understood that if achieved could foster social inclusion and participation in mainstream society. However, normative assumptions had harmful effects on parents whose children faced challenges in achieving these skills and competencies. For example, the parents’ accounts reflected that social expectations to promote as close to a normal progression as possible to a ‘proper’ adulthood for their children, which
involved significant planning and pursuit of the limited services and interventions available once their children left high school. The parents’ accounts reflected the negative consequences (e.g., feeling fatigued, burdened, or anxious about the future) of continuing to pursue as close to a normal life as possible for their children. The policies assumed that parents would do this extraordinary work without question as part of being a responsible or ‘good’ parent. Yet, the policies did not account for the extraordinary effort and energy expended by parents or for the impact on parents’ own life trajectories. Rather, they neglected to account for the needs of parents who deferred their own goals of employment, social participation, leisure activities, and future retirement.

In what follows, I discuss how my findings relate to critical scholarship on disabled children and their transitions to adulthood.

2 Producing Future Citizens: Locating the Findings in Critical Scholarship

My findings revealed that ideas of normal bodies and normal ways of becoming and being an adult were central to producing the ‘disabled child’ as a ‘problem’ or object of interest for policy, which resonated with critical scholarship on childhood disability. In particular, the implied problem constituted as the ‘disabled child’ aligns with work by Goodley and Runswick-Cole (2011) that examined “the kinds of ‘child’ configured, assumed and addressed in policies in England around disabled children” (p. 74). They suggest that the ‘disabled child’ is constructed in particular ways based on traditional notions of childhood, which may unintentionally position disabled children on the margins of society (e.g., exclusion from education and care, living in poverty). In addition, they suggested that both ‘children’ and ‘disability’ are constructed as social categories in relation to adulthood, with the latter largely shaped by neoliberal notions of citizenship. My critical examination of transition policy suggests similar constructions of disabled children. Although English policies appeared to focus on changing social and physical barriers to inclusion and participation of disabled children in mainstream society they tended to “locate the deficit within the child” (Goodley & Runswick-Cole, 2011, p. 76). Similar to my study, the authors suggested that disabled children continue to be measured and compared to ‘normal’ children to identify ‘deficits’ and to assess their potential as future citizens. I agree with
these authors that valuing disabled children in their own right rather than comparing them to normal children is a potential way forward in rethinking of the ‘disabled child’ in policies.

Prevailing assumptions of normal development embedded in transition policies and the parents’ accounts shaped understandings of the disabled child as undeveloped or incomplete. Critical scholarship suggests that dominant discourses of a normal progression from childhood to adulthood function to privilege and normalize particular world views about ‘proper’ child development (Burman, 1995; Gibson, Teachman, & Hamdani, 2015; Riggs, 2006; Walkerdine, 1993). In examining discursive constructions of the ‘developing child’, Walkerdine (1993) and Burman (1995, 2008) referred to ‘developmentalism’ as the particular logic that shapes dominant understandings of childhood, in which children are presumed to follow a relatively proscribed pathway to reach adulthood. They argue that developmental logic presumes there are key truths that we can know about children, growth, maturation, and change over the lifespan and suggest that traditional scholarship on normal development neglects to acknowledge that these truths presuppose particular understandings of ‘childhood’ and ‘adulthood’ as social categories. These social categories are arranged in an implicitly understood hierarchy of social value and status, in which adults are positioned as the dominant group. The characteristics of this dominant group shape constructions of the idealized adult citizen, to which all other groups (e.g., children) are compared and expected to aspire.

Disabled children are represented as ‘un-adults’ in need of social investment and intervention in transition discourses. In Western societies, an adult citizen characterized by financial and residential independence, and participation in paid employment is constructed as an idealized outcome of child development (Gibson, Teachman, & Hamdani, 2015). A social hierarchy is produced that construes children as ‘adults-in-the-making’ (Burman, 2008; Walkerdine, 1993) or ‘nonadults’ (Priestley, 2003). Following Priestley (2003) and Tisdall (2001), my research suggests that many young people with DD remain as ‘adults-in-the-making’ because they experience challenges in achieving the roles and activities associated with an independent and productive adulthood, potentially never achieving them at all. Discourses about normal development and adulthood underpinning transitions policies may inadvertently perpetuate the marginalized status of young people with DD who cannot achieve valorized adult roles and activities.
Developmental logic has significant implications for children with DD because their progressions to adulthood are measured and compared to normative standards based on the progressions of nondisabled children. My research demonstrated how dominant notions of normal bodies and development underpin understandings of the ‘disabled child’ as problematic, which direct children with DD to a trajectory of services and interventions that may unintentionally perpetuate their marginalized status as ‘adults-in-the-making’ and exclude them from accessing roles and activities associated with a normal adulthood in mainstream society. Along these lines, McLaughlin and Coleman-Fountain (2014) found that the bodies of disabled children were compared to normal bodies, often from birth or near birth, which triggered a series of ongoing medical and social interventions to correct bodily differences, to foster as close to a normal progression as possible, and to maximize their future potential as self-reliant adults to the extent possible. They suggested that the disabled bodies of the young people in their study became “objects of ongoing intervention” (p. 83) in the same way that my research demonstrated how children with DD are constructed as ‘problems in transition’.

In my doctoral research I found that parents pursued normal roles and activities to the extent possible as transition goals for their children with DD, despite the possibility that their children might never achieve them or that other goals might be healthier or better suited. This resonates with other research involving young men with Duchenne muscular dystrophy (DMD) that found normative assumptions about adulthood had shaped their conduct towards achieving particular roles and activities, which had potentially harmful effects on their health and well-being. In the study, in which I was involved as a graduate student trainee, Gibson, Mistry, et al. (2014) found that young men with DMD had internalized social expectations for pursuing normal adult roles and activities (e.g., independent living and paid employment) as transition goals. In an analysis related to this research, I found that generally accepted best practices for health care transitions were underpinned by discourses of normal social and developmental trajectories, which young men with DMD reproduced in their accounts of their transitions experiences (Hamdani, Mistry, et al., 2015). Their accounts reflected that they pursued goals of normal adult roles and activities to the extent possible despite progressive impairments, and social and environmental barriers that made it challenging to do so. Moreover, they did not question the relevance of these goals for their life circumstances and did not indicate that they had been exposed to ideas for other ways
of living that might be more feasible, manageable or even healthier for them. Together, these studies illuminate that transition policies and practices are underpinned by dominant understandings about the kind of adulthood that is socially valued adulthood in Western societies, which can have unintended deleterious effects on some young disabled people who cannot achieve this particular kind of adulthood.

Developmental discourses embedded in transitions policies and the parents’ accounts operated to shape the conduct of parents in particular ways aligned with normative standards for ‘good’ and ‘responsible’ parents. In a similar vein, Riggs (2006) found that developmental discourses underpinning foster care policy in Australia functioned to shape normative assumptions about ‘proper’ parenting, which set expectations for gay and lesbian parents to conduct themselves like heterosexual parents. Although Riggs’ study did not specifically focus on parenting disabled children, his findings about the powerful effects of developmental discourses on parenting behaviours are consistent with my findings. In both studies, parents’ accounts reflected that they had internalized expectations to take up parenting responsibilities and practices geared towards fostering as close to a normal progression from childhood to adulthood as possible in order to illustrate that they were ‘good’ parents. However, my findings suggest that normative assumptions about ‘proper’ parenting also shaped implicit expectations for parents of children with DD to remain responsible until this progression was successfully achieved, although in a context of diminishing services and supports for families and young people themselves. Dominant discourses of normal development perpetuated expectations of ‘good’ parents to remain responsible for their children’s life course progression, or make alternative arrangements for their lives.

The parents in my study took on extraordinary roles and work (e.g., seeking and applying to programs and services, managing daily routines and schedules, etc.) to plan their children’s transition to adult services, particularly when access to public school ended at 21 years of age. Yet, the effect of this extraordinary work on parents was often unrecognized or neglected in transition policies. This finding is consistent with Pascall and Hendey’s (2004) study about the politics of parenting disabled children during their transition to adulthood. Their findings highlight the key role of ‘exceptional’ parents in supporting the transition to adulthood for their children with physical disabilities when responsibilities were extended compared to parents of
nondisabled children and services mandated for children came to an end. The young people in Pascall and Hendey’s study set traditional goals of independent living and employment with their parents. Although some parents in my study focused on traditional goals for their children with DD, these goals were not realistic for all families. Instead, many parents focused on goals of social participation and inclusion in the local community. Interestingly, Pascall and Hendy (2004) noted that ‘adulthood’ and ‘independence’ were problematic concepts because their meanings were open to interpretation in policies and by the study participants. On this note, my study contributes knowledge about the normative assumptions underpinning key concepts (e.g., disability, adulthood) in transitions policies. Although these concepts can be understood in multiple ways, particular meanings tend to dominate and shape how transition to adulthood is constructed as a problem and what is proposed to address it.

At first glance, it would appear that my findings are at odds with the primary literature on transition to adulthood for young disabled people in which the ‘problem’ is largely taken-for-granted as a service transition issue. My research was guided by a critical paradigm that aimed to question the problem of transition to adulthood rather than solve the problem. The dominant literature tends to focus on the latter and largely draws on a positivist paradigm. However, I propose that my findings about normative assumptions about disability, development and adulthood underpinning problematizations of transition contributes to understanding the macro-level influences (e.g., sociopolitical influences that shape power relations between dominant and nondominant groups) on transitioning to adulthood. In this regard, my findings fill a gap in knowledge about macro-level influences on the transition to adulthood, such as ideology and structural organization of social institutions, which has been identified as missing in the literature (Wang et al., 2010).

3 Limitations and Future Directions

Like all research, this study had limitations that present opportunities for further inquiry. For example, my study focused on parents’ perspectives on their experiences of transitioning their children to adult services, which shed light on how they characterized the issue of transition and the effects of policies on their health, well-being and life circumstances. Future research can examine the perspectives of young people themselves, service providers and policymakers, to
gain a deeper understanding of how multiple stakeholders constitute the ‘problem’ of transition and how their problematizations compare. In addition, there were two main methodological limitations that had an impact on my analysis and interpretation of the findings.

First, I examined one document for each of the three policy sectors of interest. It is possible the documents were not representative of the problematizations of transition to adulthood within and across sectors. Second, the process of recruiting and selecting participants for my study relied on parents self-selecting and contacting me in response to recruitment advertisements disseminated by CLT and FAO. This process may have set unintended limits on the types of parents who volunteered. For example, it is possible that parents from particular sociodemographic groups received the recruitment advertisements and/or parents with particular views about transition were inclined to volunteer. Hence, the sample may not reflect a complete range of parents’ views or ways of thinking about the transition to adulthood for young people with DD. In what follows, I describe these two limitations in more detail and considerations for future research.

Documents published by governments and related organizations are usually carefully crafted and written for a public audience. They are the final product or outcome of a policy and/or research process and may not reflect the full range of ideas involved in deliberating how the problem was conceptualized and what courses of action were proposed. With this in mind, my findings about problematizations of transitions within and across sectors are limited to the text in this particular sample of documents. To address this in my analysis, I made links to relevant policies or documents as needed. For example, I examined text from the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008 in my analysis of the adult developmental services document. These were deliberate choices to ensure the feasibility of including policy from across the three sectors and allow a comparison to the parent data. Future research in this area would be enhanced through the inclusion of a wider array of documents (e.g., Hansard transcripts from government sessions and committee meetings, government bulletins and announcements, newspaper reports) and other data sources, such as interviews with policy analysts or policy decision-makers. These additional data sources would potentially enrich the descriptions and explanations generated through my research and contribute additional insights into the assumptions underpinning transition policy.
The recruitment process relied on efforts by two organizations (i.e., FAO and CLT), which may have had an impact on the range of parents who volunteered. After completing 13 interviews, I identified that the parents’ accounts were relatively similar in reflecting ‘unsuccessful’ transition experiences. With an interest in including a range of accounts, I contacted the CLT coordinator to request assistance in recruiting potential participants with ‘successful’ transition experiences. However, she was unable to identify anyone (which might be telling in itself). The research coordinator leaving her position vacant during the course of data collection complicated recruitment. Despite these limitations, my analysis was able to provide a robust critical interpretation or ‘reading’ of the two data sets to generate knowledge about the dominant ways in which the transition to adulthood for young disabled people is problematized in Ontario and to understand the potential effects of policies on young people with DD and their parents. The findings contribute new knowledge about how transition to adulthood is conceptualized as a problem in policies and by parents, and about potential areas for changing Ontario policies to mitigate unintended harmful effects of policies on young people with DD and their families.

4 Research Rigour

I used a variety of analytic devices consistent with a critical methodological approach, which served “as the means to achieve rigour” (Tracy, 2010, p. 841). Guided by a critical ‘triple hermeneutic’ approach, I examined the policies and parents’ accounts using the theoretically-informed WPR questions and drawing on theorizations of key concepts (e.g., disability, generation, development and citizenship) to dig below the surface of the explicitly stated problem. The theoretical construct of problematization was a key lens for making explicit the implicit problem and underlying assumptions embedded in the documents and interview accounts. Below I briefly review the strategies used to ensure a rigorous analysis.

I employed several strategies to maintain transparency of the decisions made and challenges faced in my research. For example, I met regularly with my supervisor, both individually and with my committee, to discuss challenges related to my analysis or research process and documented decisions in meeting minutes or notes. The analytic memos and summaries that I prepared for meetings with my committee served to record and make transparent my key findings as the research progressed. In addition, I included several documents, such as a policy
analysis form, reflexive memos and an interview field note form, to record my thoughts and ideas related to my analysis. The meetings with my supervisor and committee members to discuss and receive feedback about my analysis contributed to producing credible findings. The array of analytic strategies and devices that I used assisted me in developing thick descriptions about the discourses and assumptions that constituted transition as a particular kind of ‘problem’, and their effects on young disabled people and their parents.

5 Implications of Findings

My findings have implications for rethinking how transition to adulthood for young disabled people is conceptualized in policies. As I have shown, normative assumptions about disability, development and what constitutes a ‘proper’ adulthood in Western societies can have negative consequences for young people with DD (e.g., feeling excluded) and their parents (e.g., anxiety and stress in pursuing a normal life), which has implications for rethinking the focus and aims of transition policies. Although these policies are well intended, they may inadvertently perpetuate the stigmatization and social exclusion of young people who have difficulties in achieving the roles and activities associated with a socially valued form of adulthood. Rethinking the ‘problem’ of transition can potentially mitigate the unintended harmful effects of these policies that were reflected in the parents’ accounts. Moreover, rethinking transitions can open possibilities for considering other ways of creating and living a ‘good’ life that have potentially been neglected, ignored, or overshadowed by a focus on pursuing as close to a normal life as possible.

Recent literature, published after the policy documents and my literature review, suggests that there are shifts in thinking about ‘normality’ as the guidepost for disability, development and transition to adulthood, particularly in the field of childhood disability. Gorter et al. (2014) suggest that the term ‘disability’ is open to interpretation and its definition has shifted from traditional biomedical views, which locate the problem in the person and his or her impairments, to definitions that reflect the interaction between features of a person’s body and the environments in which he or she lives, which are associated with the ICF conceptualization of health, functioning and disability. Similarly, the authors suggest that developmental trajectories and outcomes are unique for each person, arising from person-environment interactions, as well
as cumulative risk and protective factors (Gorter et al., 2014). These interactions influence a young person’s opportunities, social relationships and life experiences (Gorter et al., 2014). This literature suggests that new approaches to childhood disability and transitional care are emerging, which place less emphasis on ‘normal’ ways of being, developing and functioning as the main or only goals.

Rosenbaum and Gorter (2011) suggest that new ways of thinking about childhood disability, development, and the socio-ecological factors that influence them are needed because there are significant limitations to traditional biomedical notions of ‘fixing’ impairments. They build on the ICF framework to propose that service providers draw on the ‘F-words’ of function, family, fitness, fun, friends, and future to guide practice in the fields of childhood disability and development (Rosenbaum & Gorter, 2011). Nyguen and Gorter (2013) suggest that service providers use the ICF framework as a tool to build on CanChild’s BJA model to guide holistic practices for young people and their families as they transition to adult healthcare. Although ideas of holistic and socioecological approaches to transition policy resonate with the findings of my study, I suggest that these approaches, left unexamined, potentially perpetuate a focus on changing the individual and his or her immediate environment rather than changing social conditions that disable and exclude young people and their parents. Furthermore, these approaches may not adequately consider the development and role changes experienced by parents themselves (Betz, Nehring & Lobo, 2015). Finally, these approaches may direct insufficient attention to the policy infrastructures that are important for supporting young people and their families during their transition to adult services and beyond, as Hepburn et al. (2015) found in an international policy review. In what follows, I discuss two potential avenues for rethinking transitions, including rethinking normality and individual life course trajectories.

5.1 Rethinking the Emphasis on Normality

Transition policies underpinned by notions of normality direct attention to pursuing as close to a normal adulthood as possible, potentially directing attention away from other possible ways of living as an adult that may be more suited to the life circumstances of young people with DD and their parents. For example, embracing disability as a dimension of difference rather than as a ‘problem’ to be fixed can open possibilities for promoting alternative ways of living a ‘good’ life.
that may be healthier, more feasible and desirable for young people with DD (Gibson, Mistry, et al., 2014; Hamdani, Mistry, et al., 2015; Hammell, 2006; Shakespeare & Watson, 2001). Moreover, valuing disabled childhood in its own right, rather than reinforcing ideas that it should be prevented, avoided or compared to a normal childhood, can open possibilities for promoting a positive disability identity in young people and fostering acceptance of multiple ways of being a child (Curran & Runswick-Cole, 2014). Rethinking the ‘disabled child’ in ways that privilege diversity over sameness can shape policies that influence service providers in rehabilitation, education, and social services who work directly with young people with DD and their parents. For example, service providers can incorporate sensitive discussions about an array of possible goals (e.g., doing activities for fun and enjoyment, maintaining friendships) for living a good life in the present as a child and in the future as an adult at regular points over the life course with young people and their parents, not just at the chronological age when they are transitioning out of childhood programs and services.

As a point of clarification, I am not suggesting that pursuing traditional roles and activities of childhood or adulthood be abandoned or avoided in policies and their implementation. Rather, I suggest that a variety of traditional and alternative options for living a good life are supported and given equal attention and consideration in policies and in discussions with families, including discussions about the potential benefits and harms of any option. For example, traditional goals of independent living or sustained paid employment may be challenging for some young disabled people to achieve, if at all, but working towards these goals may be desired as an end in itself. At a minimum, families should be exposed to a number of ways for disabled children to live a good life into adulthood and be given opportunities to evaluate the goals and options that make sense for their life circumstances.

My findings indicated that young people with DD are pathologized and compared to normative standards throughout their lives and across services from multiple sectors, which has implications for considering how policies from these sectors function to inadvertently perpetuate the social marginalization of these young people from mainstream society. Young people with DD and their families are set on path of ongoing interventions in pursuit of normality across these services that does not achieve this end by the time they ‘age out’ of services funded for children. The parents in this study indicated that their children were most involved in health and
rehabilitation services during the early childhood years, then in education services during the school-age years, then adult developmental services in young adulthood. On the whole, the parents’ accounts reflected that parents had internalized expectations to foster as close to normal development as possible. However, parents discussed having fewer services, resources, and supports once their children left public school to achieve this end. These findings have implications for considering how the services across sectors function and work together to perpetuate ideas about the ‘disabled child’ as an object of interest for intervention and normalization, yet, fail to adequately address situations in which young people with DD cannot or do not achieve indicators of a normal adulthood at a point in time when they are no longer eligible for childhood services. Examining policies as a whole can create opportunities to rethink and harmonize both the explicit and implicit messages about disability, adulthood and who counts as a citizen that are conveyed within and across multisector policies.

5.2 Rethinking Life Course Trajectories

Beyond embracing a variety of life course trajectories for young disabled people themselves, rethinking the issue of transitions can account for the entwined life course trajectories of young people, their parents, and other important people in their lives (e.g., siblings, extended family members, paid and unpaid caregivers). Parents are expected to take on extraordinary roles and extended responsibilities to foster as close to a normal life course trajectory as possible for their children with DD, yet their own life course trajectories are neglected or ignored in transitions policies. A way forward can involve rethinking transitions from the perspective of interconnected life course trajectories of families. Such a perspective would include considering the significant unpaid work conducted daily by parents whose children rely on them for personal care and support into adulthood, and also in creating and following up on transitions plans. Moreover, this lens can draw attention to the ways in which the life trajectories of these parents follow a different path than the life trajectories of parents of nondisabled, typically developing children when it comes to providing ongoing and necessary personal and financial support.

Rethinking life course trajectories as interconnected can draw attention to what families need to support young people with DD, not only at the point of service transitions between 18 and 21 years of age, but across the lifespan. This perspective can direct attention to shaping policies that
expand the availability of services and supports for parents and other caregivers. Parents of children with DD often have to defer their own goals for paid work, going on vacation, engaging in social and recreational activities, and planning for retirement. The mental and physical energy and effort to sustain this unpaid work can have adverse effects on their health and well-being (Kersh, Hedvat, Hauser-Cram & Warfield, 2006; Singer, Ethridge, & Aldana, 2007). If policies assume that parents are the main mechanism for supporting children with DD in their adult lives, then it is imperative to identify ways to mitigate the potential harms of these policies on parents’ lives. Furthermore, transition represented as a service transition problem at a particular chronological age risks leaving the issue unresolved by shifting the consequences to a future point when parents age themselves or pass away, and have less capacity and fewer financial resources to provide planning and support. Rethinking transitions from the perspective of family rather than individual life course trajectories can open possibilities for policies that support the needs of parents, siblings, and other family members alongside those of the young people with DD in their lives.

6 Research Contributions

6.1 Theoretical Contributions

My research contributes to theorizations of disabled childhood, particularly in the context of transitioning to adulthood in Western industrialized societies. Guided by a critical approach, my analysis revealed that the ‘disabled child’ is produced as an object of intervention in policies focused on addressing the assumed ‘problem’ of their service transitions between childhood and adulthood in Ontario. My findings illuminate that normative assumptions about disability, development and adulthood, underpinned by prevailing ideas of independence and productivity in Western societies, function to shape implicit understandings of the ‘disabled child’ as a problem to be addressed in transition policies and parents’ accounts of their children’s transition experiences. These normative assumptions construct standards for child development and adult citizenship of which all young people are expected to work towards and achieve with the support of their parents. As my analysis revealed, policies underpinned by normative ideas of ways of being, becoming, and acting as an adult can have negative consequences for young people with DD and their parents who provide them with care and support. Yet, theorizations of disability,
development and generation (e.g., childhood, adulthood) that can potentially illuminate normative discourses and assumptions and their effects have been neglected in the literature that has informed transition policies in Ontario. Theoretical understandings of how the ‘disabled child’ is constituted as a ‘problem’ can open possibilities for refining how transition to adulthood is conceptualized in ways that can potentially mitigate the inadvertent negative consequences of courses of action for young people with DD and their parents.

My research contributes to theorizing how transition to adulthood is constructed as a problem in policies, challenging dominant approaches to theorizing the problem based on normative ideas about disability and development. It also fills a gap in knowledge about the macro-level sociopolitical influences on young disabled people’s transitions to adulthood. My findings contribute new knowledge about the sociopolitical assumptions entrenched in Western industrialized societies, such as Ontario, that operate to construct the ‘disabled child’ as a problem to be prevented, avoided or fixed. These assumptions, underpinned by neoliberal values of individualism and equality of opportunity, shape taken-for-granted expectations for children and their parents to take responsibility for working towards and becoming an independent, productive, adult citizen (Goodley & Runswick-Cole, 2011; Lister, 2006), which has implications for the focus of transitions policies.

Transition policies generally focus on minimizing impairments and deficits of young disabled people, and maximizing their skills, competencies, and future potential as adult citizens. This approach draws attention away from considering the possibility of changing the broader sociopolitical conditions that shape notions of a socially valued adult citizen. For example, Lister (1998) suggested that a male who is white, heterosexual and nondisabled is constructed as the idealized citizen in Western societies to which all people are compared. She argues that citizenship is more than a status that can only be earned or achieved by people with particular characteristics. Instead, she proposes that citizenship should be about active political participation, incorporating a positive sense of difference among groups of people in order to foster inclusion. Similarly, Shakespeare and Watson (2001) propose that disabled people must reject the notion of sameness (of the norm) and that disability citizenship should not be based on claims for equality with nondisabled people, but rather through a claim of accepting their differences. The BJA document from the rehabilitation sector was the only document that
explicitly suggested active citizenship as a transition outcome rather than traditional outcomes of independent living and employment. However, what is meant by active citizenship is not clearly defined or described leaving its meaning open to interpretation and susceptible to being shaped by prevailing neoliberal views in which particular kinds of citizens are valorized. Further work to examine conceptualizations of citizenship in relation to disability and the life course offers opportunities to reframe the issue of transition to adulthood beyond the focus on service transitions in current policies.

Further research on transition to adulthood might adopt a disabled children’s childhood studies approach. Curran and Runswick-Cole (2014) propose that the disabled child has been theorized in relation to Western norms for the ‘standard child’ in contemporary childhood studies. It has also been theorized from critical disability studies perspectives, which aim to critique dominant medicalized views of disability and draw attention to the social conditions that create disability. Although both perspectives have been valuable in theorizing disabled childhoods, they suggest that further work should consider building on them through a disabled children’s childhood studies approach to inquiry. The main premise of this approach is that disabled children and their childhoods should be valued in their own right—not in comparison to other groups and social categories. Additional premises include paying attention to the experiences of disabled children in the contexts of both the Global North and Global South, with the former generally associated with wealthy, Western industrialized societies (Curran & Runswick-Cole, 2014). In addition, a disabled children’s childhood disability studies approach begins with the concerns of disabled children and young people, and their families and allies, rather than researchers, policymakers, and service providers. Adopting this approach in future research, theorizing disabled children’s life course trajectories in their own rather than in comparison to ‘normal’ developmental and social trajectories, and from the perspective of young people themselves, can inform new ways of understanding life stages and moving across them as a young disabled person. In addition, further research that compares how life course trajectories of disabled children are thought about in the Global South compared to the Global North can shed new light on the conceptual generalizations that can be made based on my findings.
6.2 Methodological Contributions

My research methodology challenges traditional problem-solving approaches and contributes new knowledge about critical approaches to policy analysis, which can be used to examine a variety of public health policy issues, particularly those involving the health and well-being of marginalized groups. In traditional approaches, the ‘problem’ is generally accepted as given, which can perpetuate prevailing ways of thinking about and addressing an issue that may inadvertently perpetuate the marginalization of nondominant groups. A critical approach involves questioning the problem and the deep-seated assumptions that shape it, which can open possibilities for understanding the issue in new ways that minimize the negative implications for the target group of a policy. If I had adopted a traditional approach in my study, my analysis might have stayed ‘on the surface’ and stopped at reiterating the explicitly stated problem of service transitions, rather than generating deeper insights into implicit problem representations of the ‘disabled child’. The WPR approach can be applied to understanding how other public health and social policy issues are constructed as problems. For example, it has been applied to examine disability policy in international development (Marshall, 2012) and social inclusion policy in Australia (Pereira, 2014). The WPR questions can also be applied to analyze discourses and problematizations in nonpolicy data sources, such as research literature, television and news stories, and documentaries to support in-depth analysis of a policy issue. In addition, the WPR approach can be used as a tool by policy makers and researchers to scrutinize taken-for-granted assumptions embedded in problem representations in policies, including scrutinizing their own problem representations and proposed courses of action.

A unique feature of my study was drawing on the WPR questions to inform my examination of the parents’ interview accounts. In the literature, I found WPR was used to examine the text in policy and related documents as it was intended, but not to examine data generated from the accounts of the target group(s) of the policy. I experienced some challenge in adopting the WPR questions to analyze the interview data. For example, I had to refine the questions so they made sense in the context of the parent data. I rephrased the first question, “What’s the problem of transition to adulthood represented to be in the policy?” to “How do parents characterize the ‘problem’ of transition to adulthood?” However, the nature and character of my questions for both data sets remained in close alignment to the theoretical underpinning of WPR. Using the
WPR-informed questions to guide the analysis facilitated the comparisons that could be made between the two data sets and provided an opportunity to dig deeper into the deep-seated social values and assumptions embedded in both the documents and parents’ accounts. In addition, I was able to draw on the parents’ accounts to identify the lived effects of transitions policies on families of young people with DD in Ontario rather than draw conclusions based on analyzing documents only. The use of multiple data sources enriched my analysis and interpretations of the findings.

7 Reflexive Conclusions

Throughout my PhD training, I found myself asking “What is wrong with promoting and pursuing ‘normal’ in transition policy and practice?” This self-questioning was usually in response to a conversation with an interested colleague or friend who asked me about my research. After briefly summarizing my project, I was often asked several questions, such as “What’s wrong with trying to be normal?,” and “What’s wrong with helping people to fix or overcome their disabilities so they can do ‘normal’ things like everybody else?” These questions are paraphrased somewhat, yet, they are good questions that I found difficult to answer convincingly in plain language and without theoretical jargon. Furthermore, I needed a nuanced way of explaining that my specific aim was to understand how disability is problematized in relation to normality, rather than to suggest that there was something wrong with pursuing normal. So I ‘tried on’ some different ways of explaining my study in a way that a ‘lay’ person with little knowledge about disability, either personally or professionally, could be convinced that my research findings were plausible and valuable.

The explanation that seemed to gain the most traction with ‘lay’ people focused on ideas about accepting social differences and how this can change over time. I pointed out that dominant ways of thinking about a myriad of differences (e.g., differences of race, gender, and sexual orientation) have shifted and changed over time to the extent that these differences are generally accepted now compared to the past—or at least by my colleagues and friends who would describe themselves as having liberal, cosmopolitan views. In my conversations, people agreed that many groups, such as women, gay and lesbians, and people from racial minority groups, have faced discrimination, stigmatization, and marginalization based on dominant ways of
thinking about them as inferior or lacking in some way compared to the ‘normal’ group. They also agreed that there have been significant shifts in how we think about these groups and their rights in society. In particular, discussing how ways of thinking about homosexuality have changed over time seemed to resonate and open the door about considering disability in a new light. For example, homosexuality was considered a psychiatric disorder or criminal activity—indicators of medical and moral deviance from the norm at different times in society. For the most part, my ‘lay’ people did not blink an eye in agreeing that ways of thinking about the rights of gays and lesbians have come a long way (and have improved for the better) since then. Thus, comparing the experiences of disabled people to the experiences of other groups who have been stigmatized and marginalized was a useful strategy to highlight that was is ‘normal’ in society is amenable to change.

From this social ‘experiment’ I learned to think about ways of translating my findings such that they are convincing and ‘stick’ with people (e.g., disabled young people, families, service providers, policy decision-makers, and others) who can take them up to foster social change. As I have discussed in this dissertation, a way forward in future research is to rethink how the ‘disabled child’ is conceptualized in policies, and in society more generally, and to incorporate understandings of disabled childhood as a dimension of difference and a valuable social category in its own right. Research from this perspective can open possibilities for policy options that are more relevant to the lives and circumstances of young disabled people and their families. At a minimum, the implications of particular ways of thinking about the ‘disabled child’ can be acknowledged and foster opportunities to mitigate the potential harmful effects of policies on the lives of young people and their families.
References


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Scotland, J. (2012). Exploring the philosophical underpinnings of research: Relating ontology and epistemology to the methodology and methods of the scientific, interpretive, and critical research paradigms. *English Language Teaching, 5*(9), 9–16.


Appendix A: Policy Analysis Summary Form

Document:

Date:

Detailed summary of “What’s the Problem Represented to Be?” policy analysis (Bacchi, 2009)

1. What’s the ‘problem’ represented to be in a specific policy?

2. What presuppositions or assumptions underlie this representation of the ‘problem’?

3. How has this representation of the ‘problem’ come about?

4. What is left unproblematic in this problem representation? Where are the silences? Can the ‘problem’ be thought about differently?

5. What effects are produced by this representation of the ‘problem’?

6. How/where has this representation of the ‘problem’ been produced, disseminated and defended? How could it be questioned, disrupted and replaced? (Bacchi, 2009; p.2)

What other questions does this policy analysis raise?

Any other comments or thoughts about this document?
### Appendix B: Visual Matrix

**“What’s the Problem Represented to Be (WPR)?” Policy Analysis (Bacchi, 1999)**

<table>
<thead>
<tr>
<th>WPR Questions</th>
<th>Pediatric rehabilitation sector</th>
<th>Developmental disability sector</th>
<th>Education sector</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What’s the ‘problem’ represented to be?</td>
<td>Developmental progression &amp; poor coordination of service transfer</td>
<td>Poor coordination &amp; planning of service transfer &amp; lack of info for families</td>
<td>Poor coordination &amp; planning of service transfer from school to work, further education &amp; community living</td>
</tr>
<tr>
<td>2. What presuppositions or assumptions underlie this representation of the ‘problem’?</td>
<td>Developmental progression over life course, self-determination, interdependence &amp; future orientation promote health</td>
<td>Knowledge &amp; planning improves quality of life (QoL) &amp; community participation; Family is responsibility for youth into adult life; Self-determination with support; Aim is QoL &amp; participation</td>
<td>Work &amp; further education are preferred goals; Productivity is valued; Aim is participation in postsecondary activities</td>
</tr>
<tr>
<td>3. How has this representation of the ‘problem’ come about?</td>
<td>Developmental perspective inherent to pediatric rehab &amp; ICF</td>
<td>Sociopolitical views of citizenship &amp; participation</td>
<td>Views of normal development &amp; expected roles of adulthood after high school graduation; Productive adult life is healthy for individual &amp; society</td>
</tr>
<tr>
<td>4. What is left unproblematic in this problem representation?</td>
<td>Atypical development; Social barriers to participation (e.g., income, attitudes about disability, etc.); Lived experience of disability &amp; impairment effects</td>
<td>Availability &amp; funding for adult services; Experiences of social marginalization</td>
<td>Atypical development; “Community living” is vague, not clearly described; Barriers to working (e.g., personal care support, transportation, etc.); Lived experience of disability &amp; impairment effects</td>
</tr>
<tr>
<td>5. What effects are produced by this representation of the ‘problem’?</td>
<td>Intended: Focus on future planning; adult citizenship &amp; participation</td>
<td>Intended: Improved quality of life &amp; community participation</td>
<td>Intended: Participation in postsecondary pursuits</td>
</tr>
<tr>
<td>---</td>
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<td>---</td>
<td>---</td>
</tr>
<tr>
<td></td>
<td>Unintended: Discourses of “normal” trajectory to adulthood; Self-doubt; Ambiguous meaning of “interdependence”; Effect on family; Anxiety/stress</td>
<td>Unintended: Poor family health; Expectations of family (i.e., finances, time, resources); Anxiety/stress</td>
<td>Unintended: Lack of access to work: Devalued citizen; Decreased self-worth</td>
</tr>
<tr>
<td>6. How/where has this representation of the ‘problem’ been produced, disseminated and defended?</td>
<td>Historical roots to medicine/medicalized view of disability; ICF</td>
<td>Social service/government re: responsibility of family; Parents &amp; advocates re: responsibility of government to citizens</td>
<td>Government &amp; school boards; Productive adult citizens are optimal for society</td>
</tr>
</tbody>
</table>
Appendix C: Coding Scheme

ACCESS. Refers to access to or experiences of accessing services & supports for disabled youth

CONSEQUENCES. References to both positive, negative, intended, unintended consequences of achieving/not achieving ideal adulthood or of parent being/not being involved in planning for future life of youth.

DEVELOPMENTALISM. Any reference to development or developmental trajectories, pathways, growing up, progressions, achieving developmental tasks and milestones.

DISABILITY/ABILITY. References to diagnosis, disability or impairments, as well as disabling barriers in society. Also references to interventions for disability or what has been identified as the ‘problem’ with disability. References reflecting individual and social models of disability.

EFFECTS ON FAMILY. Any references to physical, social or emotional effects on family. Also includes discursive, subjectification and lived effects of transition planning or policies on family as described in Bacchi’s WPR approach to policy analysis.

ENVISIONING THE FUTURE. References to how the family envisions the future circumstances of the adult, such as future living situations, personal care, decision making and financial arrangements, employment, and social participation.

FINANCES. Any references to money, funding, income, trust funds, costs of equipment, attendant care, programs or services, or cost of living. References to financial planning.

FUTURE PLANNING/PREPARING. References to putting plans in place for the youth in the near or distant future, such as planning for personal care supports, financial security, housing arrangements, etc.
GENERATIONAL CATEGORIES. References to how life stage categories (e.g., childhood, adolescence, adulthood) are understood, how these categories are distinguished from one another, how do they relate to each other.

GUARDIANSHIP. Refers to roles, activities, responsibilities of parents/caregivers for decision making and providing or overseeing personal care and daily living support on behalf of the adult-aged children.

HEALTH & WELL-BEING. Any references to the health and well-being of the youth, parents or family unit. Physical or mental health and well-being and strategies for maintaining health.

IDEAL ADULTHOOD. Any references to characteristics, skills, knowledge, traits or social expectations of idealized notion of adulthood. References to functioning as an adult or explicit or implicit ideal outcomes of transition to adulthood planning/preparation. References to skills and knowledge that are being targeted in transition planning/programs or that the youth should develop. References to values and beliefs about a good and proper adult life.

INDEPENDENCE/DEPENDENCE. References to independence, autonomy or dependence for activities of adulthood.

NORMALIZATION. Any reference to living a normal life, participating in normal roles of adulthood, or socially accepted roles, activities and responsibilities of the youth. Also any reference to normal roles, activities and responsibilities of parents/caregivers and family

PARENTING. Any reference to roles and responsibilities of parent in caring for youth, teaching youth, responsibilities for providing a good life now and in the future. Any reference to the current or future nature and scope of the parent/child relationship, how relationship might be shifting or staying the same. Any references to emotional relationships/connections or emotional responses changing relationships.

SELF-RELIANCE. References to being able to take care of things for oneself, such as personal care, finances, activities of daily living, decision making, etc.
SERVICE TRANSITIONS. References to changes in services and supports, eligibility criteria for services, service changes related to age, and the experience of service transitions.

SERVICES AND SUPPORTS. Any reference to involvement in health care, education, community or social services or other services and supports, or types of services that would be helpful/beneficial or services and supports that are missing/lacking.

SOCIAL INCLUSION/BELONGING/CITIZENSHIP. References to social participation, belonging, citizenship, being involved with family, friends, and the broader community or expectations for these social connections.

SUCCESSFUL TRANSITION. Refers to ideal outcome of transition planning/preparation, circumstance or situation in which youth is considered to have successfully transitioned to adulthood.

TEMPORAL ORIENTATION. Any references to living in or focusing on the present or future. Emotional responses to thinking about the future.
Appendix D: REB Approval Letter

PROTOCOL REFERENCE # 29370

November 1, 2013

Dr. Rebecca Renwick
DEPT OF OCCUPATIONAL THERAPY
FACULTY OF MEDICINE

Ms. Suryani Hamdani
DEPT OF OCCUPATIONAL THERAPY
FACULTY OF MEDICINE

Dear Dr. Renwick and Ms. Suryani Hamdani,

Re: Your research protocol entitled, “A critical examination of policies on transition to adulthood for severely disabled youth in Ontario”

ETHICS APPROVAL

Original Approval Date: November 1, 2013
Expiry Date: October 31, 2014
Continuing Review Level: 1

We are writing to advise you that the Health Sciences Research Ethics Board (REB) has granted approval to the above-named research protocol under the REB’s delegated review process. Your protocol has been approved for a period of one year and ongoing research under this protocol must be renewed prior to the expiry date.

Any changes to the approved protocol or consent materials must be reviewed and approved through the amendment process prior to its implementation. Any adverse or unanticipated events in the research should be reported to the Office of Research Ethics as soon as possible.

Please ensure that you submit an Annual Renewal Form or a Study Completion Report 15 to 30 days prior to the expiry date of your current ethics approval. Note that annual renewals for studies cannot be accepted more than 30 days prior to the date of expiry.

If your research is funded by a third party, please contact the assigned Research Funding Officer in Research Services to ensure that your funds are released.

Best wishes for the successful completion of your research.

Yours sincerely,

[Signature]
Appendix E: Information and Consent Letter

Parent and caregiver perspectives on transition to adulthood for severely disabled youth in Ontario

Date: September 1, 2013

Principal Investigator: Yani Hamdani, PhD Candidate
Dalla Lana School of Public Health
647-274-9264, y.hamdani@utoronto.ca

Thesis Supervisor: Dr. Rebecca Renwick
Graduate Department of Rehabilitation Sciences
416-978-1818. r.renwick@utoronto.ca

What is this research study about?

In this research study, we want to learn about parent and caregiver experiences of planning for transition to adulthood and for the transition from childhood to adult programs and services, including health, education, developmental disability and social services, for their children with severe developmental disabilities. We will also explore how these experiences affect the health and well-being of your family.

Provincial policies to improve the transition from childhood to adulthood programs and services for youth with disabilities have been developed in Ontario over the past 10 to 15 years. The results of this study can help to understand how these policies affect the daily lives of severely disabled youth and their families and can help identify areas that need further policy development.

How will I be involved in this study?

We are inviting parents and caregivers of youth who are 16 to 29 years of age and who have severe developmental disabilities to take part in this research study. Your participation in the study involves an interview of approximately 60 to 90 minutes in length and will take place in a mutually agreed upon location that is private and quiet, such as your home or at the University. We will decide together on a location and time that allows you to share private information without being overheard by your family members or others. The interview will be audio-recorded and then professionally transcribed. After the interview, I may contact you by telephone to ask you if I have understood the main points we discussed or to get further information about what we discussed during the interview. Some participants may be contacted to give feedback on a summary of the main themes that came from the interviews as a whole.
What are the risks?

There is little risk anticipated to you as a participant in this study. You do not have to answer any of the researcher’s questions. You can take a break or stop the interview at any time you wish. It is possible that you could become upset when talking about your experiences. If this happens, we can stop the interview. The researcher will help get you other help, such as counselling, if needed.

The final decision about participation is yours. This study has been reviewed and been approved by a University of Toronto Research Ethics Committee. If you have any comments or concerns about your participation in this study or questions about your rights as a participant, please contact the Office of Research Ethics at the University of Toronto at 416-946-3273 or ethics.review@utoronto.ca.

What are the benefits?

There are no direct benefits to you as a result of participating in this study. The study information will be used to make recommendations for improving policies and programs for youth with disabilities and their families in Ontario. We will send you a summary of the study findings if you wish.

Is it private?

All information we collect about you and your family will be kept private. Your name will not be used. We will not make public anything that might identify you or your family unless required by law. For example, we have to report any information that would lead us to suspect child abuse or neglect.

All the information that we collect from you will be safe. It will be kept on password protected computers or in locked cabinets. Only researchers on the project will see information from your interview. The recordings will also be typed out word for word by a professional transcriber who will sign a confidentiality form. We will not use names in the typed transcripts. We will not use any other identifying information in the transcripts. Service providers from the health, education and social services that you use will not know what you said.

When the study is finished the results may be published or presented. Your identity will not be made known in any way without your permission. All study information will be destroyed seven years after the study ends.
**Do I have to do this?**

Being in this study is up to you. You may choose to not answer any of the interview questions if you so wish. You can decide to drop out of the study at any time before, during or after the interview by letting me know in person or by phone. Withdrawing from the study will not have any negative effects on your or the services your child receives. However, once interviews are analyzed, it will be too difficult to withdraw your information because it will already be combined with other participants’ information. You will be given a $10 gift card as a token of thanks after the interview.

**What if I have questions?**

Please feel free to ask any questions. You may contact the Principal Investigator, Yani Hamdani at 647-274-9264 or y.hamdani@utoronto.ca or the Thesis Supervisor, Rebecca Renwick at 416-978-1818 or r.renwick@utoronto.ca.
Parent and caregiver perspectives on transition to adulthood for severely disabled youth in Ontario

Please complete this form below:

A member of the research team has explained this study to me. I read the Information Letter dated September 1, 2013 and understand what this study is about.

I understand that I may drop out of the study at any time with no negative effects for me or my child’s services.

I understand that I may choose to not answer some questions.

I agree to participate.

__________________________________________________________________________

Participant’s Name (please print)        Signature

Date:

I have explained the study to the participant above and have answered any questions.

__________________________________________________________________________

Researcher’s Name (please print)        Signature

Date:

If you would like a summary of the study results, please provide an email or mailing address below:

Email:

OR

Mailing address:
Appendix F: Recruitment Advertisement

Participants needed for a PhD research study:
“Parent and caregiver perspectives on transition to adulthood for severely disabled youth in Ontario”

We are looking for participants who are parents or caregivers of youth aged 16 to 29 years of age and who have severe developmental disabilities to participate in a study about the experience of transition to adulthood in Ontario.

As a participant, you will be asked to take part in an interview in your home or in a private location. You will be asked about your experiences of planning for transition to adulthood for your child and for the transition from childhood to adult programs and services, including health, education, developmental disability and social services.

Your participation will take approximately 60 to 90 minutes.
You may be contacted after the interview to provide additional information.

This research is conducted under the supervision of Dr. Rebecca Renwick, Graduate Department of Rehabilitation Sciences and has been approved by an ethical review committee through the Office of Research Ethics, University of Toronto.

For more information and to volunteer for this study, please contact

Yani Hamdani at 647-274-9264 or y.hamdani@utoronto.ca.
Appendix G: Telephone Screening Tool for Inclusion in Study

In this research study, we want to learn about parent and caregiver experiences of planning for transition to adulthood and for the transition from childhood to adult programs and services, including health, education, developmental disability and social services, for their children with severe developmental disabilities. We will also explore how these experiences affect the health and well-being of your family.

We are inviting parents and caregivers of youth with severe, lifelong developmental disabilities who can answer questions about experiences of planning for the transition to adulthood on behalf of or in collaboration with their son/daughter/child. In order to determine if you meet the criteria to participate in the study, I have a few questions for you.

1. Are you the biological parent, legal guardian or foster parent for a young person with a disability? (Circle parent/caregiver status)

□ YES □ NO

2.a. What is your preferred language for participating in an interview?

2.b. I am only able to conduct an interview in English. Would you feel comfortable to do the interview in English?

□ YES □ NO If no, go to 12b

For the purpose of this study, we are interested in hearing about youth who are 16-29 years of age and who have a diagnostic label associated with lifelong intellectual or developmental
disabilities, and also physical disabilities (e.g., fine motor, gross motor and/or mobility impairments). Based on this, I have some questions about your son/daughter/child:

3. How old is your son/daughter/child?

4. Is your son/daughter/child’s disability considered lifelong in nature?

   ☐ YES ☐ NO

5. Did your son/daughter/child’s disability begin before he/she was 18 years of age?

   ☐ YES ☐ NO

6. Does your son/daughter/child’s disability affect areas of major life activity, such as personal care, language skills, learning abilities, and the capacity to live independently as an adult?

   ☐ YES ☐ NO

7. Does your son/daughter/child have a medical diagnosis that you would like to tell me about?

   ☐ YES ☐ NO

8. Is your son/daughter/child eligible or could be considered eligible for services for persons with
developmental disabilities?

☐ YES ☐ NO

9. Does your child receive services and supports or has received services and supports in the past from:

   o A developmental disability community service agency?

      ☐ YES ☐ NO

   o a pediatric rehabilitation hospital or community agency?

      ☐ YES ☐ NO

   o Special education services and supports?

      ☐ YES ☐ NO

   o Another hospital or agency?

      ☐ YES ☐ NO

10. Have been involved in planning for transition to adult services and supports on behalf of or in collaboration with your son or daughter?
11. Do you live in the Greater Toronto or Greater Hamilton Area?

☐ YES ☐ NO

12.a. Based on what you have told me, you are eligible to participate in this study. I can mail you an information letter and consent form if you do not have one already. Would you like to set up a time for the interview now? Would you prefer to meet at home or another location? If we meet at your home, we will need a quiet, private place for about an hour and a half, where you feel comfortable sharing information with me that you may not want your family members to overhear. Do you have a private place in your home or a time of day that would be more private? If not, would you prefer to meet at another location? What times work best for you to meet for an interview? Do you have any questions for me?

OR

12.b. Based on what you have told me, you are not eligible to participate in this study because……… Thank you very much for your interest in the study. Do you have any questions for me?
Appendix H: Guide for In-depth Interviews with Parents/Caregivers

Preamble: The purpose of my study is to understand how disability and transition to adulthood are talked about in policies and strategies from different ministries in Ontario and to understand how these policies and strategies affect the life of your son/daughter and your family. The plan for our interview today is to discuss your experiences with the transition from childhood to adulthood for your son/daughter. I will ask you some questions about what you have done with your family to prepare for your son’s/daughter’s transition to adult life and to adult programs and services. Finally, I will ask some additional background questions about you, your son/daughter and your family. Remember you can choose not to answer any of the questions. If you become tired and need a break or want to stop, let me know. Do you have any questions for me about the interview?

Interview Questions and Probes

• Can you tell me a bit about your family?
  o Probes: Tell me about your family and your daily family life. Tell me about your house and who lives at home with you? Where do you live? Do you have other children? What do you like to do as a family? Are there other people involved in making decisions or caring for your son/daughter?

• Can you tell me a bit about your son/daughter?
  o Probes: Tell me about your son’s/daughter’s disability. What is your child’s diagnosis? How old is your child? Who provides the main personal care and support for your child? How much personal care and support? Does your son/daughter attend school? If so, when will he/she graduate? Tell me what types of things he/she does on a daily/weekly basis.

• What services is he/she involved with?
o Probes: What health, education, community or social services is he/she involved with? Is he/she connected to any services in the developmental disabilities sector?

• Tell me about planning for your son’s/daughter’s transition to adulthood.

  o Probes: Have you participated in any programs or services to help you plan the transition? Has your son/daughter participated in any transition to adulthood programs? What about life skill programs or other related programs?

• How would you describe your experience of planning for your son’s/daughter’s transition to adulthood?

  o Probes: What services or supports were helpful to you in planning for transition, and what was helpful about them? What services were less helpful, and why? What programs or services had the biggest impact on your son’s/daughter’s process of transition to adult life? How were they helpful (or not helpful)?

• How do you picture your son’s/daughter’s life as an adult? What types of programs or services would help to support your son/daughter as an adult?

  o Probes: What programs or services do you think are most important for youth with disabilities in adult life?

• What would you describe as a “successful” transition to adulthood for your child? Would this describe your family’s experience so far?

  o Probes: Do you know anyone who has been successful in planning for their son’s/daughter’s transition? Anyone who has been unsuccessful?

• Can you tell me what led you to participate in this study?

  o Probes: What interested you about the study that led to your decision to participate in this interview?
I have a few questions about you to help me describe as a whole, in a broad way, who participated in this study.

- Do you work outside of your home?
  - Probes: What is your occupation? Do you work full or part time?

- Do you have a partner or spouse? Does he/she work outside the home?
  - Probes: What is his/her occupation? Do he/she work full or part time?

- What are the main sources of funds for your son/daughter?
  - Probes: Do you or your child receive government funds, such as Assistance for Children with Disabilities, ODSP? Are there other sources of funds?

- Tell me a little about any ethnic or cultural groups that you are part of.
  - Probes: Are these groups a source of support for you and your child? If so, in what ways?

- Tell me a little about any religious groups you are part of.
  - Probes: Are these groups a source of support for you and your child? If so, in what ways?

- Is there anything that we haven’t talked about that you would like to tell me about your son/daughter and planning for adult life?
Appendix I: Interview Field Note Form

Participant #: 

Date: 

Describe how consent for the interview was obtained.

Did the participant sign the consent form?

What were the main issues or themes that struck you in this interview?

Summarize the information you got (or failed to get) on each of the key questions in this interview.

Describe/summarize any silences during the interview. Describe any nonverbal communication or gestures that seemed significant.
What else struck you as salient, interesting, illuminating or important in this interview?

What new (or remaining questions) would you have for this participant?

Describe the setting of this interview (e.g., geographic location, type of housing, etc).

Describe your impressions of the interviewer-participant interaction.

Adapted from Miles & Huberman’s (2014) Contact Summary Form