Tensions in Care: Caregiving for an Adult Child with Developmental Disability

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ABSTRACT

For this research, semi-structured qualitative interviews were conducted with primary caregivers that have adult children with disabilities. These interviews explored the lived experience of caregiving of primary caregivers. Three main themes surrounding care were found, all falling within the larger context of tensions in care. The first theme captures tensions in policy that promote empowerment but also produce disablement. Second, tensions exist between service agencies and lived experience of care. Lastly, tensions exist between were between the burdens and rewards of caregiving. It is these three themes and tensions that impact caregiving experiences at a personal level with the participants. These tensions are explored at a qualitative level and are illuminated by the lived experiences of the participants. Through this research the complex and understudied world of disability and care are explored. This research has implications for future policy development of support services for families that have an adult child with developmental disabilities. Further, these tensions illuminate the complex world of caregiving for those with disabilities in a way that examines life course impacts on caregivers themselves.

Keywords: caregiving; developmental disability; tensions in care; life course

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# INTRODUCTION

Families that have a child with developmental disabilities face unique challenges. Apart from their worries about their children’s future, the heavy caregiving responsibilities they carry take considerable time and energy away from themselves. Financial challenges also exist, as families struggle to meet both their own needs, as well as those of their children. Many of these challenges have been documented in the literature, often in the form of large-scale studies that have surveyed the needs of these families. Yet, not long into conversations with these caregivers, there will also be references to the rewards connected with having a disabled child, and even the transformational power of their relationships with their children. These mixed emotions speak to the complexity of the circumstances in which these caregivers find themselves.

My goal in this thesis is to move beyond the surveys and studies that document the hardships that families with developmentally disabled children endure, to consider their lived experiences from a more in depth or holistic perspective. My aim is to provide a glimpse into their lives as they experience them, capturing their challenges and frustrations but also the joys and benefits they derive from their caregiving roles. The thesis is based on nine intensive qualitative interviews with caregivers who are providing care for their developmentally disabled adult children.

There are a growing number of parents that are caring for their adult child with developmental disabilities into late adulthood (Community Living Ontario 2013). This prolonged caregiving has been the result of increased life expectancy of those with disabilities and a shift from institutionalization to private and informal caregiving (Haley and Perkins 2004; Heller, Caldwell and Factor 2007). As a result, research has begun to explore the experiences of family caregivers of an adult child with developmental disabilities. Research has focused mainly on the impact that caregiving has on families' health and well-being (Haley and Perkins 2004; Murphy et al. 2007; Ward et al. 2014), and finances (Fast et al. 2008; Lewis et al. 2000). Additionally, concerns over prolonged caregiving are starting to be recognized by researchers, and are a source of research studies. Academics have started to examine the impacts that different policies and support services have on families of children with disabilities (Caldwell 2006; Caldwell 2007; Heller and Caldwell 2005). The majority of this research, however, takes place within the United States and Britain. Little research is focused within a Canadian context, and no known research, with the exception of Damiani et al. (2004) focuses on Ontario specifically. This present research will contribute to the literature on family caregiving of adult children with developmental disabilities in Ontario.

I focus specifically on families looking after adult children because this group has tended to be neglected in the literature, as they fall outside the two dominant fields in family caregiving research – childcare and eldercare. Further, this group of adults with disabilities is growing in number as the lifespan of people with disabilities increases. As a result, this thesis seeks to understand the lived experiences of primary caregivers of adult children with developmental disabilities. Doing so sheds light on a population that is often overlooked in caregiving and disability literature.

First, this thesis begins with definitions of disability internationally, nationally and provincially. Following are the theoretical frameworks (social constructionism and a life course perspective) that guided my research and analysis of the data. Next, is a review of the research literature on caregiving for adult children with disabilities. Lastly, an overview of disability support services within Ontario is completed.

Chapter Two describes the methods I used in carrying out the study, including how I recruited participants, conducted the interviews and analyzed the data. The chapter also provides information about the participants. In Chapter Three, I present my findings. The chapter is organized around three major themes: tensions between the lived reality of disability policy that promotes empowerment as well as disablement; tensions in support agencies and the lived experience of care; and tensions between the burdens and rewards of caregiving.

In the final chapter, Chapter Four, I employ both a social constructionist and a life course perspective to draw out the analytical insights in my study. I present a new and refined way of understanding disability caregiving across the life course. Finally, this thesis concludes with a summary of the findings, an overview of the limitations I faced while doing this research, and suggestions for future research.

# CHAPTER 1

In this chapter, I explore many aspects of the caregiving literature with an emphasis on research that focuses on family caregiving for children with developmental disabilities. The chapter starts with international, national, and provincial definitions of disability and developmental disability. Following, I describe the theoretical approaches I employ in this research to situate the analysis and discussion that follows. Then the literature review discusses caring for a child with disabilities and the challenges that parents face with respect to caregiving. An examination of the formal support services available to families in Ontario is further presented as part of the larger caregiving context. Lastly, gaps in formal support services are explored, which help situate the impact supports can have on family caregiving. The sections of this chapter help to contextualize my research interests on the caregiving experiences of families that have adult children with developmental disabilities.

## DISABILITY DEFINITIONS

The World Health Organization (WHO) defines disability as transient and ongoing where one may have a permanent disability or move from disabled to non-disabled or vice versa. It recognizes that disability is impacted by society and one’s environment (WHO 2015). The International Classification of Functioning, Disability and Health (ICF) is the WHO's framework for measuring health and disability at individual and population levels. ICF uses a broader understanding of disability as they recognize that experiences will vary based on the person. Further, the ICF acknowledges that disability is impacted by social, not solely medical factors.

The (ICF) defines disability as an "umbrella term for impairments, activity limitations and participation restrictions. Disability is the interaction between individuals with a health condition (e.g. cerebral palsy, Down syndrome and depression) and personal and environmental factors (e.g. negative attitudes, inaccessible transportation and public buildings, and limited social supports)" (WHO 2015).

The government of Canada does not provide their own definition of a disability but rather encourages the use of the World Health Organization (WHO) and the UN's definitions of disability (Government of Canada 2013). Specifically, at an Ontario level, the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act (2008) defines developmental disability as a person having significant limitations in cognitive and adaptive functioning where those limitations "originated before the person reached 18 years of age; are likely to be life-long in nature; and affect areas of major life activity, such as personal care, language skills, learning abilities, the capacity to live independently as an adult or any other prescribed activity" (Government of Ontario 2010). As this definition is used within this policy as a basis for understanding developmental disability, it impacts funding, support services, eligibility for services and enforcement of the different parts of the 2008 Act.

## THEORETICAL ORIENTATION

Two theoretical frameworks have been used to orient my research. The first is social constructionism. Social constructionism, described below, has informed how I interpret and understand disability within society. The second, a life course perspective, guides and structures my research to explore the impacts of caregiving on the life course of carers, as well as the interpretation of my findings.

### *Social Constructionism*

Gordon and Rosenblum (2001) argue that there is little disability research that takes a constructionist approach. This is because disability research – as a field – does not tend to use sociological frameworks, but rather takes place within medical understandings and considerations. Gordon and Rosenblum (2001) use a social constructionist approach as a way to understand disability. They assert that disability is a societal process similar to how master statuses of race, gender and sexual orientation are constructed. A master status is the role of greatest significance in one's life (West and Zimmerman 2007). A master status often supersedes other traits and roles as a means of identifying. As a result, ones master status becomes a signifier of belonging to a certain group. This status may be placed on the individual by society or may be adopted by the individuals themselves. Gordon and Rosenblum (2001) attribute four similarities in the social construction of the aforementioned that can be applied to disability. First, social constructionism involves the creation of categories of people. For these authors the creation of categories is done through policy and law, for instance those with disabilities have been referred to as 'the handicapped', 'disabled' and more recently, 'people with disabilities.' Often laws, regulations and policies at various levels of government lay out the criteria for such categories. Despite disability being on a continuous scale and quite ambiguous, such categories create a perceived dichotomy between disabled and non-disabled (Gordon and Rosenblum 2001). Second, these dichotomous categories can override other characteristics that can contribute to a master status. For example, if one is seen under the label of being disabled, being a woman or being gay may be overlooked or overshadowed as an important part of one's identity. Third, categories create a non-stigmatized group, and a stigmatized other where the stigmatized other is 'visibly present' in comparison to a non-stigmatized person. For example, being able bodied is not connected to someone's master status, but being ‘disabled’ is. Further, Gordon and Rosenblum (2001) argue that with stigmatization comes segregation as seen with special education, intervention programs and the institutionalization of those with disabilities. Lastly, characteristics of those who have disabilities are similar to those from other stigmatized groups (e.g. racial/ethnic minorities, non-heterosexual individuals). For example, individuals within stigmatized groups are often considered lazy, helpless, and/or deviant. Further, persons with a disability are assumed to embody childlike characteristics that include being dependent, helpless and useless. Such attributions are often applied to people whatever their disabilities, relating back to the dichotomous categories - disabled or non-disabled.

Priestly (1998: 81) argues that the social construction of disability is a result of specific cultural conditions. He writes: "[P]eople of difference have existed in all societies, the degree to which they are integrated or excluded will vary according to predominant cultural perceptions of that difference." Juxtaposed with a life course perspective of what is deemed to be normative development, those who fall outside this normative development are considered disabled.

Families that have a child with a developmental disability are often thought of as disabled because of the child (Dowling and Dolan 2001), therefore creating the social construct of ‘a disabled family.' Dowling and Dolan (2001) use the term 'families with children with disabilities' to indicate that families are not disabled by their child, but rather by society. They argue that families with children with disabilities experience a range of inequalities, and these inequalities manifest themselves into a lower quality of life. Dowling and Dolan's (2001) research consisted of interviewing families that had children with a range of disabilities in order to understand how social services disable the family as a whole. Their use of the term families with children with disabilities follows the logic of the social construction of disability, where the emphasis is placed not on the child being disabled, but rather a child possessing disabilities based on societal oppression (Dowling and Dolan 2001).

Understanding disability as a social construct allows researchers to examine various social problems that arise for families that have a child with disabilities. Further, through this framework one can understand the impacts that different policies have on families that have a child with disabilities. A social constructionist approach to disability also gives room to interpret the experiences of disability in a way that can be linked to a life course perspective, as the life course perspective is often recognized as being social constructed as well (Hunt 2005).

### *A Life Course Perspective*

Researchers utilize a life course conceptual framework to better understand the movement, roles and trajectories of people across the life span (George 1993; MacMillan and Copher 2005). Originally the life course was considered a life cycle with normative stages of development and progression across the life span (Hunt 2005). These stages were considered universal and enduring in relation to institutions like the family. However, late and post-modern society with its breakdown of some institutions like marriage (Hunt 2005), have shown that generalizations and predictions over the life cycle are problematic. The life course perspective allows for more flexibility within stages across the life span. Further, within sociology, the 'inevitability' of the life course stages is constantly being challenged by new research. As a result, "sociology verifies that contemporary society with its relativism, pluralism and reflexivity, points to the social construction of such 'stages'" (Hunt 2005:9). Therefore, like disability itself the life course is socially constructed. The life stages, trajectories, and pathways of the life course are then merely a guideline for understanding normative life course projections.

A life course perspective is premised on the notion that "human development involves the order and timing of social roles over the life course" (MacMillan and Copher 2005:858-9), where a role is the position that one occupies within social institutions. Social actors hold multiple roles at any one time (e.g. mother, employee, daughter) and those roles are dependent on the presence or absence of other roles. Further, role configuration refers to the social roles that an individual occupies at any given point in the life course (MacMillan and Copher 2005).

Beyond roles, it is important to acknowledge other concepts of the life course perspective, including transitions, trajectories, and, timing and sequencing. Transitions refer to the movement in and out of different life stages or institutions, roles, and statuses such as child, student, parent, and employee. A transition is then the movement from childhood to adolescence, or from employed to retired. Usually, there are more transitions early in life and fewer as individuals age (Pearlin 2010). Trajectories are the "long term patterns of stability and change, often including multiple transitions" (George 1993:358). An example of an individual’s marital status trajectory over one's life course might be the transition from single to married, then to divorced, then to remarried, and finally to widowed. Trajectories and transitions are interrelated where transitions mark significant role or status changes within life trajectories. Transitions may be compressed or dispersed over time. The sequences and timing of transitions may vary depending on one's life course. However, a normative sequence of life transitions in early adulthood involves leaving school, first full-time job, and then marriage (George 1993).

Another important aspect of the life course perspective is the concept of agency within the life course. Social actors do not live in a vacuum where their lives are completely determined by social processes or social structures, but rather people are also active agents in making choices and decisions that shape their life transitions and trajectories within these social processes and structures (Thoits 2006). Agency becomes an important concept when seeking to understand the control individuals have over their own life course. Agency is also an important concept to explore when understanding caregiving and how it impacts an individual's life course.

Little research using the life course lens focuses on the impact that caregiving has on the lives of parents who are caring for adult children with disabilities. Most often a stress and coping perspective is used to understand the impacts on parents’ lives of having a disabled child (Seltzer et al. 2001). An exception is Seltzer et al.'s (2001) research where the Wisconsin Longitudinal study was used to examine the extent that having a child with a developmental disability disrupted the life course of parents. The researchers examined this at two different life points, when the participants were in their mid-thirties and then 15 years later. They found that parents with a child with developmental disabilities worked less than the comparative group at both points in time. This was especially true for mothers who had the lowest number of employment hours. Further, the social lives of these families were also disrupted. Parents who had a child with a developmental disability had less visits with family than the comparison group. Mothers of a child with developmental disabilities had the least number of visits with friends than any other group (Seltzer et al. 2001). Surprisingly, physical health and mental well-being were not found to be different between the two groups of parents. Such results are in line with cross sectional research that found resilience in parental well-being of disabled children (Seltzer, Greenburg, Krauss 1995).

One area of the life course that Seltzer et al. (1995) found to be clearly disrupted was the child’s transition out of the home. Parents were still caring for their developmentally disabled children when parents were into their fifties. This was different than the comparison group where parents were experiencing the life transition of their children leaving home at the expected time. This finding is similar to McMarle and LeRoux (2001), who argue that certain life stages of families with children with disabilities may be longer or non-existent. As a way of coping, families may then create their own developmental line that does not include all of the normative life course transitions, such as their children’s graduation, moving out, marriage, and grandchildren.

Todd and Jones (2005) found that another stressful point in the lives of parents with children with disabilities is their child’s transition to adolescence. This transition marks not only that their child is aging but also their own transition to mid-life. Therefore, parents, and mothers particularly, are not only experiencing their own mid-life transition, but also an important life transition for their child with disabilities. Todd and Jones (2005) found that this latter transition is especially difficult because it involves the loss of many formal supports such as school (completed in Ontario at the age of 21), which had helped relieve some of the caregiving responsibilities from carers. Further, Todd and Jones (2005) found that mothers were anxious about the future as support services became less predictable. Todd and Jones (2005) argue that policy does not recognize this convergence of life transitions.

This convergence of life transitions of the parent and the child is captured by the life course concept of 'linked lives.' Caring for a child with a disability creates an instance of linked lives, whereby individuals are impacted by larger social changes, which impacts their interpersonal relationships (Elder et al. 2003). For example, giving birth to a child with developmental disabilities creates a turning point in the life trajectories of the parents (Seltzer et al. 2001). Aging with a lifelong disability shapes not only the life course of the individual but also their family members (DeMarle and le Roux 2001; Dowling and Dolan 2001; Whitaker 2013). Parents of children with disabilities, perhaps more so than other parents, have lives that remain particularly connected to their child, and therefore their child's turning points and life trajectories throughout their life affect the parent’s life course. This is especially true related to the parent’s role as caregiver.

Another life course concept related to linked lives is turning points. A turning point, as defined by Elder, KrikPatrick and Crosnoe (2003), is a substantial change in the direction of one's life. A number of significant turning points occur in the lives of the participants, related to their child, including the day that they learned that their child was ‘disabled.' Here, the normative life course trajectory may be disrupted from the beginning (Seltzer et al. 2001).

Priestly (2002) argues that social policy is actually life course policy where traditional frameworks for a 'normative' life progression are used as the basis for policy creation and implementation. A life course perspective represents the way in which lives are divided into stages or phases of life, and how one's life flows through such stages (Priestly 2000:426). He argues that such stages are socially created, not biologically determined, and that the "construction of the life course is culturally embedded and socially contingent." The stages expected through a life course lens become limited or altered in terms of disability because relevant labels do not exist for unique stages of the life course, for example, independent adulthood for those with disabilities. What is more, labeling new life stages for those with disabilities is difficult because of the societal expectation that there is only one type of adulthood – independent adulthood. Priestly (2000:430) concludes that as a result of the social construction of the life course, disability has been constructed as an enduring 'adolescence' that leaves "many people (often with learning difficulties) to a nether world of unresolved transition in which true adult status is neither envisaged nor attained." This group of people is often marginalized because they are disabled, young, and permanently 'in transition.' This conception is worth exploring when one considers current Ontario disability policy that has put independent adult life on hold for those who have been put on waiting lists for social support services that might allow them their independence. The social construction of disability approach and a life course perspective will guide this research and provide a framework for understanding the experiences of families who have an adult child with disabilities. The intent is to fill in some of the gaps related to the lived experience of parents of children with developmental disabilities in the disability caregiving literature.

# LITERATURE REVIEW

## CONTEXT OF CAREGIVING

Caregiving is typically divided into two forms, formal and informal (Damiani et al. 2003), and sometimes a third type (self-care). Formal care most often involves paid labour (Duffy, Albedla, and Hammonds 2013) and is facilitated by paid care providers, not by family or friends. In contrast, informal care is typically performed by family members or friends (Duffy et al. 2013). The majority of informal care is often performed by women. Informal care has been defined by Beigel, Sales, and Schulz (1991) as providing extraordinary, uncompensated assistance that is often long term (months or years) to others mainly within the home. Such tasks performed may be physically, emotionally, financially and socially demanding and require large amounts of time and energy. Examples of tasks include personal care, helping with medical needs, and providing social support. Pearlin and Anaseal (1994:146) suggest that paid and unpaid care can at times substitute for one another, but very often both are important and complementary to each other as "providing care involves a complex network of unpaid family members and paid care workers whose labor supports and enhances each other."

A small but growing body of research has sought to understand the caregiving experiences of family carers of children with disabilities. This research has focused on financial impacts, well-being, experiences of informal care, and formal care. Informal caregiving is the primary focus of this literature review.

## INFORMAL CAREGIVING

Family members are typically the primary caregivers for their children, grandchildren, spouses, and older parents. As a result, the family caregiving literature is immense. Yet, despite the vast amount of research on family caregiving, there is no single universally agreed upon definition of caregiving (Ory, Yee, Tennstedt, and Schultz 2000) or family caregiving (Grant, Nolan, and Keady 2003). Broadly defined, caregiving refers to "helping behaviour that provides, or is intended to provide aid or assistance to individuals in need" (Brown and Brown 2014:75).

It has been found that the majority of children with disabilities living with parents are in fact adults (Shearn and Todd 1997). Moreover, the age at which caregivers are caring for their disabled children is on the rise. Within Ontario, a growing proportion of caregivers are entering their sixties and older (Community Living Ontario 2013).

Caring for a child with disabilities often spans more decades than caring for children without disabilities (Todd and Shearn 1996). Families that have children with disabilities often experience adverse effects on physical and psychological well-being (Eker & Tuzun 2004; Ward et al. 2014), and have less opportunity to engage in non-parenting activities like social activities outside of the home (Haley and Perkins 2004; Ward et al. 2014). Murphy et al. (2007) have found that caregivers also have less time for self-care, care of other family members, and other daily tasks. Research has also shown that families with children with disabilities often have higher levels of financial stress and out of pocket expenses than other families with children. Fast, Keating, and Yacyshy (2008) compared the consequences of supporting adults with spinal cord injury, cerebral palsy, or schizophrenia with veterans who have service related injuries. They concluded that families that supported adults with disabilities had high levels of economic challenges including reduced income, loss of benefits and retirement pensions, or the ability to save for retirement. Further, all experienced greater out of pocket expenses including medical travel expenses, with over one third of caregivers paying more than $5,000 a year for these expenses. Moreover, families with an adult with cerebral palsy had the highest financial hardships including reduced earnings and benefits, and perceived financial hardship (Fast et al. 2008).

Financial and employment strain has been linked particularly to mothers of children with disabilities. Mothers of children with disabilities often experience employment reduced to levels of mothers with young children (Glendinning 1992). Shearn and Todd (2000) found in their qualitative study of 18 mothers of children with disabilities and 80 survey participants, mothers often could not work due to their caregiving responsibilities. When mothers did work, it was often part-time, or for no overall financial gain because of the costs of specialized childcare that was required to allow them to work (Shearn and Todd 2000). Further, these participants felt that the time demands placed on them were far greater than mothers of children with no disabilities (Shearn and Todd 2000). Finding employment that was flexible and understanding of their children's care needs was difficult.

Lewis, Kagan and Heaton (2000) interviewed 32 families and ­­eight single parents to gain an understanding of family/work dynamics. As previous research has shown, many families with a child with disabilities experience financial burdens**.** Lewis et al. (2000) concluded that for the majority of participants, a dual income was necessary for families. Work for these participants was found to be negotiated with care situations based on constraints and supports of each family situation. Work and care decisions were constructed by participants as choices, however, they were constrained choices (Lewis et al. 2000). Choices were constrained by family size, nature of the child’s disability, availability of appropriate care services, employer support, and flexibility of employment (Lewis et al. 2000). In order for families to have dual earner income available, support services in the community were necessary along with flexible and supportive employers (Lewis et al. 2000).

A gendered division of care is not uncommon in caregiving broadly, with women providing the majority of family care; the literature in general supports such findings (Lewis et al. 2000; Parish 2006; Shearn and Todd 2000). Parish (2006)sought to understand the supports available to working mothers of an adult child with developmental disabilities, as well as how these mothers balance their work and caregiving responsibilities. Two focus groups, with two sets of participants, were utilized to answer these questions. Participants reported issues regarding support services. Despite support services being helpful for participants and their families, participants found that the services were inadequate. These services were most inadequate during the summer months and days when school was not in session. Additionally, there were concerns from participants about the 'drastic' decline in support services once children reached adolescence.

As a result, mothers experienced a lot of stress securing and arranging support for their children. This led to additional stress associated with balancing work and family responsibilities and arranging quality care for their child. Part of the concern over quality of care was related to high caregiver support turnover (Parish 2006). This is similar to Getch’s (2012) findings that suggest caregivers experience difficulties finding affordable quality care, which can increase stress and caregiver burden. Further, like Lewis et al.'s (2000) findings, inadequate caregiving support was the main reason mothers had to reduce or end their employment. Lack of caregiving support also affected the type and number of hours mothers worked. Such experiences lead to high stress levels among the mothers, and feelings that they carried the burden of caring for their child. Getch (2012) notes that these feelings can be framed under caregiver burden, defined as "the extent which caregivers perceive their physical, psychosocial, emotional, social, and financial problems as a result of providing care for their family members" (pg. 30 as cited in George and Gwyther 1986).

This burden of care was also found by Miltiaes and Pruchno (2001). A growing trend of deinstitutionalization of persons with developmental disabilities, coupled with longer life spans means some mothers are caring for their disabled children for over half a century. By extension, mothers’ work force participation is adversely affected, and subsequently the duration of feelings of helplessness and caregiver burden.

Caregiving burden was further emphasized by Hooyman (1992), who contends that caregiving policies often assume that women are available for the majority of care work. As a result women's economic status suffers, as they have to leave the workforce more frequently than men. There are higher levels of unemployment for parents where a child is disabled. Mothers experience stress related to financial, emotional, social and caregiving responsibilities. Families with a disabled child experience greater financial burdens even after a child's death.

Cant (1992) found that mothers can feel isolated within the community. Cant (1992) interviewed 73 mothers in Australia who cared for their disabled child. Cant (1992) concluded that having a child with a disability can close opportunities for socializing, as mothers may fear reactions to their disabled child by others. Similarly, Yantzi et al. (2006) concluded that mothers are dependent on external supports in order to have their own time and social life. External supports can help mitigate the negative effects on carers. Such experiences may lead to mothers (and parents more generally) feeling 'captive' by their parenting roles (Todd and Shearn 1996).

A 'captive' parent is described by Todd and Shearn (1996) as a parent who felt they could not participate fully in the same social or work world as their peers; they felt that their parenting restricted them from participating in the nondisabled world. In contrast, a 'captivated' parent was defined as a parent who felt that the parenting role was important and central to their identity. Captivated parents also viewed caregiving as a positive life experience.

Conversely, Scorgie and Sobsey (2000) discuss that caregiving can be a positive transformational process. Scorgie and Sobsey (2000) concluded that in general participants who had children with developmental disabilities had positive or beneficial outcomes. These outcomes came in the form of 'transformations.' Such transformations included: personal transformations like gaining new skills and roles; relational transformations such as learning to relate better to others; and perspective transformations which included the participants trying to make the best out of each day. The results of Scorgie and Sobsey (2000) study support that although there are challenges to caring for a child with disabilities there are also positive outcomes.

## FORMAL SUPPORT SERVICES

With the privatization of care and deinstitutionalization, new forms of funding have been created to give support to those with disabilities and their families. Some research has begun to focus on the restructuring of the welfare state where public care is increasingly becoming a private matter (Oliver 1996). Caldwell (2007) identifies a growing form of formal support known as 'direct payments,' 'consumer direction,' or 'cash counselling,' where the main intent is to give more authority to families in the design and direction of services. Families often receive control over resources, usually provided by the government in the form of cash allowances or individualized budgets (Heller and Caldwell 2005).

Caldwell (2006; 2007) and Heller and Caldwell (2005) used data collected from a survey distributed to the Illinois Home Support Services Program in order to measure the impact of this program (294 participants were surveyed, 9 participants were interviewed). A budget of approximately $1,656 a month was given to adults with intellectual disabilities to access services including respite, personal assistance services, home modifications, assistive technology, employment services, social/recreational services, therapies and transportation (Caldwell 2007). With this program individuals could also hire their own family members for caregiving support.

Many benefits to this program were found: (1) it allowed carers to work outside the home or be paid for caregiving; (2) it provided a break from caregiving, allowing for personal time with other family and friends; (3) it prevented institutional placement (Caldwell 2007). Additionally, the program provided greater access to health care for fewer out of pocket expenses (Caldwell 2006). When comparing families that have direct funding to those on a waiting list, families with direct funding used more respite services and personal assistant services, and spent less money out of pocket than families on a waiting list. Further, there were greater benefits to low-income families including better mental health and access to healthcare, than those on the waiting list.

Caldwell (2006; 2007) and Heller and Caldwell (2005) concluded that there are many benefits to direct services. Further, there is a broad demand for this kind of funding (Heller and Caldwell 2005). Despite the benefits and demand, there have been few research studies that have examined the impact of this form of funding on families (Heller and Caldwell 2005). Moreover, research on direct payments has been mainly quantitative in nature. Little research focuses on the impacts that this form of funding has at a qualitative level. Additionally, research is concentrated within Britain and the United States. No known research looks at the qualitative impacts of such funding in Canada, and Ontario specifically.

## ONTARIO SUPPORT SERVICES

Within Ontario the main body of funding for families with disabled children falls under the Ministry of Community and Social Services. Disability policy for social support services is legislated under the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008 (Services and Supports Acthereafter). This act outlines the process for access to direct funding and support services for those with developmental disabilities. As part of the eligibility criteria for direct funding and support services, applicants must also prove their children are developmentally disabled through assessment that is conducted by a professional deemed appropriate by the Services and Supports Act. The act states:

A person has a developmental disability for the purposes of this Act if the person has the prescribedsignificant 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 life-long 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 (Government of Ontario 2008:1-2).

Moreover, eligibility requires the individual with the developmental disability to be 18 years of age or older and residing in Ontario. Once eligibility has been established, persons with developmental disabilities are further required to partake in another assessment process that takes "into consideration the preferences of such persons" (Government of Ontario 2008:9). This assessment is part of the "Service and Support Profile" (Section 17 of the Act) that is used to prioritize the needs of applications for direct funding and social services. Once the assessment is complete, families are then put on a waiting list for services such as the 'Passport Program.'

The ‘Passport Program’ is an initiative that helps adults with developmental disabilities to participate in their communities. Passport funding follows the premise of the social model of disability, where, "[P]eople who have developmental disabilities are [considered] members of the community... focus[ing] on independence, dignity and self determination" (Government of Ontario 2014a) of these individuals. The Passport Program is considered a direct consumer funded program whose key goals include: fostering independence; increasing opportunities for participation in the community; promoting social inclusion; transitioning from school to life as an adult; and supporting families and caregivers of an adult with a developmental disability (Government of Ontario 2014a). The Passport Program is funded by the Ontario government and administered through local passport agencies within cities across Ontario. Unlike other direct services discussed in the literature, passport funding does not go directly to families, but rather is monitored and administered through local agencies.

Passport funding has a maximum allocation of $35,000 a year for those who qualify. This funding can be paid in two ways: through a passport agency, or by families managing their own supports and finances with the aid of support service agencies such as the Victorian Order of Nurses (VON). Families may use the money for support including community service providers, developmental service agencies, private services and support providers, adult education providers, personal support workers, neighbours, non-primary family members, and friends. Unlike the direct funding that Caldwell (2006, 2007) examined, passport users are not permitted to use the funds to pay primary caregivers. Passport funding may not be used for living expenses, medicine, fees for therapies, specialized services, assistive devices/technologies or other out of pocket expenses (Government of Ontario 2014).

Currently in Ontario there are waiting lists of 8,000 families seeking Passport funding (Community Living Ontario 2013). Moreover, families that do receive funding are averaging about $4,200 dollars a year; this translates into about eight hours of support a week (Community Living Ontario 2013). The current Ontario government has promised $810 million dollars over the next four years in new funding for Passport and other support services for those with disabilities (Government of Ontario 2014b).

In addition to passport funding, those who have disabilities may also receive financial assistance from the Ontario Government through the Ontario Disability Support Program (ODSP). One of the main goals of this program is to provide financial support for those that the government identifies as having a disability. To be eligible for ODSP one must be 18 years of age or older, live in Ontario, be in need of financial aid, and have a disability as defined under the Ontario Disability Support Act. One is considered disabled if one has a 'substantial' physical or mental impairment that is recurrent and expected to last a year or more. Further, the impairment must restrict the individual's ability to work, take care of oneself, and participate in the community. The disability must be verified by a health care provider (Government of Ontario 2014c).

The Ontario Disability Support Program has two components: basic needs and shelter allowance. Financial aid is provided based on cost of food, clothing, and other necessary personal items in addition to the number of people in one's family, disability status of other family members, and age of family members. The shelter allowance is allocated to help cover the cost of rent, heat, utilities, property taxes, home insurance and condominium fees. If one lives in the same place where food is also provided such as at home with parents, a different (reduced) amount of money is allocated to the candidate. ODSP is given out on a monthly basis with a maximum allowance each year (Government of Ontario 2014c).

## CHALLENGES WITH SUPPORT SERVICES

Despite funding for the Passport Program being public, the intent of Passport funding is to move public care to the private home. This can be seen as both empowering and disempowering. The funding allows for more control over resources and to tailor services for a child (Caldwell 2007) but it also runs the risk of leaving families to find their own care. Within the neoliberal society that emphasizes private solutions to caregiving, families must resort to finding their own private means of care through private services or informal supports like family and friends (Boyce, Krogh, Boyce 2006; Kiefe, Legane and Carriere 2007; Lord and Hutchison 2011; McColl et al. 2006).

Research on primary caregivers has investigated the ways services can affect caregivers when there has been a shift to private care. Research has shown that at a broad level there needs to be a national policy for family members that care for disabled elderly (Kiefe et al. 2007). Such a policy need could be extended to families that have children with disabilities. The majority of care services have been found to fall short of family care needs (Damiami et al. 2003). Lord and Hutchison (2011) found that participants of their study did not feel that their formal support services provided enough care support, and identified feeling the need to rely on other family or community supports.

Other issues with formal supports have been found. The process of obtaining social services or funding for social services is often long, slow, time consuming and complicated, which can cause a great deal of anxiety and stress. Long waiting lists are due to a lack of funding and competition with other families. Participants in Dowling and Dolan's (2001) study felt that respite care was often service-led instead of needs-led, meaning that many times families felt there were gaps in the services they received.

Research has found that respite and other social support services are important for families that have children with disabilities (Shearn and Todd 2000; Yanzti et al. 2007). The majority of research in this area focuses on respite care specifically. Respite care is defined as care that is done by formal care workers both inside and outside of the home that provides short breaks to caregivers (Damiani et al. 2004). Respite care remains a vital aspect to the well being of families with a child with disabilities (Diamani et al. 2004; Doig et al. 2009; McConkey et al. 2004; Mullins et al. 2002) because it allows caregivers a break from caregiving in order to spend time with family or care for their own needs (Diamani et al. 2004; Doig et al. 2009, McConkey et al. 2004; Mullins et al. 2002).

Despite the benefits that have been seen with social support services, flaws in these systems and supports have also been found. Many services are not adequate enough to cover all of the family's needs (Diamani et al. 2004; Yantzi et al. 2006). Yantzi et al. (2006) found that mothers depended on respite services, but these services did not always meet their needs. Some mothers required nurses to provide medical care as part of respite, but were often unavailable due to cost (Yantzi et al. 2006). Mothers also stated that respite was limited during important times like summer or days when school was cancelled. Dowling and Dolan (2001) found that the way the services were provided was often inadequate. Families found the services to be inflexible and felt that they had to fit the service instead of the service fitting the family needs.

Morris (2004) considers the services for independent living to be a disempowering model. Morris (2004) outlines issues with the British model (similar to Canada's model) where there is a duty to provide services instead of giving rights to individuals to receive supports. There is no entitlement to live at home as an alternative to residential care, and not enough money is given to cover leisure, work, and relationships or to look after children. Further, individuals have to look for separate supports for education, work, and help within the home. As a result, there is inappropriate support when trying to use direct payments as it can be difficult to access advice and systems of advocacy for clients.

Research has explored the issues surrounding support services. Most of the issues are concerned with respite care. A limited amount of research has focused on other forms of support, for example, the new direct payments that are being used within Britain, the US and Ontario. Additionally, little of the research explores in any depth the impact that these gaps in services have on caregiving experiences. Research shows there is stress to the caregivers (Dowling and Dolan 2001; Yantzi et al. 2006) and financial burdens but little is explored beyond this. Moreover, little research examines these impacts on families through a life course lens, a theoretical framework I employ in this research.

The goal of this thesis is to begin to fill in some of the gaps in the literature. Specifically, this research seeks to give more understanding to how Ontario policy and support services impacts the lived experience of the participants. Further, by highlighting the lived experience of participants this research gets at both the burdens in care and the positive aspects of care that the participants experience. This is in contrast to the majority of the literature that focuses on the burdens in caregiving and overlooks the positive experience that caregiving for a disabled child can give (Brown and Brown 2014). Finally, by employing both a life course and social constructionist lens, this research provides a new understanding to the lived experience of caregivers of adult children with developmental disabilities.

# CHAPTER 2

# METHODS

This qualitative research explores the caregiving experiences of families that have an adult child with developmental disabilities, and particularly how caregiving is experienced by parents who are primary caregivers. As such, one main research question guided this thesis: *What are the lived experiences of primary caregivers caring for an adult child with developmental disabilities?*

To answer this question semi-structured, face-to-face qualitative interviews were conducted with nine parents who were primary caregivers to their adult child with development disabilities. In this chapter I review how I recruited my participants and conducted the interviews. What then follows is a summary of some demographic characteristics of the participants. Lastly, I describe the way in which I analyzed my data.

## RECRUITMENT

This research sought to understand the experiences of primary caregivers who have adult children with developmental disabilities. As such, after acquiring ethics clearance, I sought both male and female carers who defined themselves as the primary caregiver of their adult child with developmental disabilities. The criteria for inclusion in this study were: the parent had to identify his or her child as developmentally disabled; the child needed to be 18 years of age or older; the child needed to live at home and require enough care that they could not live on their own without support. These criteria were chosen as I am interested in the experiences of carers of adult children with developmental disabilities who need care beyond what is considered 'normative' for their age. The participants came from two geographic locations - Hamilton and London, Ontario. These locations were chosen for geographical access, and for my connections with disability communities in both regions.

For this research, I used both community organizations and community member connections to recruit possible participants. It has been shown that knowing someone within the research population you seek to understand is important and useful as it provides the researchers with a faster and more effective means of making contact with participants (Clark 2010). Specifically, community organizations can be important for quickly and effectively gaining contact with potential participants because organizations have access to hard to reach groups and bridge the gap of trust between participant and researcher (Clark 2010, McAreavey and Das 2013; Mulchay 2012). Therefore, before recruitment took place I met with the head of a local disability support agency in London, Ontario. There, the intentions of my research were laid out. Research by Mulcahy (2012) shows that it is important to gain trust with such agencies because they are the gatekeepers to the rest of the community.

The initial meeting was quite successful. The CEO of the agency offered to pass around my recruitment information to their clients in addition to posting my recruitment poster within their office. This meeting yielded contact with only one participant who worked at the agency. No further participants were recruited through this agency.

To recruit more participants, I sought out other disability support organizations (including Victorian Order of Nurses, Community Living Hamilton, and Community Living Ontario) within the Hamilton and London regions. These organizations ranged in the types of support they provide to families with children with disabilities including respite support, housing, passport funding services, and formal support services. Seven organizations in Hamilton and three in London were contacted. Organizations were contacted in three ways: by physically going to the organization when possible; through sending emails to program co-ordinators and general managers; and phone calls to organizations. In person visits to organizations proved to be the most successful for gaining contact with employees within the organization. Email was also a successful strategy for making contact within some organizations. Phone calls were not successful, as no one was willing to communicate over the phone.

While the methodological literature suggests that there are advantages to working through organizations (Clark 2010), this strategy was not particularly effective for recruiting participants. Of the three organizations I was able to meet with, none were willing to place my recruitment poster within their organization. Two reasons were given for not doing so: no place to put the poster, and the organization not having a lot of potential participants come into their building. Of the emails I sent to the organizations only one responded. This organization agreed to pass my recruitment information on to their clients. One potential participant responded to the recruitment information but later declined to participate.

Using disability organizations proved to not be a successful way of recruiting participants. This is mainly due to gatekeepers within the organizations. Because I was an outsider to the community (See Corbin-Dwyer and Buckle 2009), organizations may have been hesitant to work with me. Some potential reasons for this could include: fear of negative perceptions of the organization (Clark 2010) as they want to maintain their reputation (Mulcahy 2012); or disruption to the agency including loss of resources like time and money (Clark 2010).

My second form of recruitment, snowball sampling, provided to be more successful. My previous experience working in the disability community had given me contacts with parents of adult children with developmental disabilities. Two of these parents agreed to be interviewed. One of these participants then referred me to three other participants. Another participant was recruited from my previous volunteer work within the community. Two other participants were recruited through help from peers in my academic cohort, where my peers contacted potential candidates and provided them with information about my research. This recruitment strategy, while challenging, yielded a diverse set of participants.

## INTERVIEWS

In this qualitative study, all semi-structured interviews lasted between 45 and 75 minutes. All interviews were audio recorded. Nine participants were interviewed in total – eight women and one man. The interview guide for the research can be found in Appendix A. During these interviews the following topics were covered: daily caregiving routines; types of funding support; how one finds support workers; how care impacts carers and their child; use of informal supports; challenges carers face with regards to caregiving; and the positive experiences carers have had due to their caregiving.

Seven of the nine interviews took place within the participant’s home. One interview took place at a coffee shop, and one at the participant’s place of work. The home was the preferred interview location as it did not require participants to commute. It also tended to be a quieter space. Having the interviews within the home also gave me a better understanding of family dynamics, and allowed me to meet some of the participants' children. Meeting the participants' children helped me build more rapport with the participants. Further, it provided participants the opportunity to include their child in the interview. Three participants, Jackie, Julia and Lisa[[1]](#footnote-1) wished for their child to be included in the interview. I felt it was important to allow participants this opportunity, as it supports the inclusion of persons with disabilities in the research process. The option of including one’s child in the interview was made clear in the research information letter, as well as when I spoke with participants to organize the location of the interview. The participants’ children that were included within these interviews were all non-verbal and so did not contribute verbally to the interviews. They however, actively listened to the interviews and expressed agreement or disagreement with the answers that the participant was providing.

## PARTICIPANTS

Eight of the nine participants were the mother or father of the adult child. One participant, Jackie, was a guardian as she fostered her 'son' Ben. Participants ranged in age from 40 to 65. The participants’ children ranged in age from 20 to 33. There were six adult sons with disabilities and three daughters. More details about family characteristics can be found in Appendix B.

The range of disabilities that the participants’ children had was broad, including Asperger syndrome, Autism, Down Syndrome, Cerebral Palsy, and undiagnosed developmental delays. Some participants’ children had concurrent disabilities. For example, Ben (Jackie’s son) had Cerebral Palsy, epilepsy, and was classified as deaf and blind.

All participants’ children were on the Ontario Disability Support Program (ODSP). The amount of funding they received was less than the regular amount provided by ODSP as all participants’ children lived at home. Two of the participants’ children had no other source of funding to help support their child. The other seven participants’ children had various forms of funding including Passport funding, At Home Special Services Funding, medical funding, or access to a day program of which costs were covered. Some participants' children had more than one form of funding. For example, Justin (Lisa's son) had ODSP, passport funding and 40 hours a week of a funded day program. Ben had ODSP, passport funding, medical funding for being deaf and blind, and funding for being a Crown Ward. Funding amounts varied greatly from $5,000 dollars to $35,000 or more a year. A more detailed look at each participant’s funding can be found in Appendix B.

Of the nine participants, Lisa, Amy, and Jim worked full-time. Penny, Polly, Grace worked part-time (Grace was unique as her work schedule alternated from one week on full-time and then one week off). Jackie, Sally, and Julia were not employed outside of the home. All of the participants except for Jim had a spouse. The diversity of my participants’ lives and experiences allowed for an in depth and rich data analysis.

## DATA ANALYSIS

My analysis of the data began with producing verbatim transcriptions of my interviews. I then printed and conducted an initial reading of the transcripts, looking for themes and concepts that emerged from the data. It was clear from the initial analysis that the nine interviews had begun to reach saturation as many of the same themes repeatedly emerged. Layden (2013) suggests that for the initial data analysis the research should use orienting concepts created from the literature review and other existing literature to start off the coding process. Layden (2013:155) recommends the researcher "break it [the data] up and organize it into meaningful segments so that they can be identified and retrieved from their original context (notes, interview transcriptions, documents), and then either examined in more detail or used to illustrate points in your final report."

Orienting concepts are preliminary concepts used to help filter and analyze the data. They are used to help structure one's analysis at the beginning phases to help determine what parts of the data fit with the research question and problem. Layden (2013:135) states that "orienting concepts should be chosen for their power to guide the analysis, *not to determine or preconceive it"* (emphasis theirs). Orienting concepts that were used included 'funding', 'care', 'disability', 'support', and 'future.' These concepts were based on previous literature that deals with issues around disability funding, challenges to care, disability experiences and definitions of disability, support programs and resources for care, and future concerns about care of the child.

After the initial coding using orienting concepts took place, the data was analyzed using a technique suggested by Rubin and Rubin (2005). They indicate that interviews should be analyzed based on a recognition of concepts, defined as words that represent an idea important to the research problem; as well as themes, which are a summary of statements and explanations of what is going on. These themes and concepts emerged in many ways, which were also in line with Rubin and Rubin's (2005) suggestions for emerging themes. Themes and concepts were found based on previous literature, questions asked, unexpected answers, commonalities in responses, stories expressed, concepts and themes that came out of other concepts and themes, and concepts/themes found to be interesting and relevant to my research question.

As I went through the transcripts, I labelled such concepts and themes, and then grouped the same labels together. During this process, I kept my orienting concepts in mind and modified them as the data emerged. Using these two methods allowed me to remain organized in my analysis, but also open to emerging themes and concepts not originally anticipated. These themes are discussed in the analysis chapter that follows.

# CHAPTER 3

# ANALYSIS

Three major themes emerged from the interviews. These themes all fall under the heading of "tensions" which emphasizes that participants are being pulled into two different directions in their experiences of caregiving. The three main themes are: tensions between policy and reality; tensions in access to care; and tensions in caregiving experiences.

*Tensions between policy and reality*

The first tension lies between policy objectives to provide support services for families with children with disabilities and the reality for families. The tensions exist because families want to view their child in terms of the child's abilities. Yet, disability policy and evaluation services for care emphasizes the deficits of the child (i.e. the coexistence of empowerment and disablement). This creates a tension between the positive intents of the policy and the negative experiences of families. Further, these service evaluations mandated by policy have created large waiting lists that then cause tensions for the family as they cannot adequately prepare for supports in caregiving.

*Tensions between services agencies and lived experience*

The second tension can be seen when discussing the disability services themselves. Though the intent of these services is to provide adequate services and care to those with disabilities, participants are not satisfied with these services. This creates tensions for the participants, as they have to learn to negotiate care at a formal and informal level. For some, this involves relinquishing caregiving control to an external source. Lastly, support for the transition to adulthood creates tensions in these participants as they have to learn how to cope with their child's 'stalled' transition to adulthood

*Tensions in caregiving experience - burdens and rewards*

Lastly, tensions are present where participants emphasized the rewarding aspects of caregiving, suggesting it enriches their lives. This is in contrast to their experiences of burden when looking after their child with developmental disabilities. Participants thus view their caregiving situation with some ambiguity.

## TENSIONS BETWEEN POLICY AND REALITY

In this first theme, parents struggled to emphasize the positive qualities and abilities of their adult child with disabilities. The policies dealing with care for the participants children emphasize the same intent, however, in reality these policies do the opposite. In order to establish the needs of the participants' children, services emphasize what the child cannot do, focusing on the child's deficits. This creates a tension between the parents desire to present their child as less disabled and the parents' desire to have support for their child. As a result, parents must emphasize the disability of their child in order to get funding from the government. If parents successfully present their child based on the child's deficits it may only get them as far as being put on a waiting list. If the participants are lucky enough to get funds to help support their child, often these funds are limited. Families face tensions when deciding how to present their child, and whether presenting ones deficits is worth the result of a waiting list or limited funds. For those that do pursue this path, frustrations with the process arise. Participants that chose not to pursue formal supports participants must then negotiate and organize care on their own.

### *Tensions with Policy*

As seen in the literature review, the Services and Supports Act is the main act through which supports and services for those with disabilities is legislated under. As part of this act, the mandate is to help promote the social inclusion of those with disabilities. This is done through: residential supports, activities of daily living supports and services, community participation supports and services, caregivers respite, and person directed planning supports and services. In order to access these services, a person must be assessed under the mandate of theServices and Supports Act.

There are however, concerns over this assessment process as families have found the process to be demeaning, frustrating and deficit based. There is a tension between what the assessment is supposed to accomplish - a priority list for providing support services and direct funding - and how participants interpret the assessment. Julia expresses her frustration with the process:

they put a 'gazillion' dollars into hiring people to do those big assessments on every adult that take hours and hours and hours, but at the end we don't know what they are going to do with it [does this translate into funding] does this translate into a priority list or anything? But it's all for nothing. They are doing it for a waiting list. So families are, and you have to do it and it's a horrible process.... the process now, the application and, you do an application which is all deficit based. And then you do a support intensity scale which is even more deficit based. It's all based on trying to make it look as needy as possible. So I think it's an awful process.... It's a difficult process. *(Julia, Mother of Jason)*

Julia goes on to explain how after the 'difficult process' there is nothing substantive at the end for those that participated in it.

And the hardest part of this whole thing is that there is nothing at the end, and it's such a lengthy process. We knew the process and got through it in six hours, whereas I know people that it took 12, 14, 16 hours with the person coming back like three times to finish it. Because they are such difficult questions. Like, could they have made it a little simpler and not have taken as much money and people to do those assessments so maybe there's some money at the end for some people? Would that not make some sense? But now they are just having to re-assess every single person over the age of 18, and they are way behind with that. *(Julia, mother of Jason)*

This quote highlights many of the issues participants find with this new assessment. First, the intent of the assessment is a priority list for support services, but as Julia points out, there is no result at the end of the assessment besides a waiting list. Issues with waiting lists are further discussed below. The main challenge with this assessment, as Julia indicates, is how deficit based and 'horrible' the process is.

Sally furthers Julia's sentiment by calling the assessment 'stupid' and describing it as a 'bunch of cant's':

**Interviewer:** And what did you think of the assessment?

**Sally:** I thought it was stupid.

**Interviewer:** Why did you think it was stupid?

**Sally:** Just asking me the questions of, you know "what does she need help with on a scale from one to five?" "Does she need help with brushing her teeth?" "yes", "does she need help with getting the toothbrush?", "yes". I mean I get that they are trying to put the people in the right spot with the right care, but it doesn't take much to meet most adults or children and figure out what they need help with. And a four hour waste of time paying someone huge dollars when that could go to housing.

**Interviewer:** Right. um, and I've heard from other people say that the whole system is deficit based. It's sort of like, looking at all of the things that your child can't do. Did you find that?

**Sally:** Yes. What do they need help with, can they do this, you know, and everything - at least in my case it's like 'no' she can't do it. Look at her, she's in a wheelchair. She can't dress herself, she doesn't go to the toilet, she wears diapers. It's all cant's really.

(*Sally, mother of Jessica)*

In line with the deficit based approach to the assessment comes the observation that in general, to get funding, one has to present their child as disabled as possible. This can be seen not only in the assessment process but also in other funding bodies such as Passport funding. Presenting one's child as disabled goes against the policies that the government of Ontario tries to promote. Amy explains what it is like.

These are the situations. You have to almost present yourself in the worst case scenario to get the most funding. It's been like that since day one. The worst you can show that your daughter is in need or child is in need the more funding you get....Whereas in the reports in order to get funding you almost had to close your eyes and say what they wanted to hear. (*Amy, mother of Kerry)*

Polly's words parallel Amy's. She says:

You just have to be so negative and that's just the way it's always been. And I mean with Jackson from when he was young I had to figure out pretty fast that I had to use 'Autism' as his label instead of 'Aspergers'. Because people didn't understand what that was and at least Autism is a little more clear. But just to get a little bit more support.

(*Polly, mother of Jackson*)

Not only does presenting a child as disabled create a tension between policy and lived experience, it also creates a tension in how parents must present their child versus how they see their child. These participants want to focus on the positive aspects of their child, not on the disability. However, assessments and procedures for funding qualification force the participants to focus on the 'cant's' rather than the 'cans.' Amy explains that she is not used to describing her child in terms of her child's deficits. She says:

If you say you know we as parents, we aren't used to saying well our kid can't do this and can't do that. We are used to saying oh my gosh look at her walk today, oh my gosh, look at her do this independently. (*Amy, mother of Kerry)*

As such, parents become conflicted by the way they must describe their child. As a consequence, such policies and criteria that determine eligibility for funding may actually be creating a child that is seen as more disabled than they actually are. This is contributes to the social construction of disability, where a disabled person is considered disabled based on assumptions of what they can and cannot do. Although it is important for these assessment processes to establish what the clients can and cannot do in order to find the right support fit, there is a disconnect between the assessment process and the families' experiences and what they must go through for that assessment.

Another disconnect between the policies and participants' was found in funding and support. Developmental Services Ontario (DSO), the main body through which families of children with disabilities engage with for support, states that one of funding and services primary goals is to increase community engagement among those that have disabilities. Further, the Services and Supports Actstates in the title itself that the objective is social inclusion. Despite this intention, participants feel as though there is not enough support provided in order to promote adequate community engagement. Sally explains what her 'At Home Special Services' funding covers for her daughter Jessica.

**Interviewer: ...**the funding for respite camps, the summer camps, the overnight respite that she does, um is that out of your at home services funding or is that in addition?

**Sally:** ...we can use our funding to pay for that. That's the nice thing that they did change a few years ago with respite services. I can use, you know if I have a worker take her out and I use bus tickets and I keep the receipt I can get that money back. Or they will respite, they will pay for respite, they will pay for camp. They will pay for people to come in and help with her. But... it's not enough. *(Sally, mother of Jessica)*

Though funding does help cover the cost of respite for Jessica, which allows her to do some activities in the community, Sally made clear in her interview that it is not enough funding. Julia furthers this by explaining recent policy changes that have resulted in a lack of funding and ultimately, a long waiting list. She says:

...Now they, what happened a couple of years ago is they restructured it and made it Special Services at Home just a program up until the age of 18 so then that, that's how they changed it so they could fund the big waiting list for zero - five [years of age]. So they cut everybody over 18. And now they [families] are eligible for 'Passport Funding' but they [government] didn't put any money into it [passport] so people who got cut off now have no money... so at 18 they cut you off Special Services at Home - and some people got completely got cut off of what they had. But you couldn't apply for passport while you were still in school and a lot of them stayed in school until they were 21.

**Me:** Right, so there's a three year gap there. And then I'm assuming that with that three year gap there would be a waiting list?

**Julia:** There's a huge waiting list for that too... [and] Most of the kids [adults] need it more because there's not school or anywhere else to go. So it was very flawed.

This waiting list was also recognized by other participants and their frustration around it was expressed.

### *Waiting Lists*

Waiting lists are described in the Services and Support Actas a result of assessments when no funding is available for support services within the clients geographical location. Within Ontario over 4000 families are on a waiting list for direct funding such as Passport funding - indicating the large gap in service funding that is being provided to families. Such waiting lists for support create a tension between polices intention to support those with disabilities and the reality that families are not being supported. First, these waiting lists are not transparent and families do not know where their child sits on them. Sally's words capture the feelings of other participants as well.

**Sally:** She's on a waiting list. They say it's a liquid list.

**Interviewer:** What does that mean?

**Sally:** Uh it means if somebody else requires the [a spot in a group] house they are going to get it before her...and so all they can tell me is that it is a liquid list. And they can't even give me a hint as to where she is on it. And she was posted a priority because of my accident.

**Interviewer:** Right, and is she still priority?

**Sally:** I hope so, but I haven't heard anything.

**Interviewer:** Okay. And so, have they indicated how many years it might take?

**Sally:** Nobody there will even guess. But I've been told by people who work in the industry that it's roughly around 20 years. They are basically waiting for older developmentally disabled people to pass away. To get their spots.

(*Sally, mother of Jessica)*

Not knowing how long their child may sit on a waiting list interrupts these families' lives, as they are unable to adequately plan for the future. Not being able to plan for the future can, in turn disrupt these participants' life course, because they cannot predict or plan out how one's life course is going to go. Lisa highlights this:

Is he going to get a job? Like the reality is, that's not going to happen. There should be no question about waitlists for services. He is an adult, let him live his life...That's like telling a kid when you turn 18 you have to put your universe on hold. And I said to them, I said, what 20 year old wants to hang around his mother? I mean, we have fun together [laughs] but I mean day in day out. Like he doesn't want to hang out with his mother! [laughs]. But then, how many years does that happen. And then, all of a sudden they tell you you've got support. Well that just rocks their world... And I've seen it happen to many times. They are just devastated. Some kids, some don't even, aren't able to transition. And some don't even get in until family passes. It wasn't a wait list, it was a death list. (*Lisa, mother of Justin)*

Here, Lisa states the waiting list for a group home disrupts her child's (and other adult children's) life because they have to wait for the funding to get the support needed to help their child live a fulfilling life. The majority of participants expressed that their children do not want to 'hang around mom' all day. However, without the necessary support, this is what occurs. The waiting lists signify a life course that is on hold because the participants children cannot get the support needed to live independently.

Another challenge is that in order to secure funding for a child, parents have to wait until funding is available, usually only when another person dies. Lisa calls this a 'death list' which is effective language that signifies the extreme nature of these waiting lists. Such waiting lists and tensions in support have lead to general concerns and frustration over the support system and the policies in place.

### *General Frustration with the System*

Despite the intention of the Services and Support Act to promote social inclusion and help provide direct funding and support services to adults that have developmental disabilities, the tensions between the intent of the act and the lived reality have created frustration among the participants. Sally expressed this in discussing her need for support:

...we've been fairly fortunate that we've gotten the respite and we've gotten the funding for special services at home but obviously when parents are dropping their kids off at a weekend or a week program and saying 'I'm not going to show up and get them' or maybe leaving them in a hospital after a procedure, something needs to be done... there's people here that need the help. And it's not that they aren't willing to work or whatever, it's they can't. And they need, they need help and I need help. I need that funding. I can't afford to pay someone to take care of her. I can go and rent her an apartment and you know with her ODSP pay that, but I can't afford the care for someone to come in, and that's what they need... And the situation isn't going to change in the years to come. These people are always going to be disabled and there will always be new people being born with disabilities or having accidents or medical conditions that cause a disability and that needs to change. (*Sally, mother of Jessica)*

Here, Sally expresses her need for the funding because she cannot personally afford additional care for her daughter. Further, Sally recognized the need for support is one that will be constant in the future and feels that more support is needed. Polly also states that she wishes the system worked better, and voices her concerns over the future of other families in light of the current policies and waiting lists.

Well, I mean we've cobbled together something that works for Jesse. I mean I, I'm not happy with the way things are set up because I don't, I mean we had to work hard to get together what we've cobbled together. And I'm very concerned about what it's looking like for all the people who are finding out they are not eligible. I have real concerns about that. I mean they ask for so much parental feedback, you sit on all these panels, you do all this input and nothing changes. You know? So, I'm, you know, it's it's really hard. I just feel that families are going to be a little more isolated the way things are set up right now and that concerns me. (*Polly, mother of Jackson)*

Not only can tensions between policy enactments and lived experience be found, but tensions between service implementation and families' lived experiences also exist.

## TENSIONS BETWEEN SERVICE AGENCIES AND LIVED EXPERIENCE

There are tensions that the participants face when deal with support service agencies. Participants face challenges with finding the appropriate care for their developmentally disabled child. These challenges are compounded by disability services that have mandates set out to help find appropriate care supports. Despite these mandates many participants find that the disability services do not provide adequate supports. This is explicitly seen in the transitioning of the participants' child to adulthood. Here, participants must relearn how to find support services for their now adult child with little support from disability organizations. Families respond to these tensions in various ways. If available, participants may use extended family and friends to help with caregiving needs. If this option is not available families manage the best they can with the supports that are given to them through disability agencies.

### *Finding the Right Care*

Similar to tensions surrounding policies of support funding, there are also tensions within the support services and agencies themselves. Accessing appropriate and quality services is challenging for families. One issue participants pointed to was that of finding proper support workers. Finding proper care for their children was difficult for the participants. This is in line with research by (Shearn and Todd 2000) who found many people feel that outsider carers do not do an adequate job. Penny expresses how she is nervous about one of her workers leaving, because it becomes difficult to find a replacement. She states:

Right now it is good. I don't want to rock the boat. Because there are so many, it's really difficult keeping support workers. And so we've had one support worker for like 6 years and yeah, it's very nice. Because Max is not the easiest guy some days. And Uh, I know we've tried with female support workers and it's been really difficult. We've never kept a female support worker. (*Penny, mother of Max*)

In Penny's situation, she prefers to have a male worker for her son Max. As support work is a female dominated field, this makes finding a male worker significantly more difficult. Not only is finding a good worker difficult for Penny, but she expressed that the agencies who manage Max's funding are of little help in finding appropriate care. Such a sentiment was also expressed by other participants. Julia states "the very first time I got them [disability agency] to send me some workers, they weren't good at all." Here, the issue is not finding support workers, but rather the quality of the workers themselves. This poses a problem for Julia, as she needs highly skilled support workers for her son Justin. Jackie also expressed that the agencies lack an understanding of the type of care that her son requires.

**Jackie:** And just the struggle with CCAC [Community Care Access Centre] is crazy.

**Me:** Is it? Do you want to, can you tell me a little bit about that?

**Jackie:** ... I mean with the PSW [Personal Support Worker] they send somebody else. You know, you never have the same, you know you could have two - for Ben they were going to try and put three people in and so training three new people and cycling through. And unless you are with him all that time that training means nothing. And so it takes you a year to train these three people and then you are supposed to feel comfortable in leaving? You know? And then if they can't come they will send somebody else, or they just don't come. And then you are sitting there going "okay, so you are sending me somebody who doesn't know Ben?" It's just that part, it's not geared to the individual, its geared to the system.

On the Disability Support Ontario website, the organization makes clear that one of the objectives is to connect parents with the proper support programs necessary for the client to engage in a fulfilling life. Further, the other organizations that these participants utilize such as Community Care Access Center (CCAC), Community Services Coordination Network (CSCN) and the Victorian Order of Nurses (VON) all emphasize as part of their mandate that they are services that help connect families with the proper care needed to promote the independence of clients. Despite these mandates, the participants felt that the agencies fall short of their responsibilities by not providing high quality workers.

As a result of these agencies providing inadequate workers participants all stated that they now find their own workers and do not utilize that part of the disability services available. Participants find their own workers through word of mouth, posting advertisements, and having other workers recommend potential support workers. Through hiring their own support workers the participants have more control over the type and quality of support that is being provided for their child. Finding their own workers was expressed as empowering for the participants and their children as it gave them more autonomy over their care. However, participants pay agencies for this service and it is not being utilized if participants hire their own support workers. Implementation of policy changes requires families to pay agencies up to 10 percent of their funding in order to utilize the agencies services. Sally expresses her frustration with this new situation:

VON deals with the Ministry of Community and Social services on our behalf. And starting this year we now pay them. It used to be a free service, I now lose 10 percent of my money. So I lose 600 dollars of my money to have them deal with the paperwork and have our worker be able to submit their forms there and have them pay... and they were good at telling me "if you don't have our services and you needed help like when you were in the hospital, you wouldn't be able to get that" because I wouldn't be employing them. And you know, obviously I don't know who to go to to say 'hey, I need extra funding' where they can call up the right people and advocate on my behalf. Which I didn't think was very fair either because how do I say no and not pay out this 600 dollars, when I'm uh, kind of screwed that way. You never know what might happen... I've been there. (*Sally, mother of Jessica)*

Here, Sally faces her own tension. She does not want to pay 600 dollars of her already limited funding in order to utilize an agency and its services. Yet, if she does not have access to this agency than she does not gain the benefits of support in emergencies that the agency provides. Therefore, Sally chose to pay 600 dollars of her funding to the agency rather that use that money for hours of care in order to have access to the agencies service 'just in case' there comes a time when she needs to utilize them.

Other frustrations with the agencies were also expressed by participants. Mainly, there were issues around the amount of funding agencies got versus how much families received. Julia explains:

...but it used to make me kind of frustrated when we would see what your contract was and they would put on how much per hour the agency got and when the workers got like 7 bucks [dollars] an hour the agency was getting 12. (*Julia, mother of Jason)*

Here, participants perceive an inequity between the amount of funding that agencies are being provided versus the amount that families are being provided. This frustration was expressed by multiple participants. Penny expressed her frustration in the following way:

And it's so frustrating. Because families - agencies' people - get cost of living allowances every year and they get a raise but families do not. So we have had our funding for what, six years?... and there's never been an increase. So how do you keep your support workers and give them a pay raise?... You can't expect a support worker to work for 15 dollars an hour for 10 years without a raise. So at the end of my budget year I often do not have any money left. But you know, fortunately we can do some out of pocket stuff. We are just really lucky that way. Otherwise, if I gave them a pay raise I'd have to cut their hours. (*Penny, mother of Max)*

There are two inequities present that are being expressed by Penny. First, like Julia, Penny recognizes that agencies are getting significantly more money than families. Further, Penny finds that without getting a funding raise in line with cost of living, her amount of funding is worth less as she needs to provide her workers with a competitive wage to retain them. Here, Penny then has to either keep her workers' wages the same and risk losing them (and then subsequently have to find new workers) or she must give them a pay raise which decreases the amount of hours of care she can have for her son. Many participants expressed it was difficult to find a balance between securing enough hours to ensure adequate supports for their child, and paying a reasonable wage to hire and retain good support workers. This balancing act has hardly been explored by current research, but is an important aspect of how these families negotiate care.

### *Service Support Challenges for Transitions to Adulthood*

Another tension identified by participants was between what agencies said and what they did related to assisting families with their child's transition from adolescence and school to adulthood and independence. On the Developmental Services Ontario website it states specifically that direct funding can be used to pay for "activities that encourage personal development - helping participants be the best they can be. This can include supports that ease the transition from school to life as an adult in the community" (DSO 2014). Despite this mandate, participants felt that there was little support in the transition of their child into adulthood. Sally explains that she had to initiate the disability assessment during the beginning of the transition to adulthood:

Well, no one could really help me when she turned 18 on what to do. I'm the one that started questioning... Um, yeah. I had to call DSO myself to say " I think we need to do this new assessment you have." *(Sally, mother of Jessica)*

Lisa expressed frustration with the lack of organizations that she found during the transition of her son to adulthood:

But that's where, and when he went from when he turned 18, I found it very very frustrating because when he was a kid we had someone from CCAC who managed everything because that's where everything came out of. All his school, physio, nursing, everything. As soon as he turned 18 it was kind of like 'see you later.' And you were left sitting there going "What do I do now? Where do I go? What's available to him?"...even working in the field you're like 'okay well, he's not going to get any funding' - there isn't anything - you know?...But one thing I was going to say was that I found it very challenging when he turned 18. Um, moving into the adult services. It's very, it lacks organization and for parents, direction. (*Lisa, mother of Justin)*

Polly shares similar sentiments as Lisa:

Well it's interesting because, school is mandated. Right? So when you start out and your child is in school you've got certain supports and certain systems and you know, I think you figure that out... And I think a lot of families just assume that once you become an adult you just transition into similar kinds of things. And a lot of families are very shocked when they find out that, no that isn't the case. Nothing is mandated as an adult. What's there we've had to fight for and you know lobby hard for and it's, it is a lot to navigate. And I, you know, I'm fairly informed and I still not exactly sure as to how everything is going to unravel. You know as right now because of the age Jackson is we are 'grandfathered' into the system and kind of we are at the status quo but at some point in time DSO [Developmental Service Organization] is going to get caught up and he's going to go through the eligibility piece and I just wonder what is going to happen then.

The lack of help with their child's transition to adulthood and the new assessment process (as discussed above) has left Polly concerned over the future, as she cannot guarantee her son will continue to have the support and funding needed for him to be engaged in the community.

The lack of help that these families experience with respect to their child transitioning to adulthood not only goes against the Disability Service Ontario mandate, but can also make life course transitions much more complicated. Coupled with the long waiting lists and inadequate supports (seen above) results in the life course of the participants and their children being disrupted. This life disruption occurs because adequate resources are not present to ease their transition to adulthood and to start a life of independent living that is taken for granted for those without disabilities. Todd and Jones (2005) have found that the hardest transition for these parents is their child's transition out of their adolescent years. Further, one of the concerns over the developmental process of children is the uncertainties surrounding service provision.

## TENSIONS IN CAREGIVING EXPERIENCE - REWARDS AND BURDENS

Finally, tensions can be found in the participants' lived experiences of caregiving. These tensions are based around both the rewards and burdens of their caregiving experiences. Participants recognize the burdens of their caregiving, (e.g. not having enough leisure time) but also focused on the positive experiences they have had with their disabled child. These conflicting positive and negative experiences create tensions around their caregiving experience. These tensions can be seen as ambivalence over their caregiving.

### *Caregiving Challenges*

Participants expressed how they were tired of, and sometimes stressed by caregiving. Grace explains how tired she is:

Tired. Always. Always tired. Always tired. Yes. And it seems like I can't ever do enough. And you know Maddie will say, "Oh okay we will just wait until tomorrow I guess" and it feels to me that there are so many times that she just doesn't get it. She doesn't get it. So yeah, I think I've been tired for a lot of years [chuckles]. (*Grace, mother of Maddie)*

Beyond being tired other participants experience a disruption in their own personal lives, where they do not have any time for themselves. Sally was a good example of this.

...I have to bring her everywhere with me. And that's not always fun... Especially with weekends you know I want to go do something and I can't just go alone. It's hard when other people I know who have kids the same age are finally living a life, doing what they want, coming and going even if their kids are home, right, they are able to be on their own and do their own thing. We don't have that situation. (*Sally, mother of Jessica)*

Here, Sally's own life is being interrupted as her life is linked to her daughter Jessica's life. Sally's child is in her 20s - an age when most parents see their children leave home, or at the very least, be able to take care of themselves. At this age, as Sally indicates, parents are often able to live their own life without worrying about the care needs of their child. For Sally, this is not the case. She must constantly care for her daughter Jessica and as a result does not have time for herself as other people do with non-disabled children. A similar sentiment was expressed by Lisa.

Well, certainly my day isn't my day. My whole day is constructed around him. So, you know... I'm usually a morning person, well, I don't do that much anymore... Yeah, so my day isn't my day. I'm not free as a bird like everyone else I guess. Everyday I get up I have to get somebody else up and ready to go. So you know, it's just...and I guess you know after doing it for twenty years it just fits into your day and it becomes the norm. Like you are on a schedule all the time. But you are always. It's that schedule.

(*Lisa, mother of Jason)*

Similar to Sally, Lisa feels that her day is not her own, but dedicated to her son's care. As such, her experiences of care for an adult child are in stark contrast to her parental counterparts who have adult children that are able to care for themselves. Despite Lisa not having her day to herself, she recognizes that this has become the norm for her and as a result, finds that she can still work through her day.

### *Lucky Despite Caregiving Challenges*

Notwithstanding the above, the participants still feel lucky to have the experiences and children they have. They also feel lucky for the support they do receive. Jackie expresses how lucky she and Ben are for the amount of support hours that Ben receives.

You know I was saying I wanted individualized funding for Ben, and this is what he needs. And so we finally got it and um, so like the 60 hours we are really blessed that... Yeah, we were really lucky and we, the agency, has recognized that we need to pay a good wage to keep that person. We've had many long term workers for Ben.

(*Jackie, foster mother of Ben)*

Lisa shares a similar sentiment, "I think he [Justin] is quite fortunate. Like I said we've been very lucky I think." Jim is a unique example because he feels lucky despite not having any of the external formal supports that other participants have. Jim cares for his son on his own with the help of his other son. He says:

Maybe, again, my experience is a little different. I think the first community we are born into is our family. And uh, I'm very fortunate to have a big family. I am very fortunate to have an adequate income and uh that Paul's first inclusive situation is with his immediate family and his wider family. I have three brothers and sisters and when Paul was born he was embraced, incredibly embraced. So he's very included at a family level.

(*Jim, father of Paul)*

Informal caregiving supports were important for all participants that interviewed as they help to supplement formal caregiving support. Informal caregiving supports were most important for Jim and Grace who did not use formal support services.

### *Worried About the Future*

Participants may feel lucky about their caregiving situations, but most still worried about the future of their children. Worrying about the future is not uncommon and other research has found this to be a theme (Todd and Jones 2005). Although concerns about the future may not be at the forefront of participants' minds all the time, it is present nonetheless, described by Polly as "this latent nasty thing that sits in the background." Participants may have an idea of what they want the future to look like for their child, but still find it hard to predict that future. Penny, for instance, knows what she would like for her son, but is not sure how it will happen. She states:

I mean I have plans, well the same plan for several years is that he moves out into his own place with someone who has a disability and has funding so he can share a support and dollars...my dream would be to buy a home...and someone who has support dollars because its expensive and there's not a lot of funding if you don't go into a group home - the funding for families is dismal as far as, like 24 hour support… yeah so it would be like in a place where someone could live with an apartment downstairs or whatever so there would be overnight support. I just don't know, I don't know how it would all play out but that would be my dream for him to do that. (*Penny, mother of Max)*

Sally worries over her ability to take care of her daughter Jessica when Sally is older.

Well I would like to see that she could at least go to a day program for a full day, at least three days a week...She needs to move out eventually. Even you know in twenty years who's to say what kind of condition I'll be in at 60 something years old.

(*Sally, mother of Jessica)*

Grace, like Sally, worried a lot over the future and what will happen to Maddie when she can no longer take care of her. She expresses it this way:

When I think of that I'm terrified. I'm terrified. Because she's my youngest right?... And of course every now and again I run this scenario through my head. That my time is going to come and then, and even though the other kids are only a couple years older than her in my mind it's like the oldest goes and then the twins go and then here's Maddie. And that thought terrifies me. Terrifies me of leaving Maddie behind... So... yeah it's something actually I never really thought of until very recently. What's going to happen with her? ... But my biggest concern is what's going to happen. You know at some point in time I'm not going to be here, at some point in time. I mean I've got nieces and nephews that are few years younger than Maddie and they understand her struggles, they've grown up with her right? So I think she's going to have people to help her if the rest of us aren't around to do it but I think I will always worry about that, what's going to happen. Because of course in my mind nobody can do it as good as I can.

(*Grace, mother of Maddie)*

Others realize that there is not enough funding for their child to live independently, and so they have resigned themselves to a future where they will care for their child until they no longer can. Despite knowing this, participants still do not know what is going to happen to their child in the future. As Jackie says:

**Interviewer:** Is your hope one day that Ben is live independently on his own or?

**Jackie:** I don't think that that can happen because there just isn't enough funding. Like he would need 24 hour one on one support. And you just can't realistically identify that. What would happen if I can't do it anymore? We really aren't sure.

(*Jackie, foster mother of Ben)*

Although some parents had set aside savings for their child and expected that their other children would care for their disabled child after they had passed, all but one expressed worry over the future.

Not having adequate supports, coupled with waiting lists and lack of enough funding for full independent living, participants are left in a precarious situation where they cannot fully plan for the future care of their child, causing stress and anxiety. Further, because participants cannot plan for the future of their child, they cannot plan for their own future. This interrupts the life course pathway of participants, as they cannot plan for an empty nest or a cessation of caregiving that is seen as normative in most parents’ lives. Further, whereas most parents can expect their children to care for them as they age, parents of children with disabilities (often) do not; they are responsible for their own caregiving into old age.

### *"It is what it is"*

Despite worries over the future, parents have adjusted to the reality that they may care for their child until their own passing. Participants have resigned themselves to the fact that their lives are what they are, that "it is what it is." Penny explains that she does not get to do the things that she wants to do, but for her that is okay.

You know what? Such is life. I have a friend who says 'you should be doing this and this and this in your life and you should be going traveling and doing this' and I say 'look [other friend] doesn't go traveling because she doesn't have the money. We all have reasons why.' We all have our reasons. And it's not, I don't really, I mean it would be nice. But I'm not resentful. I guess I've learned to just, I dunno if it's rationalizing. But I'm used to it. It is what it is. It's my life and, all well. (*Penny, mother of Max)*

Grace shares a similar sentiment:

Well I mean it is what it is right? You know that's how she is and she's ours and we just got to work with it right? And that's what we do. We just keep on keeping on. Because that's what you got to do. (*Grace, mother of Maddie)*

Polly too expresses that she understands the reality of her situation and has chosen to be okay with that. She says:

Could it be better? Sure. But the reality is there is only so many dollars there's only so many, you know? And I have to say I'm satisfied with what we have in place for Jackson.

(*Polly, mother of Jackson)*

There emerge tensions between the participants’ expressions of frustration over the lack of support for families and their own stresses and worries over the future, and the fact that the participants are still satisfied with their care and feel lucky for what they have. This speaks to the complexity of the lived experience of parents with children with disabilities. Most research only focuses on the fact that families caring for children with disabilities face great burdens (Brown and Brown 2014), however, what emerged from this research is that these parents do not see themselves as being burdened by caregiving. There is then a complexity in how these families experience caregiving; they recognize the short coming of their care support and the challenges they face being a parent to a child with developmental disabilities, but also have accepted that their situations could be worse and are therefore satisfied overall. Further, literature that only focuses on the challenges of families caring for children with disabilities may actually be missing an important piece of the whole picture of caregiving. The section below captures how families see their situations in a positive light.

### *Positive Experiences in Caregiving*

As seen within the themes discussed in this chapter, there are many tensions within participants’ experiences with care and support. Tensions further exist between negative experiences with caregiving related to supports and policy and their lived experience, for despite the frustration and challenges in care, participants have chosen to be satisfied with their caregiving situations. Jim, who has no formal support services, expresses his satisfaction with his caregiving situation:

So it's worked out very well. I've had the best job, it's been fantastic. And I'm very close to retirement, but I would not do anything differently. And people don't believe me and occasionally I might say "what would it be like" but I have learned so much from Paul and he's taught me so much. Truly truly has, and sometimes the hard way, but um yeah... Paul generates no stress for me at all. And again I've got the perfect situation I've got this beautiful person I live with and care about a great deal. He cares about me and it's so obvious and his brother is rather remarkable. If there is any stress it's what's going to happen with his relationships long term. It's not a problem for me because I'm healthy and again our family network I have three siblings that I'm very close. So anyway, all of the nephews and nieces there's about 20 of them ranging different ages so Paul will be well cared for a very very long time. (*Jim, father of Paul)*

Although not all participants' caregiving experiences were as 'stress free' as Jim's, all had positive things to say about their experiences of caring for their child. It is important to highlight these experiences, because they are not often a focus of research. There are many positives to having a child with a developmental disability that are often overlooked by the literature. Additionally, in order to fully understand the whole caregiving picture, research cannot just focus on the negative aspects of caregiving. Through understanding the positive aspects of caregiving one can begin to see how families may learn to cope with more difficult aspects of caregiving. One can also see how caregivers may become 'captivated' by their caregiving instead of 'captive' (Todd and Shearn 1996).

Additionally, research by Scorgie and Sobsey (2000) shows that caregivers may experience many transformations through caring for a child with disabilities that carers of non-disabled children do not experience. These 'transformations' are seen as positive and character building. Penny is an example of relational and perspective transformations. As seen in the literature review, relational transformations are changes in the way one relates to other people, that includes an expansion of family networks and learning not to judge others (Scorgie and Sobsey 2000). Perspective transformations are positive changes in the way one views their life situations (Scorgie and Sobsey 2000). Penny demonstrates both of these transformations.

**Interviewer:** Um, and what's the best things about still having Max here and the life that you guys have together?

**Penny:** Well he certainly keeps you grounded and um…I don't know, it's just having a person with a disability in your life just kind of changes how you see other people. And you know, for me, I try to be less judgemental. I mean we all have that little piece that we can't shake but, um, I think he's helped me recognize that you know, it's not, I shouldn't be um, judging other people...I mean he does have moments where he's really annoying but he has moments where he's so funny and he brings a lot of people into our lives that we probably never would have met or had any contact with. (*Penny, mother of Max)*

Not only does Penny recognize that her caregiving experiences have led to her being less judgmental, but she is also grateful for all the different people she's met and connections she has made because of her son Max. Penny also sees her son as having a personality beyond his disability by recognizing that he is a funny person. Grace also recognizes all the positives about her daughter Maddie.

She's so sweet and caring and helpful. Um and she really tries really hard. She'll, she's got a phone and we've showed her how to text um and that's how her and I communicate when I'm at work and she'll text me and say "oh there's a surprise waiting for you" when you get home and I'll come home and there will be a chocolate bar on my pillow. Just sweet sweet things that she does. She'll tidy up, she'll do dishes she'll clean the bathroom as best she can, you know? She's just an amazing kid and she makes me laugh. She makes me laugh. It's almost like, I hear these parents talk about "oh when your kids grow up and the empty nest syndrome." And I think that for me that's fantastic because I just love having my kids around. So there's two sides to that right? (*Grace, mother of Maddie)*

Here, Grace shows signs of captivated parenting described by Todd and Shearn (1996), where she has embraced her caregiving role and is content still caring for her adult child. Many other participants have also expressed signs of captivated parenting by stating that they would not want to trade their lives for another and that they still care for their child. As Polly says:

Well just the broadening of my horizons, our whole family's horizons. It makes you, just a broader person. The people that I've met, the other people that I've met it's been fantastic. Just a whole world that I didn't ever know about before right? And you know as a person you have to start fighting, you have to, you know, it makes you a bigger person. Challenges are not a bad thing, you know? So on that side of things. And I mean just seeing Jackson's growth and just you know seeing what - I mean it's a lot easier to fight for stuff when you can see the impact it has. So, you know, that's been a really good part too. (*Polly, mother of Jackson)*

Despite parents negative experiences with formal caregiving supports, many participants are happy with their current caregiving situations. Such a finding runs counter to much of the literature that places an emphasis on the burdens of care (Brown and Brown 2014). Further, these findings indicate that one does not have to follow the traditional life course trajectory of care in order to be satisfied or adjusted to their lives. As will be seen in the discussion that follows, these participants have adapted to their caregiving roles, becoming 'captivated' parents demonstrating agency and mastery in the way they view their current caregiving situations.

# CHAPTER 4

# DISCUSSION

For this research, I used semi-structured interviews to primarily explore the lived experience of caregivers of adult children with developmental disabilities. The experiences I discovered can be categorized as a series of tensions. Tensions between policy and the lived reality of the policy, tensions between service agencies and lived experience of care; tensions between caregiving experinces with respect to the burdens and rewards of caregiving. First, tensions can be found between the policy reforms and the participants’ lived experience of these policies. While the policies clearly stated a mandate of supporting adults with developmental disabilities to live as independently as possible, participants felt their children were labeled as more disabled through the assessment processes that determined proper and appropriate formal support services. Further, a current lack of funding for such support services has resulted in long waiting lists for support services funding which lead to a tension between the mandates of theServices and Supports Act, and the lived experience of the participants. This has lead to a general frustration among the participants with the current policies and services put in place by the Ontario Government.

Second, tensions can also be found in the lived experience of support services. Disability agencies mandate aid and support to help with caregiving, but an unequal distribution of funds between agencies and families leaves the participants feeling there is inadequate support from the agencies. Further, participants felt that that despite agencies mandates to help with the transition to adulthood, little support was actually given. This recognized inconsistency in the support they receive during the adult child’s transition from adolescence to adulthood results in caregivers and their children experiencing a stagnated life course path (continuing adolescence for adult children, and extended caregiving years for participants).

Lastly, tensions exist between how the participants chose to view their caregiving situations. Participants recognized the burdens of their caregiving, particularly in light of the aforementioned tensions. The burdens of their care include: little time for oneself; stress around finding proper care for their child; and worrying over the future. However, they also view their caregiving to be a positive and transformative experience. Participants expressed that they would choose not to change their situation, that they have learned many valuable lessons from their child with developmental disabilities.

*Dilemmas Faced by Participants*

As a result of these tensions, caregivers face complex dilemmas caring for their adult child with developmental disabilities. First, as their child turns 18, caregivers must relearn social support services and funding processes, as services change when one turns 18. Additionally, once a child turns 21, they are no longer eligible to attend publically funded school; ultimately eliminating a large chunk of care that is designated five days a week for six to eight hours a day. Upon their child turning 18 and leaving school by the age of 21, caregivers must begin to transition their child from adolescence to adulthood. This can be a difficult process for the participants and their children when supports to do so are not available.

Further, participants are faced with the dilemma of finding adequate support and care for their child on limited support funding. As participants expressed, there are limited funds available for their children, and this funding does not increase as cost of living does. Participants must decide how to find proper support for their child on these limited incomes. Participants are often presented with two options: Pay a competitive wage to retain a good support worker (resulting in fewer overall hours of support) or; pay a lower wage (for more hours of support) and risk the worker leaving.

Related to the challenge of finding the right supports on within a limited budget comes the challenge of relinquishing some of their caregiving responsibility to another person. This proved to be difficult for some participants, as they felt that no one could care for their child as best as they could. As a result, participants spent a lot of their time worrying over the care of their child. In contrast, Jim and Grace chose not to use external supports, as they felt it was important to keep the care within the family. As a consequence of choosing not to use formal support services, these participants had to negotiate more informal care networks. Both Jim and Grace were successful in doing so, however, other participants stated that informal supports like family and friends were not possible. For these participants, despite not always wanting to use formal supports, they had to utilize them.

Lastly, participants face the dilemma of how to view their caregiving situation. For many, their caregiving was found to be ambiguous. Participants recognized the challenges caregiving created, such as lack of time for oneself, stress, and worrying of the future, however; participants also emphasized many positive aspects of caregiving including the transformational process that they had experienced, and the positive qualities that their disabled child brought to their lives. This ambiguity has not been explored extensively by current caregiving research on disability, where the negative and burdensome aspects of caregiving are often emphasized.

*Policy as Contributing to Tensions*

Policies and formal support services play a critical role in the participants lives. Despite the policies and support services positive intensions to help families that have children with disabilities, these services and policies actually contribute to many of the tensions that are experienced by families. For instance, the assessment process laid out by the Services and Supports Actwas designed with the intent to help establish the needs of the disabled client in order to fit them with compatible services. During this process, however, a series of questions are asked that emphasize the deficits of the child (e.g. What does the child need help with? What can't the child do?). Focusing on these deficits leads to the social construction of participants child as more disabled than they are. This could affect how participants ultimately view their own child. When policy and services emphasize a disability over ability, participants then engage in resistance to this by choosing to emphasize the child's abilities whenever possible. This can prove to be challenging as many policies and social support do not give an opportunity to emphasize the positive aspects of their disabled adult child.

Further, participants' experience of disability policy and formal support systems indicate that in order to receive the most funding for their child, parents must present their child as 'needy' and disabled as possible. Participants want the most funding for their child because that leads to better care of their child. Yet, they must present their child as disabled as possible, which runs counter to their beliefs in presenting their child based on their child's ability. As a consequence, the policies and formal support services are socially creating adult children as more disabled than is necessary.

Waiting lists have been implemented by policy where there are too few services available. These waiting lists have the intention of prioritizing those that need care most. Currently, the waiting lists for families that have a child with disabilities is 8,000 families long. Additionally, families do not necessarily know where they sit on these waiting lists, making it difficult to plan for the care of their child. As a result, participants experience frustration with the current social support system being unable to adequately plan for the care of their child. Since the waiting lists are not transparent, and participants do not know where their child sits on them, they cannot adequately plan for the future of their child. As a result, this compounds and leads to participants worrying over the future.

Lastly, policy mandates and formal support services indicate that a main goal is to help families transition their child to adulthood. Despite this mandate, participants felt that there was little to no support in the transition to adulthood. As a result, participants had to relearn funding application procedures, as well as deal with the loss of childhood funding and formal supports such as school. Participants found this process to be quite challenging and disruptive to their child's lives as well as their own. Relearning these processes is time consuming and confusing for the participants. Further, without help in the transition to adulthood participants felt that their child's lives were being 'put on hold' as they had to wait for new funding and deal with waiting lists.

Policy and formal support services heed significant impacts on participants. This research is one of the first to find links between policy and formal support services, and impacts on the lived experience of the caregivers. What results is a discovery of the tensions that caregivers of children with developmental disabilities must face and negotiate through. Such experiences are different from families that do not have a child with developmental disabilities.

## LIFE COURSE DISCUSSION

A life course framework proved valuable for guiding this research, and the analysis of the findings. Participants are each on their own life trajectory and have different experiences. Using a life course approach allows the researcher to get at the fluidity of such experiences and to identify the tensions that are aroused from caregiving. In many cases there are links that tie the tensions discovered in this thesis to the life course. As will be seen in this discussion, the life courses of families with children with developmental disabilities, and those with disabilities themselves, experience what is often considered a non-normative life course. This non- normative life course, and tensions found throughout this research, begin to highlight a new way of understanding the life course of those with disabilities and their families. Within the life course perspective there is a recognition that "society continues to shape and limit life experiences and life chances throughout the life course" (Hunt 2005:34). This can be explicitly seen within my research that shows tensions in waiting lists, service delivery, and participants worries over the future.

### *Turning Points*

Waiting lists can create a turning point in one's life course. A turning point is when a life transition changes the life course trajectory. Such a turning point identified in the interviews was being placed on a waiting list for funded support. When children become adults, families reach a turning point, as their children are placed on a waiting list for new funding, such as Passport funding. Though no participants were on a waiting list for care, all had received some form of social support funding. Participants also expressed a growing concern for future families that have to experience waiting lists. For instance, as Julia expressed, Special Services at Home is now limited to the age of 18, where families are then cut off, reassessed and put on a waiting list for Passport funding. This disrupts the life course transition to adulthood because families no longer have external supports for care that may help participants children participate within their community. Further, access to school, which provides consistent daily care five days a week for disabled children ends at the age of 21 within Ontario. If families are still on waiting lists and no longer have mandated school, parents are then responsible for finding additional care supports for their children. This can disrupt the life course of not only the child but also the parents, as new employment arrangements may need to be made. Such arrangements may result in a transition out of full-time employment in order to provide adequate care for one's child. This transition was expressed by Lisa, whom before her son was placed in a day program, she had to consider altering her career in order to provide full-time care to her son when he left school. Such a situation is likely not uncommon among families in similar situations.

### *Transitioning to Adulthood*

Waiting lists then create a barrier to normative life progressions. What should be a time for a turning point (Elder et al. 2003) in one's life course is now 'put on hold' and one's transition into adulthood is stagnated. The transition to adulthood is often marked by financial and emotional independence from the family, finishing school, leaving home, working, and forming a family through marriage and parenthood (Pallas 2003). As such, it can become clear how adult children with disabilities do not fit the normative transition to adulthood. Though many of the participants' children graduated high school with a certificate, none work in paid employment, and all live at home require 24 hour assistance. All would be unable to live on their own. Independence from parents and the ability to participate within the community is only possible with support from someone other than the parent. Therefore, with waiting lists and lack of funding to pay for external support, participants' children's transition to adulthood is hindered. Their ability to accomplish some of the normative transitions that are markers of adulthood are further complicated. It is for this reason that participants feel that their child's lives are 'put on hold.' It may also be why Priestly (2000) suggests that those with a disability are often considered to live in perpetual adolescence because of the way society views normative transitions to adulthood.

It was found in this research that my participants felt that supports were inadequate enough. Such inadequate supports included finding proper workers, having enough funding, and receiving help for their child's transition to adulthood. Whitaker (2013) in her study of families that had ageing adult children with disabilities found similar results. She found that though participants embraced policy reform that stemmed from normalization and social integration of disabled peoples, many participants expressed that the reforms were limited, where services were viewed to give families inadequate supports that were not adjusted to families specific care needs.

Whitaker (2013) found in her study that a central event in both her participants lives and their children's lives was the transition to adulthood which involved "liberation, leaving the parents home, and becoming independent" (96). Part of this process involved parents reaching a point in their lives where they were ready to 'let go' and leave the caring responsibility to others. Unlike Whitaker's (2013) participants, the participants in this research have not been able to reach a stage where they have an opportunity to 'let go' of their caregiving responsibility, despite most being ready to do so. Further, my participants expressed concern over finding the proper care for their child if they were to leave because they felt that no one could take care of their child as well as they could. More, this transition is made difficult by social organizations that do not provide the necessary guidance for the transition to adulthood. For example, Lisa expressed her frustration over not being informed of the processes that needed to take place for her to get her son on waiting lists, new assessments and application processes for adult funding. Additionally, like Whitaker's (2013) participants, there was no transition from childhood medicine to adult medicine and services. Penny described this as a relearning process that was very difficult, time consuming and unfamiliar where little guidance was provided from support organizations. Such limited support for the transition to adulthood limits the opportunities for full dependence, what Lisa referred to as "a life on hold." Such limitations may conflict with expectations and rhetoric from the disability community that emphasises "independence, influence and power of action" (Whitaker 2013:97). Further, the lack of help to transition to independent adulthood goes against policy reform and social service mandates that promote developmentally disabled children as independent with a right to participate fully in their community. Such a prolonged adolescence may make it difficult to plan for the future.

### *Worrying About the Future*

The waiting lists, inadequate supports, and lack of help to the transition to adulthood compound in a way that causes worry over the child's and by extensions the participants' future. Worrying about the future was a common theme among participants. This has also been found by Whitaker (2013). Participants were worried about the future of their child in terms of their own ageing and inevitable death. Aging in general has the potential to limit the amount of care participants could provide their child, as participants start to face their own limitations. Sally, whom suffers from chronic pain, expressed concern over "the kind of shape" she will be in twenty years from now. Sally was worried over the future because she did not know when her daughter Jessica would get into a independent living home. This worry was sometimes neglected by participants who chose not to deal with the future preoccupations and put it to the back of their mind. For others, the fear of the future immobilized them, and they did not know how to plan for it. For others still, future worries caused participants to set up savings accounts for their children, and to have people in line to care for their child once they were gone. Despite these provisions, participants still worried about their child's future and were uncertain what the future would look like a year or twenty years from now. Since participants cannot fully plan for the future of their children, their life also cannot be planned for. Normative transitions of middle age such as moving close to retirement and leisure was not foreseen as possible by all participants. Participants were unable to express how their future and their child's future would look.

### *Agency and Positive Experiences*

Sociologists often assume that there are negative consequences for those that deviate from the norms, but this has not been explored extensively in terms of the life course (Settersten 2003). It may be for this reason that the majority of research on prolonged caregiving or caregiving of children with disabilities focuses on the burdens of caring, as it is assumed that there are negative consequences. This research begins to build on the study of deviations from a 'normative' life course as my participants do not follow a normative life course. As has been shown above there are certainly challenges to a non-normative life course, but the negative consequences are not apparent in this research. Rather, through mastery and agency the participants of this research study have chosen to view their lives as still quite positive and would not change it for another life.

A constructionist perspective is often favoured when understanding how the life course is shaped (Elder 1994). "Increasingly there are new constructivist views of human development where social actors are the primary architects of their lives" (Settersten and Gannon 2005:39). Settersten and Gannon (2005:36) focus on *agency within structure* to understand "how individuals set goals, take action, and create meanings within-and often despite- the parameters of social settings and even how individuals may change those parameters through their own actions." As a result, human lives and social structures are dynamic and can be changed.

What is important about agency in the case of the participants is that they choose to modify their goals. For example, Lisa explains that she is normally a morning person, but cannot have her own morning routine due to the needs of her son. When I asked Lisa about this she shrugged it off and said that she has just learned to work around it and that "such is life." Lisa has then chosen to view her situation and the restrictions she is in as positive instead of negative, despite not always being able to do the things she would like to do.

Agency can also be found in the two participants (Jim and Grace) who have chosen not to engage in formal caregiving supports. Rather, these two participants have opted to rely on informal supports including themselves in order to provide care for their child. These two participants were in stark contrast to the rest of the participants who used formal supports almost on a daily basis. Both Jim and Grace have made an active choice to not pursue formal support services, and doing so may make their life course look much different than the other participants. For example, Jim was looking forward to retirement where he would then spend his time with his son Paul. Jim expected to take care of Paul until he no longer could. Grace also anticipated caring for her daughter Maddie until she no longer could. Grace expressed that she enjoyed having her daughter with her because she did not have to experience the empty nest syndrome. Jim and Grace have both anticipated a full life of caregiving and have chosen to look at this positively. Such is different than the other participants who still hope to one day have their child live with external supports. Neither option is wrong, but there is a difference in how each views the progression of their life course.

Since parents spend the majority of their lives with their child with disabilities, parenthood emerges where many of the experiences of the parent and child are shared (Whitaker 2013). As a result of these shared experiences the family may itself appear to be disabled. As a result, in "the eagerness of disability policy to achieve autonomy, influence, participation, citizenship and so on, the significance of the family has come not only to be ignored but above all to be associated with something negative" (105-106 Whitaker). This may be one of the most important tensions found between policy intent and actual lived experience. Despite this negative experience and the tensions that exist families remain resilient, and choosing a positive outlook may help mitigate the negative effects.

### *Positive Experiences*

Research by Greenberg et al. (2004) has shown that optimism is a mediating factor in psychological well-being of mothers of adult children with schizophrenia, autism, and Down syndrome. It may be that choosing to view their life situations as positive or "lucky", and accepting "it is what it is" helps the participants mitigate the negative effects of caregiving, helping them live more positive lives. This may be in line with the differences that Todd and Shearn (1996) found between 'captivated parents' and 'captive parents.' For example, Grace and Jim would be considered 'captivated' parents who have embraced their extended caregiving role and continue to plan for it in a positive manner.

Further, there can occur a 'transformation' process that can impact one's life course. Scorgie and Sobsey (2000) found this transformation occurs where caregivers expressed positive transformations in friendships, marriages and personal outlooks on life. As lives are linked to one another, such transformations (for instance meeting new people) can impact the life course. This was found with some of my participants. Participants expressed that a positive to having a child with a developmental disability was the people they met and the advocacy work that they participated in.

Though participants identified some burdens to their caregiving, all wanted to focus on the positive aspects of caregiving for their adult child with developmental disabilities. This could contribute to an attempt to mask the burden of care by individuals, as doing so may imply that the child themselves are the burdensome. This may be one of the reasons why participants were apt and enthusiastic in talking about the positive experiences they have had with their child. Talking about the positives and avoiding the negatives may be done as a mechanism to prevent feelings of helplessness (Getch 2012) and feelings of being 'captive' (Todd and Shearn 2006) by their caregiving role. This may be particularly so as all the participants recognize that they will be caring for their children for a prolonged amount of time, if not until their own death.

Despite the challenges that participants face with regards to their caregiving roles, participants made it clear in their interviews that their experiences are overall positive, that they love their children, and would not change their situation for another. This is a significant finding, as much of the research currently available does not focus on the positive experiences of caregiving (Brown and Brown 2014). It is evident in this research that caregiving for their child - even in a prolonged way - is accepted as part of their love and care as a parent.

## LIMITATIONS OF THE RESEARCH

There are many limitations to this current study. For instance, more diversity in participants is needed. All participants were white and belonged to the middle or middle upper class. Many participants (though not all) could afford to pay out of pocket for extra care. Therefore, the funding that the participants receive may not be as valuable to them as participants that have no other external resources for care, or who cannot afford to pay out of pocket for care.

For this research I encountered many challenges with gatekeepers who denied access to their formal support services agencies. Issues with gatekeepers made it difficult to recruit a robust amount of participants. As a result snowball sampling was used, however this lead to a concentrated amount of participants that were already connected to one another and already had funding. Through not accessing participants without any formal support services, a whole population of parents with children with disabilities has been missed. These participants likely do not have connections to the disability community that provide them external supports to caregiving. As a result, such a populations may have vastly different caring experiences.

Additionally, all participants were of white European decent. Cultural variations in care may exist among primary caregivers that are a part of an ethnic minority. For instance, immigrants who have a child with a disability may not utilize care giving services at all due to lack of knowledge, denial of services, mistrust for the service, or reliance on informal support such as family members and friends. Future research should seek to include a more robust group of participants to get at the diversity of caregiving experiences.

## FUTURE RESEARCH DIRECTIONS

Little research has focused on what it is like to spend many years as a parent to a disabled person who requires care (DeMarle and le Roux 2001; Jeppsson Grassman and Whitaker 2013). This research begins to take a step in that direction. Further, Jeppsson Grassman and Whitaker (2013) argue that the normative life course is often the starting point for understanding the concept associated with the life course. The authors, in light of their research on disability, assert that more research needs to focus on atypical life courses. This research has begun to contribute to this through focusing on families that do not follow a normative life course due to prolonged caregiving of an adult child with a disability. There is also a need to focus on the future within the life course (Jeppsson Grassman and Whitaker 2013). My research has begun to explore the impacts that policy, services and caregiving have on future life course trajectories of the participants and their adult children.

This research is just the stepping stone to future work on disability, caregiving and the life course. In order to get a fuller picture of how the life course is impacted by prolonged caregiving, longitudinal studies would be very useful. Life course scholarship utilizes longitudinal studies regularly, but little if any take place for those with disabilities or their carers (Jeppsson Grassman 2013). Doing longitudinal studies may give more insight into how the life course affects lived experiences and vice-versa.

Further, more research should focus on the positive outcomes of caring for adult children with disabilities across the life course, as positive experiences are often overlooked by researchers. Doing so may help researchers better understand how life courses that 'deviate' from the 'norm' are experienced.

Research can be done at a larger scale with more participants that include both participants on waiting lists and participants who have funding. Doing so would give a comparative analysis as to how the experiences differ when funding is available and when funding is being waited upon.

Many participants emphasized the importance of formal care to their own care experiences, but more research needs to be done on informal care. For instance, how do families utilize family supports and peers to help with caregiving? Further, to what experience does informal supports impact the life course of participants? Is it possible that siblings of children with developmental disabilities will eventually take over the care of their disabled sibling in addition of care for their aging parent? This research does not focus on the impacts that having a sibling with developmental disabilities has on the siblings life course.

This research sought to understand deeper the lived experience of primary caregivers that have adult children with developmental disabilities. What was found is that these participants may lead lives that are more challenging, where care is more complex than other families. Challenges that families face include: tensions between policy and reality; tensions between services agencies and lived experience; and tensions between the rewards and benefits of their caregiving. Despite these challenges, the participants show resilience and a commitment to the care of their child. Participants have found ways to negotiate care despite the challenges that policy and support services have presented them. As a result, the participants are dedicated to their caregiving and have embraced their caregiving roles in order to provide the necessary and prolonged proper care that they feel their children with developmental disabilities deserve.

APPENDIX A

Interview Guide

This list of questions was a guide that helped facilitate my interviews in a conversational form.

* Please tell me about [name] (son or daughter being cared for)
* Do you have other children?
  + do they help out with [name]
* Can you please explain your care routine for [name].
  + How many hours of the day does this require of your time? Who does most of the care-giving? How is this decided?
* Can you please explain what the process for getting formal support services is like?
* Has the funding your children receives remained consistent or changed over time?
* Does [name] have formal care workers that take him out and into the community?
  + How many care workers do they have
  + (Alternatively) how many hours of support are you given per week?
* How did you acquire your support hours?
* What kind of public funding does your child or you receive to aid in care-giving?
* Do you wish for [name] to live independently on his/her own?
* How do you found your care workers?
* Did you receive any training that taught you how to access formal support services?
  + How did you learn to access such services?
* Do you have any other forms of support for caregiving, such as family or friends?
  + How do they help? How does this help you?
* How does the formal support services help your child?
  + How do they help you? Your family?
* Do you work? Are you able to work full-time?
* Who takes care of [name] while you are at work? How have you arranged for this? Are you satisfied with this arrangement?
* What do you do with the time you have when you have external caregiving supports (informal and formal)?
  + How does this time help you?
* What is the hardest part about caregiving?
* When you do not have additional care support how to you negotiate through day to day activities?
* Final Comments?

# APPENDIX B:

Participant and Family Characteristics

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| PARTICIPANT\* | CHILD'S NAME\*\* | AGE OF CHILD | DIAGNOSIS | SUPPORT FUNDING \*\*\* | EMPLOYMENT STATUS | MARITAL STATUS |
| PENNY | Max | 29 | Autism | ODSP  $25,000 Passport  $8000 Special Services at Home (SSAH) | Part-time | Married |
| LISA | Justin | 20 | Cerebral Palsy | 40 hours day program  ODSP  $5000 Passport | Full-time | Married |
| AMY | Kerry | 29 | Did not disclose | ODSP  $23,000 Passport and SSAH (combined) | Full-time | Married |
| POLLY | Jackson | 29 | Aspersers  Syndrome | ODSP  $12,000 Passport | Part-time | Married |
| GRACE | Maddie | 28 | Undiagnosed | ODSP | Part-time | Married |
| JIM | Paul | 26 | Down Syndrome | ODSP | Full-time | Widowed |
| JACKIE (foster parent) | Ben | 33 | Cerebral Palsy  Deaf/blind  Epilepsy | ODSP  Enough for 60hrs of support a week | No | Married |
| JULIA | Jason | 27 | Undiagnosed | ODSP  $32,000 | No | Married |
| SALLY | Jessica | 20 | Cerebral Palsy | ODSP  $6,000 SSAH | Part-time | Married |

\* Participants names have been changed to maintain confidentiality

\*\* Children's names have been changes to maintain confidentiality

\*\*\*The support funding category changes based on how participants disclosed information. Some did not give an actual monetary figure.

# References

Beigel, D., E. Sales, R. Schutlz. 1991. *Family caregiving in chronic illness: Alzheimer's disease,*

*cancer, heart disease, mental illness, and stroke*. Newbury Park, CA: Sage Publications

Boyce, W., K. Krogh and E. Boyce. 2006. “Policy Shifts and Challenges: Coping Strategies of

Disability Organizations.” Pp 188 – 209 in *Disability and Social Policy in Canada,* 2nd ed. edited by Mary McColl and Lyn Jongbloed. Concord, ON: Captus Press

Braddock, D. 1999. "Aging and developmental disabilities: demographic and policy issues

affecting American families. *Mental Retardation* 37:155-161

Brown, M. and S. Brown. 2014. "Informal Caregiving: A Reappraisal of Effects on Caregivers"

*Social Issues and Policy Review* 8(1):74-102

Caldwell, Joe. 2007. "Experiences of families with relatives with intellectual and developmental

disabilities in a consumer-directed support program" *Disability and Society* 22(6):549-562

Caldwell, Joe. 2006. "Consumer-Directed Supports: Economic, Health, and Social Outcomes for

Families" *Mental Retardation* 44(6):405-417

Cant, Rosemary. 1992. "Friendship, Neighboring and the Isolated Family: The Case of Families

with Disabled Children" *International Journal of Sociology of the Family* 22(2):31-50

Clark, Tom. 2010. "Gaining and Maintaining Access" *Qualitative Social Work* 10(4):485-502

Community Living Ontario. 2013. "Waiting List Statistics in Ontario" *News and Events*.

retrieved on November 10 from: <http://www.communitylivingontario.ca/news-events/news/media/waiting-list-statistics-ontario>

Corbin Dwyer, Sonya and Jennifer Buckle. 2009. "The Space Between: On Being an Insider-

Outsider in Qualitative Research." *International Journal of Qualitative* Methods 8(1):54-64

Damiani, G., Rosenbaum, P., Swinton, M. & Russell, D. 2004. “Frequency and determinants of

formal respite service use among caregivers of children with cerebral palsy in Ontario.”

*Child: Care, Health and Development* 30: 77–86

DeMarle, D. and P. Le Roux. 2001. "The Life cycle and disability: experiences of discontinuity

in child and family development" *Journal of Loss and Trauma* 6:29-43.

Doig, J., J. McLennan and L. Urichuk. 2009. "‘Jumping through Hoops’: Parents' Experiences

with Seeking Respite Care for Children with Special Needs."*Child: Care, Health & Development* 35(2):234-242

Dowling and Dolan (2001). "Families with children with disabilities - inequalities and the social

model *Disability and Society* 16:141-158.

Duffy, M., R. Albedla, C. Hammonds. 2013. "Counting Care Work: The empirical and Policy

Applications of Care Theory." *Social Problems* 60(2):145-167

Eker,L. and E. Tuzun. 2004. "An evaluation of quality of life of mothers of children with

cerebral palsy." *Disability and Rehabilitation* 26(23):1354-1359

Elder, G. 1994. "Time, Human Agency, and Social Change: Perspectives on the Life Course"

*Social Psychology Quarterly* 57(1):4-15.

Elder, Glen., Monica KirkPatrick Johnson, Robert Crosnoe. 2003 "The Mergence and

Development of Life Course Theory" Pp 3 -19 in *Handbook of the Life Course* edited by Jeylan Mortimer and Michael Shanahan NY, NY: Plenum Publishers.

Fast, J., N. Keating, A. and Yacyshyn. 2008. "'I wish that I could just have a break':

Consequences of supporting adults with disabilities" *Hidden Costs/Invisible Contributions* Department of Human Ecology, U of A, Edmonton.

Fuijiura, G. 1998. "Demography of family households" *American Journal of Mental Retardation*

103:225-235

George, L. 1993. "Sociological Perspectives on Life Transitions" *Annual Review of Sociology*

19:353-373

Getch, Y. 2012. "Feelings of Family Caregivers" Pp 29 - 67 in *Multiple Dimensions of*

*Caregiving and Disability*: Research, Practice, Policy.

Glendinning, C. 1992. "Employment and community care: policies for the 1990s." *Work*

*Employment and Society* 6:103-111

Gordon, B. & K. Rosenblum. 2001. "Bringing Disability into the Sociological Frame: A

comparison of disability with race, sex, and sexual orientation statuses" *Disability and Society* 16(1):5-19.

Government of Ontario. 2014a. "Help with Daily Living" *Ministry of Community and Social*

*Services* retrieved on January 23, 2015 from: http://www.mcss.gov.on.ca/en/mcss/programs/developmental/servicesupport/passport.aspx

Government of Ontario. 2014b. "Budget 2014 Fostering Fair Society" *Ministry of Finance*

retrieved on September 9 2014 from:

http://www.fin.gov.on.ca/en/budget/ontariobudgets/2014/bk3.html

Government of Ontario. 2014c."Ontario Disability Support Program" *Ministry of Community*

*and Social Services* retrieved on February 20, 2015 from: http://w ww.mcss.gov.on.ca/en/mcss/programs/social/odsp/

Grant, G., M. Nolan, J. Keady .2003. "Supporting families over the life course: mapping

temporality" *Journal of Intellectual Disability Research* 47(4/5):342-351

Greenberg, Jan, Marty Wyngaarden Krauss, Rita Jing-Ann Chou, Jinkuk Hong. 2004. "The

Effect of Quality of the Relationship Between Mothers and Adult Children with Schizophrenia, Autism, or Down Syndrom on Maternal Well-being: The Mediating Role of Optimism" *American Journal of Orthopsychiatry* 74(1)14-25

Haley, William, and Elizabeth Perkins. 2004. "Current Status and Future Directions in Family

Caregiving and Aging People with Intellectual Disabilities" *Journal of Policy and Practice in Intellectual Disabilities* 1(1):24-30

Heller, Tamar and Joe Caldwell. 2005. "Brief Research Report: Impact of a Consumer-Directed

Family Support Program on Reduced Out-of-Home Institutional Placement" *Journal of Policy and Practice in Intellectual Disabilities* 2(1):63-65

Heller, T., J. Caldwell, and A. Factor. 2007. "Aging Family Caregivers: Policies and Practices."

*Mental Retardation and Developmental Disabilites Research Reviews* 13:136-14

Hooyman, N. 1992. "Social Policy and Gender Inequalities in Caregiving" pp. 181 - 201 in

*Gender, Families and Elder Care* edited by D. Dwyer and R. Coward. London: Sage Publications

Hunt, Stephen. 2005. *The Life Course: A Sociological Introduction* NY, NY: Palgrave

MacMillan.

Jeppsson Grassman, Eva and Anna Whitaker.2013. "Ageing with Disability: an Introduction" Pp

1 - 15 *Ageing with a Disability: A lifecourse Perspective* Edited by Eva Jeppsson and Anna Whitaker

Keefe, Legare, Carriere .2007. "Developing new strategies to support future caregivers of older

Canadians with disabilities: Projections of need and their policy implications" *Canadian Public Policy 33(1)* S65-S80

Kerckhoff, Alan. 2003. "From Student to Worker" PP 251 - 267 in *Handbook of the Life Course*

edited by Jeylan Mortimer and Michael Shanahan NY, NY: Plenum Publishers

Kluhlthau. K. 2012. "Parent Caregivers of Children with Disabilities." Pp 67- In *Multiple*

*Dimensions of Caregiving and Disability: Research, Practice, Policy.*

Knox, Marie and Christine Bigby. 2007. "Moving Towards Midlife Care as Negotiated Family

Business: Accounts of people with intellectual disabilities and their families "Just getting along with their lives together" *International Journal of Disability, Development and Education* 54(3):287-304

Leisering, Lutz. 2003. "Government and the Life Course" Pp. 205 - 225 in *Handbook of the Life*

*Course* edited by Jeylan Mortimer and Michael Shanahan NY, NY: Plenum Publishers

Lewis, S., C. Kagan, P. Heaton. 2000 "Dual-Earner Parents with Disabled Children" *Journal of*

*Family Issues* 21(8):1031-1060

Lord, J. and P. Hutchison. 2011. *Pathways to Inclusion: Building a New Story with People and*

*Communities.* 2nd Ed. Concord, ON: Captus Press

MacMillan, R. and R. Copher. 2005. "Families in the lIfe Course: Interdependency of Roles,

Role Configurations, and Pathways." *Journal of Marriage and Family* 67:858-879

McAreavey, Ruth and Chaitali Das. 2013. "A Delicate Balancing Act: Negotiating with

Gatekeepers for Ethical Research When Researching Minority Communities." *International Journal of Qualitative Methods* 12:113-132

McColl, M., A. Jackson, W.Boyce, and S. Shortt. 2006. “Disability Policy Making: Evaluating

Evidence Base.” Pp 25 – 46 in *Critical Disability Theory: Essays in Philosophy, Politics, Policy, and Law,* edited by Dianne Pothier and Richard Devlin. Vancouver, BC: UBC Press

Mcconkey, R., M.Truesdale and C.Conliffe. 2004. "The Features of Short-Break Residential

Services Valued by Families Who have Children with Multiple Disabilities."*Journal of Social Work* 4(1):61-61-75.

Miltiaes, H. and R. Pruchno. 2001. "Mothers of Adults With Developmental Disability: Change

over time." 106(6):548-561

Morris, J. 2004. "Independent living and community care: A disempowering framework"

*Disability and Society* 19(5):427-443

Mulcahy, Niamh. 2012. "Narrating Developmental Disability: Researchers, Advocates, and the

Creation of an Interview Space in the Context of University-Community Partnerships" *International Journal of Qualitative* Methods 11(2):165-180

Mullins, L., K. Aniol, M.Boyd, M. Page and J.Chaney. 2002. "The Influence of Respite Care on

Psychological Distress in Parents of Children with Developmental Disabilities: A Longitudinal Study."*Children's Services: Social Policy, Research & Practice* 5(2):123-138)

Murphy, N., A. B., Christian, D, Caplin, P., Young. 2007. "The health of caregivers for children

with disabilities: Caregiver perspectives" *Child: Care, Health and Development* 33(2):180-187

Oliver, M. 1996. "A sociology of disability or a disablist sociology" Pp 18-42 in *Disability and*

*Society: Emerging issues and Insights* Eds by L. Barton NY: Longman Limited

Oliver, M and C. Barnes. 2012. *The New Politics of Disablement* UK: Palgrave Macmillian

Ory, M., J. Yee, S. Tennstedt, R. Schultz. 2000. "The extent and impact of dementia care:

Unique challenges experienced by family caregivers." Pp 1-32 in *Handbook of dementia caregiving: Evidence-based interventions for family caregivers.* Edited by R. Shultz. New York: Springer

Pallas, Aaron. 2003. "Educational Transition, Trajectories, and Pathways" Pp 165 - 184 in

*Handbook of the Life Course* edited by Jeylan Mortimer and Michael Shanahan NY, NY: Plenum Publishers

Parish 2006, S. "Juggling and Struggling: A preliminary Work-Life Study of Mothers with

Adolescents who have developmental Disabilities" *Mental Retardation* 44(6):393-404

Pearlin, L. 2010. "The Life course and the Stress Process: Some Conceptual Comparisons"

*Journal of Geronology Social Sciences* 65B(2):207-215

Pearlin, L. and C. Aneshensel. 1994. "Careigving: The unexpected Career" *Social Justice*

*Research* 7(4):373-390

Priestly, M. 2000. "Adults Only: Disability, Social Policy and the Life Course" *Journal Social*

*Policy* 29(3):421-439

Priestly, M. 1998. Constructions and Creations: Idealism, Materialism and disability theory."

*Disability and Society* 13(1):75-94

Rubin, Herbert and Irene, Rubin. 2005*. Qualitative Interviewing: The Art of Hearing* Data (2nd

Eds) LA,CA: Sage Publications

Scorgie, Kate and Dick Sobsey. 2000. "Transformational Outcomes Associated with Partenting

Children Who Have Disabilities" *Mental Retardation* 38(3):195-206

Seltzer, M., J. Greenberg, F. Floyd, Y. Pettee, J. Hong. 2001. "Life course Impacts of Parenting a

Child with a Disability" *American Journal on Mental Retardation* 106(3):265-286

Seltzer, M. J. Greenburg, M. Krauss. 1995. "A comparison of coping strategies of aging mothers

of adults with mental illness or mental retardation."  *Psychology and Aging* 10:64-75

Settersten Jr., Richard. 2003. "Age Structuring and the Rhythm of the Life Course" pp 81-98 in

*Handbook of the Life Course* edited by Jeylan Mortimer and Michael Shanahan NY, NY: Plenum Publishers

Shearn, J. and S. Todd. 2000. "Maternal Employment and Family Responsibilities: the

Perspectives of Mothers of Children with Intellectual Disabilities" *Journal of Applied*

*Research intellectual Disabilities* 13:109-131

Shearn, J. and S. Todd. 1997. "Parental work: an account of the day-to-day activities of parents

of adults with learning disabilities" *Journal of Intellectual Disability Research* 41(4):285-301

Thoits, P. 2006. "Personal Agency in the Stress Process" *Journal of Health and Social Behavior.*

47(4):309-323

Todd S. and S. Jones. 2005. "Looking at the future and seeing the past: the challenge of middle

year of parenting a child with intellectual disabilities" *Journal of Intellectual Disability Research* 49(6):389-404

Todd, S. and J. Shearn. 1996. "Struggles with Time: the careers of parents with adult sons and

daughters with learning disabilities" *Disability and Society* 11(3):379-401

Ward, K. L. Chiarello, D. Barlett, R. Palisano, S. Westcott McCoy, L. Avery. 2014. "Ease of

Caregiving for Children: a measure of parent perceptions of the physical demands of caregiving for young children with cerebral palsy." *Research in Developmental Disabilities* 35:3403-3415

West, C. and D. Zimmerman. 2007. “Doing Gender." Pp 61 – 72 in *Gender Relations in Global Perspective: Essential Readings* Edited by Nancy Cook. Toronto, ON: Canadian Scholars Press Inc.

Whitaker, Anna. 2013. "In the shade of disability reforms and policy: Parenthood, ageing and

lifelong care" Pp 91 - 107 in *Ageing with a Disability: A lifecourse Perspective* Edited by

Eva Jeppsson and Anna Whitaker

WHO. 2015. "Disability and Health" World Health Organizations Fact Sheet N. 352 . Retrieved

from: http://www.who.int/mediacentre/factsheets/fs352/en/

Yantzi, N., M. Rosenberg, P. McKeever. 2006 "Getting out of the house the challenges mothers

face when their children have long-term care needs" *Health and Social Care in the Community* 15(1): 45 - 55

1. all participants and their children's names have been changed to maintain confidentiality [↑](#footnote-ref-1)