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**THE LIVED EXPERIENCES OF PEOPLE WITH DISABILITIES AND THEIR
FAMILIES: TRANSITIONING TO ADULthood AND THE ROLE OF
INDEPENDENT FACILITATION**

by

Emily C. Tang

Wilfrid Laurier University, 2020

THESIS

Submitted to the Department of Kinesiology and Physical Education

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Master of Kinesiology

Wilfrid Laurier University

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It was truly an honor to listen and learn of the lived experiences from youth and adults of varying disabilities on their challenges and needs, but also their successes, in reaching their adult lives. I will be forever inspired by their stories and strength, and I hope it will inspire others by sharing their experiences in this paper. I would like to thank my participants in making the time to share their vulnerabilities, hardships, successes, and dreams with me, and trusting me to convey their experiences in this study.

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ABSTRACT

Objective

Emerging adulthood can be a stressful life stage due to the many life choices available and is especially challenging for emerging adults with disabilities (EADs) who face additional barriers in accessing supports and information regarding adult opportunities. This qualitative study investigated the experiences of transitioning to adulthood, and the role of a person-directed facilitation service, for EADs and their families.

Methods

Fourteen participants were recruited through purposeful and convenience sampling. Data collection procedures consisted of background questionnaires and one-on-one semi-structured interviews which were then thematically analyzed. Field notes, member checks and triangulation were used throughout the analysis process to ensure trustworthiness.

Results

Three salient themes emerged which described participant perspectives of support, challenges, and overall experiences of EADs transitions to adulthood: Haves and Have Nots of Support, The Many Hats of Adulthood: Living with a Disability, and “Community is When People Notice You’re Not There”.

Conclusions

Transitioning to adulthood for people with disabilities and their families was a “challenging yet rewarding” process. This study was novel in its inclusion of EADs’ voices in formal research. Findings brought to light the diversity of journeys into adulthood. Although many hardships were discussed, positive aspects of the journeys into adulthood emerged which showed the role of independent facilitation, a concept which had not been formally studied previously.

CHAPTER 1: LITERATURE REVIEW

1.0 INTRODUCTION

Emerging adulthood is known as the in-between stage of life for young people between the ages of approximately 18-25 years old (Arnett, 2014). The current generation has more freedom to explore different options compared to previous generations, as a result of residential changes, marrying and child rearing at later ages, enrolling in college or university, multiple job changes and identity exploration (Arnett, 2014). Although emerging adulthood can be an exciting stage, it can also be stressful due to the many life choices available and the instability associated with this stage.

It is especially challenging for emerging adults with disabilities (EADs) for a variety of reasons. For example, children with disabilities are often supported through government funding for essential services, such as therapy or caregiving needs, and supported through school resources. However, once a child becomes the ages of approximately 17 to 21, they graduate from school and typically, the funding and resources abruptly ends (Autism Ontario, 2017). Thus, individuals who rely on school supports and government funding to access services must now apply for other sources of funding to access adult services and supports. Also, there is generally a lack of support to accommodate individuals with disabilities in the emerging adult life stage which results in their transition to adulthood being prolonged (Cooney, 2002). Therefore, they may not have the same opportunities or the possibilities to explore life options like typically developing individuals.

For this literature review, an in-depth review of the effects of life transitions for emerging adults with disabilities (EADs) regarding employment, post-secondary education, health care transitions, independent living, developing meaningful relationships and the possible

development of positive attributes for EADs will be reviewed. Canadian information will be cited where available as the majority of research resides in the United States. The implications of emerging adulthood for people with disabilities is discussed in the following section.

1.1 EMERGING ADULTHOOD FOR PEOPLE WITH DISABILITIES (EADs)

According to the Canadian Survey on Disability Reports (2018), an estimated one in five people (6.2 million) aged 15 years and over have one or more disabilities limiting their activities of daily living. Of the 6.2 million Canadians aged 15 years and older with a disability, 37% are classified as having a mild disability, 20% a moderate disability, 21% a severe disability, and 22% a very severe disability. More specifically, more than 540,000 youths aged 15 to 24-years (13%) had one or more disabilities. In the 15 to 24-year-old age group, the most common types of disabilities included mental health-related disabilities (7.8%), learning disabilities (5.5%) and pain-related disabilities (4.4%). Due to the challenges and obstacles EADs face in their everyday lives, full participation in their communities may be limited (Statistics Canada, 2018).

In Ontario, there are many services and local programs to help children with disabilities and their families. For example, there are a range of services and supports (See Ministry of Ontario, 2018) for children and youth with autism, developmental disabilities, Fetal Alcohol Spectrum Disorder, mental health challenges, and those who may require rehabilitation services. There are also financial and respite supports for families such as services for at home, assistance for children with severe disabilities, and respite programs to support families with day-to-day care. However, when children with disabilities age out of their funding services, there is little support in transitioning to adult services. In addition, programs that are available after aging out of youth services often have an eligibility criterion, such as type/severity of disability and financial requirements to receive such services. This is dependent on regulations, such as

eligibility to receive passport funding, which is government funding for people with developmental disabilities (Developmental Services Ontario, 2019) where they can allocate their funds for community participation services and supports, activities of daily living (ADLs) and person-directed planning. In addition, one can apply for Direct Funding where adults with physical disabilities can become employers of their own attendants (Ontario Ministry of Health and Long-Term Care, n.d.). Attendants assist with ADLs for individuals. Eligibility for these funding programs can limit placement for most individuals with disabilities. For example, passport funding is only for those who have developmental disabilities, and Direct Funding for those with physical disabilities. In addition, to apply for Direct Funding, individuals must complete a written application on their own, and cannot receive assistance from professionals or family members. So, those who need assistance in writing and do not have anyone outside of family to help, would be ineligible. These requirements, in turn, leave individuals dependent on their families, and prolong their transitions to adulthood (Cooney, 2002). Although the challenges associated with receiving government funding are just one example of lack of support for EADs, insufficient support in other domains exist for their transitions into adulthood, which will be discussed further in the next section.

Although this literature review and study uses the term ‘emerging adults with disabilities (EADs)’; where ‘emerging adult’ stemmed from Arnett (2014), in the literature, this demographic is also referred to as young adults in transition, youth in transition, youth with disabilities, young people with disabilities, adults with disabilities and people with disabilities. The purpose of this literature review is to provide an overview of the areas that have been researched for this demographic thus far, and to provide a better understanding of life transitions for EADs.

1.1.1 Experiences of Life Transitions for EADs

Transitions are referred to as “any event or non-event that results in changed relationships, routines, assumptions, and roles” (Evans, Forney, & Guido-DeBrito, 1998, p. 111). Transitions occur throughout life and are faced by all young people as they progress from childhood to adulthood (Barron, Coyle, Paliokosta, & Hassiotis, 2014). The emerging adulthood phase is a difficult time and perhaps the one with the most challenges and difficulties (Pandey & Agarwal, 2013). It can be argued that people with disabilities are more likely to experience non-events, which are transitions that are expected but do not occur, such as non-completion of high school, failing to obtain a job, non-admittance into post-secondary education, etc. (Evans et al., 1998). This is because options for EADs are limited as they are no longer able to access supports and services they were receiving in elementary and high school. Individuals could become reliant on their parents, and more likely to be isolated while their self-esteem suffers (McGrath & Yeowart, 2009). Due to possible communication difficulties, a lack of confidence in arguing for what they want, or the failure by community agencies to consult with them, many young people who could have gone on to higher education, had interesting jobs and independent lives, are held back before their adult lives have even begun (McGrath & Yeowart, 2009).

Although EADs face many personal challenges as described, environmental barriers often present the most significant challenges for transitions. In the Canadian context, Pandey and Agarwal (2013) contend that environmental barriers may include people’s negative attitudes towards youth with different types of disabilities, which can negatively influence all aspects of transitioning (see also Annable et al., 2003). In addition, a lack of knowledge about options and understanding of disability-related needs of youth by service providers, educators, parents and community members affecting their transition process negatively (see also Hitchings et al.,

2003). As well, a lack of opportunities, choices and experiences in childhood through adolescence which affect the transition itself, as well as adult outcomes (see also Foster, 2004). Also, the family environment can impose barriers such as socioeconomic status (SES), parents' low expectations for their children's future (Chambers, Hughes, & Carter, 2004) and their lack of knowledge to help their young adults (Jokinen, Janicki, Hogan, & Force, 2012; Learning Disabilities Association of Canada, 2017).

Due to the barriers EADs must overcome to transition to adulthood, emotional wellbeing can be negatively affected. For example, EADs may feel different or "not normal" (Hogansen, Powers, Geenen, Gil-Kashiwabara, & Powers, 2008, p. 225) compared to others without disabilities. Also, EADs often feel this period of time is emotionally demanding (Pandey & Agarwal, 2013) because their perceptions of their disabilities, impairments and self-identities are constructed the most (Barron et al., 2014) during this period. In addition, they can often experience marginalization and isolation from negative perceptions and lack of accessibility from their communities (Hamilton, Mesa, Hayward, Price, & Bright, 2017), which leads to low self-esteem, lack of self-confidence and mental health issues (Pandey & Agarwal, 2013).

EADs' transition experiences differ from those experienced by typically developing EAs (Barron et al., 2014). Although they may express similar life aspirations and goals as their counterparts without disabilities, ultimately, EADs face more obstacles during the transition to adult life (Gallivan-Fenlon, 1994; Stewart, 2010). Some of these differences include transitions leaving the family home, managing money, independence, social and leisure roles, fulfilling meaningful relationships, and finding employment (Betz, Nehring, & Lobo, 2015; Dyke, Bourke, Llewellyn, & Leonard, 2013). As well, parents of EADs acknowledge concerns in changing expectations pertaining to future planning, changes in their parenting roles, changes in their

children's roles, and parental stressors due to caregiving and transition demands (Betz et al., 2015; Jokinen et al., 2012). Barriers for EADs to transition into adulthood include, but are not limited to, finding employment, admission to higher education, transitioning to adult health care services, independent living, and limited social interaction which inhibits the creation of meaningful relationships (Centers for Disease Control and Prevention, 2018). Each of these factors will be discussed in the sections further.

1.1.2 Employment

Employment is a crucial avenue through which young people with disabilities can experience “material wellbeing and social participation” (Honey, Kariuki, Emerson, & Llewellyn, 2014, p. 151). However, in Canada, persons with disabilities face lower employment rates where 59% of working-age adults (15-64 years old) with disabilities were employed compared with approximately 80% of typically developing people (Statistics Canada, 2018). Further almost one third of working age adults with severe disabilities reportedly live in poverty in Canada (Jetha, Bowring, Furrie, Smith, & Breslin, 2018; Statistics Canada, 2018). Even with supportive services, youth with disabilities encounter significant employment challenges (Honeycutt, Thompkins, Bardos, & Stern, 2013; Noel, Oulvey, Drake, & Bond, 2017) which may be related to low employment rates for this population. Noel et al. (2017) outlined barriers EADs face with respect to employment including lack of work experience, transportation problems, cognitive issues, lack of social skills, behavior problems, family pressures, poor physical health, difficulties with housing, and lack of needed services.

To alleviate these barriers, the Employment Equity Act was implemented in Canada to achieve equality in the workplace (Government of Canada, 2019). The goal of this act is to correct the conditions of disadvantage in employment experienced by minority groups, such as persons

with disabilities, by treating persons in the same way but also providing accommodations (Government of Canada, 2019). As well, for EADs to gain employment, it may be necessary to obtain a minimum of a high school diploma. In Ontario, a program known as the Individual Education Plan (IEP) developed by the Human Rights commission, also known as Special Education Plan (SEP), exists to accommodate the needs of children/adolescents in school (Ontario: Ministry of Education, 2018). An IEP is a written plan describing the special education programs and/or services required by students and is developed in collaboration with the parent(s)/guardian(s) and from the students if they are 16 years of age or older (Ontario: Ministry of Education, 2018). An IEP can be developed as early as kindergarten and in theory, their IEP stays in effect until the requirements to graduate high school are obtained (Ministry of Education, 2004).

The process of developing a transition plan typically begins for students who are 14 years of age or older (Ministry of Education, 2004). Parent(s)/guardian(s), teachers and the students themselves all have an integral part in the planning for leaving school and according to the Ontario Ministry of Education (2016), it is required that schoolboards develop transition plans for all students who have an IEP or who are in a special education program. Transition plans are made to help students with disabilities transition to appropriate postsecondary endeavors such as, work, further education, and/or community living.

Although there are services in place to help students transition into aspects of emerging adulthood (e.g., employment, further education), challenges are often experienced when attempting to follow the plan. For example, challenges include: transition plans are uninformative and late to be implemented, lack of knowledge sharing between transition stakeholders, care takers in daily activities do not know enough about the EAD, parents act as

navigators for their child, which is exhausting (Gauthier-Boudreault et al., 2018). Further, there is a lack of research on the effects of Ontario IEPs and transition plans for students with disabilities, such as if the students are adhering to their plans, the types of obstacles students face, if any, while following their plans, or if the transition plans are successful in preparing the students for the transition to adulthood.

Beyond the school system, there are community resources available that aid in the preparation of adulthood such as Youth in Transition programs (Independent Living Centre of Waterloo Region, n.d.; YMCA of Hamilton Burlington and Brantford, n.d.), online resource booklets and toolkits (Community Living Toronto, n.d.; Transition Network Committee of Waterloo Region, 2020), and employment, housing, funding, and mental health services (Developmental Services Ontario, 2020; Local Health Integration Network, 2014; Lutherwood, 2020). However, it is unknown in what capacity these resources are used and if they are considered sufficient/helpful.

In the United States (U.S), the Individuals with Disabilities Act (IDEA) in 2004 was implemented nation-wide whereby children with disabilities received appropriate public education that ensured special education and services (U.S Department of Education, 2011). The goal of these programs was to help children with disabilities succeed in obtaining education, with many programs offering school-to-work transitions. This act assisted students with disabilities to obtain stable employment after they graduated high school as substantially fewer youth with disabilities worked for pay after leaving high school than typically developing youth (Shandra & Hogan, 2009).

Longitudinal studies have found the transition to employment programs successful when youth with disabilities were in these programs throughout high school. For instance, work-based

initiatives, such as participating in cooperative education programs (Shandra & Hogan, 2009), or having a job during high school (Rabren, Dunn, & Chambers, 2002), were related to obtaining stable employment, being offered health insurance and paid sick days. As well, those who received special education and were involved in school-to-work programs were seen to continue to higher education, have a paid job, be engaged in their communities, live independently and have a personal bank account (Newman et al., 2011). Overall, school-to-work programs are associated with improving the likelihoods that young adults with disabilities will obtain stable paid employment, and achieve successful post-high school outcomes (Sanford et al., 2011).

1.1.3 Post-Secondary Education

Like employment, another common avenue to pursue is post-secondary education (PSE), such as university or college. PSE is an important option in the educational and employment paths of students with disabilities (Alqazlan, Alallawi, & Totsika, 2019). This is because, as stated previously, people with disabilities are less likely to be employed than their typically developing counterparts, thus PSE can improve the skill set of young adults with disabilities and better prepare them to enter the workforce (Giust & Valle-Riestra, 2017). For example, students who attended PSE experienced increased self-determination and self-esteem (Ju, Zeng, & Landmark, 2017), confidence (Stefánsdóttir & Bjornsdottir, 2015), self-advocacy (Hengen & Weaver, 2018), and made more friends (Nasr, Cranston-Gingras, & Jang, 2015). As well, PSE can provide non-academic experiences such as co-ops, summer employment, and internships (National Education Association of Disabled Students (NEADS), 2018), where students can network with future employers and have prospective job opportunities once graduated.

There have been increases in the percentages of students with disabilities attending and graduating PSE. However, having a disability still has its effects on an individual's access to

university in accordance with their abilities (Hindes & Manther, 2007). For example, inclusion and accommodation from institutions, negative attitudes and stereotypes from peers and professors, access to transportation to get to campus, and financial barriers (Ontario Human Rights Commission, n.d.) often function as obstacles. Specifically, in Ontario people with disabilities are less likely than those without disabilities to graduate from university at the bachelor's level or higher (Human Resources and Social Development Canada, 2009; McCloy & DeClou, 2013). For instance, 14% of people with disabilities aged 25 to 64 years had at least a university certificate, diploma or degree at the bachelor's level compared to 27% of people without disabilities (Statistics Canada, 2012). Therefore, despite the benefits that PSE can have for young adults with disabilities, there are many barriers that create missed opportunities for them to attend university institutions.

In contrast, participation rates in colleges are roughly similar for those with or without a disability (McCloy & DeClou, 2013). In Ontario, 37.8% of people with physical disabilities attained college education, compared to 32.1% of non-disabled people (Statistics Canada, 2006). Compared to the rest of Canada, 38.2% of people with physical disabilities attained college education, versus 36.6% of non-disabled people (Statistics Canada, 2006). In addition, 46% of those with a disability at age 15 attended college by age 21, whereas 22.1% attended university (Finnie, Childs, & Wismer, 2011) suggesting that students with disabilities are able to attend college at an earlier rate than university. As well, 71% of college students used services for students with disabilities, whereas only 56% of university students used such services (McCloy & DeClou, 2013). This may imply that college students are more comfortable disclosing their disability and accessing supports than university students (NEADS, 2018), and there remains a

gap in availability of resources between university and college institutions (Chambers, Sukai, & Bolton, 2011)

Although PSE attainment is increasing in the population with and without disability, the gap in the university sector remains. In addition, students with disabilities may also be less engaged with other students and their institutions in general, but more engaged with faculty and staff (McCloy & Declou, 2013). As well, significant transition barriers into and out of PSE remain, especially from post-secondary to the workforce (NEADS, 2018). This may be due to post-secondary institutions lacking accommodative resources students may have had in high school, and disability offices not having the funding to provide support beyond academic accommodations, such as career educators on campus. Although there are barriers that exist, PSE provides students with disability experiences to build on their own capabilities and expand their choice in careers. Another area that requires transition is from pediatric to adult health care. This topic will be discussed next.

1.1.4 Health Care Transitions (HCT)

Health care transition is described as the purposeful, planned movement of adolescents from child to adult-oriented care (Carroll, 2015). For EADs, the transition from pediatric care to an adult care system is especially challenging. Not only are they entering a new life stage of adulthood, they are also tasked with learning how to manage their health, medical and social needs within an adult health system and community not necessarily designed to address their unique needs (Major et al., 2014). As well, young adults with disabilities and their caregivers see health care services and supports as inadequate, which is unsurprising considering the significant drop-off of services after EADs complete high school (Sosnowy, Silverman, & Shattuck, 2018).

In Canada, successful transition programs can significantly reduce both the quality and the cost of healthcare by reducing emergency department visits, increasing continuity of care, and increasing patient and physician relationships (British Columbia Medical Association, 2014). However, unsuccessful transitions from pediatric to adult services for EADs have been associated with deteriorated health status and acceleration of mortality (Fredericks, 2009), increased time in long-term care and more repeat hospitalizations and emergency room visits (McQuigge, 2019). Unsuccessful transitions can occur from lack of adherence to proposed treatment plans, deficiencies in the knowledge about the condition and limited self-care skills which may be due to the significant differences between the mandate and functioning of pediatric and adult services (Canadian Paediatric Society, 2007). Around the age of 18 is when persons obtain adult status in many programs and systems in Canada, including people with disabilities and, so it is important for EADs and their families to plan their HCT ahead of time.

There are transition planning resources available in Canada for EADs (see Canadian Mental Health Association, 2019; Children's Healthcare Canada, 2018; SickKids, 2014). However, the transition between health care systems is predominantly based on chronological age, not developmental age meaning that EADs may reach the age of transition, but still have to rely on the level of support that is typical for someone in the child and youth health care system (Canadian Mental Health Association, 2019).

As well, especially in the case for EAs with developmental disabilities (DDs), health care professionals (HCPs) are not necessarily trained to recognize such disabilities or provide appropriate care in adulthood. Also, HCPs often have misconceptions about DDs and expect their patients to show symptoms and behaviors based on stereotypes the EADs have grown past (McQuigge, 2019). EADs with "invisible disabilities" may not be willing or able to

communicate their situations when transitioning to adult health care services (Canadian Paediatric Society, 2007; Children's Healthcare Canada, 2018; Learning Disabilities Association of Canada, 2017).

The Canadian health care system is in need of better accommodation for the needs of EADs and the variety of disabilities they may present, as stated in an article by McQuigge (2019), "when you're perceived as not competent, you're denied autonomy and the ability to take control over your own decisions in relation to your health... If you try to assert your own control, they assume you don't actually need support" (para. 24). As well, it is necessary to provide EADs a more prominent voice in their own care, establish more supports to keep people with disabilities out of long-term care, and review premature mortality cases for prevention purposes (McQuigge, 2019). Many barriers exist that prevent the transfer to adult services such as lack of adequate reimbursement, reluctance by adult providers to serve special need populations, and time constraints (Geenen, Powers, & Sells, 2003), such as being put on agency waiting lists (Kingsnorth, Gall, Beayni, & Rigby, 2011). Other issues include family and consumer reluctance to leave pediatric specialists and lack of insurance coverage (Betz, 2003). As well, many adult services have discriminative eligibility criteria, such as criteria based on IQ thresholds, rather than adaptive functioning relative to a young person's ability to be independent. This is especially the case for young people with Autism Spectrum Disorder (ASD) because of pre-judgements of capability (Milen & Nicholas, 2017) and lack of knowledge of the condition from HCPs (Carroll, 2015; Cheak-Zamora & Teti, 2015). Unfortunately, these situations have resulted in insufficient funding and services for EADs which could ultimately lead to poor health outcomes during their adult lives. Further, there is a lack of individualized care for EADs during their HCT (Cheak-Zamora, Teti, & First, 2015). The lack of individualized care requires families

to continue to engage as primary service providers, further limiting EADs from developing a sense of independence and responsibility external to their family unit and relying on families which may or may not have the required resources (Kingsnorth et al., 2011; Milen & Nicholas, 2017).

EADs reported feeling anxious and uncomfortable about their new “adult” care given by providers that lack knowledge about their conditions (Carroll, 2015; Cheak-Zamora & Teti, 2015) and from the lack of rapport formed between the EADs and service providers (Betz et al., 2015; Milen & Nicholas, 2017; Pallisera, Vilà, & Fullana, 2014). Due to the lack of individualized care, EADs do not fully understand the HCT process and lack guidance about transitions caregivers provide. Therefore EADs often cannot develop health-related independence (Carroll, 2015) and skills such as setting up their own appointments and making medical decisions.

There is a need for clear guidelines to be established regarding the distribution of roles and responsibilities between the professionals and services involved in transitioning to adult services (Pallisera et al., 2014). It is important to build and maintain a working alliance with the family, envisioning a future, promoting parent effectiveness in medical management; promoting the adolescent’s development potential (e.g., self-care); promoting autonomy, self-efficacy and individuation, independence and exploration in adolescence; and finally, transferring to adult-focused providers and facilities (Reiss, 2012). This way, parents can be informed throughout the HCT process while including EADs participation, while allowing for smooth transitioning to adult services.

1.1.5 Independent Living

A major milestone in the emerging adulthood phase is living independently (Arnett, 2014). Independent living is a way for people with disabilities to access their human and civil rights similarly to non-disabled people (Morris, 2004), as well as have the opportunity to make their own decisions, take risks, make their own mistakes and assume the consequences (PACE, 2019). Although they may require some additional assessments, such as mobility needs, communication assistance, personal assistance, tenancy support for assisted living, emotional support and familial support, it is the individual's right to live with dignity in his or her chosen community and to participate in all aspects of life (PACE, 2019).

Even though people with disabilities may have the desire to live independent lives, many constraints exist that limit their opportunities to do so. For example, in Canada, a large proportion of people with disabilities over 25 years of age live with their parents, in group homes or institutional settings (Wiesel et al., 2015). This may be the case as 28.6% of individuals with disabilities have unmet needs due to the inability to afford the costs associated with aids, devices and medication (Statistics Canada, 2018) required for independent living. Therefore, people with disabilities who live alone with more severe disabilities are more likely to live in poverty, to experience housing stress, are over-represented in housing assistance programs and in the homeless population, and are under-represented in property-owner-occupation (Statistics Canada, 2018; Wiesel et al., 2015). Other than financial barriers, contextual constraints on independence exist such as restricted range of activities, educational and employment opportunities available for adults with disabilities (Hamilton et al., 2017) due to recent provincial government funding cuts in Ontario falling heavily on adult support sectors.

Familial influences may also contribute to whether people with disabilities live alone or stay within the family home. These factors include family values and beliefs, finances, opportunities within the community, parental retirement plans and health status of either the parent or their children (Jokinen et al., 2012). For example, for older-aged families, adults with disabilities may have to transition from living at the parental home to accommodate living arrangements, such as group homes or assisted independent living, due to underlining health issues of the caregivers in situations where they can no longer care for their children with disabilities. However, even planned independent living transitions have challenges such as extensive residential wait lists, unexpected medical issues that intercept smooth transitions, uncomfortable living situations and lack of support by service providers (Bond & Hurst, 2010).

In turn, the majority of stress is put on family members, and more often than not, care for adults with disabilities is placed on the siblings of said adults once the parents have passed (Jokinen et al., 2012), resulting in permanent co-residency of the siblings, and lack of opportunity for independence for individuals with disabilities.

1.1.6 Experiences of Developing Meaningful Relationships

Developing meaningful relationships is a gateway to improving a person's quality of life. Relationships provide "practical aid, emotional support, information, assistance with decision making, and opportunities to broaden existing support networks" (McVilly, Stancliffe, Parmenter, & Burton-Smith, Rosanne, 2006, p. 191). Alternatively, there are adverse consequences associated with having poor social networks, such as loneliness and depression (Callus, 2017; Lesseliers & Van Hove, 2002; McVilly et al., 2006). Despite progress in improving service provision to help integrate people with disabilities in communities, EADs continue to sense a lack of citizenship (MacIntyre, 2014) in that they do not have the

accessibility to contribute to their local communities through work and participating in local programs. Compared to their typically developing peers, EADs are more at risk for social isolation, poor health and to experience loneliness with less life satisfaction (Van Asselt, Buchanan, & Peterson, 2015). In part, this is due to intrinsic factors such as lack of knowledge of existing resources, lack of knowledge of disability-specific activities, lack of skills necessary to participate, lack of friends with whom to participate, and transportation barriers (Abbott & Mcconkey, 2006; Hall, 2017; Ralph & Usher, 1995; Simplican, Leader, Kosciulek, & Leahy, 2015).

Moreover, according to Biggs and Carter (2016), the domains of social support and relationships with peers had the lowest ratings in terms of quality of life for transition age-youth with disabilities. In community settings, this may be due to barriers that prevent EADs to engage in social settings. For example, the attitudes and perceptions of others may contribute to an initial reluctance or resistance to participate in activities in the community (Abbott & Mcconkey, 2006; Jobling, Moni, & Nolan, 2000; Simplican et al., 2015; Test, Smith, & Carter, 2014). As well, inclusive services that do exist in communities, such as adapted physical activity programs, often have irregular volunteers/support staff or not enough volunteers/staff to accommodate individuals in need (Ralph & Usher, 1995; Van Asselt et al., 2015). These challenges may lead to insufficient support and creating barriers in attendance. Further, service delivery and support models used in most secondary schools in the U.S can limit the opportunities students with and without disabilities have to engage with each other. For example, in the U.S, only 40.2% of students in special education spend most (i.e., 80% or more) of their day in general education classrooms, despite regulations specifying students must attend classes for certain periods of time (Test et al., 2014; U.S Department of Education, 2011). Therefore, students with disabilities

can be limited in their opportunities to engage and possibly create friendships with their typically developing peers. These findings signal the need for more inclusive practices and policies within the school system (Test, Bartholomew, & Bethune, 2015).

Another factor limiting EADs' ability to develop meaningful relationships is their own lack of understanding of friendships. Jobling et al. (2000) reported individuals with disabilities may not develop an understanding of emotions and relationship-building incidentally or from normalized environmental experiences like their typically developing peers. Friendships are often limited for this population and as a result meaningful interpretation of friendships are portrayed by television shows or through creating imaginary friends. Thus, people with disabilities typically lack an understanding of the emotional aspect of friendships through personal experiences of having or being a friend (Jobling et al., 2000). Furthermore, they may feel hesitant to pursue friendships as they may not feel accepted or safe with non-disabled people for fear of being taken advantage of (Callus, 2017), fear of rejection, and/or fear of experiencing lack of reciprocity within the friendships (Chappell, 1994; Hall, 2017). Overall, there is a lack of opportunity for EADs to develop close and meaningful friendships. Therefore, advocacy for EADs' autonomy and quality of life is needed.

1.1.7 Positive Attributes

Although EADs experience many barriers and challenges throughout their lives, they can also develop positive attributes, such as higher levels of resilience prior and during the transition process (Test et al., 2015). Mannino (2015) found that EADs had similar goals to their typically developing peers, such as pursuing higher education and employment, and to becoming more independent. As well, EADs with mental health disorders experienced less burden on their mental health than the general population of adults in the U.S. during the emerging adulthood

phase (Mannino, 2015). This is because throughout their lives, people with disabilities have had to become resilient in order to deal with the adversity related to overcoming challenging barriers, such as social barriers to be included in their community, ability to obtain finances to access needed services, and receiving social support from others (Langone, Clees, Oxford, Malone, & Ross, 1995).

Being consistently faced with barriers may result in EADs becoming exceptionally resilient and self-determined (Mcguire & McDonnell, 2010; Seong, Wehmeyer, Palmer, & Little, 2015). These characteristics help them to reach their goals, especially when in combination with a strong support system involving caregivers, adult services, and the community. Self-determination, defined as acting voluntarily, based on one's own will (Chou, Wehmeyer, Palmer, & Lee, 2017), consists of many components such as self-advocacy, choice making, goal setting and problem solving. These skills can be positively correlated with adult outcomes and individuals' perceptions of their quality of life (Mcguire & McDonnell, 2010) for EAs with significant disabilities. As well, EADs who have acquired self-determination skills are correlated with higher productivity and organization during school, a predictor of academic achievement, and quality of life outcomes in adulthood (Gaumer-Erickson, Noonan, Zheng, & Brussow, 2015). EADs who develop self-determination are more likely to move from their parents' home, manage their finances, and find long-term employment than their peers who have lower levels of self-determination (Wehmeyer & Bolding, 2001). Research has shown that EADs are able to develop realistic goals which promote problem-solving skills, self-reliance, and self-sufficiency (Henninger & Taylor, 2014; Mannino, 2015), thus allowing them to successfully transition to adulthood. Therefore, despite having a disability, EADs can succeed, be satisfied with life and be independent. However, the skills necessary for development of these positive attributes such as

resiliency, self-determination, problem-solving and self-reliance, and sufficiency, are best learned in social settings where they have greater generalizability and are built from experiences and opportunities rather than skills learned out of social context (Langone et al., 1995). As a result, accessibility to recreation and community involvement is crucial for the development of these positive attributes for EADs, and self-determination skills and experiences should be promoted in school curriculums, as they can assist in the successful transition to adult life (Gaumer-Erickson et al., 2015; McGuire & McDonnell, 2010).

Many aspects of transitioning to adulthood for EADs were discussed in this literature review including, schools preparing students for adult life, employment, PSE, HCT, developing meaningful relationships and positive attributes. The topics that were discussed are not exhaustive, as each experience is unique and depends on one's disability, life situation, and personal factors on how a person experiences becoming an adult. In the next section, a Canadian organization will be discussed that assists individuals in the transition process by helping them navigate their communities.

1.2 Independent Facilitation

In Canada, the Ontario Independent Facilitation Network (OIFN) is an organization that helps people with disabilities by supporting them to direct their own lives and live as valued community members and citizens. The OIFN provides support through independent facilitation, which is an ongoing support relationship designed to assist people with disabilities as they work to create lives for themselves. With the independent facilitation service, people with disabilities are able to create, direct and control change in their lives, have access to customized support, seek community support for inclusion, and live as citizens. Independent facilitation is person-directed, one-on-one support that focuses on the needs of individuals with disabilities and their

families within the context of creating a meaningful life in the community (Ontario Independent Facilitation Network, 2018).

Together, the Independent Facilitator (IF) and person with the disability (i.e. focus person) can create and pursue many goals ranging from exploring passions and interests, finding volunteer or paid work, inclusion in the community, creating new friendships and independence. IFs are partnered with multiple focus people and are paired based on the IFs experience, the focus person's goals, and availability of IFs. IFs use their resources to help individuals pursue goals such as providing transportation to a community center or chaperoning romantic dates. IFs may also "support the supporters" (Partners for Planning, 2019) where they connect with personal support workers and other family and friends in the support network of the persons with the disabilities to ensure everyone is focused on the same objectives. For this study, I partnered with an organization in Southern Ontario that is part of the OFIN network and this organization will be described next.

This organization is located in Ontario, is part of the OIFN and works specifically with adults with disabilities to help integrate them into the community. Specifically, their mission is to create meaningful relationships with their 'focus-people' through independent facilitation, whereby the facilitators support their focus-people by building on their abilities to create the lives their focus-people want in the community. The IFs offer person-directed planning, relationship development, social inclusion, and community participation and contribution. The role of independent facilitation is to guide the process, not direct it, as in they are to walk with the person as they take action on their plan. Organizations like this are unique and an integral component in the lives of EADs who use the service. As explained in the literature review, EADs experience more challenges than typically developing individuals during this life stage. These

challenges create barriers to living independently, finding employment, accessing social programs and health care services and to developing meaningful relationships. Therefore, this study will explore the role of independent facilitation for EADs and how it may have an impact on these challenges EADs face in this life stage. In order to protect the anonymity of participants, the name of the organization will not be used.

1.3 LIMITATIONS IN THE LITERATURE

While research exists in explaining different aspects of emerging adulthood for people with disabilities, gaps lead to an incomplete understanding of EADs experiences. For instance, most studies are quantitative, such as collecting data through surveys and questionnaires. For example, information on PSE for people with disabilities was largely based on stakeholder perspectives. Although these studies provide a better understanding of the phenomenon by indicating the various challenges and factors related to emerging adulthood, they lack the personal experiences of the individuals involved, especially the EADs and their caregivers. In addition, qualitative studies that do exist, lack a holistic approach and fail to capture the experiences of EAs and their entire support networks. For example, in addressing meaningful relationships, some studies included focus groups with people with disabilities. Although useful to gather large amounts of data, there was a lack in personal, in-depth experiences from individuals and families. Most often, the experiences of caregivers, professional workers and teachers are the voices being captured, leaving the EADs excluded from telling their experiences, or only obtaining the voices of certain people in the network. As well, the demographic within studies are dominated by people with intellectual/learning disabilities and less focused on people with developmental or physical disabilities. There is also a lack of research in the Canadian context pertaining to the effects of life transitions for EADs, including longitudinal studies, and information available is

largely U.S data. Finally, to my knowledge, the effects of independent facilitation have not been previously studied. Therefore, little is known about the independent facilitation service during this life stage. As a result, research addressing these gaps is warranted.

1.4 PURPOSE AND RESEARCH QUESTIONS

This study will examine the lived experiences of transitioning to adulthood for people with disabilities and how independent facilitation plays a role during this life stage. A qualitative approach was used in order to obtain rich, thick, descriptions of the participants' experiences. Examining the experiences of emerging adulthood was holistically explored from the perspectives of the EADs (if able), their caregivers, and independent facilitators (IFs). Two research questions were addressed:

1. What are the perceived experiences of transitioning to adulthood for people with disabilities and their families?
2. What role does independent facilitation have in transitioning to adulthood from the perspective of people with disabilities, their caregiver(s) and their independent facilitators (IFs)?

Implications for this research included giving individuals with disabilities a 'voice' in the research and increasing public awareness of the need to develop better resources for EADs.

CHAPTER 2: METHODOLOGY

2.0 WORLDVIEW

This study followed a constructivist worldview being that it is qualitative in nature. A constructivist paradigm assumes multiple and equally valid realities (Ponterotto, 2005; Schwandt, 1994). These realities are constructed by the individual, rather than an externally singular entity (Ponterotto, 2005) and use a hermeneutical approach which holds that meaning is hidden and is brought to surface through reflection. This reflection is encouraged through communication between the researcher and each participant, creating a dialogue where a deeper meaning can be unfolded. Therefore, the researcher and participants co-construct realities from their conversations and interpretations (Ponterotto, 2005). In the current study, interviews were used to gather in-depth information of participant experiences to develop the findings.

2.1 PARTICIPANTS

To accurately depict the lived experiences of EADs and their families and support persons (i.e., caregivers and IFs), participants who underwent the experience of emerging adulthood and independent facilitation firsthand (Patton, 2002) were asked to participate in the study. After ethics clearance was obtained, purposeful sampling was used, specifically, criterion and snowball sampling. Purposeful sampling was used to recruit participants who were considered information-rich and could describe their experiences in great detail (Creswell, 2014). Criterion sampling was based on the principle that participants were included if they “meet some criterion” (Creswell, 2014, p.158), while snowball sampling allowed for individuals to refer me to other possible information-rich cases (Creswell, 2014). The goal was to recruit a variety of cases (e.g., EAs with physical, developmental and intellectual disabilities, EAs living alone, in their parents’ home, different purposes of using facilitation, etc.) in order to capture an array of experiences.

2.1.1 Recruitment

Recruitment occurred in two forms. One form was through word of mouth to individuals with disabilities and families that I knew personally. I encouraged participants to pass on the study information to others that might be interested in participating. The second was through the independent facilitation organization. I contacted the Director of said organization, who first reached out to the IFs by word-of-mouth and by email to participate in the study. The Director had no other role other than connecting me to the IFs. Once the IFs consented to participate, they then helped recruit their focus people (i.e., individuals with disabilities and families using the service) by connecting me to them through email once they had consented to be contacted.

The inclusion criteria for EADs included: (1) any disability to capture a variety of cases; (2) 16 to 37 years of age. Although the definition for an EA are those aged 18 to 25 years, those younger than this age range (Pre-EAs) were asked about what they anticipated for adult life, whereas those older (Post-EAs) were asked to describe their transition experiences retrospectively; and (3) any or no experience with independent facilitation.

The wide age range and broad facilitation experience was due to recruitment difficulties. Originally, all participants were to be recruited from the independent facilitation organization to capture the transition and facilitation experience collectively. However, in June 2019, the organization's provincial funding was cut, where they lost the majority of their focus people, and had IFs cut to less than 20%. After approximately 3 months of recruitment from the organization, there was little response in willing participants. As a result, I had to broaden my recruitment criteria from originally proposed.

Further, the inclusion criteria for caregivers and support persons included: (1) must be of consenting age; (2) may be the EADs' parent (mother or father), or any support person the EADs

felt was their main caregivers (e.g., a sibling another relative, friend); (3) did not have to be currently providing assistance to the EADs'; and (4) if there was not a caregiver/support person for an EAD, or if their caregiver/support person did not want to participate, the EADs would still be able participate, and vice versa. Finally, the inclusion criteria for the IFs included: (1) must be of consenting age; and (2) 3 to 6 months of experience as a facilitator with the organization.

2.2 RESEARCH TOOLS AND PROCEDURE

2.2.1 The Qualitative Method

To fulfill the purpose and answer the research questions of this study, the most appropriate methodology to use was qualitative in nature. These methods allowed for a holistic understanding of a particular experience or phenomenon. Specifically, a qualitative approach allowed me to study participants in a natural setting where I could gather information by talking to participants directly and see them behave and act within their environments (Creswell & Creswell, 2018). Further a qualitative design offered a thick description of individual experiences, highlighting their stories in their own voices. Often, the voices of individuals with disabilities are void in research (Williams & Moore, 2011) so using a qualitative design allowed for their voices to be heard.

Specifically, the theoretical orientation of phenomenology was used for this research as it was most fitting to fulfill the study's purpose. Patton (2002) described phenomenology as focusing on what people experience, and how, by using methods that capture such experiences. Thus, in-depth one-on-one interviews, background questionnaires, field notes, and member checks were used to capture the lived experiences of people who had direct experience with the phenomenon of emerging adulthood so the true essence of their experiences could be fully understood.

2.2.2 Ethics

Ethics clearance of all materials and procedures was granted by the Research Ethics Board at Wilfrid Laurier University. Before procedures began, the participants read and signed an informed consent form where a summary of the study and their requirements as participants were described. Their participation in the study was voluntary, with no repercussions if they decided not to participate. Participants were able to ask the researcher any questions at any time throughout the study.

2.2.3 Background Questionnaires

Participants completed a background questionnaire specific to their roles (e.g., EAD, caregiver, IF) (see Appendix A). Since some cases did not include the EAD, but their caregiver and/or support person participated on their behalf, then the EADs demographic information was provided by their caregivers and/or support person in the caregiver/support person background questionnaires (e.g. Heather & Cory & Luke's caregivers provided their demographic information. See Table 2 on page 36). The EADs background questionnaires consisted of: (1) demographic information such as age, gender, education and employment; and (2) their experiences with independent facilitation (if applicable). The caregivers' background questionnaires consisted of: (1) demographic information such as age, education, employment, and relationship status; (2) their children's diagnosis process, work and living situations; and (3) their experiences with independent facilitation. The IFs background questionnaire consisted of: (1) demographic information such as age, education and employment; (2) previous experience working with people with disabilities; (3) their roles in working with the independent facilitation organization; and (4) their experiences working with the EADs in question. The questionnaires

were used to help me gain an understanding of each case prior to the interviews, and to build rapport for their interviews.

2.2.4 Interviews

One-on-one semi-structured interviews were conducted with all participants. The interview protocol is included as Appendix B. This interview style allowed me to cover an array of topics with flexibility as the responses from participants determined the direction of the interviews. Semi-structured interviews are the most common type of interview in qualitative research (Stuckey, 2013), allowing for connections “between ourselves, others, and those in between to be shown” (Dilley, 2000, p.134). Interviews with EADs included questions about support they received, and their experiences of becoming an adult. Although originally proposed that the EADs would participate in Photo Elicitation Interviews, it was found when speaking with participants that it was preferred to address the interview questions with their words, and they either felt uncomfortable or did not see the need to use visual representation. As a result, all participants completed semi-structured, individual, interviews.

Caregiver and support person interviews included questions about support they provided to their children or siblings, and their children’s or sibling’s experiences becoming an adult and their experiences with facilitation. Families who were not using facilitation services were given a description of the service and were then asked if the service would have helped the transition experience, if at all. Independent Facilitator interviews included their experiences as a facilitator and the kind of support they provided to their clients.

All interviews were audio-recorded through a password-protected device and transcribed verbatim. An inductive approach with the interviews was predominately taken, where findings and themes emerged from analysis of interview data. However, a deductive approach was

utilized with respect to support, as questions were asked about childhood. Information about current supports were provided without probing or being asked questions about support. Time was given before and after each interview for any questions from participants. The participants were reminded before the interviews that they were free to discontinue the study at any time and to choose not to respond to any questions.

2.2.5 Field Notes

Data collection was enhanced by the collection of field notes (Creswell & Creswell, 2018). I took notes before, during, and immediately following each interview. Field notes were taken to record participants' reactions, body language, and emotions in response to particular questions. Field notes provided additional context to their experiences and feelings towards the topics at hand. As well, notes taken during the interviews were used to highlight important pieces of information disclosed by participants, which assisted in post-interview data analysis. For instance, during data analysis when reviewing transcripts, I would refer back to my field notes to remind me of important topics discussed as some interviews were lengthy and it was an asset to have my notes to refresh my memory. Lastly, field notes were taken afterwards to record my reflective thoughts after the completion of the interviews.

2.2.6 Member Checks

After transcription, all participants were given copies of their transcripts in order to clarify any information discussed during the interviews, which allowed for greater accuracy of the data, as well as to build rapport and trustworthiness between the interviewer and participants (Creswell & Creswell, 2018). Member checks were completed in order to give participants an opportunity to "correct, amend, or extend" (Lincoln & Guba, 1985 p. 236) information existing in their transcripts so they were comfortable with the data being presented in future research

papers, posters, or presentations. Participants had two weeks to review and return their member checks, otherwise I proceeded with each transcript as is.

2.2.7 Triangulation

Data triangulation was used to increase the study's credibility by employing multiple methods of data collection (e.g., background questionnaire, field notes, and interviews). Themes were established based on converging several sources of perspectives from participants (Creswell & Creswell, 2018). Source triangulation was used by considering perspectives of the EADs, the caregivers and IFs where information provided from each participant was triangulated and transformed into themes (Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2014). Finally, investigator triangulation was used whereby my supervisor and I analyzed and interpreted the data separately, and then came together to discuss themes and subthemes. By including three triangulation methods, the credibility of this study was enhanced (Patton, 2002).

2.3 TRUSTWORTHINESS

It is important to establish the trustworthiness of a study in order to determine the study's value. Credibility, transferability, and confirmability are three means by which to establish trustworthiness (Lincoln & Guba, 1985). Each of these concepts will be discussed in turn.

2.3.1 CREDIBILITY

Credibility allows the researcher to create confidence in the data presented (Lincoln & Guba, 1985). To establish credibility in qualitative research, one must have: (1) rigorous methods and techniques to obtain high-quality data, (2) ensure the researcher is credible, and (3) a belief in qualitative research and its value (Patton, 2002). The methods previously mentioned (field notes, member checks, triangulation), allowed for greater integrity of the data to be formed, as well as gaining rapport between myself and participants (Lincoln & Guba, 1985). Additionally, I

was an integral tool in the qualitative research process. In order to gain an understanding of qualitative methodologies and theoretical approaches, I completed multiple qualitative research courses and an extensive review of the literature regarding emerging adulthood for individuals with disabilities. My supervisor and I reviewed all transcripts as they were completed and discussed what questions worked well and vice versa in order to improve future interviews, such as to ensure questions were asked in a certain order. I also completed field notes and journaled throughout the research process in order to disclose any biases or preconceived notions I brought into the study, such as previous knowledge on emerging adulthood, my experiences working with people with disabilities through volunteering, and having family members with disabilities. Therefore, journaling was done to remain as neutral as possible during the thesis process, from the interview phases to data analyses and interpretation. Finally, I chose a qualitative study design as it allowed for participants' voices to be heard and allowed for the experiences of EADs to come forward, as well as address the multifaceted views of these experiences.

2.3.2 TRANSFERABILITY

Transferability was maintained by obtaining high-quality data so that the information from this study could be applicable to other contexts. As such, only information-rich participants and cases were included. This way, findings from this study are applicable to Canadian school systems, governing bodies that control funding allocation, workplace and housing associations and community services/programming in how to better support EADs.

2.3.3 CONFIRMABILITY

Lincoln and Guba (1985) contend that confirmability is the degree of neutrality within a study. This refers to how participants and their responses influenced the data, rather than the researcher's motivations. Lincoln and Guba (1985) state using field notes and triangulation

are integral to this process of establishing confirmability. Field notes were completed before, during, and after interviews in order to capture my feelings and/or perspectives. Additionally, field notes were used to collect the feelings and perspectives of the participants throughout the interview process. Thus, field notes captured the essence of participants' experiences, and allowed the true experiences to emerge in the data. Also, three triangulation methods (i.e., data, source and investigator) were used and permitted participants' interpretations of their experiences to shape the data.

2.4 CONFIDENTIALITY

All data collected in the form of questionnaires, field notes, transcripts, and audio recordings, were stripped of identifiers and assigned pseudonyms to ensure confidentiality. Data stored digitally was password protected. The consent form was the only data which contained participants' names and was locked separately from all other data in the KPE department at Wilfrid Laurier University. Interviews took place individually and the audio recordings were only accessible to me, and the transcripts and questionnaires only accessible to my supervisor and I. Since there were limited IFs on staff at the organization, complete anonymity was not possible for them. The IFs were made aware of this risk and made clear their participation in this study was voluntary. Further, the name of the organization was left out of the thesis document in order to protect participants' identities.

2.5 THEMATIC ANALYSIS

According to Creswell and Creswell (2013), thematic analysis is when the researcher focuses on key issues to understand the complexity of the case. For my analysis, I followed the steps as outlined by Braun and Clarke (2006) (See Appendix C): I read through the transcripts from participant interviews several times to familiarize myself with the data. To answer the research

questions, I organized the questions I asked in each interview with the research question it answered (See Appendix D). I then identified initial codes by underlining and using sticky notes to highlight important quotes and create categories from each transcript. Next, I organized the codes by creating mind maps (See Appendix C) for each participant and provided information from the transcripts and field notes to support each category. The mind maps served as a visual summary of the data, which made it possible for me to review and compare the categories and turn them into themes. Then, I organized important quotes from transcripts into their respective themes in tables. I then read through the transcripts again to confirm that each theme was refined and able to tell the story the data showed. This process occurred over and over as I continued to complete interviews, all while rereading previous transcripts and formulating themes and subthemes. As explained previously, background questionnaires and field notes were used as context throughout the analysis process.

Investigator triangulation was used to confirm findings through the use of different perspectives which “added breadth to the phenomenon of interest” (Carter et al., 2014, p. 545). After my supervisor and I reviewed the transcripts individually, we met to discuss our findings. We presented our categories and ideas from each of our analyses. We worked together to connect all our ideas to develop themes that best fit the data.

CHAPTER 3: RESULTS

3.0 OVERVIEW OF PARTICIPANTS

This study included the perspectives of six people with disabilities, five caregivers, one support person, and two independent facilitators. Once again, for this study, people with disabilities may be referred to as EAs or EADs, even if they were past the EA age range.

As stated previously given the recruitment challenges, I had to recruit outside the independent facilitation organization to people I knew through word of mouth. As a result, not every participant had a connection to independent facilitation, and not every EAD was interviewed, even if their caregivers or support persons were, either because they were unable or did not feel comfortable. Thus, in some cases EADs were represented by their caregivers and/or support persons. Finally, some cases only included the persons with the disability as their caregivers did not want to participate, the EADs did not feel their parents needed to participate or needed help to describe their experiences. A variety of cases were created from the sample. In the following section, Tables 1 to 3 summarizes participant demographic information. Participant relationships are color coded to demonstrate the variety of cases, and to show pairings with affiliated participants.

The age range of EADs who were interviewed ranged from 16 to 37 years old. EADs had a variety of disabilities including, cerebral palsy (3), Autism Spectrum Disorder (ASD) (1), Spinocerebellar Ataxia (1), and Global Developmental Delay (GDD) (1) (see Table 1).

EADs who were represented by their caregivers and/or support persons (3 individuals) aged from 20 to 22 years old and had the following disabilities: ASD (1), Asperger's and Generalized Anxiety Disorder (1), and quadriplegic cerebral palsy (1). Demographics were provided by their caregivers and are presented in Table 2.

Caregivers and support person ages ranged from 26 to 53 years old. They consisted of one father, four mothers, and one sister. All caregivers and support person were currently providing care for the people with disabilities at the time of their interviews. For the most part, they provided financial, housing, meal preparation, and transportation supports for their persons with disability (see Table 2).

The IFs interviewed for this project had two to three years of experience with independent facilitation. Each facilitator had one focus person included in the study. Supports provided for their focus-people included, but were not limited to, community engagement, networking, housing, and employment. Although not all participant facilitators were interviewed, EAs' experiences with facilitation were told within their individual interviews (see Table 3). Themes that emerged from interviews will be described next. In the following tables, to protect participant identities, pseudonyms were used, and colors indicate participant relationships. Those without color did not have connections with other participants. Figures 1 and 2 visually represent the corresponding participant relationships.

Table 1*Demographic Information for EADs who Participated in Interviews*

| Participant | Sarah | Charlie | Steven | Tara | Rachel | Grace |
|-----------------------------------|--|--------------------------|------------------------|--|--|--|
| Current Age | 35 | 37 | 18 | 23 | 36 | 16 |
| Diagnosis | Cerebral Palsy | ASD | Spinocerebellar Ataxia | GDD, seizures. Suspected ID and FASD | Cerebral Palsy | Cerebral Palsy |
| Current Living Situation | Independently with PSW supports | Independently | In parent's home | Homeless [Living in between shelters] | Independently with PSWs | In parent's home |
| Current Occupation | Part Time | Part-Time | Volunteering | N/A | Part Time and Volunteering | Volunteering |
| Highest Level of Education | Master's Degree | Various College Diplomas | High School | High School | Master's Degree | Currently in High School |
| Current Supports | PSW support for ADLs ¹ , parent support for some IADLs ² | Independent Facilitation | [See Kristen] | Independent Facilitation, housing services | Student Support Workers for ADLs, social support from family | ADLs and IADLs from parents, EAs in school |
| Current Funding Received? | Some government funding | No | No | Passport Funding ³ | Direct Funding ⁴ | N/A |
| Independent Facilitation? | Yes [Works with IFs'] | Yes. [See Table 3] | No | Yes. [See Table 3] | Yes [IF not interviewed] | No |

¹ ADL: Activities of Daily Living (e.g., bathing, dressing, toileting, eating, transferring, etc.)

² IADLs: Instrumental Activities of Daily Living (e.g., shopping, doing laundry, preparing food, etc.)

³ Passport Funding: Government funding for community participation services and supports, activities of daily living and person-directed planning

⁴ Direct Funding: a funding program which allows adults with physical disabilities to receive monthly funds for attendants to help with personal care

Table 2*Demographic Information for Caregivers/Support Persons*

| Participant | Michael | Lucy | Kristen | Isabelle | Macy | Julia |
|--|---|--------------|---|--|--------------------------------|---|
| Current Age | 40 | 37 | 53 | 50 | 26 | 52 |
| Relationship to EA | Father | Step-Mother | Mother | Mother | Sister | Mother |
| EA's Name | Heather | Heather | Steven [see Table 1] | Cory | Cory | Luke |
| EA's Age | 20 | | 18 | 22 | | 21 |
| EA's Diagnosis | ASD, Turners Syndrome | | [See Steven] | Asperger's, Hearing impairment, MID, GAD | | Spastic quadriplegia CP, profound ID, GERD |
| EA's Current Living Situation | In parent's home | | [See Steven] | In parent's home | | In parent's home |
| EA's Current Occupation | No, never worked | | Various volunteering | Grocery store clerk | | N/A |
| EA's Highest level of Education | High School | | High School, applying to college programs | High School | | N/A |
| EA's Current Funding | ODSP [Ontario Disability Support Program] | | None | None | | Respite, malpractice lawsuit compensation/award |
| Current Supports | Some ADLS, Mostly IADLS | Mostly IADLS | Cook meals, do laundry, driving | Some IADLS | Driving, take grocery shopping | Live-in Caregiver All ADLS and IADLS |
| Independent Facilitation? | No | | No | No | | Yes [IF not interviewed] |
| EA Interviewed? | No | | Yes | No | | No |

Table 3*Demographic Information for Independent Facilitators*

| Participant | Amanda | Maya |
|---|--|--|
| Time [in years] as an IF | 3 | 2 |
| Focus-people in study | Tara (see Table 1.0) | Charlie (see Table 1.0) |
| Time [in years] worked with focus-person | 2-3 | 1 |
| Type of supports provided | Community supports, networking, physical activity, housing, employment | Meal preparation, community supports/engagement, life skills |

Figure 1

Outline of Participant Relationships

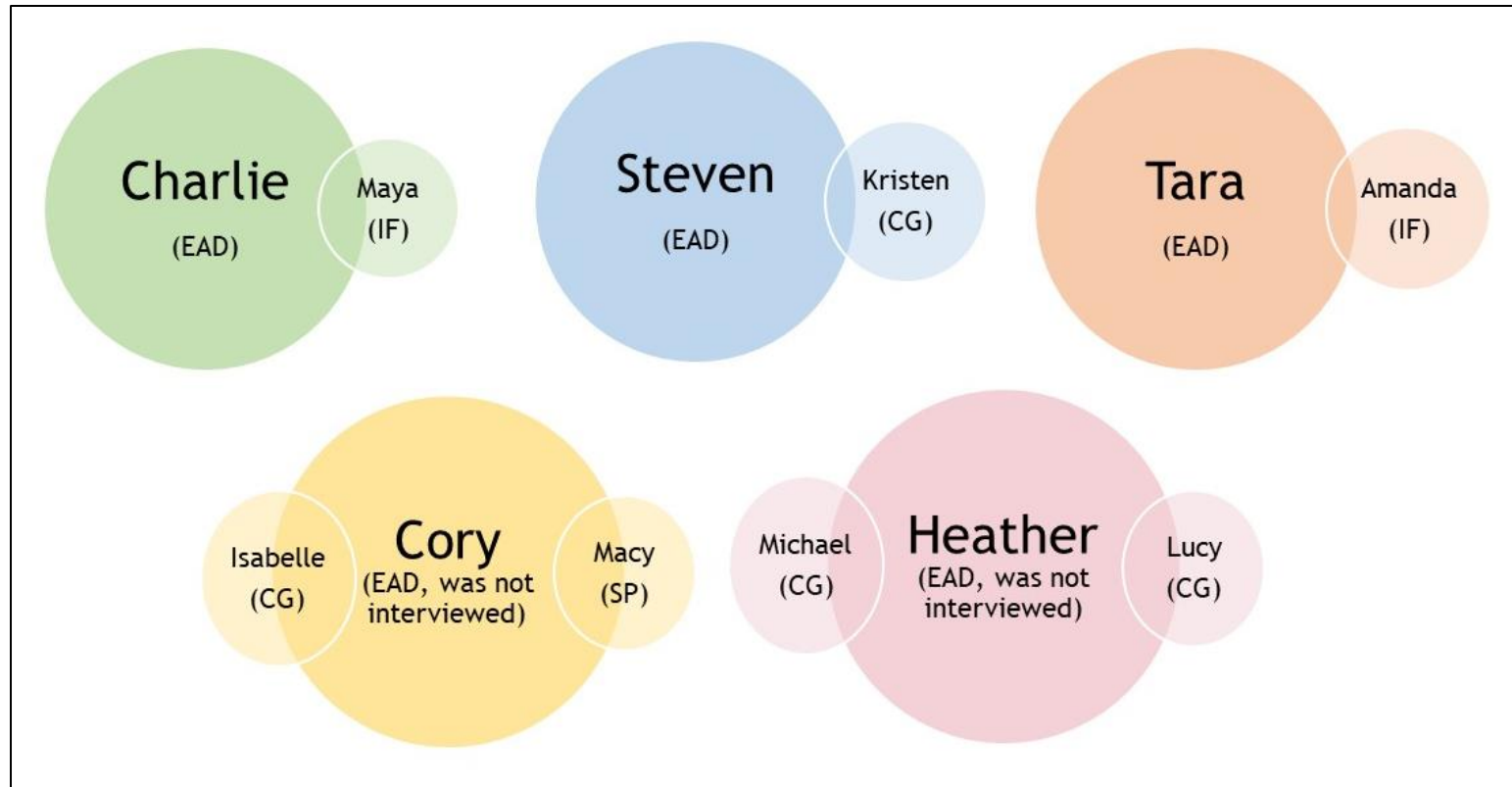
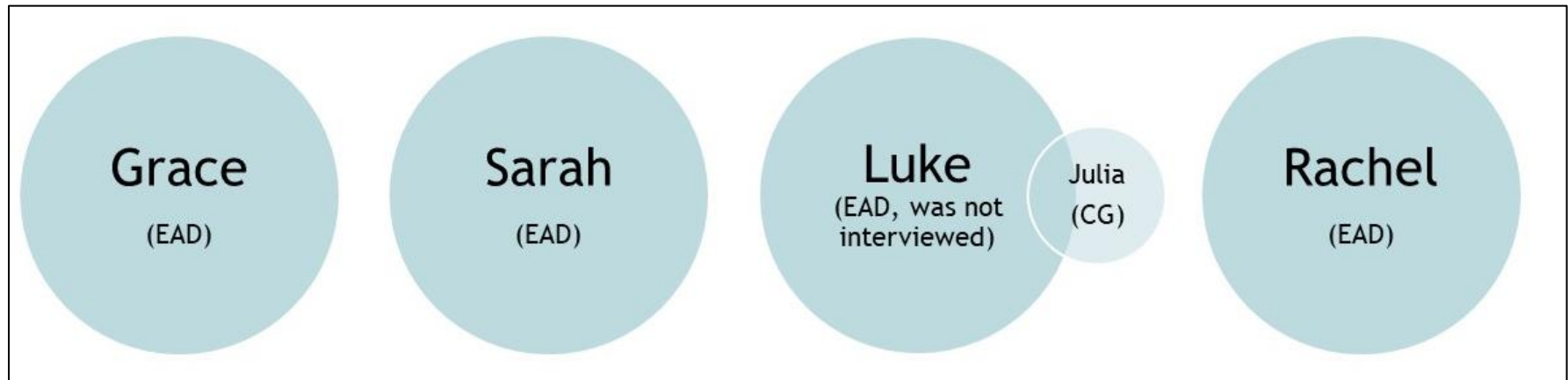


Figure 2

Outline of Participant Relationships



3.1 THEMES

A number of salient themes emerged after analyses of the participant interviews which described their perspectives of support, challenges, and overall experiences of EADs' transitions to adulthood: (1) "He Was Just Never a Great Fit": Haves and Have Nots of Support; (2) The Many Hats of Adulthood: Living with a Disability; and (3) "Community is When People Notice You're Not There". Theme 1 described support received from personnel, institutions, and monetary support. Theme 2 addressed the many lifestyle transitions that occurred during the transition to adulthood. Lastly, Theme 3 pertained specifically to community involvement, such as independent facilitation (Table 4).

Table 4

Themes and Subthemes derived from participant interviews

| Theme | Subthemes |
|--|--|
| 1. "He Was Just Never a Great Fit" Haves and Have Nots of Support | i) School Supports ii) "Privilege Helps" iii) "I've Dealt with A Lot of Social Isolation" |
| 2. The Many Hats of Adulthood: Living with a Disability | i) The Post-Secondary Experience ii) School to Work Transition iii) "There's Not A Lot Out There in Terms of Housing" |
| 3. "Community is When People Notice You're Not There" | i) Networking ii) "Helpful and Validating." The Role of Independent Facilitation |

Table 5 summarizes the themes and subthemes, in addition to the participants who contributed to the themes/subthemes in question. Since participants were in different life stages, some were unable to speak to certain themes, such as PSE, because they were too young and had not yet experienced it, or the issue was irrelevant to their cases. Although not every participant related to every theme/subtheme, data saturation was reached from the use of collecting rich and thick data. As explained previously, information-rich participants were recruited and data triangulation was used to enhance the reliability of results and the attainment of data saturation (Fusch & Ness, 2015).

It is important to keep in mind the experiences of each case differ, such as their relationships with family, the geographic areas they reside, the supports available where they reside, and the type and severity of their disabilities. As said by one participant, Sarah, “whatever I say or anyone says in this interview, everyone’s experiences are different and individual”. So, although themes emerged collectively from all participant interviews, each case had its own unique situations and issues. The context of each case will be described when necessary.

Table 5*Outline of Participants in each Theme*

| Theme | Subthemes | Included | Not Included |
|---|--|---|---|
| “He was Just Never a Great Fit” Haves and Have Nots of Support | <i>School Supports</i> | All Participants | |
| | <i>“Privilege Helps”</i> | All but one | Grace (Too young to comment) |
| | <i>“I’ve Dealt with A Lot of Social Isolation”</i> | All but one | Julia (Did not come up) |
| The Many Hats of Adulthood; Living with a Disability | <i>The Post-Secondary Experience</i> | Most | Grace (Had not yet experienced) Michael /Lucy (Was not relevant) Julia (Was not relevant) Tara (Was not relevant) |
| | <i>School to Work Transition</i> | All but one | Julia (Was not relevant) |
| | <i>“There’s Not A Lot Out There in Terms of Housing”</i> | All but one | Sarah (Was not relevant) |
| “Community is When People Notice You’re Not There” | <i>Networking Within the Community</i> | Most | Isabelle & Macy (Was not relevant) Michael & Lucy (Had not yet experienced) |
| | <i>“Helpful and Validating” The Role of Independent Facilitation</i> | Rachel Sarah Julia Amanda & Tara Maya & Charlie | Grace (Was not relevant) Steven & Kristen (No experience) Michael & Lucy (No experience) Isabelle & Macy (No experience) |

3.2 “HE WAS JUST NEVER A GREAT FIT”: HAVES AND HAVE NOTS OF SUPPORT

All participants expressed areas of support they had (or did not have) to help them in their transitions to adulthood. The amount and quality of support varied across participants due to personal reasons, such as type and severity of disability, family relationships, and the communities within which they lived. Areas of support included support in school (e.g., follow through of their Independent Education Plans), supportive teachers, and the sharing of knowledge/information concerning plans after finishing school. Another support area consisted of how “privilege” helped alleviate the challenges of the transition experience, such as having family support and advocacy, and having money to be able to afford supports like Personal Support Workers (PSWs). Finally, the last support area was related to the challenges of relationship building that lead to social isolation during the transition to adulthood. The respective areas will be discussed in turn.

3.2.1 School Supports

All individuals commented about the inconsistencies with school prior to post-secondary at the structural level, such as the follow-through of Independent Education Plans (IEPs) and availability and support from Educational Assistants. One mother expressed how her son could not have an Educational Assistant because his disability “was not severe enough” to qualify for one.

He had IEPs all the way through [school], and every year I would get a call from his teacher [concerned about his learning], and I'd be like, 'have you read his IEP?' ... They just wouldn't read it.... It was fighting with school every year, during the year. He couldn't have an Educational Assistant, which meant he was swimming upstream in his class. – Isabelle (Cory's mother)

Cory_(EAD)'s sister, Macy, concurred:

He got put there [at his high school] because he couldn't stay in a regular high school stream, but not low functioning enough to be put in a developmentally delayed program. And he did get an IEP, but the issue was the school wouldn't always follow the IEP.
– Macy (Cory's Sister)

Charlie_(EAD) also experienced the 'have nots' of support as a result of her "invisible disability":

[My disability] is quite invisible when you meet me. I'm very well-spoken. There were some people that were less independent than me, so no one really thought of assistance in the classroom for me. – Charlie (EAD)

For Sarah_(EAD), she had Educational Assistants throughout high school, but felt hindered by their supports at times.

The Educational Assistants would stand there and stare at me during an exam... so if I wrote a wrong answer on my math test for example, I could see their expression change, which I'm sure was involuntary, but made me second guess myself. – Sarah (EAD)

Sarah_(EAD) went on to say "the aids would kind of follow me around [the school]. And so, I kind of forgot how to make friends, and to be a friend." Although the Assistants were meant to facilitate Sarah_(EAD)'s involvement in school, their very presence hindered her confidence in learning, as well as in social situations.

Similarly, Rachel_(EAD) experienced impediments with her Educational Assistant:

Many [of my] Educational Assistants wanted to have more of a teaching role, but really, I just needed them to take me to the washroom, take my notes and help me with lunch. I didn't want them to interfere with my social scene. I didn't want them to interfere [with] my teacher relationship. – Rachel (EAD)

Rachel_(EAD) also commented about the lack of support she received from teachers about her future after high school.

... if you look at just my diagnoses or just the things that I can't do, that can say to you, 'well clearly she's not going to succeed in university'. But there are so many ways to get around one or two obstacles. The middle school, high school education system is so

*limited to what you **can't** do, and the teachers didn't have the academic expectations of myself that I knew I was capable of.* – Rachel (EAD)

Another mother expressed,

... it was a bit of a struggle, especially in school. He was integrated in the regular classroom, and had EA support all along but then you'd have things like skating days, and I'm like 'he can't skate'. – Kristen (Stephen's mother)

Michael_(Caregiver) commented how Heather_(EAD) was prone to skin conditions and other physical characteristics of her disability, which resulted in push-back from teachers in supporting her in her mainstream classes.

... it was a struggle with the school against you, it's like you're dealing with her, and you're dealing with the other people looking at you. It can be pretty hard sometimes.
– Michael (Father)

Luke_(EAD)'s mother, Julia, faced similar challenges. She found her son was put in compromising positions in terms of health and safety, where he was left unattended which could be fatal due to his fragile condition. They ended up pulling him from high school and into a supported day program.

... in high school, there's much more segregation, and we were finding there was segregation within the segregation. He was the only individual with his level of complex needs. – Julia (Luke's mother)

There were also shortfalls concerning information being transmitted by schools to educate students on what their options were after high school. When asked if they received such information, the answers were a resounding no.

Nope they never told me anything like that... they said 'you're old enough, do it on your own'. Like I can't do it on my own, cause I can't think straight.
– Tara (EAD)

He graduated and that was it. Like best of luck in the world. That was really it. There were no supports. – Macy (Cory's sister)

No, not really. I know what I can do on my own now because I just did it on my own because there was no help. – Charlie (EAD)

They did have people come in and present, but I'm not sure. – Steven (EAD)

No, I was thinking of being a designer or something... but these are my ideas for after high school. – Grace (EAD)

Despite these challenges, some participants explained positive areas with their school supports. For example, a mother reminisced when her son received positive support from teachers, which happened by chance.

... he had a really great morning teacher who had a brother just like Cory which was great. Cory loved her... And then in grades 7 and 8 he had a male teacher who had a brother like Cory so he landed another one... so that was kind of the first time we actually got help. – Isabelle (Cory's mother)

In high school, Tara_(EAD) “was able to do placements, and she enjoyed those”, which was one of the only times she had the opportunity to gain work experience, take responsibility of following a work schedule, and her self-esteem increased as a result of having meaningful work. In addition, Isabelle_(Caregiver) complimented how Cory_(EAD)'s high school taught them “how to be employable” which was “brilliant”. The school incorporated practicums that focused on trades skills, where parts of their semesters Cory_(EAD) would be in co-ops in certain areas of trade. Cory_(EAD) graduated certified in horticulture and construction trades, obtained real work experience in these fields, giving him an extra step forward in the workplace.

Rachel_(EAD) had a much more positive experience when completing high school correspondence classes instead of in-class.

I was being marked by teachers who didn't actually know I had physical disabilities. Because while I was in public school, I often had teachers that would, I think, inflate my marks. And so, the correspondence experience gave me the ability to be anonymous, and the ability to earn my marks for my merit, and not for the fact that I had disabilities. So that was really, really cool. – Rachel (EAD)

Steven_(EAD) acknowledged his Educational Assistant was “helpful” with his courses, especially math, and Grace_(EAD) concurred saying hers was “funny” and helped her with “spelling and anything” she needed.

In summary, all participants revealed various experiences with school supports, although more negatives than positives. The main message from this subtheme was there was a lot of work to be done with IEPs in terms of consistency and follow-through of the IEPs and Educational Assistants supporting students with disabilities.

3.2.2 “Privilege Helps”

All but one participant commented on privilege, albeit different degrees of privilege. Privilege was described in many forms as sources of support for adult life, such as money and/or family support, which either helped or hindered transition into the adult years. Those who had ‘more privilege’ had more positive experiences than those who had less. For instance, Sarah_(EAD) explained her situation as the “holy grail”, where she was very supported by her parents as “they have money”. As a result, Sarah_(EAD) could afford her own accessible condominium and pay for PSWs so she could have 24/7 care, even though she did not need it.

I’m lucky because I’m financially able to pay the [PSWs] to have good hours. Do I literally need them 24/7? No. But it is very good to have them here because then I can do pretty much whatever I want, whenever I want. – Sarah (EAD)

In Sarah_(EAD)’s case, the PSWs also functioned as a form of social support as Sarah had someone with her all the time, sometimes for companionship.

Rachel_(EAD) also explained how her access to Direct Funding provided her the opportunity to hire attendants for personal care, which ultimately allowed her to live independently and transition from her mother being her primary caregiver.

I think back to how much more limited my life would be if I didn’t have Direct Funding. I know direct funding is a lot of responsibility, if I don’t find the right people, hire and

train them, then like no one shows up right? But my mom helped me with that and she was there for me, and then like slowly as I built up confidence and was able to do it completely independently, that just kind of took shape as well. So, it [the funding] does provide me the freedom to travel and do what I want, when I want to. – Rachel (EAD)

Julia_(Caregiver) concurred that access to funds provided her the opportunity to “make decisions on what Luke_(EAD) needs and what’s in his best interest”, rather than what they could afford to provide him.

There’s no denying that increased funding and increased supports has a massive effect on Luke’s quality of life. And that comes with privilege, so we don’t have to worry or rely on income for Luke’s care. I’m educated, [my husband’s] a lawyer... as he gets more support, I am less burdened. - Julia (Luke’s mother)

Michael_(Caregiver) commented the government funding they were granted enabled them to hire respite care workers that came in to “spend one-on-one time” with Heather_(EAD), and “there were camps that we could put her in”. As well, “She’s on ODSP [Ontario Disability Support Program] which would cover group home costs” if they decided to take that route.

In addition to money, having family advocates for the needs of EADs was also discussed. For example, Kristen_(Caregiver) “really wanted to be proactive” with Steven_(EAD), and she “never really made excuses for him” where she pushed him to get involved in his community and get the support he needed in school. As well, Lucy_(Caregiver) described herself as a “pusher” for Heather as she said, “if these are the skills she’s learning [in school], then okay let’s put these skills to action.” Similarly, Isabelle_(Caregiver) described, “if you don’t [advocate], no one else will. Because we didn’t have social workers and all that, it was just me.” Therefore, having access to money and family support provided participants opportunities and services they otherwise would not have had access to, and the freedom to pursue activities they wanted.

However, not all participants had the “privilege” of money and family support, which made for different transition experiences. Charlie_(EAD), for example, could only pursue certain paths after high school due to financial limitations.

I only applied to colleges because of money issues and colleges cost less. But then [as she changed programs] I didn't have any money left, so education was put on hold for a couple of years because I figured 'well I'll just work and I'll get some money up because I want to continue my education' ... and then realized that I wasn't ever going to have the money on my own... So, I still wonder what would have happened. Like coming right out of high school, whether I would have been accepted to university with my grades and everything if I knew I had the money for it. – Charlie (EAD)

Similarly, Isabelle_(Caregiver) explained how Cory_(EAD)'s disability was too “in-between” severe and not severe enough to be granted funding.

We didn't get any money. He's never enough of this, and not enough for that, and a little too much for this, so he just never fell in [any category for funding]. They're not ready for Asperger's. They don't know where they fit. If you're on the spectrum, and you're really low functioning, they get that. They get the support, all that. Asperger's, you are functioning, you look normal, but it starts to break down after a few minutes of conversation. – Isabelle (Cory's mother)

Although Rachel_(EAD) was grateful for her Direct Funding to hire attendants, she was limited as it was her responsibility to hire her own attendants based on her own connections. In one instance, the lack of available attendants affected Rachel_(EAD)'s ability to accept her “dream job” in a different country as her attendant at the time was unavailable. Later on, she was offered the same job opportunity, and needed to find an attendant last minute to travel and live with her. Since it was short notice, Rachel_(EAD) had to settle for a new attendant she had not known for very long, which resulted in personality clashes and uncomfortable situations for Rachel_(EAD).

Three weeks before the internship I had to find someone new and train them and trust them. And it ended up really rocky because there were all kinds of things that I didn't know [like] I was very extroverted, and she was very introverted. I liked to do everything all the time, she liked to sit at home and read. So, there were negative things happening and I didn't really know how to communicate them back home, because if I were to send an email, for example, I would need her to type the email. – Rachel (EAD)

As a result, Rachel_(EAD) took this instance as a “not-so-fun learning experience”. She explained that if she did not have to rely on a funding program, and had the financial resources available to hire a team of reliable support workers, rather than rotating through different attendants every so often, she would have more freedom and less hurdles to overcome to pursue opportunities, such as moving for a job.

In Tara_(EAD)’s situation, she had very little support from her family. After high school, she was “kicked out of her step-mom’s house” and was currently living in and out of shelters and friends’ couches.” According to her IF, Amanda, Tara_(EAD) had dealt with conflict and trauma her entire life, and “her mother basically gave Tara_(EAD) to her step-mom and biological dad” at birth. Further engaging in unhealthy relationships led to her “being engaged with the police numerous times in the last year because of this individual”, and as a result she lost her apartment and she became homeless. Unfortunately, a diagnosis was never obtained for Tara_(EAD) as a result of the “25 to 3000 dollars just for a psych assessment”. The lack of a formal diagnosis was further exacerbated by Tara_(EAD) not understanding her condition, in addition to never having her condition explained to her by parental figures. She ultimately faced a myriad of obstacles in accessing community resources, although she relied on places such as youth shelters for survival. Amanda_(IF) explained,

She’s been in constant conflict at her shelter. She continuously gets barred from services and I have called to advocate for her, but they are very, very rigid in their guidelines. So, it’s really hard for her because she has a lot of attitude and temper issues which comes from her disability, and I believe from a lot of trauma. – Amanda (Tara’s IF)

Although Tara_(EAD) qualified for Passport Funding, she was not able to use it for mental health services that “she desperately needs”.

There is a huge gap in the service and support. People are directed at agencies and maybe you get referred to a program, maybe you don’t qualify... but the hurdle is she’s

had a lot of psychological damage over the years, so [mental health services] needs to be supported. It's not funded. It's not something she could spend Passport money on.

– Amanda (Tara's IF)

Tara_(EAD) also felt the weight of being unsupported from family and the hurdles she had to jump through to get access to basic needs like housing.

[The shelter] is okay. It's just the youth people get on my nerves and then they start yelling and then I get restricted for a couple of days... I need to find work, so I'm not at [the] fricken' [shelter] every day and bored out of my mind every day. – Tara (EAD)

As well as the sadness she felt from being on her own, “I hate being or living on my own... I just want people to know I'm a good person to be around.”

Her case clearly demonstrated the gaps in services. Although there were resources available in the community, getting access was not always an easy process or on a “need help now” but a “apply and wait” process. Tara_(EAD)'s independent facilitator summarized her case as one of the extremes whereby services were desperately needed, but not provided and as a result, Tara_(EAD) fell through the cracks.

This is not typical, like not at all a typical experience, but that's the scenario with Tara. She's just had so much stuff in her life that...it's not good [tears up a little]. I'm sorry. And that's why she doesn't want to talk about it, and that's why I'm getting emotional about it! – Amanda (Tara's IF)

There is a huge gap in the service and support. People are directed at agencies, which again you kind of check some boxes, maybe you get to be referred to a program, maybe you don't qualify for a program, and maybe you don't qualify for funding because you don't have enough disability. So, they kind of go into this strange void. – Amanda (Tara's IF)

The purpose of highlighting Tara_(EAD)'s story in this section was to show the spectrum of experiences one can have based on the haves and have nots of supports and “privilege” during the transition to adulthood. Although Tara_(EAD)'s case is an extreme example, it is important to highlight how people may take for granted the basic necessities, like having a place to call home, and a family to provide love and support. One of the issues that resonated with me after the

conclusion of Tara_(EAD)'s interview, was she asked if she could keep my pen, because she had never owned a pen before in her life.

Overall, having financial and family supports enabled EADs and caregivers the freedom to pursue opportunities and access resources with more ease. On the other hand, EADs who did not have the same level of 'privilege' described hardships they experienced and how having more supports would have helped.

3.2.3 "I've Dealt with A Lot of Social Isolation"

This subtheme pertained to the challenges of building relationships with peers during the transition into adulthood. Most EADs voiced concerns of stigma, discrimination, being misunderstood or being bullied, all leading to feelings of being unsupported or feeling isolated.

In high school I would say I was very ignored... No one really made overtures to me like 'do you want to be my friend?' – Sarah (EAD)

...grade 7 and the beginning of grade 8 was the only time that I ever experienced any kind of intense teasing or bullying. My mother thought it was best that she takes me out of junior high school and do homeschooling for a few years. So, then I dealt with a lot of social isolation. – Rachel (EAD)

I didn't really like [high school]. Sometimes my friends wouldn't want me to eat with them in the cafeteria. – Tara (EAD)

It's difficult for me to lie, or something that I said or did was unexpected, or people take it the wrong way and then they don't realize that I meant well. So, I wish there was something to help me explain that. – Charlie (EAD)

Grace_(EAD) and Steven_(EAD) said they had friends at school, but when asked if they hung out with their friends outside of school, Grace_(EAD) had very little to say and responded, "Not really" and Steven_(EAD) said they "talk and hangout" online when playing video games. This implied their perspective of friends was simply other students they interacted with during school, but not solid relationships where they interacted outside of a school setting. As

Kristen, Steven's mother, explained, "He just doesn't have a friend, friend". Similar sentiments were conveyed by caregivers, support persons, and IFs with respect to bullying:

He really doesn't have friends... One kid bullied him. One kid stabbed him with a pencil... A couple of kids beat him up on the way home... One of the girls punched him in the side of the head and smacked his face into the window. – Isabelle (Cory's Mother)

She's experienced various forms of bullying, not having friends, not having enough time to keep friends. – Amanda (Tara's IF)

Other caregivers discussed the lack of friends EAs had, or not fitting in with their environments.

The only friend she has is her sister. – Michael (Heather's Father)

He's at that awkward [stage], like he's not low functioning autism, he's not Down Syndrome, but he's also not like myself you know? So, he's at that awkward in-between. – Macy (Cory's Sister)

There's that difference between intellectual and developmental disabilities, and Steven has a bit of everything. He was just never a great fit. – Kristen (Steven's Mother)

As well, some participants noted barriers in terms of pursuing romantic relationships, particularly characteristics of their disabilities which complicated forming relationships or were not understood by potential suitors.

... there are some gentlemen that I have been connecting with that think I'm either asexual and don't have a desire for a relationship, [or] if we are romantic, they're going to end up doing my personal care. And I don't want to be so forward [and say] I'm like single and open for business! Or like, sexually active, call me! [laughs] – Rachel (EAD)

... people don't just usually come up and start talking to me like either people for non-romantic purposes or surely enough for romantic purposes. That's literally never happened in [my]life ever... I would like to be in a romantic relationship. Is that going to happen? I don't think automatically. – Sarah (EAD)

... he'd be a really great husband because he loves so hard. But he certainly can't take care of himself. Like he can't pay a bill, he doesn't understand a mortgage, so yeah that's the one thing that kind of gets me. He won't have his own family. – Isabelle (Cory's Mother)

In the end, bullying and discrimination was evident at some point in the EADs lives that negatively impacted their transitions to adulthood. Caregivers and support persons spoke of

similar concerns and wished for more inclusive environments for their EADs. All of these issues led EADs to feeling alone. Sarah_(EAD) described her situation as follows:

... My biggest barrier is probably loneliness. I do not feel comfortable going somewhere “random” and making friends. I think this is unfortunately due to my lack of confidence as a woman with a disability. – Sarah (EAD)

All participants unanimously supported the contention of the loneliness and isolation felt by EADs. To conclude, participants revealed what they struggled with in terms of support in school, finances, family and social support, and some positive aspects that helped them along the way. In most cases, these feelings were exacerbated by discrimination, stigma, and/or being bullied.

3.3 THE MANY HATS OF ADULTHOOD: LIVING WITH A DISABILITY

There were many components associated with the transition to adulthood expressed by EADs and caregivers. As explained in this section these components included, The Post-Secondary Experience (PSE), School to Work Transitions, and “There’s not a lot out there in terms of housing”. Although participants were in different life stages, they were all able to share issues along the path to adulthood.

3.3.1 The Post-Secondary Education Experience (PSE)

Participants who had experience with PSE shared the freedom they felt from being on their own and taking responsibility of their own care, but also the challenges they encountered. This theme pertained to all participants except Grace_(EAD) who was much younger than other participants, and not yet in this phase of her life. This subtheme was also not relevant for Tara_(EAD), Michael_(Caregiver) and Lucy_(Caregiver), and Julia_(Caregiver) as their EAs’ disabilities were too severe to pursue PSE.

Some participants revealed accommodative residences and accessibility services enabled them to thrive as students. For example, Rachel_(EAD) was able to move out of her mother’s home

for the first time to a fully accessible on-campus residence, manage her care, and had access to many accessibility services to help with her work.

... when I moved into residence at the [university], the house was fully accessible... I got the opportunity to manage my own health care needs ... I had peer volunteers for each of the courses that I took. They would help me organize my notes and complete my assignments. – Rachel (EAD)

Likewise, Sarah_(EAD) celebrated how “freeing” it was to attend university. She felt it was a “magical experience” that belonged to her, without help from her parents. It allowed her to make mistakes and “figure things out” for herself which was “huge”. As she described,

... [post-secondary] gave me more freedom, like this experience belongs to me. We actually get to make decisions without input from our parents! I remember the first time that I went from my class to an accessible bus stop, and even though it was like literally feet away from the building, I felt like it was such a victory, like, I found it myself!” – Sarah (EAD)

However, it was important to understand the context of each case, such as the institutions they attended, and where the institutions were located, as they each had different services and policies. For instance, Rachel_(EAD)’s positive experience with PSE was mostly attributed to the institution she attended for her undergrad. She gave an example of her residence placement: “[they] had a policy that let students know that they might be living with someone who has a disability”. Whereas the institution she attended post-graduate work had “much different privacy policies” and would not give her potential roommates notice, even with Rachel’s permission. This was upsetting for Rachel_(EAD), as she understood there could be conflict if her potential roommates had issues due to her additional needs. As she explained,

... roommates that I had [in my master’s], unfortunately, there was resentment on a number of levels. There was resentment that I had extra space. There was resentment that I was accepted to the [program] and I was only in part time. They were doing really odd things; they were really angry at me because my attendants didn’t do my dishes frequently enough. So, at one point they took all my dishes out of the sink and hid them, so I didn’t have any dishes. At another point my attendant was out doing my laundry while I was in my room, and my attendant accidentally locked herself out, and my

roommates were home but they wouldn't let her in even though she was knocking. And the 3rd incident was the fire alarm went off, and I was trying to get out of the apartment, as were my roommates, and they wouldn't hold the door for me. – Rachel (EAD)

Although there were some very positive moments in Rachel_(EAD)'s university journey, she continued to face barriers, as well as stigma and discrimination as a result of her disability.

For Sarah_(EAD), she attended a university “that was very well known for its support of students with disabilities, physical disabilities in particular.” She lived in a dorm that was fully accessible and had a built-in support worker system from students in an occupational therapy (OT) program where the OT students obtained their practicum hours by helping the dorm students with their personal care. This allowed Sarah_(EAD) to learn how to “schedule her support workers” on her own, so it was her “responsibility, that was incredibly, incredibly freeing”. Her dorm experience was the highlight of her PSE as she described, “the dorm helped me so much, like I didn't feel alone... I remember just feeling like ‘Holy crap! This really does feel like coming home’”.

Charlie_(EAD) encountered several more challenges than the previous cases. This, in part, had to do with her disability being “invisible” as described earlier. As a result, she was not diagnosed until her early 30s, which meant she attended PSE without having access to any supports that would have helped her succeed.

For college, I didn't have any supports... I only found out about the Autism when I was 32 or 33 and I am 37 now. There were a lot of resources that I would have had access to, to help me with my studies – Charlie (EAD)

It was not until she had a formal diagnosis, did Charlie_(EAD) obtain the accessibility supports she needed to succeed in her program.

Until I went to school for [clerical work] and got a diagnosis, I had something on paper so I could register with accessibilities and I thrived though [clerical work] and had all the supports that I needed... and they got me like special things. I got a laptop, and I got like a special pen to help me write notes or somebody could help me write out all of my

notes like auditory, and like all the things that were helping me get through that so that was very helpful. – Charlie (EAD)

For Steven_(EAD), he was just beginning his PSE journey at the time of his interview. He had applied to a local college for a program “aimed at Life Skills kids” where they have a supportive “buddy system” to help students get acquainted with college lifestyle. Steven hoped to gain “more experiences” with kids with disabilities and was looking forward to becoming “more mature and more independent” while attending college. His mother, Kristen, wanted to push him to continue his education in this program.

When he leaves Life Skills, he’ll get a certificate, but it’s not anything that would enable him to go into post-secondary. They also don’t graduate [from this college program] with a degree of any sort. It’s probably called a certificate again, but it just gives him the opportunity to experience college, and in his case, build a little path that he wants to take. – Kristen (EAD)

Lastly, Cory_(EAD)’s family expressed challenges taking the PSE route specifically for Cory and his particular disability.

... we talked about him going to college. There was a bridging program [in his high school] where his last semester he could spend at the college level, but that was one step too far... he can’t do the writing. He can’t memorize, so that college level would just be too much. – Isabelle (Cory’s Mother)

To summarize, PSE allowed participants to become more resilient and face challenges, such as roommate conflict, issues surrounding accessibility, and finding programs that “fit” their needs. PSE also enabled EADs to grow and become as independent as possible. For instance, taking responsibility of their health care needs, living on their own, navigating their campuses, and advocating for themselves, were some of the means by which EADs became independent. It was important for some participants to attend PSE as Sarah_(EAD) explained, “we [people with disabilities] sometimes get more education because even if we try to go in the job market we can’t, so then the thing that makes the most sense to do next is to get more education.” It is

important to remember that each case was different from the next, and a small goal or challenge for one person may be a tremendous goal or challenge for another (e.g., going to bus stop on own). The experiences of the workforce will be discussed next.

3.3.2 School to Work Transition

All participants, but one, commented on their experiences on the different access to having school supports to finding work that was meaningful to them and could accommodate their needs. Julia_(Caregiver) did not comment as employment for Luke_(EAD) was irrelevant due to the severity of his disabilities and inability to work. Most participants had multiple job changes due to lack of accessibility and inclusion in the workforce compared to supports they received during school. For instance, when Cory_(EAD) had his high school co-op placement in construction, it was an unsupportive environment for his needs, as he “likes structure and is big on rules which isn’t really followed in construction. People weren’t wearing hard hats or being safe” (Macy – Cory’s sister). He was not able to thrive in an environment which did not fit with his disability, so he could not continue with the placement. This lack of fit continued with several work environments, that were not inclusive or adequately adhered to his needs.

As Macy_(Sibling) explained after Cory_(EAD) was “let-go” twice without reason, “People were jerks I think it was actually related to his disability”. His mother concurred with specific details about two jobs.

When he went for an interview for [building cabinets], they also had a girl come in and do the [practice test] where they build it coming down the belt. So Cory was doing his, he said the girl couldn’t keep up so he was doing hers, and at the end of the day, according to Cory, [the supervisor] came in, and because Cory can’t talk that quick, he can talk but he can’t formulate it quick enough, so the girl’s like ‘oh I did that, and that, and that, and that’ and by the time Cory could say ‘no’, he was fired and they kept the girl... Then he got into [hardware store]. He had some trouble there. Everyone liked him, but he needs direction, and they didn’t lay it out for him, and they said he was talking too much and fired him. – Isabelle (Cory’s mother)

Similarly, for Charlie_(EAD), she had to switch post-secondary programs several times because she had issues finding permanent or full-time work.

It was always disappointing every time I finished school and I would try to find work and it wouldn't come. Because I've had lots of jobs, lots of work, but they're very temporary or they're permanent but very part-time because I have to find an environment and an atmosphere I can work with, so I'm still looking. – Charlie (EAD)

Even when Charlie_(EAD) found her ideal job as a [clerical worker], because she preferred the structure “going to the same building, working 9 to 5, and just know what my day is supposed to be like”, she still faced challenges expressing her needs to potential employers.

Most people who want a [clerical worker], they also want you to be a secretary or receptionist, and be on the phone all the time. And so, you have to multi-task and my Autism assessment says to stay away from multi-tasking and fast-paced environments... so I'm having trouble finding the type of environment that I need... I don't know what to ask for with support. Places that I've worked where they are aware are very supportive and understanding and I was able to keep the job longer. So, I think I need to tell [future employers] ahead of time, but most people don't hire like that. Like if I need extra time or training, why would they hire me if they can hire someone who's a quick learner who's just going to get it right away? So, it's very discouraging. – Charlie (EAD)

Participants who were successful finding jobs that suited their needs still encountered problems with finding meaningful work due to the limitations of their disabilities and lack of funding in their workplaces to accommodate their needs. For example, Rachel_(EAD) had a bursary for students with disabilities in her master's which paid for equipment she needed to support her needs.

... it was the bursary for students with disabilities that helped provide my special keyboard, and my large monitor and my support worker, and not for the whole day, but to accommodate me for 50% of my day was as competitive as another intern or employee might be similarly – Rachel (EAD)

However, when she graduated school and was hired on as an employee, she no longer qualified for the bursary as she was no longer a student. Unfortunately, the “kinds of supports that I benefited from and experienced success from in school aren't available in the workforce,

and that's the challenge there". Thus, Rachel_(EAD) was limited in the number of hours she could work, as a result of lack of accommodations in the work force.

I wish that I could be working for them full time or almost full time, but it's just a money game... I would like my job to increase to carry more responsibility, but without the additional support of someone to like be my hands [type for her] and do my editing for me. So, the fact that I don't have added support in the workplace is a little bit limiting.
– Rachel (EAD)

Equivalently, Sarah_(EAD) felt intimidated in big corporate work environments due to her disability.

[My] lack of confidence also affects my experience in the job market. I get nervous when I am in big and/or corporate employment settings. I think I feel like any mistake I make will be attributed to being "the disabled woman" and this make me feel nervous and bad about myself and my skills. – Sarah (EAD)

Sarah_(EAD) eventually found a place to work that was meaningful to her in the disability realm, but always wanted to expand the work she was doing. When she did enter the corporate world, she had a less comfortable experience than her job in the area of disability where her bosses were more inclusive and sensitive to her needs.

My bosses [at disability job] trust me, they respect me, my ideas, and my physical limitations of my disability... and I feel very fortunate that I get to pick my own work hours... but sometimes I wonder if people with disabilities would necessarily be my first choice to work, or if I just landed here because I have a disability. So, I did some human resources administrative work at [company]. They did such a great job accommodating me in a physical sense, but I was only there [part-time] hours and the environment was much more corporate than I was ever used to. So, I think my lack of confidence showed, especially with my boss, like sometimes I'll send her an email and she won't answer and I feel like she's going to be annoyed with me... - Sarah (EAD)

Another factor that played a role in finding meaningful work was having support from family. Tara_(EAD) did not have family when trying to find employment. She explained she was unable to get a job because her seizures were "unexpected" and "employers would be hesitant" to hire her. However, when I followed up with Amanda (Tara's IF) of how her spontaneous

seizures held her back from employment, she provided an alternative explanation for Tara's situation and questioned her mother's motives:

I think that is information her step mother has been feeding her. I think she's capable. I thought because she is very active and moves quickly and is energetic, I had been thinking "okay maybe landscaping in the summer", even just to try part time, landscaping. Get her out there moving, see the value in her work, like a growing tree or whatever it may be. But her mom said, 'oh she's on meds right now. She can't be in the sun'. So, there's always a reason why it's a no. There's never a positive or 'but do this, maybe think this'. So, she's never had that support. – Amanda (Tara's IF)

In contrast, although Cory_(EAD) encountered "some bumps" finding employment, with support from family, he persevered and found a job he loved and felt appreciated.

So, he's at [a grocery store] now, and loves it. He does well, he gets tips, he likes it... he gets and stacks the carts, fill the carts, so he did really well with that. Now if any of the carts are broken, he's in charge of logging them, taking them to the back, making sure they get fixed, and bringing them back. It's not a huge piece but it's an extra responsibility. It's on a much smaller scale than most people, but for him it was like amazing. He came home and he was so happy. – Isabelle (Cory's Mother)

Despite being the youngest participant, Grace_(EAD) already had a potential job in mind after learning about her family's restaurant business and felt optimistic about her future. "I was thinking of joining my family's work... I'm just ready for anything!"

Similarly, Heather_(EAD)'s father, had come to terms that she may never work due to the severity of her disabilities, but would do anything "to see her a little bit happier".

She'll probably never work. I know that. It would be nice to see her work or volunteer for something. Like I know it won't be much because her attention span is only so long... But one of my favorite things is if you ask her what she wants to do when she's done school when you grow up, she goes "I'm going to be Heather". That's what she's going to do. – Michael (Heather's Father)

In addition, although Grace_(EAD) and Steven_(EAD) did not have paid jobs, they were avid volunteers in their communities. The volunteer positions provided real work experiences and valuable skills similar to those in the workforce. As Steven said, "I help kids with disabilities, like I help them in the pool and get them on the bus." Similarly, Grace shared the following, "I

like volunteering because you get to hang out with the little kids, helping them if they need anything”.

To conclude this section, Sarah_(EAD) discussed the gap of supports between school and the workforce, “...we know at least in some sense, education is becoming more and more accommodative, whereas the job market isn’t necessarily always accommodative”. It was clear across cases, participants struggled finding employment and wished it was an easier, more accepting, process. Further, work experiences were also obtained through volunteer opportunities for EADs, positions that provided value and meaning. Employers need to recognize the needs of prospective workers with disabilities, and to normalize people with disabilities feeling comfortable disclosing their needs to employers, without fear of discrimination and not getting hired. Further, communities should provide inclusive, accessible volunteering for people with disabilities in order that EADs are provided with relevant experiences that enable them to feel part of the community.

3.3.3 “There’s Not A Lot Out There in Terms of Housing”

As stated in the literature review, a major milestone in the emerging adulthood phase is moving out of the family home. However, finding available and affordable housing came with its challenges. All participants except for Sarah expressed housing challenges.

As Charlie_(EAD) stated, “it has not been easy finding housing in the first place”. Similarly, Tara_(EAD) did not have a home with family or on her own, and the lack of subsidized housing left her homeless.

[Tara] doesn’t have a permanent home, so her main goal is to get a little bit of sleep, get up when she’s told, or skip a meal to sleep a little longer, than wait all day and make sure she gets back to the shelter so she has a bed. That’s her cycle. Every day. Every week. – Amanda (Tara’s IF)

I helped her fill in the subsidized housing application, almost 3 years ago. So, we hear nothing. We put the application in and hear nothing until hopefully your name comes up on that list.... we hear every day, there is no housing. It's not available. People who have disabilities are waiting up to 28 years for supportive housing scenario. – Amanda (Tara's IF)

Rachel_(EAD) almost faced the same situation after finishing graduate school. She lived in residence during her graduate degree, not realizing the extent of the housing crisis. After completing her schooling, she reached out for help, and was astonished at the response.

So, when I finished school, I started to panic. I called up a social worker and she literally said 'if you make yourself homeless, and go into a shelter for even a day, then you'll be bumped up to the top of the waiting list for housing'. – Rachel (EAD)

Luckily Rachel_(EAD) was able to find accessible housing with help from her support circle of friends from her church group and co-workers. If she did not reach out to others, her housing situation would have been dire.

Others considered group homes as an ideal alternative to independent living; however, the criteria and qualifications to be approved into a home had its own set of challenges. As Kristen (Steven's Mother) said, "we're not convinced he's ever going to be able to live independently. There's not a lot out there for independent living in terms of housing for these kids and he's certainly not a group home candidate [due to the extent of his disability]." As a result, Steven_(EAD) would remain living at home once he graduated high school, and be dependent on his mother.

Michael_(Caregiver) and Lucy_(Caregiver) also contemplated sending Heather_(EAD) to a group home when she finished high school as a way for her to live independently and with others her own age. But after investigation, they were concerned for the level of care she would receive in a home and they decided Heather_(EAD) would be better off living with them full-time.

I thought at first it would be better for her to be around [people her own age and others with disabilities], and [the group home] could care for her... but she has to be a fit for it

or she'll go back on the waiting list. And Lucy said she's worked in an old-age home and a lot of people forget about visiting you after a while, or they get forgotten by staff. So, she didn't want that to happen with Heather. – Michael (Heather's Father)

As well, Julia (Mother of Luke) expressed similar care concerns placing Luke_(EAD) in a group home. She tried to set up a shared care model with the home in question, rather than the standard institutional model. However, after much negotiating, Julia_(Caregiver) faced the facts that the group home was not structured in a way to facilitate a shared care model, and so Luke_(EAD) resided at home dependent on his live-in caretaker and parents.

... there is a privately run group home here in town. And we thought we'd explore a shared care model with them, where Luke spent some time here at home and maybe weekends there... But what I learned after 2 years is that there can be these wonderful intentions, and I was dealing with fairly senior management, but by the time it got down to the front-line staff, it's an institutional model, and we couldn't change that.
– Julia (Mother of Luke)

Even if perceived unable to live independently as a result of their disabilities, some EADs maintained independent living as one of their future adult goals. As Steven_(EAD) said, “I would like to [live on my own] one day”, but his mother said they were “not in a rush” to decide if that was feasible for him, as Steven_(EAD) struggled with time management, needed reminding to do self-care (e.g., shower), and his meals and transportation were provided by his mother. Grace_(EAD) expressed similar goals, “You never know!”; however, she acknowledged her health conditions may compromise moving out of her parents' home as she explained, “But if I did have a roommate, I would tell her about [my seizures] and she would help me with that.” In addition, Isabelle_(Caregiver) knew Cory_(EAD) “can't take care of himself” but that “one of his goals is to have his own place” even though they fully anticipated he would continue to live at his parents' house.

Overall, there were many gaps in the housing sector. Further, resources that did exist, came with long wait lists and specific criteria to be considered. Some participants faced dire situations

with respect to housing options, whereas others were left dependent on their families for housing support. As Rachel_(EAD) summed up,

... the fact that a lot of adults with disabilities or people transitioning between youth to adulthood are most concerned about their vital necessities, like housing and food, like there's not enough options. Like Maslow's Hierarchy of Needs, if you're most concerned about food, shelter and security, you're not going to aspire to education and career and that stuff. – Rachel (EAD)

3.4 “COMMUNITY IS WHEN PEOPLE NOTICE YOU’RE NOT THERE”

Throughout this theme, the term community encompasses supports and resources outside of one’s family. Community included having experiences where they were able to develop networks of support and having access to resources to help them on their journeys to adult life. The importance of being part of a supportive community was common across most participants. However, Isabelle_(Caregiver) and Macy_(Sibling) explained Cory “did not have any supports” in his community, and as such felt they were alone in supporting Cory. Michael_(Caregiver) and Lucy_(Caregiver) had not yet investigated community supports for Heather_(EAD) at the time of their interviews. Therefore, both cases were not included in this section.

4.4.1 Networking Within the Community

Networking in one’s community was an integral piece for some participants, allowing for connections to be built and fostering future opportunities. The ability to network also enabled EADs to develop a sense of belonging when engaging with others in their communities, and to envision a future for themselves as active members of their communities.

Grace_(EAD) and Steven_(EAD) actively participated in programs and were volunteers in their communities, which led to them wanting to work in the field of disability when they grew up. As Steven_(EAD) said, “I really want to help kids when I get older and do something that I like. Get more experiences like that”.

Steven_(EAD) decided to apply for the college program (as described earlier) because as he explained, “I was in that program at [a rehabilitation center] when I was a little boy.” As such he was able to envision a career for himself from his experiences in his community as a participant and a volunteer. Kristen, his mother, concurred:

He does really want to work with kids. He likes an idea of that job. He’s been consistent for the last 3 or 4 years when he started volunteering, so again if he has the support around him to allow him to work with the kids, I think that would work really well.

– Kristen (Steven’s Mother)

Grace_(EAD) became an avid volunteer for her community as a result of programs she participated in as a child. When she aged out of programs, she was given opportunities to become volunteers for such programs, giving her practical experiences and making connections in various fields of work. She explained, “I have a lot of good friends [at volunteering]. And I was thinking of [doing] this volunteering thing while I’m doing [PSE] at the same time.”

As well, Sarah_(EAD) volunteered “for a couple of years” at a local community site where she was then employed and “had more of an administrative” role. Subsequently, she was referred to a community meeting “of what gaps are still in our community and how they can fill them” which led to her obtaining her current job from connections within the meeting.

[The meeting] led to the realization there wasn’t a lot of social opportunities for people with disabilities after 21. So that’s how I started [a local community program for adults with disabilities]. From there [opportunities] escalated... [My bosses] asked me to sit on the special education advisory committee for the school board and now very recently I’ve taken over doing the majority of [a local] newsletter. – Sarah (EAD)

Rachel_(EAD) was also very active in her community and made connections that enabled her to develop confidence in herself, PSE career, as well as her independence. For example, while in high school she discovered a program that could help with her swimming therapy which also helped increase her self-esteem.

They had a community program where able-bodied [university] students were paired up with people with disabilities from the community, and they would either use the pool together or use the gym together, and so interacting with university students when I was [young] was really, really helpful for my self-esteem, and realizing that I was capable of maintaining conversation, and probably was capable of studying the things that they were studying too. – Rachel (EAD)

Rachel_(EAD) ended up meeting the director of said program. After conversations concerning the fact that her correspondence high school experience was taking too long to complete with little support, the director set her up with peer volunteers and admission to an introductory university level program that kick-started her PSE experience.

... then he said, 'well I work for the Center of Disability at [the university] and we have volunteers who typically help students with disabilities complete their assignments, I can set one up for you!' ... And then he said, 'the university has the Open Learning Program... do you want to try that?' So, I said 'yes, I would!' ... And that is how my [PSE] took off from experiences back when I was just a high school student. – Rachel (EAD)

Further, participants voiced being part of a community was vital in adulthood. As a mother explained,

I want a community that sees Luke as an active member and notices when he's not there. We tried to intentionally create other communities of people who know Luke.... We want him to live a good life with meaningful activities, where he's not isolated and an active member in the community... And yes, he may not contribute to the GDP, but that doesn't mean he doesn't contribute to the fabric of their communities in creative and meaningful ways. – Julia (Luke's Mother)

Charlie_(EAD) had similar views, commenting on the importance of feeling included and meaningful to her community.

This year I'm the treasurer of my choir and I'm on the board of directors. And I'm part of [autism support groups]. And just a lot of community involvement because if there's an event in town I'm very social, so I'll always find something to do and where I fit in. – Charlie (EAD)

To conclude, participants appreciated their experiences in their communities. The connections they made from their community involvement led them to start their paths to

adulthood, such as obtaining work experiences, getting supports they needed, and envisioning lives for themselves. Fostering opportunities to network, such as schools providing co-ops and practicums, being volunteers and participating in community programs, contributed to participants making connections and thriving in their communities.

4.4.2 “Helpful and Validating.” The Role of Independent Facilitation

Independent facilitation refers to services that foster networking for people with disabilities in their communities. Five cases were involved with facilitation in this study, including Rachel_(EAD), Sarah_(EAD), Julia_(Caregiver), Tara_(EAD) and Charlie_(EAD). In addition, two independent facilitators, Amanda and Maya, worked with Tara and Charlie, respectively. Participants who were not involved with facilitation expressed that it may have been helpful to them in areas such as learning skills to live independently and connecting with their communities; however, they were either not aware of the services IF provided. Participants within the study used independent facilitation for many reasons related to becoming an adult including, building support networks, housing, employment, and developing skills to live independently. One of the IFs explained the following:

I think the main reason for why we work is to help them build that circle of support, of that network around them, so that they can have that support all the time. Because sometimes we forget to be more intentional about that piece, and I think that’s like a main thing, like everyone needs --- relationships. – Maya (IF)

For Julia, Luke’s mother, she used facilitation mainly as a “sounding-board role” where the facilitator “helped establish micro-boards” for Luke’s care. As she explained, “We needed someone to help walk us through this and to be supportive... but also call me out if I’m not making good decisions. She [the IF] knows the community resources!”.

In addition, Charlie_(EAD) was extremely appreciative “having support and acknowledgement, validating the issues” she would be facing, familial support she did not have growing up. She

recalled the one-on-one support from her IF was extremely helpful in organizing her busy schedules and boosting her self-esteem.

[Maya] helped me with the garden stuff, social stuff, getting out in the community, and then help with food management stuff, figure out meal planning... Facilitation helps [me] focus. It's been very helpful to just have one-on-one. Figure out types of things I need so that I can have independence. It's very helpful and validating. I'm getting out in the community, very helpful for my mental health. – Charlie (EAD)

Maya, Charlie's IF, expressed that Charlie had difficulties managing her time to make proper meals due to her inconsistent work schedules; however, with her IF's help of reaching out to a local food bank that provided meal kits, Charlie_(EAD) had been able to manage proper meal planning, which ultimately helped her live her life from day to day.

I think that the difficulty there was [Charlie] not having a consistent [work] schedule throughout the week. It was hard to know when she would have enough time to cook, and when she wouldn't... So I'm so happy because she's been able to schedule her week better [with the help from facilitation] so that she can have some time to cook and have food available through the week, so that's been really easy for her to organize herself but know that she has all the ingredients she needs to cook that food. So, I think that has been great. – Maya (Charlie's IF)

When asked how she would describe her experience transitioning to adulthood, Charlie_(EAD) said, “With facilitation, encouraging! Being on my own, probably less positive”. Facilitation was an integral part of Charlie's adult life and she reminisced on how it would have been “very much helpful” if she knew about the service when finishing high school. As she explained, “I could have learned early on about everyday things like food prep and meal planning”.

When Tara_(EAD) first started using facilitation while finishing high school, her IF helped her find an apartment, apply for counselling for her mental health, volunteer jobs and social activities. However, Tara's life shifted when she entered an unstable relationship. Facilitation for Tara went from help with housing, finding work and getting engaged in the community, to

getting her out of her current crisis situation, namely homelessness. The following two quotes by Tara's IF, Amanda, articulated her situation:

... [at the beginning] she was doing amazing. She was motivated, she loved going out with me and checking things out. We would go to a café now and then and meet up with regular people who were trying to help her build, you know, solid relationships with, get to the point of taking it beyond that café to other activities, which is what we do. So, when she met the person, it all went downhill from there. Like she'll sit on her phone, with him, for an hour back and forth, when she's supposed to be like hanging out with me, or you know focusing on whatever goal that may be. – Amanda (Tara's IF)

I really only hear from the family when I get a text if there is a crisis going on, and there is more crisis than not. And without receptive, good housing it's going to be really hard to help her get out of this. So, if she is in a crisis, she really does not have anyone to help her get out.... – Amanda (Tara's IF)

Facilitation was the only form of support Tara received during her journey to adulthood.

Amanda's role as Tara's IF meant more than just providing a service. Amanda was Tara's advocate and her lifeline.

Amanda_(IF) concluded her interview by saying,

I hope [Tara] has a life that she enjoys. [One] that is not full of tension and frustration which it is right now. She doesn't know what it's like to live without that kind of constant frustration. She's never really gotten a lot of perks in life, like special things. So, having a job and an income, knowing that she can buy whatever... and of course a stable home [where she is able to] make decisions.... – Amanda (Tara's IF)

Rachel_(EAD) also noted the integral role of facilitation in her life. As explained previously, when she finished her masters, she was at risk for being homeless due to lack of housing. However, her facilitator helped her create her own circle of support close to her from her church and coworkers. This support group helped her find a motorized wheelchair, proper orthotic shoes, minimized her student loan payments, and most importantly helped her find “co-operative housing that is fully accessible” with flexible rent. Rachel_(EAD) shared:

... it was basically the final year of my Masters and I couldn't delay it any longer, like I was slowing down my educational journey just so that I could stay in residence. And finally, I [reached out to a facilitator] and was supported where I gathered a bunch of

people from my church and my work. So essentially what I did was I made my own informal support system and said we'll figure this out together. And after much digging, we were able to find this private co-op that I currently live in.

– Rachel (EAD)

Sarah_(EAD) did not use facilitation herself, but her line of work was involved with the organizational side of independent facilitation. She explained that facilitation was a “unique gift that can work for everybody in different life periods”, as it not only helps people with disabilities create networks but can also provide caregiver respite.

It's hard for them [disabled people] to build those automatic networks and we find that for people with disabilities it's super important. First of all, for them to be involved in the community and not just like isolated over here with a bunch of people with disabilities, but also like a huge thing is that eventually parents are going to die, and there needs to be people to step in for when mom and dad aren't there anymore. So, then they have people, of which the facilitator is one. The goal is for the facilitator to help figure out how things are going to work and then hopefully have supports from the community. The goal is not that the facilitator becomes the PSW. – Sarah (EAD)

She also commented how IFs can help families “think outside the box” with supports:

... obviously there's going to be situations where the individual and their family has a different idea of what they want to happen. And so, I think that it's important to have the buffer [the IF] there, where parents might be like 'what I can't let my son or daughter learn to take the bus by themselves. They've never done that before - what if something happens!?' Whereas the facilitator might be like 'okay I get it, but we can try and we can practice going on this route and what to say if there's a stranger' ... something that really hits home for me is just having that objective person to be like, 'yes this is scary, but also this could happen'. – Sarah (EAD)

The facilitators interviewed reiterated the pride their “focus-people” felt when establishing goals set through independent facilitation. Unfortunately, IFs also talked about cuts to IF support from government funding as of June of 2019, and the catastrophic effect this had on EADs and their families.

*It always comes down to community, or lack of. Or lack of network. Most of the people that we're having, have these problems. Do not have networks, do not have supportive parents, don't have supportive siblings, maybe see them 2 times a year out of obligation. So that is **our goal**, to help them [build networks]. But if they come from a history of*

neglect, disrespect, anger, whatever, it's a big jump. It's a huge hurdle for an independent facilitator to get them to be in the mental state of mind that 'I am valuable' that 'I do deserve' And the government needs to fund it. It is a huge job for facilitators to take on, it involves a lot of crisis. Because we're not heavily funded, and we do rely on certain amount of money every year for independent facilitation, it does limit us without having reliable ongoing funding. – Amanda (IF)

Maya_(IF) reflected similar sentiments in her interview: “I think having more funding would be great, so we can support more people in that practice. I think it's hard when you see people that need that help and you're not able to give it”.

In addition, Amanda_(IF) explained how important it was for family to be involved.

I think that families need to know about independent facilitation way before their child turns 21. And it also requires a lot of dedication from the family, if there is a family involved, they can't basically say “here independent facilitator, have fun” it needs to be a partnership. It needs to be a full cycle partnership where everyone works together and hopefully pushing the person forward into whatever, you know, goal or success they are kind of striving for. – Amanda (Tara's IF)

In conclusion, facilitation was more than just providing a service. It allowed participants to feel a sense of belonging in their communities, build support networks, and reach their goals in adult life. In some cases, facilitators became part of their families, as their main supporters, and in extreme cases, their lifelines. According to Amanda_(IF), “not a lot of people understand or know that independent facilitation exists”, and so from participant interviews, a better understanding and awareness of the service needs to be brought to light.

CHAPTER 4: DISCUSSION

The purpose of this study was to understand (1) the experiences of transitioning to adulthood for people with disabilities and their families, and (2) the role of independent facilitation during this life stage. To answer the first research question, the perceived experiences of transitioning to adulthood for people with disabilities included support being integral in the process from school, financially and family. Participants explained there are many life events within the transition to adulthood, including PSE, employment and living independently, and the challenges they encountered with each. Finally, community played a significant role providing experiences and connections for people with disabilities which helped them envision lives for themselves. In terms of the second research question, during the transition to adulthood independent facilitation functioned as the bridge to make community connections and networks for individuals. IFs served as a major form of support for their focus-people, but for families as well. The IFs used their support connections within communities for their focus-people, and taught them how to access such supports on their own. The ultimate goal of facilitation was to help individuals feel valued and worthy of having meaningful lives they wanted in adulthood.

Theme 1: “He Was Just Never a Great Fit” Haves and Haves Not of Support

Theme 1 described the haves and have nots of supports, one area being in school supports. Many EADs had negative experiences with school, where they felt misunderstood because of their disabilities from unsupportive teachers and felt hindered by Educational Assistants. Research by Shifrer (2013) showed similar results in that teachers are more likely to hold lower educational expectations for students labeled with disabilities than those who are not. Further special education placement can limit, rather than expand, opportunities for students with

disabilities (Wagner, Newman, Cameto, Levine, & Marder, 2007) by keeping students separated from their main classrooms.

In addition, often students with disabilities are assigned an Educational Assistant and placed in regular classrooms without clear expectations established between Assistants and teachers about which professional will plan, implement, monitor, evaluate and adapt instruction (Giangreco, Edelman, Luiselli, & Macfarland, 1997). Without clarity, confusion between the main teachers in the classrooms and the Assistants may ensue, where the Assistants' roles become excessive. Therefore, students with Assistants are more likely to be separated from classmates, leading to dependency on adults and limited peer interactions. As well, EADs are limited on receiving instruction directly from primary teachers, and can experience loss of personal control where the Assistants will speak or make choices for them (Giangreco et al., 1997). EADs in this study mirrored these concerns and felt over supported by their Educational Assistants. Some felt their Assistants had too much of a teaching role that hindered their relationships with their main teachers. EADs also felt limited in their interactions with classmates, as their Assistants were constantly by their sides, which deterred other students from approaching them.

Caregivers also expressed their frustrations with the schools' lack of follow through with IEPs. Additionally, the lack of information regarding possible avenues once schooling was completed left caregivers with little information about what to do. In Ontario, the primary goal of IEPs is to provide educators with a consistent approach to developing individualized plans that meet the needs of individual students and their long-term goals. In theory, the IEPs are supposed to be developed in collaboration with youth themselves, their families, professionals, and surrounding communities (Readhead, Whittingham, McKay, Bishop, & Hope, 2019). However,

participants who voiced concerns of lack of IEP follow-through did not explain if they were part of the development process, or what the IEP entailed. U.S studies have shown caregivers to be disappointed in their children's IEPs, and specifically noted vague, ineffective plans (Jobe & Glidden Masters, 2008; Leonard et al., 2016). One example of an IEP had one sentence that simply said, "[students name] will transition into college" (Hetherington et al., 2010, p. 168) with no steps or instructions as to how that would happen. Thus, future research could investigate the involvement of IEP development in Canadian school systems.

Caregivers also felt alone during this transition process, stating they had to constantly advocate for their children to get the supports they deserved, and to push their children to reach their potentials as schools focused more on what EADs could not do. These concerns are echoed in previous literature, where caregivers described how tiring it is to "constantly battle with the school district" (Hetherington et al., 2010, p. 167) and are met with lack of communication and information from schools. In addition, caregivers felt transition planning was happening too late and an IEP was "nothing more than a piece of paper" (Hetherington et al., 2010, p. 169) as teachers did not have time to teach or work towards specific goals outlined in the IEPs. Parents felt 'left in the dark' and unsupported by schools and agency staff planning their EADs futures (Fish, 2008; Gallivan-Fenlon, 1994; Underwood, 2010). The conflict or lack of communication not only resides between parents, coordinators and teachers, but between transition coordinators and community service providers as a result of their non-collaborative relationships. For example, adult services [health care services (Betz et al., 2015); social programs (Rimmer, Riley, Wang, Rauworth, & Jurkowski, 2004)] are typically not available for most young adults due to lack of inclusion, accessibility, and resources available within their communities (Cocks & Boaden, 2011; Cooney, 2002; Factor, Heller, & Janicki, 2012; Gallivan-Fenlon, 1994). Due to

these factors, EADs and their parents are restricted in accessing the necessary services and fall victim to prolonged transition processes.

Efforts are needed to improve the transition planning process for students with disabilities (Hendricks & Wehman, 2009). Caregivers experienced worry about their EADs being unprepared finishing school (Jobe & Glidden Masters, 2008; Leonard et al., 2016). This was compounded by the fact schools and their associated supports (e.g., respite and educational services) are lost once EADs graduate (McKenzie, Ouellette-Kuntz, Blinkhorn, & Démoré, 2017) and so parents are forced to fill the void. Almost all participants in this study revealed they received little to no information about next steps after high school. IEPs should include students viewing presentations from the school where they explain different avenues they can take once graduated, such as university/college, apprenticeship programs and workplace opportunities. As well, teachers, caregivers, and principals and the students themselves should be included in creating their IEPs and have check-ins with the plan every few months so everyone is on the same page. Finally, community organizations should be able to present in schools about programming and services families can access once they no longer have the supports from school. As a result, more effective communication and resources are needed from schools to inform families of opportunities for their children in their adult lives.

Despite systemic challenges within school environments, one main positive aspect participants expressed was how schools offered practicums and co-ops for students to obtain work experience and skills. This allowed participants to build up resumes and start to think about future careers. Work experiences during high school can provide numerous benefits to students, such as learning valuable workplace skills (e.g., the ability to follow directions and take

responsibility) which can contribute to an increased sense of control and heightened self-esteem (Burbidge, Minnes, Buell, & Oullette-Kurtz, 2008).

Another area that emerged from participant interviews was about “privilege” influencing quality of life. Specifically, EADs who were financially stable and had family support fared better in terms of quality of life in adulthood than those who did not have the same privilege.

Although limited research exists in this area, sufficient family income and support were positively correlated with life satisfaction (Parish, Rose, & Swaine, 2010; Schertz, Karni-Visel, Tamir, Genizi, & Roth, 2016) for families with children with disabilities. Further, positive associations existed between adequate supports/services, financial well-being and health (Parish et al., 2010; Schertz et al., 2016).

In the current study, money allowed some participants to afford high quality care from PSWs, and to make decisions about their needs and interests, rather than just what they could afford. In addition, EADs who had supportive families and who had their own set of values, beliefs, and goals to achieve during the adulthood phase were pushed to achieve their full potential. Alternatively, those who faced financial limitations and had little support from family were limited in opportunities after high school and faced a myriad of obstacles in accessing community resources during their transitions to adulthood.

Further, some EADs felt ignored by their peers and experienced feelings of social isolation due to bullying from peers. Unfortunately, students with disabilities are at a greater risk of being bullied in comparison to their typical-developing peers (Estell et al., 2009; Rose & Monda-Amaya, 2012) as a result of characteristics associated with their disabilities (e.g., social awkwardness), being in a special education classroom, being perceived as vulnerable (Janus, 2009; Rose, Monda-Amaya, & Espelage, 2011; Yun, Jung, & Yoo, 2015) and lack of meaningful

inclusion in typical education settings (Coster et al., 2013; Taheri, Perry, & Minnes, 2016). In addition, previous research has shown that social isolation and having fewer friendships are associated with lower well-being and increased risk for mental health problems (Mikkonen & Raphael, 2010; Young-Southward, Cooper, & Philo, 2017). As well, societal views have traditionally devalued and stigmatized persons with intellectual disabilities, thereby limiting their opportunities for experiencing social and emotional connectedness with others (Gilmore & Cuskelly, 2014) making them more vulnerable to loneliness.

Some participants in this study expressed feelings of loneliness and lower self-esteem, where they felt less confident and out of place. This especially held true for participants with “invisible” disabilities, where because their disabilities were not physically apparent, they were misunderstood by their peers. Some caregivers and support persons also reported their EADs being in an “awkward in-between” where they had a mix of intellectual and developmental disabilities, and as a result “were just never a great fit” with their peers. It is clear that people with intellectual and developmental disabilities have fewer opportunities to create and maintain friendships due to peers misunderstanding their disabilities (Callus, 2017; Friedman & Rizzolo, 2018). Participants with physical disabilities also expressed feeling isolated, but also felt they missed opportunities for romantic relationships or would never have any opportunities. Due to characteristics of their disabilities, potential suitors assumed EADs were asexual or their roles with EADs would turn into one like a PSW, rather than a romantic partner. Research supports the views that people with physical disabilities are often stereotyped to be asexual and that they do not desire, or are not capable, of romantic relationships (Janus, 2009; Milligan, Aldred, & Neufeldt, 2001).

Theme 2: The Many Hats of Adulthood: Living with a Disability

For Theme 2, the many hats, or transitions, within the transition to adulthood were described. Some participants highlighted their PSE experiences as being very positive and a time when they felt freedom over their lives for the first time; however, others struggled to complete programs due to lack of accessible services. For the most part, positive experiences were attributed to EADs having access to school supports, inclusive residences, and opportunities to be independent. Research has shown that educational institutions with adequate policies and funding for learning supports needs, peer mentorship programs, accessible equipment, flexible library systems, appropriate assistance with exam arrangements and awareness from academic staff resulted in positive experiences for students with disabilities (Burgstahler & Cronheim, 2001; Holloway, 2001). Similarly, participants in this study who explained positive experiences noted having accessible learning equipment, inclusive institution policies and other supports such as peer mentors and accommodative residences. In contrast, within the literature experiences were described as negative when there was a lack of assistance from student services, such as being denied extra time on tasks, note takers, and barriers in participating and interacting in class (Fuller, Bradley, & Healey, 2004), and expressed significant feelings of uncertainty, worry, financial burden and frustration (Goode, 2007; Harrison & Holmes, 2013; Holloway, 2001). In the current study, similar challenges existed including not qualifying for accessibility services and switching programs multiple times due to financial limitations and frustration from lack of employment opportunities once graduated.

In Ontario, many colleges offer Community Integration through Co-operative Education (CICE) programs. These programs are designed for life skill high school graduates with the incorporation of mainstream academic classes and student supports and accommodations. In

these programs, students typically participate in co-op placements that allow them to develop workplace skills (Readhead et al., 2019). As a mother described in this study, her EAD had applied to a local CICE program, as it was the only PSE option he had, since life skills students do not graduate with a high school diploma. Further, the mother explained graduates of CICE programs also do not graduate with a degree or diploma. Thus, CICE students remain limited when compared to peers who attend mainstream PSE programs. For instance, in one Ontario college, CICE graduates were less likely than mainstream students to find general employment (e.g., 71% employed compared to the 84% college total), and even less likely to find employment related to their area of interest (e.g., 14% working in related field compared to the 55% college total) (Readhead et al., 2019).

Overall, although there are supportive mechanisms in place for EADs to attend PSE, more work needs to be done to include all disabled students, and even with CICE programs, EADs are still disadvantaged outside of school settings, such as finding employment. It is important not to underestimate disabled students' abilities, and to dwell on what they cannot do. As described earlier, students in school felt their potential was often overlooked by teachers and Educational Assistants due to their disabilities, limiting information and motivation about future opportunities. The post-secondary experience was important to most current participants to order to prove their independence and build confidence in their abilities. As stated in the literature, those with disabilities can succeed in PSE when they have access to technology, appropriate supports, and trained academic staff (Matthews, 2009; Yarbrough, 2019).

Another area discussed in Theme 2 was employment. Many participants expressed challenges when trying to enter the workforce due to lack of accommodations in the workplace. For example, lack of accommodations inhibited some participants from working in certain

careers, getting full time hours, and having limited responsibilities within their current positions. Research suggests young people with disabilities experience significant barriers during transitions from school to employment (Beyer, Kaehne, Grey, Sheppard, & Meek, 2008; Hashim & Wok, 2014; Kaehne & Beyer, 2008; Kaya, 2018). In 2011, the employment rate of Canadians aged 25 to 64 years with disabilities was 49% compared with 79% for Canadians without a disability (Turcotte, 2015). Among Canadians with disabilities, 12% reported having been refused a job in the last five years as a result of their conditions. This percentage rose to 33% specifically among 25 to 35 years old (Turcotte, 2015).

The literature cites employment not being considered as a viable option by professionals in transition planning and not enough well-structured work awareness training for employers (Beyer et al., 2008; Kaehne & Beyer, 2008) as barriers to employment. Caregivers experienced frustration when employment was rejected as a legitimate next step by professionals for their EADs (Case, 2001). The probability of paid employment after completing their education was increased only when employment agencies promoted and offered concrete advice regarding next steps for EADs, (Kaehne & Beyer, 2008; J. Rose, Saunders, Hensel, & Kroese, 2005). In addition, workplace discrimination significantly reduced current job satisfaction for people with disabilities, particularly access discrimination where they were not hired for job-irrelevant reasons, received lower starting salaries and lacked access to higher skill level jobs (Perry, Hendricks, & Broadbent, 2000). Particularly, negative attitudes and beliefs were the greatest barriers to equal opportunity for individuals with disabilities (Kilbury, Benshoff, & Rubinm, 1992) in the workforce. Research found employers to be concerned with the cost of accommodation, even though when accommodations are made, they are fairly simple and

dissatisfactory for disabled workers (e.g., reduced work hours) (McFarlin, Song, & Sonntag, 1991).

A compounding issue to this is whether EADs should disclose their disability to employers, and if so, the best time to disclose this information. Current participants revealed less confidence in their workplace environments due to their disabilities, particularly EADs with “invisible disabilities” who struggled to find permanent work. Specifically, participants were worried if they disclosed their disabilities, they would be less likely to be hired as they would require accommodations and extra training compared to individuals without disabilities. This is consistent with previous research by Sellevoll (2016) who found individuals with disabilities were hesitant about disclosing a disability when applying for jobs due to fears of discrimination. As well, they wanted to be considered for positions based on their competence, not their impairments, thus not revealing their disabilities in interviews or in applications. Even when hired for positions, some were reluctant in disclosing their disabilities, as many had experiences of being met with anger by the employer who felt they were caught off guard or felt they were hiding something. Therefore, there is a need for more information on the legal implications of disclosing one’s disability (or not) in the workplace (Brohan, Henderson, Slade, & Thornicroft, 2014).

Findings from previous research did reveal positive aspects in finding employment for EADs. For example, job placement in post-secondary, on-the-job support and training, technical assistance, and supported work experiences provided through external employment services were significantly associated with competitive employment among youth with disabilities (Beyer et al., 2008; Kaya, 2018). In addition, workplace accommodation was essential to the vocational well-being of workers with disabilities (Moore, Konrad, Yang, Ng, & Doherty, 2011). As well,

family expectations, work experiences in high school, and transition services and supports led individuals with disabilities to be more likely to obtain postschool employment (Lindstrom, Doren, & Miesch, 2011). Similarly, in the current study, participants had positive experiences with practicums embedded in their PSEs. This allowed them to make connections with future employers and thus they were able to find employment once graduated. However, although grateful for their jobs, with lack of accommodation and funding in the workplace, participants still felt limited in the amount of work they were responsible.

Given the challenges of finding paid employment for people with disabilities, volunteering is an alternative option for people with disabilities (Burbidge et al., 2008). Unfortunately, despite the Ontario secondary school curriculum requirement of obtaining 40 hours of volunteer service, about 75% of students with disabilities were not involved in any type of volunteer activity, or required to do so (Burbidge et al., 2008). In the present study, two participants discussed their volunteer experiences in their communities as being meaningful and enjoyable. Success of these experiences mostly likely had to do with their caregivers' support in finding such programs and pushing them to pursue volunteering. As a result, there is a need for more opportunities for customized and supported employment and volunteering for people with disabilities. These opportunities need to have more funds dedicated to workplace accommodations so that employment and volunteer experiences among EADs may be more within reach.

Finally, housing was the last subtheme in relation to Theme 2. Some participants noted the difficulties they had finding accessible housing due to long wait lists. Others almost ended up homeless, where one participant who was severely unsupported was currently homeless and experienced the hardships of accessing youth shelters for her survival. According to Crawford (2013) people living with disabilities are twice as likely to live below the poverty line, and vice

versa. In Canada, it is estimated that 45% of all people experiencing homelessness are disabled or diagnosed with a mental illness (Center for Justice and Social Compassion, 2014).

Specifically, in Toronto, it was found that 55% of people experiencing homelessness had a serious health condition, and of those, 63% had more than one (Shartal, Cowan, Khandor, & German, 2004). Although poverty plays a large role in why people with disabilities are more likely to experience homelessness, there are many interrelated causes in Canada including long-term employment issues, difficulty accessing benefits, and limited availability of affordable, supportive housing (The Canadian Observatory on Homelessness (COH), n.d.).

Most current participants commented on the lack of supportive housing in their communities. According to the Canadian Human Rights Commission (2012), housing needs are 6.2% higher for people with disabilities than those without. To extenuate the housing problem, in 2013, 12,000 adults in Ontario were waiting for supportive housing “in a system that is backlogged and engineered to solve crises, but not prevent them” (COH, n.d., para 16). As a result, people with disabilities are more likely to experience homelessness, and often find themselves struggling to find shelter that can accommodate them. Participants echoed similar sentiments. In fact, one participant stayed in a student residence for 6 years to avoid homelessness, while another participant who was homeless struggled to find accommodative youth shelters. As a result of behavioral issues related to her disability, she was constantly barred from shelters she relied on for safe housing.

Caregivers in this study also commented on their experiences with group homes. Participants who initially wanted to place their EADs in a group home environment eventually changed their minds due to eligibility criteria and concerns of quality of care. Although there is limited research in this area, participants in group home settings experienced greater choices and control

over their everyday lives; however, they felt they could not control the support they received from staff, experienced restrictions on life experiences in the community, and feelings of loneliness (Bigby, Bould, & Beadle-Brown, 2017; Bowey, McGlaughlin, & Saul, 2005). As well, it was found the average size of group homes, and combination of housing with 24-hour support, made it difficult for staff to provide adequate support when support needs changed. Additionally, those living in group homes felt limited as they did not have a choice about their housemates (Mansell, 2010). Although participants in this study voiced that independent living was a goal for them in adult life, their caregivers confessed the reality was limited opportunity for housing due to the complex needs of their disabilities.

Theme 3: “Community is When People Notice You’re Not There”

Lastly, Theme 3 discussed the importance of community involvement for participants. Having opportunities to network within their communities allowed EADs to build connections and experiences which fostered future opportunities and helped them envision a future for themselves. It also provided them a sense of belonging when engaging with others in their communities. Both people with and without disabilities have a need for social interaction and inclusion. Close relationships can help improve quality of life, health, and self-esteem (White & Summers, 2017), therefore it is important for people with disabilities to have equal opportunities to participate in their communities (Dattilo et al., 2019).

A model that helps explain the best practices and importance of community for EADs was developed by Stewart et al. (2009) named The Best Journey to Adult Life (BJA) Model (see Appendix E). The hot air balloon represents the journey to adult life. As seen in the model, the main people involved in the journey (i.e. the EAD, parents and navigators) are in control of the balloon. The basket represents the EADs and their family’s community. Community is an

integral part of the youth's journey, and must be inclusive and flexible in its support in all aspects of the EADs journey to adulthood (i.e. preparation, journey and "landing" phases) (Stewart et al., 2009).

According to Stewart et al. (2009), communities should want to work collaboratively with youth and families from the start, and schools should work collaboratively with community groups and service providers to begin early transition planning. In addition, to promote capacity-building among EADs, it is important to bring down silos within school and community programs, by schools offering courses in which students attend community programs to develop skills for the future. In the current study, participants who had such connections (e.g., community practicums in high school; post-secondary institutions) helped them obtain employment and connections in adult life.

As well, it was suggested by Stewart et al. (2009) that IEPs transition planning documentation needs to begin no later than grade five, reviewed every two years at first, then every year in high school. Educational Assistants also need to know about a young person's accommodations, and how to encourage a younger person to direct their own care, so he/she is able to advocate for him/herself in the workforce and post-secondary institutions where supports are not guaranteed. Also, some EADs felt the role of the Educational Assistant should be phased out as EADs approached the end of high school to better prepare for independence and self-advocacy in adult life.

Stewart et al. (2009) recommended that it is important for communities to establish transition network committees, which consist of representatives from different supportive organizations who can share and compare resources and information. Developing inclusive peer mentoring opportunities in schools and communities could also help encourage commonalities between

students with disabilities and their nondisabled peers. For example, peer mentoring was helpful for a participant in this study, where it made her realize her capabilities of learning at a university level and motivated her to pursue PSE. Overall, more research is needed to understand the experiences of EADs and community members in different adult settings such as PSE, housing, employment, etc.

Finally, independent facilitation was investigated to understand its role in the transition to adulthood for people with disabilities. EADs involved with facilitation described it to be helpful in navigating their adult lives, such as developing circles of support, managing inconsistent lifestyles, finding housing and mental health services, as well helping caregivers think outside the box for avenues for their EADs to pursue. These findings are consistent with the Ontario Independent Facilitation Network (OIFN) (2018) core elements of facilitation (See Appendix F), where its core value is to be a person-directed, individualized and community first support for people with disabilities. Facilitators were clearly mentioned as important pieces to participants' lives, whether serving as lifelines for EADs saving them from crises or assisting with valuable connections in terms of resources in their communities. As a result, participants were able to live confident, independent lives with facilitation.

The BJA Model developed by Stewart et al. (2009), described a “navigator” to be an important aspect in one’s journey to adulthood. The navigator provides support and guidance to the youth and family. IFs are prime example of navigators, as they promote collaboration between parties and find information, resources and supports, connections, etc. according to the needs of the person and their family. Facilitators address individual needs, not the disability, and work collaboratively with youth and their families (Stewart et al., 2009). Facilitators also help form circles of support as recommended by the BJA Model for EADs to have. Additionally, one

of the main goals for facilitators to is to help their focus-people develop. Finally, the BJA Model defined a navigator as “someone who has personal investment and dedication to families, understand how asking for help is difficult for families, is a creative thinker, have ethnocultural and socioeconomic considerations, take a whole family approach, assist in community inclusion, and to help families develop, implement, and monitor a plan ensuring the person/family’s choices are being honored” (p. 27). After interviewing IFs, the roles of navigators seem to mesh with those of IFs. Therefore, more research to determine the effectiveness of IFs as integral components of EADs’ transition process, as suggested by the evidence-based BJA Model, is warranted. Research of this nature would help to solidify the necessity of IFs in the lives of EADs, so policy makers make IFs a provincial funding priority. In the current study IFs explained there was confusion about the role of facilitation in the life transitions of EADs; however, it is clear that IFs can have a key role as navigators for EADs in their journeys to adulthood to help deepen connections and to create customized, meaningful and supportive lives.

5.1 LIMITATIONS

Some limitations exist within this research. To begin, participant cases were not complete, in that not all cases had the EAD participate, and vice versa, where not all EADs had their caregivers or supports persons participate. In addition, not all participants were involved with independent facilitation, where only five out of the nine cases were able to speak to the service IF provides, and only two independent facilitators were interviewed. Having more complete cases could have brought a more holistic view of EADs’ experiences becoming adults and having more perspectives of independent facilitation could have brought to light more information about its effects in helping EADs transition to adulthood. Finally, participants were

recruited largely through convenience sampling, either through word of mouth or one agency, which suggests a possible sampling bias.

5.2 IMPLICATIONS

The implications of this study were four-fold. First, this research provided EADs a “voice” that is often void within the research. Most EAD research is quantitative in nature and uses surveys for data collection, therefore, little was known about the in-depth experiences of EADs in this life stage. Further, the voice of people with disabilities is typically over-shadowed by their caregivers and professionals (e.g., therapists, teachers) that complete the research, since EADs’ compromised communication has been a major hindrance to full inclusion in research (Knight, 2015). Thus, previous literature lacked the personal experiences of EADs. The use of semi-structured, one-on-one interviews in this study was valuable as it was an accessible and adaptable method which helped EADs express themselves and provided a better understanding of this life stage from their perspectives. As well, this study consisted of EADs with various types of disabilities including physical, intellectual, and developmental. Previous literature focused mostly on youth with intellectual disabilities, so having a variety of types of disabilities added to the literature.

Secondly, the majority of the current literature surrounding EADs is negative in nature, such as the effects of caregiving and lack of support for EADs as they transition into adulthood (see for example: Rapanaro et al., 2008). Further, most research addressing EADs occurred a few years after individuals transitioned into adulthood. Thus, this study included EADs who were in various stages, including those currently experiencing the life stage of emerging adulthood. This allowed for a holistic view of the phenomenon, where perspectives from EADs early in the process, those currently in the process, and those post the process were collected.

Thirdly, this research increased public awareness of the supports EADs need, such as the instrumental role of independent facilitation. There is a paucity of information concerning barriers and challenges EADs face. This is evident by the cuts the current Ontario government made concerning independent facilitation services (Molnar, 2019), forcing EAD organizations to search for funding elsewhere to offer independent facilitation (Ontario Independent Facilitation Network, 2018). I am unaware of any research that has examined the effects of independent facilitation; thus, this study provided evidence of the role independent facilitation had for EADs transitioning into adulthood, and can vouch for its necessity in communities within the Ontario context.

Lastly, researchers, health care workers, and school boards can use the findings from this study to expand their knowledge of EADs needs. This study was also done in Canada, whereby most previous research is based in the U.S and United Kingdom in relation to school systems, employment and mandated policies. As a result, capturing EADs voices in a Canadian context, we have learned their perspectives concerning this life stage and can use the findings to assist in the development of supportive policies, and further investigate the experiences of emerging adulthood for people with disabilities.

5.3 SUGGESTIONS FOR FUTURE RESEARCH

Some suggestions for future research include delving more into the preparation for transitioning into adulthood, particularly in the Canadian school system, and the specific experiences of employment, housing and community participation. The majority of current research is based on U.S and United Kingdom data, where they have different protocols for disabled youth than in Canada. As such, qualitative research focusing on the perceptions of school stakeholders regarding the development of IEPs, education assistant use, and parent

collaboration would be beneficial as well. In addition, using focus groups with EADs and their families would be beneficial to gather more information surrounding the effects of transitioning to adulthood for EADs and their families. As well, research on PSE and employment in Canada for students with disabilities is needed, so investigations into the experiences of accessibility services within institutions, and the general experiences for EADs are completed. Suggestions for recruitment for future research include thoroughly investigating IF organizations. Future areas recommended to research include: profit vs non-profit organizations and their roles, whether people are currently using their services, specific roles of IFs, for example. This way, more information would be available regarding the benefits of IFs in the lives of EADs. Finally, longitudinal studies tracking EADs with diverse characteristics (e.g., socio-economic status, type of disability) who use or do not use IF across Ontario would provide more information about the effects of IF on the transition process.

5.4 CONCLUSION

The experiences of transitioning to adulthood for people with disabilities and their families was a “challenging yet rewarding” process. It should be recognized that programs and services that help marginalized groups, such as EADs and their families, must be adequately funded, as without, individuals can fall through the cracks, putting a strain on the already overwhelmed health care, mental health, and housing sectors. This study helped fill the void that existed in previous literature by including the voices six of emerging adults with various disabilities which brought to light the diversity of their journeys into adulthood. Although many hardships were discussed, positive attributes emerged which showed the role of independent facilitation which had not been formally studied previously. Caregivers noted “bumps in the road” but also how proud they were of their EADs, and that in the end, above all, they wished for “happiness” for

their EADs in their adult lives. In conclusion, this study highlighted how individual factors, such as level of support, systemic factors from schools, workplace and housing, and community are instrumental elements in EADs transitioning to adulthood.

References

- Abbott, S., & Mcconkey, R. (2006). The barriers to social inclusion as perceived by people with intellectual disabilities. *Journal of Intellectual Disabilities*, 10(3), 275–287. Retrieved from <http://www.embase.com/search/results?subaction=viewrecord&from=export&id=L44237316%5Cnhttp://dx.doi.org/10.1177/1744629506067618%5Cnhttp://limo.libis.be/resolver?&sid=EMBASE&issn=17446295&id=doi:10.1177%2F1744629506067618&atitle=The+barriers+to+social+inc>
- Alqazlan, S., Alallawi, B., & Totsika, V. (2019). Post-secondary education for young people with intellectual disabilities: A systematic review of stakeholders' experiences. *Educational Research Review*, 28(April), 100295. <https://doi.org/10.1016/j.edurev.2019.100295>
- Annable, G., Watters, C., Sienstra, D., Symanzik, A., Tully, B. L., & Stuewer, N. (2003). Students with Disabilities: Transitions from Post-Secondary Education to Work. *Phase One Report*, (September), 1–63.
- Arnett, J. J. (2014). What Is It Like to Be an Emerging Adult? Chapter 2. In *Emerging Adulthood: The Winding Road from the Late Teens Through the Twenties* (pp. 1–25). Oxford Scholarship Online. <https://doi.org/10.1093/acprof:oso/9780199929382.001.0001>
- Autism Ontario. (2017). Funding. Retrieved from <http://www.autismontario.com/client/aso/ao.nsf/Durham/Funding+Services?OpenDocument>
- Barron, D. A., Coyle, D., Paliokosta, E., & Hassiotis, A. (2014). Transition For Children With Intellectual Disabilities. Retrieved from <http://www.intellectualdisability.info/life-stages/articles/transition-for-children-with-intellectual-disabilities>
- Betz, C. L. (2003). Pediatric Hospitals Are Not Appropriate for Adult Admissions. *Journal of Pedia*, 18(5), 303–304. [https://doi.org/10.1053/S0882-5963\(03\)00198-2](https://doi.org/10.1053/S0882-5963(03)00198-2)

- Betz, C. L., Nehring, W. M., & Lobo, M. L. (2015). Transition Needs of Parents of Adolescents and Emerging Adults With Special Health Care Needs and Disabilities. *Journal of Family Nursing, 21*(3), 362–412. <https://doi.org/10.1177/1074840715595024>
- Beyer, S., Kaehne, A., Grey, J., Sheppard, K., & Meek, A. (2008). The transition of young people with learning disabilities to employment: What works? *Journal on Developmental Disabilities, 14*(1), 85–94.
- Bigby, C., Bould, E., & Beadle-Brown, J. (2017). Conundrums of supported living: The experiences of people with intellectual disability. *Journal of Intellectual and Developmental Disability, 42*(4), 309–319. <https://doi.org/10.3109/13668250.2016.1253051>
- Biggs, E. E., & Carter, E. W. (2016). Quality of Life for Transition-Age Youth with Autism or Intellectual Disability. *Journal of Autism and Developmental Disorders, 46*(1), 190–204. <https://doi.org/10.1007/s10803-015-2563-x>
- Bond, R. J., & Hurst, J. (2010). How adults with learning disabilities view living independently. *British Journal of Learning Disabilities, 38*(4), 286–292. <https://doi.org/10.1111/j.1468-3156.2009.00604.x>
- Bowey, L., McGlaughlin, A., & Saul, C. (2005). Research note : Assessing the barriers to achieving genuine housing choice for adults with a learning disability: the views of family carers and professionals. *British Journal of Social Work, 35*(1), 139–148. <https://doi.org/10.1093/bjsw/bch167>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- British Columbia Medical Association. (2014). Guidelines and Protocols Advisory Committee Handbook: Developing Clinical Practice Guidelines and Protocols for British Columbia, 1–

31. Retrieved from <https://www2.gov.bc.ca/assets/gov/health/managing-your-health/patient-information-guides/2014-gpac-handbook.pdf>
- Brohan, E., Henderson, C., Slade, M., & Thornicroft, G. (2014). Development and preliminary evaluation of a decision aid for disclosure of mental illness to employers. *Patient Education and Counseling*, 94(2), 238–242. <https://doi.org/10.1016/j.pec.2013.10.008>
- Burbidge, J., Minnes, P., Buell, K., & Oullette-Kurtz, H. (2008). Preparing to leave school: Involvement of students with intellectual disabilities in productive activities. *Journal on Developmental Disabilities*, 14(1), 19–26.
- Burgstahler, S., & Cronheim, D. (2001). Supporting peer-peer and mentor-protégé relationships on the internet. *Journal of Research on Technology in Education*, 34(1), 59–74. <https://doi.org/10.1080/15391523.2001.10782334>
- Callus, A. M. (2017). ‘Being friends means helping each other, making coffee for each other’: reciprocity in the friendships of people with intellectual disability. *Disability and Society*, 32(1), 1–16. <https://doi.org/10.1080/09687599.2016.1267610>
- Canadian Human Rights Commission. (2012). *Report on Equality Rights of People with Disabilities*. Retrieved from [https://www.homelesshub.ca/sites/default/files/attachments/Report on Equality Rights of People with Disabilities.pdf](https://www.homelesshub.ca/sites/default/files/attachments/Report%20on%20Equality%20Rights%20of%20People%20with%20Disabilities.pdf)
- Canadian Mental Health Association. (2019). Transitioning from Youth to Adult Mental Health Services. Retrieved from <https://ontario.cmha.ca/documents/transitioning-from-youth-to-adult-mental-health-services/>
- Canadian Paediatric Society. (2007). Transition to adult care for youth with special health care needs. *Paediatr Child Health*, 12(9), 785–788.

- Carroll, E. M. L. (2015). Health Care Transition Experiences of Young Adults With Cerebral Palsy. *Journal of Pediatric Nursing*, 30(5), e157–e164.
<https://doi.org/10.1016/j.pedn.2015.05.018>
- Carter, N., Bryant-Lukosius, D., DiCenso, A., Blythe, J., & Neville, A. J. (2014). The Use of Triangulation in Qualitative Research. *Oncology Nursing Forum*, 41(5), 545–547.
- Case, S. (2001). Learning to Partner, Disabling Conflict: Early indications of an improving relationship between parents and professionals with regard to service provision for children with learning disabilities. *Disability and Society*, 16(6), 837–854.
<https://doi.org/10.1080/09687590120083985>
- Center for Justice and Social Compassion. (2014). Myths of Homelessness. Retrieved from <https://homelesshub.ca/blog/infographic-wednesday-myths-homelessness>
- Centers for Disease Control and Prevention. (2018). Disability Barriers to Inclusion. Retrieved from <https://www.cdc.gov/ncbddd/disabilityandhealth/disability-barriers.html>
- Chambers, C. R., Hughes, C., & Carter, E. W. (2004). Parent and sibling perspectives on the transition to adulthood. *Education and Training In*, 39(2), 79–94. Retrieved from http://daddcec.org/Portals/0/CEC/Autism_Disabilities/Research/Publications/Education_Training_Development_Disabilities/2004v39_Journals/ETDD_200406v39n2p079-094_Parent_Sibling_Perspectives_Transition_Adulthood.pdf
- Chambers, T., Sukai, M., & Bolton, M. (2011). Assesment of Debt Load and Financial Barriers Affecting Students with Disabilities in Canada Postsecondary Education- Ontario Report. *Toronto: Higher Education Quality Council of Ontario*.
- Chappell, A. L. (1994). A Question of Friendship: Community care and the relationships of people with learning difficulties. *Disability & Society*, 9(4), 419–434.

<https://doi.org/10.1080/09687599466780431>

Cheak-Zamora, N. C., & Teti, M. (2015). “you think it’s hard now ... It gets much harder for our children”: Youth with autism and their caregiver’s perspectives of health care transition services. *Autism*, 19(8), 992–1001. <https://doi.org/10.1177/1362361314558279>

Cheak-Zamora, N. C., Teti, M., & First, J. (2015). “Transitions are Scary for our Kids, and They’re Scary for us”: Family Member and Youth Perspectives on the Challenges of Transitioning to Adulthood with Autism. *Journal of Applied Research in Intellectual Disabilities*, 28(6), 548–560. <https://doi.org/10.1111/jar.12150>

Children’s Healthcare Canada. (2018). Canadian Transition Clinics and Programs. Retrieved from <https://ken.childrenshealthcarecanada.ca/xwiki/bin/view/Transitioning+from+Paediatric+to+Adult+Care/Canadian+Transition+Clinics+and+Programs>

Chou, Y. C., Wehmeyer, M. L., Palmer, S. B., & Lee, J. (2017). Comparisons of Self-Determination among Students with Autism, Intellectual Disability, and Learning Disabilities: A Multivariate Analysis. *Focus on Autism and Other Developmental Disabilities*, 32(2), 124–134. <https://doi.org/10.1177/1088357615625059>

Cocks, E., & Boaden, R. (2011). A quality framework for personalised residential supports for adults with developmental disabilities. *Journal of Intellectual Disability Research*, 55(8), 720–731. <https://doi.org/10.1111/j.1365-2788.2010.01296.x>

Community Living Toronto. (n.d.). Becoming an adult: Transition planning for youth with a developmental disability. Retrieved from <https://connectability.ca/2018/04/25/becoming-an-adult-transition-planning-for-youth-with-a-developmental-disability/>

Cooney, B. F. (2002). Exploring Perspectives on Transition of Youth With Disabilities: Voices

- of Young Adults, Parents, and Professionals. *Mental Retardation*, 40(6), 425–435.
- Coster, W., Law, M., Bedell, G., Liljenquist, K., Kao, Y. C., Khetani, M., & Teplicky, R. (2013). School participation, supports and barriers of students with and without disabilities. *Child: Care, Health and Development*, 39(4), 535–543. <https://doi.org/10.1111/cch.12046>
- Crawford, C. (2013). *Looking into Poverty: Income Sources of Poor People with Disabilities in Canada*. Retrieved from [http://www.ccdonline.ca/media/socialpolicy/Income Sources Report IRIS CCD.pdf](http://www.ccdonline.ca/media/socialpolicy/Income%20Sources%20Report%20IRIS%20CCD.pdf)
- Creswell, J. W. (2014). *Research Design: Qualitative, Quantitative and Mixed Methods Approaches*. SAGE Publications (4th ed.). <https://doi.org/10.1063/1.1150549>
- Creswell, J. W., & Creswell, J. D. (2018). *Research design: qualitative, quantitative and mixed methods approaches* (5th ed.). Los Angeles, California: Sage Publications, Inc.
- Dattilo, J., Siperstein, G. N., McDowell, E. D., Schleien, S. J., Whitaker, E. B., Block, M. E., ... Hall, A. (2019). Perceptions of Programming Needs for Inclusive Leisure Services. *Journal of Park and Recreation Administration*, 37(4), 70–91. <https://doi.org/10.18666/jpra-2019-9514>
- Developmental Services Ontario. (2019). Passport Funding. Retrieved from <https://www.dsontario.ca/direct-funding>
- Developmental Services Ontario. (2020). Your Access Point for Adult Developmental Services. Retrieved from <https://www.dsontario.ca/>
- Dilley, P. (2000). Conducting Successful Interviews: Tips for Intrepid Research. *Theory into Practice*, 39(5), 1–7.
- Dyke, P., Bourke, J., Llewellyn, G., & Leonard, H. (2013). The experiences of mothers of young adults with an intellectual disability transitioning from secondary school to adult life.

Journal of Intellectual and Developmental Disability, 38(2), 149–162.

<https://doi.org/10.3109/13668250.2013.789099>

Estell, D. B., Farmer, T. W., Irvin, M. J., Crowther, A., Akos, P., & Boudah, D. J. (2009).

Students with exceptionalities and the peer group context of bullying and victimization in late elementary school. *Journal of Child and Family Studies*, 18(2), 136–150.

<https://doi.org/10.1007/s10826-008-9214-1>

Evans, Forney, & Guido-DeBrito. (1998). *Schlossberg's Transition Theory. Student*

Development in College: theory, research, and practice.

[https://doi.org/http://dx.doi.org/10.1016/0965-8564\(95\)90007-1](https://doi.org/http://dx.doi.org/10.1016/0965-8564(95)90007-1)

Factor, A., Heller, T., & Janicki, M. (2012). *Bridging the Aging and Developmental Disabilities*

Service Networks: Challenges and Best Practices. Chicago, Illinois.

Finnie, R., Childs, S., & Wismer, A. (2011). Access to Postsecondary Education: How Ontario

Compares. *Toronto: Higher Education Quality Council of Ontario.*

Fish, W. W. (2008). The IEP Meeting: Perceptions of Parents of Students Who Receive Special

Education Services. *Preventing School Failure: Alternative Education for Children and*

Youth, 53(1), 8–14. <https://doi.org/10.3200/psfl.53.1.8-14>

Foster, S. (2004). The Role of Mentoring Relationships in the Career Development of Successful

Deaf Persons. *Journal of Deaf Studies and Deaf Education*, 9(4), 442–458.

<https://doi.org/10.1093/deafed/enh053>

Fredericks, E. M. (2009). Nonadherence and the transition to adulthood. *AASLD*, 15(S2).

Retrieved from <https://aasldpubs.onlinelibrary.wiley.com/doi/full/10.1002/lt.21892>

Friedman, C., & Rizzolo, M. C. (2018). Friendship, Quality of Life, and People with Intellectual

and Developmental Disabilities. *Journal of Developmental and Physical Disabilities*, 30(1),

39–54. <https://doi.org/10.1007/s10882-017-9576-7>

Fuller, M., Bradley, A., & Healey, M. (2004). Incorporating disabled students within an inclusive higher education environment. *Disability and Society*, 19(5), 455–468.

<https://doi.org/10.1080/0968759042000235307>

Fusch, P. I., & Ness, L. R. (2015). Are we there yet? Data saturation in qualitative research. *Qualitative Report*, 20(9), 1408–1416.

Gallivan-Fenlon, A. (1994). “Their Senior Year”: Family and Service Provider Perspectives on the Transition from School to Adult Life for Young Adults with Disabilities. *Journal of the American Society of Hypertension*, 19(1), 11–23.

<https://doi.org/10.1177/154079699401900102>

Gaumer-Erickson, A. S., Noonan, P. M., Zheng, C., & Brussow, J. A. (2015). The relationship between self-determination and academic achievement for adolescents with intellectual disabilities. *Research in Developmental Disabilities*, 36, 45–54.

<https://doi.org/10.1016/j.ridd.2014.09.008>

Gauthier-Boudreault, C., Couture, M., & Gallagher, F. (2018). How to facilitate transition to adulthood? Innovative solutions from parents of young adults with profound intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 31(July), 215–223.

<https://doi.org/10.1111/jar.12394>

Geenen, S. J., Powers, L. E., & Sells, W. (2003). Understanding the role of health care providers during the transition of adolescents with disabilities and special health care needs. *Journal of Adolescent Health*, 32(3), 225–233. [https://doi.org/10.1016/S1054-139X\(02\)00396-8](https://doi.org/10.1016/S1054-139X(02)00396-8)

Giangreco, M. F., Edelman, S. W., Luiselli, T. E., & Macfarland, S. Z. C. (1997). Helping or Hovering? Effects of Instructional Assistant Proximity on Students with Disabilities.

- Exceptional Children*, 64(1), 7–18. <https://doi.org/10.1177/001440299706400101>
- Gilmore, L., & Cuskelly, M. (2014). Vulnerability to Loneliness in People with Intellectual Disability: An Explanatory Model. *Journal of Policy and Practice in Intellectual Disabilities*, 11(3), 192–199. <https://doi.org/10.1111/jppi.12089>
- Giust, A. M., & Valle-Riestra, D. M. (2017). Supporting mentors working with students with intellectual disabilities in higher education. *Journal of Intellectual Disabilities*. <https://doi.org/https://doi.org/10.1177/1744629516651019>
- Goode, J. (2007). “Managing” disability: Early experiences of university students with disabilities. *Disability and Society*, 22(1), 35–48. <https://doi.org/10.1080/09687590601056204>
- Government of Canada. (2019). Employment Equity Act. Retrieved from <https://laws-lois.justice.gc.ca/eng/acts/E-5.401/page-1.html#docCont>
- Hall, S. A. (2017). Community Involvement of Young Adults with Intellectual Disabilities: Their Experiences and Perspectives on Inclusion. *Journal of Applied Research in Intellectual Disabilities*, 30(5), 859–871. <https://doi.org/10.1111/jar.12276>
- Hamilton, L. G., Mesa, S., Hayward, E., Price, R., & Bright, G. (2017). ‘There’s a lot of places I’d like to go and things I’d like to do’: the daily living experiences of adults with mild to moderate intellectual disabilities during a time of personalised social care reform in the United Kingdom. *Disability and Society*, 32(3), 287–307. <https://doi.org/10.1080/09687599.2017.1294049>
- Harrison, A. G., & Holmes, A. (2013). Mild intellectual disability at the postsecondary level: Results of a survey of disability service offices. *Exceptionality Education International*, 23(1), 22–39.

- Hashim, J., & Wok, S. (2014). Predictors to employees with disabilities' organisational behaviour and involvement in employment. *Equality, Diversity and Inclusion*, 33(2), 193–209. <https://doi.org/10.1108/EDI-03-2012-0018>
- Hendricks, D. R., & Wehman, P. (2009). Transition from School to Adulthood for Youth with Autism Spectrum Disorders. *Focus on Autism and Other Developmental Disabilities*, 24(2), 77–88. <https://doi.org/10.1177/000992288302200503>
- Hengen, S., & Weaver, A. (2018). Post-Secondary Students with Disabilities: Increasing Self-Advocacy Through Educational Plan Participation. *The School Psychologist*, 72(2), 7–18.
- Henninger, N. A., & Taylor, J. L. (2014). Family perspectives on a successful transition to adulthood for individuals with disabilities. *Intellectual and Developmental Disabilities*. <https://doi.org/10.1352/1934-9556-52.2.98>
- Hetherington, S. A., Durant-Jones, L., Johnson, K., Nolan, K., Smith, E., Taylor-Brown, S., & Tuttle, J. (2010). The lived experiences of adolescents with disabilities and their parents in transition planning. *Focus on Autism and Other Developmental Disabilities*, 25(3), 163–172. <https://doi.org/10.1177/1088357610373760>
- Hindes, Y., & Manther, J. (2007). Inclusive Education at the Post-Secondary Level: Attitudes of Students and Professors. *Exceptionality Education Canada*, 17(1), 107–128.
- Hitchings, W. E., Luzzo, D. A., Ristow, R., Horvath, M., Retish, P., & Tanners, A. (2003). The Career Development Needs of College Students with Learning Disabilities: In Their Own Words. *Learning Disabilities Research and Practice*, 16(1), 8–17. <https://doi.org/10.1111/0938-8982.00002>
- Hogansen, J. M., Powers, K., Geenen, S., Gil-Kashiwabara, E., & Powers, L. (2008). Transition goals and experiences of females with disabilities: youth, parents, and professionals.

- Exceptional Children*, 74(2), 215–234. Retrieved from
<http://go.galegroup.com.libproxy.wlu.ca/ps/i.do?&id=GALE%7CA173148975&v=2.1&u=wate18005&it=r&p=AONE&sw=w>
- Holloway, S. (2001). The experience of higher education from the perspective of disabled students. *Disability and Society*, 16(4), 597–615.
<https://doi.org/10.1080/09687590120059568>
- Honey, A., Kariuki, M., Emerson, E., & Llewellyn, G. (2014). Employment status transitions among young adults, with and without disability. *Australian Journal of Social Issues*, 49(2), 151–170.
- Honeycutt, T., Thompkins, A., Bardos, M., & Stern, S. (2013). State differences in the vocational rehabilitation experiences of transition-age youth with disabilities. *Mathematica Policy Research*, (October), 1–55. Retrieved from
<http://web.a.ebscohost.com.helios.uta.fi/ehost/pdfviewer/pdfviewer?vid=1&sid=2d517883-3410-46bd-b011-3c6455c1c076%40sessionmgr4010>
- Human Resources and Social Development Canada. (2009). *Advancing the Inclusion of People with Disabilities. Federal Disability Report*. Retrieved from
http://www.hrsdc.gc.ca/eng/disability_issues/reports/fdr/2009/page08.shtml#_8.1 Accessed September 12, 2011.
- Independent Living Centre of Waterloo Region. (n.d.). Youth in Transition. Retrieved from
<https://www.ilcwr.org/youth-transition>
- Janus, A. L. (2009). Disability and the Transition to Adulthood. *Social Forces*, 88(1), 99–120.
<https://doi.org/10.1353/sof.0.0248>
- Jetha, A., Bowring, J., Furrie, A., Smith, F., & Breslin, C. (2018). Supporting the Transition into

- Employment: A Study of Canadian Young Adults Living with Disabilities. *Journal of Occupational Rehabilitation*, 29(1), 1–10. <https://doi.org/10.1007/s10926-018-9772-z>
- Jobe, M., & Glidden Masters, L. (2008). Predicting maternal rewards and worries for the transition to adulthood of children with developmental disabilities. *Journal on Developmental Disabilities*, 14(1), 73.
- Jobling, A., Moni, K. B., & Nolan, A. (2000). Understanding friendship: Young adults with Down syndrome exploring relationships. *Journal of Intellectual ...*, 25(3), 235–245. <https://doi.org/10.1080/1366825002000632>
- Jokinen, N. S., Janicki, M. P., Hogan, M., & Force, L. T. (2012). The middle years and beyond: Transitions and families of adults with Down syndrome. *Journal on Developmental Disabilities*, 18(2), 59–69. Retrieved from <http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=2012-22520-006&site=ehost-live%5Cnjokinenn@unbc.ca>
- Ju, S., Zeng, W., & Landmark, L. J. (2017). Self-Determination and Academic Success of Students With Disabilities in Postsecondary Education: A Review. *Journal of Disability Policy Studies*. <https://doi.org/https://doi.org/10.1177/1044207317739402>
- Kaehne, A., & Beyer, S. (2008). Carer perspectives on the transition of young people with learning disabilities to employment. *Journal on Developmental Disabilities*, 14(1), 95–104.
- Kaya, C. (2018). Demographic Variables, Vocational Rehabilitation Services, and Employment Outcomes for Transition-Age Youth With Intellectual Disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 15(3), 226–236. <https://doi.org/10.1111/jppi.12249>
- Kilbury, R. ., Benshoff, J. J., & Rubinm, S. E. (1992). The interaction of legislation, public attitudes, and access opportunities for persons with disabilities. *Journal of Rehabilitation*,

58, 6–9.

- Kingsnorth, S., Gall, C., Beayni, S., & Rigby, P. (2011). Parents as transition experts? Qualitative findings from a pilot parent-led peer support group. *Child: Care, Health and Development*, 37(6), 833–840. <https://doi.org/10.1111/j.1365-2214.2011.01294.x>
- Knight, A. (2015). Democratizing disability: Achieving inclusion (without assimilation) through “participatory parity.” *Hypatia*, 30(1), 97–114. <https://doi.org/10.1111/hypa.12120>
- Langone, J., Clees, T. J., Oxford, M., Malone, M., & Ross, G. (1995). Acquisition and Generalization of Social Skills by High School Students with Mild Mental Retardation. *Mental Retardation*, 33(3), 186–196.
- Learning Disabilities Association of Canada. (2017). Parents- Children’s Best Advocates. Retrieved from <https://www.ldac-acta.ca/causes/for-parents/>
- Leonard, H., Foley, K. R., Pikora, T., Bourke, J., Wong, K., McPherson, L., ... Downs, J. (2016). Transition to adulthood for young people with intellectual disability: the experiences of their families. *European Child and Adolescent Psychiatry*, 25(12), 1369–1381. <https://doi.org/10.1007/s00787-016-0853-2>
- Lesseliers, J., & Van Hove, G. (2002). Barriers to the Development of Intimate Relationships and the Expression of Sexuality among People with Developmental Disabilities: Their Perceptions. *Research and Practice for Persons with Severe Disabilities*, 27(1), 69–81. <https://doi.org/10.2511/rpsd.27.1.69>
- Lincoln, Y., & Guba, E. G. (1985). *Naturalistic Inquiry*. Newbury Park, CA: Sage.
- Lindstrom, L., Doren, B., & Miesch, J. (2011). Waging a living: Career development and long-term employment outcomes for young adults with disabilities. *Exceptional Children*, 77(4), 423–434. <https://doi.org/10.1177/001440291107700403>

- Local Health Integration Network. (2014). Ontario LHINs. Retrieved from <http://www.lhins.on.ca/>
- Lutherwood. (2020). Welcome to Lutherwood. Retrieved from <https://www.lutherwood.ca/>
- MacIntyre, G. (2014). The potential for inclusion: young people with learning disabilities experiences of social inclusion as they make the transition from childhood to adulthood. *Journal of Youth Studies*, 17(7), 857–871. <https://doi.org/10.1080/13676261.2013.878794>
- Major, J., Stewart, D., Amaria, K., Nguyen, T., Doig, J., Adams, S., ... Wilson, L. (2014). Care in the Long Term for Youth and Young Adults with Complex Chronic Care Needs. *Canadian Foundation for Healthcare Improvement*, 1–66. Retrieved from <https://www.cfhi-fcass.ca/sf-docs/default-source/reports/care-in-the-long-term-major-e.pdf>
- Mannino, J. E. (2015). Resilience and Transitioning to Adulthood among Emerging Adults with Disabilities. *Journal of Pediatric Nursing*, 30(5), 131–145. <https://doi.org/10.1016/j.pedn.2015.05.017>
- Mansell, J. (2010). Raising out sights: services for adults with profound intellectual and multiple disabilities. *Kent Academic Repository*, 1–43. Retrieved from https://kar.kent.ac.uk/24356/1/DH_2010_Raising_our_sights.pdf
- Matthews, N. (2009). Teaching the “invisible” disabled students in the classroom: Disclosure, inclusion and the social model of disability. *Teaching in Higher Education*, 14(3), 229–239. <https://doi.org/10.1080/13562510902898809>
- Mccloy, U., & Declou, L. (2013). Disability in Ontario: Postsecondary education participation rates, student experience and labour market outcomes The Higher Education Quality Council of Ontario, (14), 1–31. Retrieved from www.heqco.ca
- McFarlin, D. B., Song, J., & Sonntag, M. (1991). Integrating the disabled into the workforce: A

- survey of Fortune 500 company attitudes and practices. *Employee Responsibilities and Rights Journal*, 4, 107–123.
- McGrath, A., & Yeowart, C. (2009). Rights of passage. Supporting disabled young people through the transition to adulthood. A guide for funders and charities., (November), 1–64.
<https://doi.org/10.1080/13698019800510041>
- Mcguire, J., & McDonnell, J. (2010). Career Development for Exceptional Individuals Relationships Between Recreation and Levels of Self-Determination for Adolescents and Young Adults With Disabilities. *Career Development for Exceptional Individuals*, 154–163.
<https://doi.org/10.1177/0885728808315333>
- McKenzie, K., Ouellette-Kuntz, H., Blinkhorn, A., & Démoré, A. (2017). Out of School and Into Distress: Families of Young Adults with Intellectual and Developmental Disabilities in Transition. *Journal of Applied Research in Intellectual Disabilities*, 30(4), 774–781.
<https://doi.org/10.1111/jar.12264>
- Mcquigge, M. (2019). People with developmental disabilities more likely to encounter healthcare problems in Ontario. *The Canadian Press*.
- McVilly, K. R., Stancliffe, R. J., Parmenter, T. R., & Burton-Smith, Rosanne, M. (2006). “I Get by with a Little Help from My Friends”: Adults with Intellectual Disability Discuss Loneliness. *Journal of Applied Research in Intellectual Disabilities*, 19, 191–203.
<https://doi.org/10.1111/j.1468-3148.2005.00261.x>
- Mikkonen, J., & Raphael, D. (2010). *Social Determinants of Health: The Canadian Facts*. Toronto, Canada.
- Milen, M. T., & Nicholas, D. B. (2017). Examining transitions from youth to adult services for young persons with autism. *Social Work in Health Care*, 56(7), 636–648.

<https://doi.org/10.1080/00981389.2017.1318800>

Milligan, M. S., Aldred, H., & Neufeldt. (2001). "The Myth of Asexuality: A Survey of Social and Empirical Evidence." *Sexuality and Disability*, 19(2), 91–109.

Ministry of Education. (2004). Questions and Answers Parents May Have Regarding Special Education. Retrieved from

http://www.edu.gov.on.ca/eng/general/elemsec/speced/Questions_and_Answers_Parents_English.pdf

Ministry of Ontario. (2018). Special Needs Supports and Services. Retrieved from

<http://www.children.gov.on.ca/htdocs/English/specialneeds/index.aspx>

Molnar, D. (2019). Family of people with developmental disabilities fighting cuts to program.

Retrieved from <https://www.cbc.ca/news/canada/windsor/facilitator-disabled-provincial-government-cuts-family-support-1.4983142>

Moore, M. E., Konrad, A. M., Yang, Y., Ng, E. S. W., & Doherty, A. J. (2011). The vocational well-being of workers with childhood onset of disability: Life satisfaction and perceived workplace discrimination. *Journal of Vocational Behavior*, 79(3), 681–698.

<https://doi.org/10.1016/j.jvb.2011.03.019>

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

Disability and Society, 19(5), 427–442. <https://doi.org/10.1080/0968759042000235280>

Nasr, M., Cranston-Gingras, A., & Jang, S.-E. (2015). Friendship Experiences of Participants in

a University Based Transition Program. *International Journal of Whole Schooling*, 11(2), 1–15. <https://doi.org/10.1017/CBO9781107415324.004>

National Education Association of Disabled Students. (2018). *Landscape of Accessibility and*

Accommodation in Post-Secondary Education for Students with Disabilities. Retrieved from

[https://www.neads.ca/en/about/media/AccessibilityandAccommodation 2018-5landscapereport.pdf](https://www.neads.ca/en/about/media/AccessibilityandAccommodation%2018-5landscapereport.pdf)

Newman, L., Wagner, M., Knokey, A. M., Marder, C., Nagle, K., Shaver, D., & Wei, X. (2011).

The post-high school outcomes of young adults with disabilities up to 8 years after high school: A report from the National Longitudinal Transition Study-2 (NLTS2)(NCSE 2011-3005)., 2, 218.

Noel, V. A., Oulvey, E., Drake, R. E., & Bond, G. R. (2017). Barriers to Employment for

Transition-age Youth with Developmental and Psychiatric Disabilities. *Administrative Policy Mental Health*, 44(1), 354–358. <https://doi.org/10.1007/s10488-016-0773-y>

OIFN- Ontario Independent Facilitation Network. (2018). Independent Facilitation Scope of the

Work. Retrieved from <https://www.facilitationwd.com/oifnontario-independent-facilitation-network>

Ontario: Ministry of Education. (2018). The Individual Education Plan Process. Retrieved from

<http://www.edu.gov.on.ca/eng/general/elemsec/speced/individu.html>

Ontario Human Rights Commission. (n.d.). Post-Secondary Education. Retrieved from

<http://www.ohrc.on.ca/en/opportunity-succeed-achieving-barrier-free-education-students-disabilities/post-secondary-education>

Ontario Ministry of Health and Long-Term Care. (n.d.). Direct Funding. Retrieved from

<https://www.dfontario.ca/#:~:text=Direct Funding is an innovative,as dressing%2C grooming and bathing.>

PACE. (2019). Philosophy of Independent Living. Retrieved from [https://www.pace-](https://www.pace-il.ca/philosophy-independent-living)

[il.ca/philosophy-independent-living](https://www.pace-il.ca/philosophy-independent-living)

Pallisera, M., Vilà, M., & Fullana, J. (2014). Transition to adulthood for young people with

- intellectual disability: Exploring transition partnerships from the point of view of professionals in school and postschool services. *Journal of Intellectual and Developmental Disability*, 39(4), 333–341. <https://doi.org/10.3109/13668250.2014.938032>
- Pandey, S., & Agarwal, S. (2013). Transition to Adulthood for Youth with Disability: Issues for the Disabled Child and Family. *IOSR Journal Of Humanities And Social Science*, 17(3), 41–45. <https://doi.org/10.9790/0837-1734145>
- Parish, S. L., Rose, R. A., & Swaine, J. G. (2010). Financial well-being of US parents caring for coresident children and adults with developmental disabilities: An age cohort analysis. *Journal of Intellectual and Developmental Disability*, 35(4), 235–243. <https://doi.org/10.3109/13668250.2010.519331>
- Partners for Planning. (2019). What is Independent Facilitation? Retrieved from <http://www.partnersforplanning.ca/what-is-independent-facilitation-and-planning-1#>
- Patton, M. Q. (2002). *Qualitative Research and Evaluation Methods*. Sage Publications.
- Perry, E. L., Hendricks, W., & Broadbent, E. (2000). Exploration and treatment discrimination and job satisfaction among college graduates with and without physical disabilities. *Human Relations*, 53(7), 923–955.
- Ponterotto, J. G. (2005). Qualitative Research in Counseling Psychology: A Primer on Research Paradigms and Philosophy of Science. *Journal of Counselling Psychology*, 52(2), 126–136. <https://doi.org/10.1037/0022-0167.52.2.126>
- Rabren, K., Dunn, C., & Chambers, D. (2002). Predictors of Post-High School Employment Among Young Adults with Disabilities. *CDEI*, 25(1), 25–40.
- Ralph, A., & Usher, E. (1995). Social interactions of persons with developmental disabilities living independently in the community. *Research in Developmental Disabilities*, 16(3),

149–163.

- Rapanaro, C., Bartu, A., & Lee, A. H. (2008). Perceived Benefits and Negative Impact of Challenges Encountered in Caring for Young Adults with Intellectual Disabilities in the Transition to Adulthood. *Journal of Applied Research in Intellectual Disabilities*, 21(1), 34–47. <https://doi.org/10.1111/j.1468-3148.2007.00367.x>
- Readhead, A., Whittingham, L., McKay, K., Bishop, C., & Hope, J. (2019). What's Next? Post-Secondary Planning for Youth With Intellectual and/or Developmental Disabilities. *Journal on Developmental Disabilities*, 24(1), 10–26. Retrieved from <http://ezproxy.montclair.edu:2048/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=a9h&AN=140266864&site=ehost-live&scope=site>
- Reiss, J. (2012). Health Care Transition for Emerging Adults with Chronic Health Conditions and Disabilities. *Pediatric Annals*, 41(10), 429–435. <https://doi.org/10.3928/00904481-20120924-16>
- Rimmer, J. H., Riley, B., Wang, E., Rauworth, A., & Jurkowski, J. (2004). Physical activity participation among persons with disabilities. *American Journal of Preventive Medicine*, 26(5), 419–425. <https://doi.org/10.1016/j.amepre.2004.02.002>
- Rose, C. A., & Monda-Amaya, L. E. (2012). Bullying and Victimization Among Students With Disabilities: Effective Strategies for Classroom Teachers. *Intervention in School and Clinic*, 48(2), 99–107. <https://doi.org/10.1177/1053451211430119>
- Rose, C. A., Monda-Amaya, L. E., & Espelage, D. L. (2011). Bullying perpetration and victimization in special education: A review of the literature. *Remedial and Special Education*, 32(2), 114–130. <https://doi.org/10.1177/0741932510361247>
- Rose, J., Saunders, K., Hensel, E., & Kroese, B. S. (2005). Factors affecting the likelihood that

- people with intellectual disabilities will gain employment. *Journal of Intellectual Disabilities*, 9(1), 9–23. <https://doi.org/10.1177/1744629505049725>
- Sanford, C., Newman, L., Wagner, M., Cameto, R., Knokey, A.-M., & Shaver, D. (2011). *The Post-High School Outcomes of Young Adults with Disabilities up to 6 Years After High School. Key findings from the National Longitudinal Transition Study-2 (NLTS2)*. SRI International. Menlo Park, CA. <https://doi.org/10.7287/peerj.preprints.26666v1>
- Schertz, M., Karni-Visel, Y., Tamir, A., Genizi, J., & Roth, D. (2016). Family quality of life among families with a child who has a severe neurodevelopmental disability: Impact of family and child socio-demographic factors. *Research in Developmental Disabilities*, 53–54, 95–106. <https://doi.org/10.1016/j.ridd.2015.11.028>
- Schwandt, T. A. (1994). Constructivist, interpretivist approaches to human inquiry. *Handbook of Qualitative Research*. Thousand Oaks, CA, US: Sage Publications, Inc.
- Sellevoll, K. S. (2016). Disability and Work Barriers to Employment. A qualitative study on disability and experiences entering the labor market. *Faculty of Public Health*, 1–69. Retrieved from <https://brage.inn.no/inn-xmllui/bitstream/handle/11250/2393110/Sellevold.pdf?sequence=1&isAllowed=y>
- Seong, Y., Wehmeyer, M. L., Palmer, S. B., & Little, T. D. (2015). Effects of the self-directed individualized education program on self-determination and transition of adolescents with disabilities. *Career Development and Transition for Exceptional Individuals*, 38(3), 132–141. <https://doi.org/10.1177/2165143414544359>
- Shandra, C. L., & Hogan, D. P. (2009). School-to-work program participation and the post-high school employment of young adults with disabilities. *Journal of Vocational Rehabilitation*, 29(1), 117–130. Retrieved from

<http://web.ebscohost.com.proxy.lib.umich.edu/ehost/pdfviewer/pdfviewer?sid=465645a3-3b6b-41d8-9c1f-90afc20623a8%40sessionmgr113&vid=4&hid=128%5Cnpapers2://publication/uuid/6AB0C6B6-2683-4B29-AEB3-88F73435B809>

Shartal, S., Cowan, L., Khandor, E., & German, B. (2004). Failing the Homeless: Barriers in the Ontario Disability Support Program for Homeless People with Disabilities. Retrieved from <https://homelesshub.ca/resource/failing-homeless-barriers-ontario-disability-support-program-homeless-people-disabilities>

SickKids. (2014). Getting Ready for Adult Care. *Good2GoProgram*. Retrieved from [http://www.sickkids.ca/pdfs/good2go/59866-6.2.7 Getting Ready for Adult Care Booklet.pdf](http://www.sickkids.ca/pdfs/good2go/59866-6.2.7%20Getting%20Ready%20for%20Adult%20Care%20Booklet.pdf)

Simplican, S. C., Leader, G., Kosciulek, J., & Leahy, M. (2015). Defining social inclusion of people with intellectual and developmental disabilities: An ecological model of social networks and community participation. *Research in Developmental Disabilities*, 38, 18–29. <https://doi.org/10.1016/j.ridd.2014.10.008>

Sosnowy, C., Silverman, C., & Shattuck, P. (2018). Parents' and young adults' perspectives on transition outcomes for young adults with autism. *Autism*, 22(1), 29–39. <https://doi.org/10.1177/1362361317699585>

Statistics Canada. (2006). Participation and Activity Limitation Survey 2006. Retrieved from <http://www.statcan.gc.ca/pub/89-628-x/89-628-x2007002-eng.pdf>

Statistics Canada. (2012). A Profile of Persons with Disabilities among Canadian aged 15 years or older. Retrieved from <https://www150.statcan.gc.ca/n1/pub/89-654-x/89-654-x2015001-eng.htm>

- Statistics Canada. (2018). Canadian Survey on Disability, 2017. Retrieved from <https://www150.statcan.gc.ca/n1/daily-quotidien/181128/dq181128a-eng.htm>
- Stefánsdóttir, G. V., & Bjornsdottir, K. (2015). “I am a college student” postsecondary education for students with intellectual disabilities. *Scandinavian Journal of Disability Research*, 1–15.
- Stewart, D. (2010). The transition to adulthood for youth with disabilities : Evidence from the literature. *Center for International Rehabilitation Research Information and Exchange*.
- Stewart, D., Freeman, M., Law, M., Healy, H., Burke-Gaffney, J., Forhan, M., ... Guenther, S. (2009). “ The Best Journey to Adult Life ” For Youth with Disabilities An Evidence-based Model and Best Practice Guidelines For The Transition To Adulthood For Youth With Disabilities. *McMaster University CanChild Centre for Childhood Disability Research*, 90. <https://doi.org/http://transitions.canchild.ca/en/OurResearch/resources/BJAmodelandbestpracticeguidelinespdf2009.pdf>
- Stuckey, H. (2013). Three types of interviews: Qualitative research methods in social health. *Journal of Social Health and Diabetes*, 01(02), 056–059. <https://doi.org/10.4103/2321-0656.115294>
- Taheri, A., Perry, A., & Minnes, P. (2016). Examining the social participation of children and adolescents with Intellectual Disabilities and Autism Spectrum Disorder in relation to peers. *Journal of Intellectual Disability Research*, 60(5), 435–443. <https://doi.org/10.1111/jir.12289>
- Test, D. W., Bartholomew, A., & Bethune, L. (2015). What High School Administrators Need to Know About Secondary Transition Evidence-Based Practices and Predictors for Students With Disabilities. *NASSP Bulletin*, 99(3), 254–273.

<https://doi.org/10.1177/0192636515602329>

Test, D. W., Smith, L. E., & Carter, E. W. (2014). Equipping Youth With Autism Spectrum Disorders for Adulthood: Promoting Rigor, Relevance, and Relationships. *Remedial and Special Education, 35*(2), 80–90. <https://doi.org/10.1177/0741932513514857>

The Canadian Observatory on Homelessness. (n.d.). About Homelessness: People with Disabilities. Retrieved from <https://www.homelesshub.ca/about-homelessness/population-specific/people-disabilities>

Transition Network Committee of Waterloo Region. (2020). *Resource Transition Guide for Youth and Adults with Disabilities in Waterloo Region*. Retrieved from https://www.kidsability.ca/uploads/Youth Services/WR_Transition_Resource_Guide2020.pdf

Turcotte, M. (2015). Persons with disabilities and employment. Retrieved from <https://www150.statcan.gc.ca/n1/pub/75-006-x/2014001/article/14115-eng.htm>

U.S Department of Education. (2011). About IDEA. Retrieved from <https://sites.ed.gov/idea/about-idea/>

Underwood, K. (2010). Involving and Engaging Parents of Children with IEPs. *Exceptionally Education International, 20*(1), 18–36.

Van Asselt, D., Buchanan, A., & Peterson, S. (2015). Enablers and barriers of social inclusion for young adults with intellectual disability: A multidimensional view. *Journal of Intellectual and Developmental Disability, 40*(1), 37–48. <https://doi.org/10.3109/13668250.2014.994170>

Wagner, M., Newman, L., Cameto, R., Levine, P., & Marder, C. (2007). *“Perceptions and Expectations of Youth with Disabilities: A Special Topic Report of Findings from the*

National Longitudinal Transition Study-2 (NLTS2).”

Wehmeyer, M. L., & Bolding, N. (2001). Enhanced self-determination of adults with intellectual disability as an outcome of moving to community-based work or living environments.

Journal of Intellectual Disability Research, 45(5), 371–383. <https://doi.org/10.1046/j.1365-2788.2001.00342.x>

White, G. W., & Summers, J. A. (2017). People with disabilities and community participation.

Journal of Prevention and Intervention in the Community, 45(2), 81–85.

<https://doi.org/10.1080/10852352.2017.1281041>

Wiesel, I., Laragy, C., Gendera, S., Fisher, K. R., Jenkinson, S., Hill, T., ... Bridge, C. (2015).

Moving to my home: Housing aspirations, transitions and outcomes of people with disability. AHURI Final Report.

Williams, A. S., & Moore, S. M. (2011). Universal Design of Research: Inclusion of Persons with Disabilities in Mainstream Biomedical Studies. *Sci Transl Med.*, 3(82), 1–10.

Yarbrough, D. (2019). Expectations of Families With Young Adults Intellectual and

Developmental Disabilities for College. *Exceptional Parent*, 49(11), 40–41. Retrieved from <http://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=139670086&site=ehost-live>

YMCA of Hamilton Burlington and Brantford. (n.d.). Youth in Transition Worker Program.

Retrieved from [https://www.ymcahbb.ca/Programs/Community-Initiatives/Youth-in-Transition-Worker-Program-\(YITW\)](https://www.ymcahbb.ca/Programs/Community-Initiatives/Youth-in-Transition-Worker-Program-(YITW))

Young-Southward, G., Cooper, S. A., & Philo, C. (2017). Health and wellbeing during transition to adulthood for young people with intellectual disabilities: A qualitative study. *Research in Developmental Disabilities*, 70(July), 94–103. <https://doi.org/10.1016/j.ridd.2017.09.003>

Yun, I., Jung, S., & Yoo, J. (2015). Disability and violent victimization in a national sample of adolescents: A longitudinal study. *Violence and Victims*, 30(6), 1099–1116.

<https://doi.org/10.1891/0886-6708.VV-D-14-00008>

APPENDIX A

Background Questionnaire for Primary Caregiver

Please complete the form to the best of your ability. You can either complete the form electronically and send to **tang8687@mylaurier.ca**. Or the form can be completed in hardcopy form and picked up by the researcher.

Date: _____

Section One: About Yourself

1) In the chart below, please provide demographic information regarding you and your family.

| | Age | Gender | Occupation (If applicable) | Highest level of education (If applicable) |
|---|-----|--------|----------------------------|--|
| Primary caregiver | | | | |
| Secondary caregiver | | | | |
| Participating child | | | | |
| Other children you may have please list in the spaces below and include their age and gender in the table: | | | | |
| | | | | |
| | | | | |

2) List any tasks or support you currently complete for your emerging adult.

Section Two: About your Emerging Adult

3) In the chart below, please provide information regarding your child's diagnosis(es). When indicating multiple conditions, please list from primary diagnosis first.

| Condition | Age Diagnosed | Treatments Receiving Now | Have you received funding at any point as a result of your child's diagnosis(es)? If yes, please specify. |
|-----------|---------------|--------------------------|--|
| | | | |
| | | | |

4) Is your child currently enrolled in school?

- A) Yes: full-time B) Yes: part-time C) No, but previously enrolled
D) No, never enrolled

5) Is your child currently working?

- A) Yes: paid full-time B) Yes: paid part-time C) Yes: Volunteering work
D) No, but has worked previously E) No, never worked

6) What is your child's current living situation?

- A) Living in parent's home B) Living in own place with assistance
C) Living in own place with roommates D) Living in a group home
E) Living in assisted residence F) Other, please specify:

7) Is your child involved in any other programs or extracurricular activities besides Facilitation Organization?

- A) No
B) Yes, please specify:

Section Three: Independent Facilitation Involvement

8) Please indicate the number of months your child has been using the independent facilitation service from Facilitation Organization: _____

9) What assistance does the independent facilitator provide for your emerging adult? Check all that apply:

- ☐ Making and retaining friendships
☐ Getting involved with groups and recreation in the community
☐ Finding volunteer or paid work that is meaningful to you
☐ Planning for future housing needs
☐ Other, please specify:

10) Are you involved with the independent facilitator and your emerging adult's relationship?

- No Yes

**Thank you for completing this questionnaire. Please submit the completed form to
tang8687@mylaurier.ca**

Background Questionnaire for the Independent Facilitators WITH specific EAD

Please complete the form to the best of your ability. You can either complete the form electronically and send to **tang8687@mylaurier.ca**. Or the form can be completed in hardcopy form and picked up by the researcher.

Date: _____

Section One: About Yourself

1) In the chart below, please provide your demographic information.

| Age | Gender | Occupation(s) | Highest level of education | Have you ever had training (i.e. workshops) that focused on working with people with disabilities? If yes, please specify: |
|-----|--------|---------------|----------------------------|--|
| | | | | |

Section Two: About Facilitation Organization

2) How many months have you been working with the independent facilitation program at Facilitation Organization? _____

3) Besides Facilitation Organization, are you involved in any other programs pertaining to people with disabilities?

A) No

B) Yes, please list: _____

4) Provide the number of Facilitation Organization clients you currently assist: _____

Section Three: About the Emerging adult

5) How many months have you been working with the emerging adult? _____

6) How often do you see him/her per week? _____

7) On average, how long (in minutes) do you spend with him/her per visit? _____

8) What assistance do you provide for the emerging adult? Check all that apply:

- ☐ Making and retaining friendships
- ☐ Getting involved with groups and recreation in the community
- ☐ Finding volunteer or paid work that is meaningful to you
- ☐ Planning for future housing needs
- ☐ Other, please specify:

Thank you for completing this questionnaire. Please submit the completed form to tang8687@mylaurier.

Background Questionnaire for the Independent Facilitators WITHOUT specific EAD

Please complete the form to the best of your ability. You can either complete the form electronically and send to **tang8687@mylaurier.ca**. Or the form can be completed in hardcopy form and picked up by the researcher.

Date: _____

Section One: About Yourself

1) In the chart below, please provide your demographic information.

| Age | Gender | Occupation(s) | Highest level of education | Have you ever had training (i.e. workshops) that focused on working with people with disabilities? If yes, please specify: |
|-----|--------|---------------|----------------------------|--|
| | | | | |

Section Two: About Facilitation Organization

2) How many months have you been working with the independent facilitation program at Facilitation Organization? _____

3) Besides Facilitation Organization, are you involved in any other programs pertaining to people with disabilities?

9) No

10) Yes, please list: _____

4) Provide the number of Facilitation Organization clients you currently assist: _____

5) How often do you see your clients per week? _____

6) On average, how long (in minutes) do you spend with your clients per visit? _____

7) What assistance do you provide for your clients? Check all that apply:

- ☐ Making and retaining friendships
- ☐ Getting involved with groups and recreation in the community
- ☐ Finding volunteer or paid work that is meaningful to you
- ☐ Planning for future housing needs
- ☐ Other, please specify.

Thank you for completing this questionnaire. Please submit the completed form to tang8687@mylaurier.ca

Background Questionnaire for the Emerging Adults

Please complete the form to the best of your ability. You can either complete the form electronically and send to **tang8687@mylaurier.ca**. Or the form can be completed in hardcopy form and picked up by the researcher.

Date: _____

Section One: About Yourself

1) In the chart below, please provide your demographic information.

| Age | Gender | Occupation(s)/Volunteering | Highest level of education | Current living situation |
|-----|--------|----------------------------|----------------------------|--------------------------|
| | | | | |

2) Are you currently enrolled in school?

B) Yes: full-time B) Yes: part-time C) No, but previously enrolled

D) No, never enrolled

3) Are you currently working?

A) Yes: paid full-time B) Yes: paid part-time C) Yes: Volunteering work

D) No, but has worked previously E) No, never worked

4) Please list any help you receive from family members or support persons.

5) Are you involved in any other programs or extracurricular activities besides Facilitation Organization?

A) No

B) Yes, please specify:

Section Two: Independent Facilitation Involvement

11) Please indicate the number of months you have been using the independent facilitation service from Facilitation Organization: _____

12) What assistance does the independent facilitator provide for you? Check all that apply:

- ☐ Making and retaining friendships
- ☐ Getting involved with groups and recreation in the community
- ☐ Finding volunteer or paid work that is meaningful to you
- ☐ Planning for future housing needs
- ☐ Other, please specify:

Thank you for completing this questionnaire. Please submit the completed form to tang8687@mylaurier.ca

APPENDIX B**Interview Guideline for the Caregivers**

The purpose of this study is to explore the experiences of emerging adults with disabilities and their involvement with Facilitation Organization.

The interview consists of four sections and will last for approximately 60 to 90 minutes. You are free to discontinue the study at any time and to choose not to respond to any question. In the event you do wish to stop the interview, the tape recorder will be turned off and you may discontinue the interview altogether.

My name is Emily and I am a Master's student at Wilfrid Laurier University. To begin I will like to start with...

A) Questions about yourself

1. Now ... can you please, tell me a little bit about yourself.
 - Occupation, hobbies, interests, etc.
2. Describe what a typical day or week looks like for you.
 - Week day vs. weekend?
 - Daily routine/activities inside and outside of the home
 - Work schedule
3. Please tell me about your family.

B) Questions About your child's diagnosis and treatment

4. Next, I would like to talk about support you received during childhood for your child's disability. What about during transition/currently?
 - Do you receive additional help from other family members, caregivers, or professionals? If yes, please describe what kind of support they provide.
5. Please describe your experience with funding now in terms of your child's diagnosis.
 - Compared to during transition when child finished high school/reached 18 years old?

C) Questions about your child

6. Please describe a typical day for your child.
7. Please, tell me about your child during high school to now.
8. Where does your child currently live?
9. How often do you see your child?
 - How often do you contact your child?
10. Please, tell me about your child's education.
11. Is your child currently working? Has he/she ever worked? Please discuss.
12. What, if any, expectations or goals have you set for your child as he or she becomes an adult? Please describe them for me.
 - Having a job, more schooling, relationships, personal growth etc.
 - Past EA phase?
13. Please describe any goals your child may have.
 - Employment
 - Health care
 - Residence
 - Making friendships/relationships

14. How, if at all, does your community supports your child as he/she becomes an adult? Discuss

- Resources available (if known)
- Opportunities for your child to be involved in the community
 - i. Employment, volunteering, social activities
- Transportation availability

15. Please describe any caregiving tasks you currently provide or assist your child with.

- Money?
- Health care?

16. What, if any, arrangements or plans for when you are unable to care for your child?

- Due to health conditions? Age? Etc.

D) Questions about Facilitation Organization

17. How did you hear about Facilitation Organization?

- Why did you register your child for Facilitation Organization?
- Independent Facilitation
- Goals (Of the program, personal goals for your child)
- Recommended
- Personal interest from your child

18. From your experience with Independent Facilitation from Facilitation Organization thus far, what, if any, changes have occurred in regard to your child's development? If so, please describe those changes for me.

- Social interactions
- Mitigating behaviors/associated symptoms
- Independence

19. Please describe, if any, the effects of the independent facilitation program your child participates.

- Does the IF support your child and your family enough?
 - How often does your child use the service?
 - Have you always had the same IF?
 - Does your IF spend enough time with your child?

20. Please describe any benefits, if any, you anticipate OR hope your child will develop while participating in the Independent Facilitation program.

- Social skills/ Building relationships
- Independence
- Employment

21. Can you describe any areas of improvement to the independent facilitation service?

22. What, if anything, does your child need that the service cannot provide?

23. What advice would you give parents of EADs?

24. To end off, what is your favourite memory with you and your emerging adult?

Thank you very much for participating in my study and for taking the time to be interviewed. Once the interview is transcribed, I will send the transcription to you for a member check. Before we end off:

25. Do you have anything you would like to say or add that I may not have asked about?

26. Is there anything you would like to ask me?

Interview Guideline for the Independent Facilitators

The purpose of this study is to explore the experiences of emerging adults with disabilities and their involvement with Facilitation Organization

The interview consists of two sections and will last for approximately 60 to 90 minutes. You are free to discontinue the study at any time and to choose not to respond to any question. In the event you do wish to stop the interview, the tape recorder will be turned off and you may discontinue the interview altogether.

My name is Emily and I am a Master's student at Wilfrid Laurier University. To begin I will like to start with...

A) Questions about yourself

1. Please, tell me a little bit about yourself.
 - Occupation, hobbies, interests, etc.
 - Background experience with Facilitation Organization
 - How many clients have you worked with? How many do you work with currently?
2. Please describe what reasons you have for choosing to work with Facilitation Organization as an independent facilitator.
 - Personal interest, recommendations etc.
3. What types of reasons do EADs (ANY WORKED WITH) tell you in why they use the IF services?
 - Independence? Social? Community? Relationships? Etc.
4. What tasks do you typically complete with your clients?
5. How long do you typically spend with your clients?
6. Please describe your relationship with the participating EAD. *****IF IT IS THEIR PERSONAL IF**
 - How long been working with
 - What kinds of tasks do you do with them?
7. Thinking back to when you first started working with EAD, have you noticed, if any, changes in regard to their development, goal purpose, abilities etc.?
 - Social skills, independence, behaviors etc.
8. In your opinion, please describe the positives and negatives of the IF service.
 - Do you think there is sufficient time spent with EAD and their family?
 - Ability to provide necessary supports?
 - Ability to pursue EADs goals?
9. What, if any, suggestions or improvements would you recommend for the independent facilitation program?
10. What is one word you would use to describe your experience as an independent facilitator and why?
11. To end of, what advice would you give to parents about emerging adulthood and using independent facilitation?

Thank you very much for participating in my study and for taking the time to be interviewed. Once the interview is transcribed, I will send the transcription to you for a member check. Before we end off:

12. Do you have anything you would like to say or add that I may not have asked about?
13. Is there anything you would like to ask me?

Interview Guideline for EADs

For this interview, our focus is learning about who you are and the experiences you have had growing up. In this interview, I will ask you questions about questions about yourself and your journey through emerging adulthood.

You are free to discontinue the study at any time and to choose not to respond to any question. In the event you do wish to stop the interview, the tape recorder will be turned off and you may discontinue the interview altogether.

My name is Emily and I am a Master's student at Wilfrid Laurier University. To begin we will start with...

A) Questions about Yourself

1. Please, tell me a little bit about yourself.
 - What do you like to do in your spare time? (Hobbies)
 - Do you have a job? Volunteer? School? Friends? Relationships?
 - What are your interests? (sports etc.)
2. Imagine you are back to when you were 17/18 years old, how was your experience in finishing school and planning to transition to adulthood?
3. Did you, if any, receive help/support from your parents/family/friends? If so, please describe what kind of help or support they provide.
4. Did you experience, if any, any challenges along the way? If so, please describe them.
 - How did you feel while trying to plan your transition to adulthood?
5. From what you know now, if you could go back, would you change anything in regard to preparing for adulthood?
6. Is there anything (i.e. supports, information, etc.) you wish you had while transitioning to adulthood?

QUESTIONS ABOUT BTOBE

7. Do you like Bridges to Belonging?
 - How long have you been using BtoBe's services?
8. Please tell me about your independent facilitator.
 - What activities do you do with him/her?
 - How often do you spend time with him/her?
 - Advice for individuals not using IF services?
9. How did the independent facilitation service from BtoBe, if used, helped or supported you during your transition?
10. How do you feel about the provincial funding cuts to the independent facilitation service?
11. What does independent facilitation mean to you?
12. If you could describe your experience in transitioning to adulthood in one word. what would it be?
13. To end off, what do you want people to know about you?

Thank you very much for participating in my study and for taking the time to be interviewed. Once the interview is transcribed, I will send the transcription to you for a member check. Before we end off:

1. Do you have anything you would like to say or add that I may not have asked about?
2. Is there anything you would like to ask me?

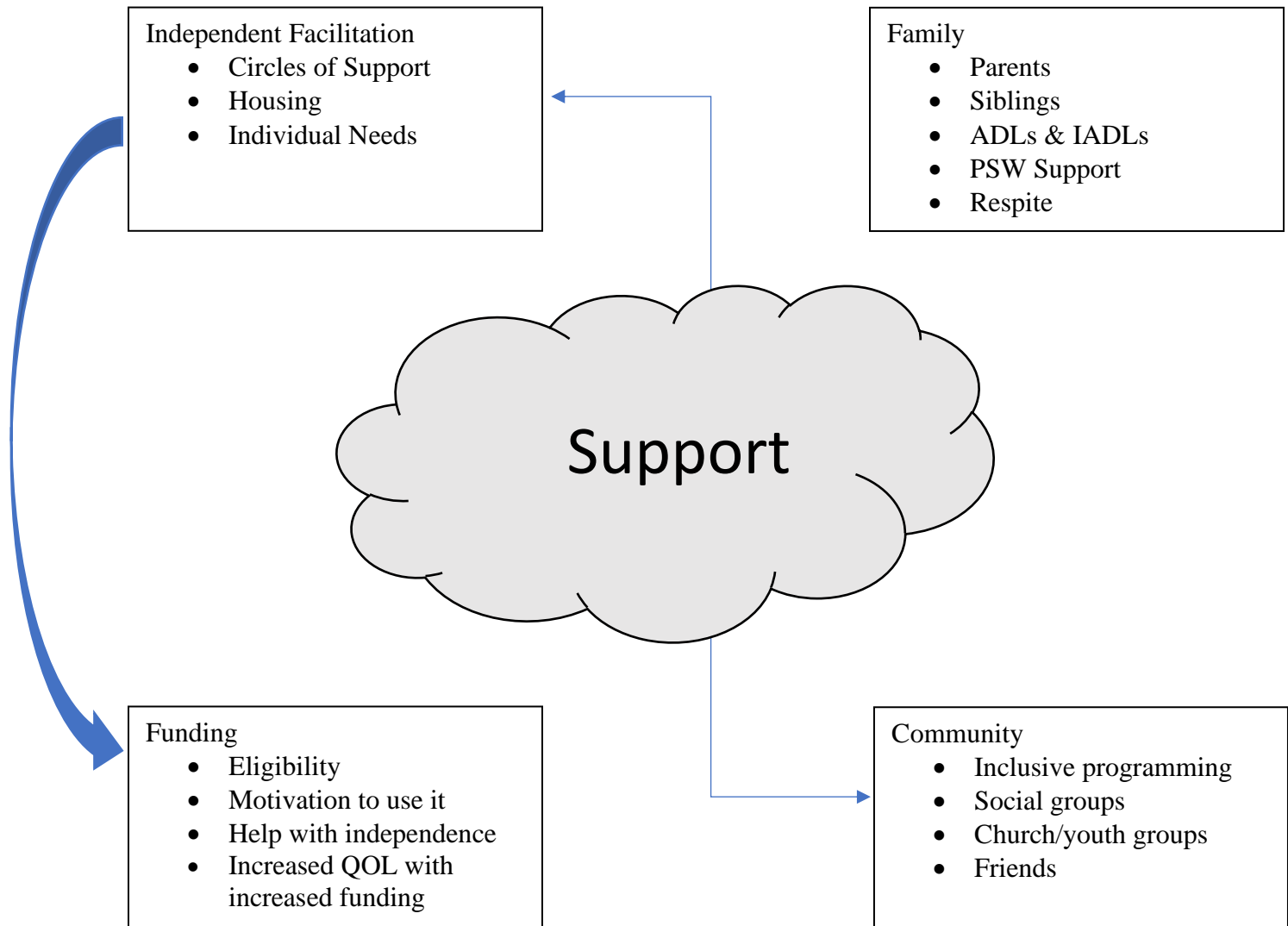
APPENDIX C

Process of thematic analysis as outlined by Braun & Clarke (2006)

Table 1 Phases of thematic analysis

| Phase | Description of the process |
|---|--|
| 1. Familiarizing yourself with your data: | Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas. |
| 2. Generating initial codes: | Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code. |
| 3. Searching for themes: | Collating codes into potential themes, gathering all data relevant to each potential theme. |
| 4. Reviewing themes: | Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis. |
| 5. Defining and naming themes: | Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme. |
| 6. Producing the report: | The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis. |

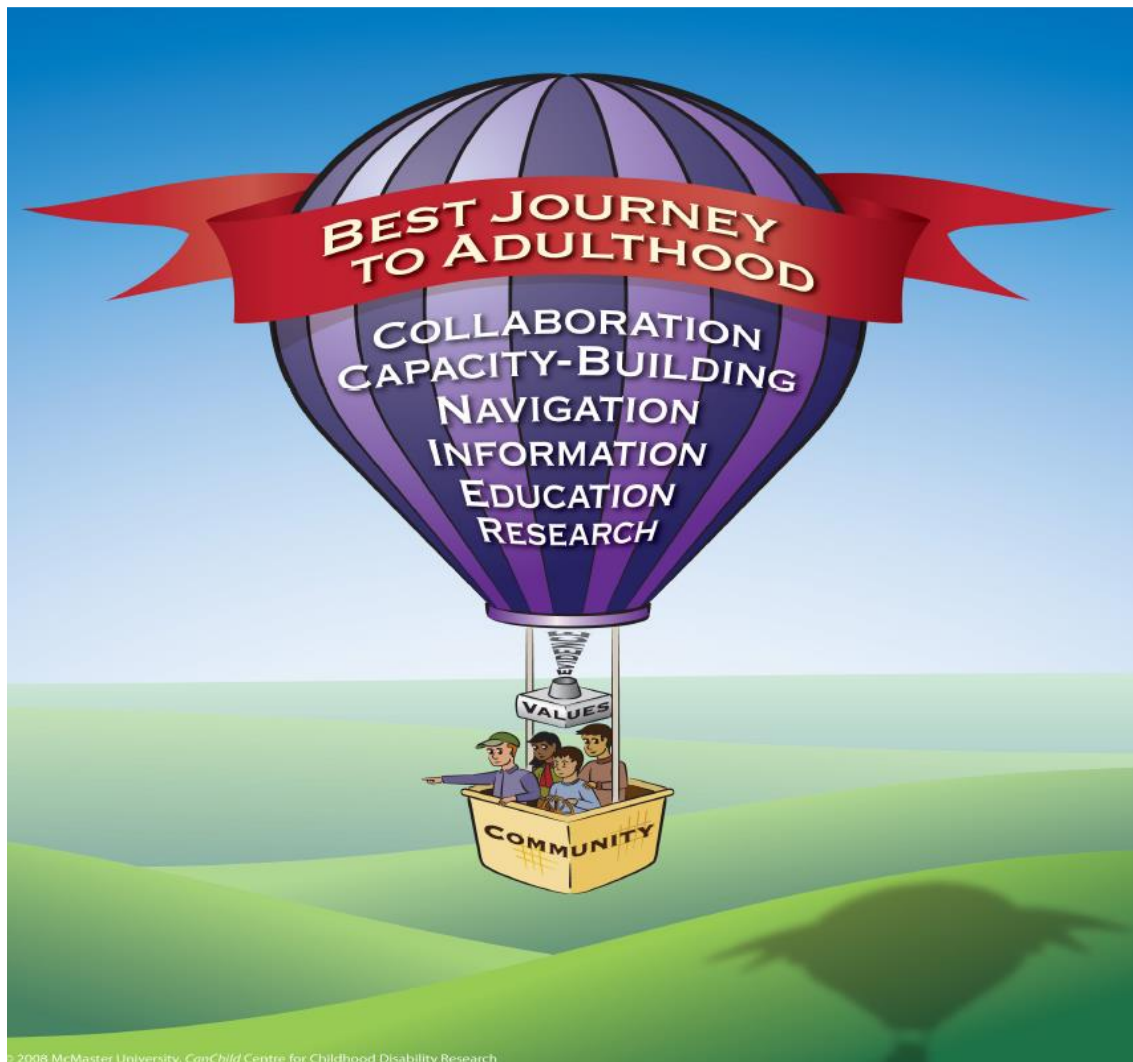
(Braun & Clarke, 2006 p. 87)

APPENDIX D**Example of Mind Map created to help develop themes in the analysis process**

APPENDIX E

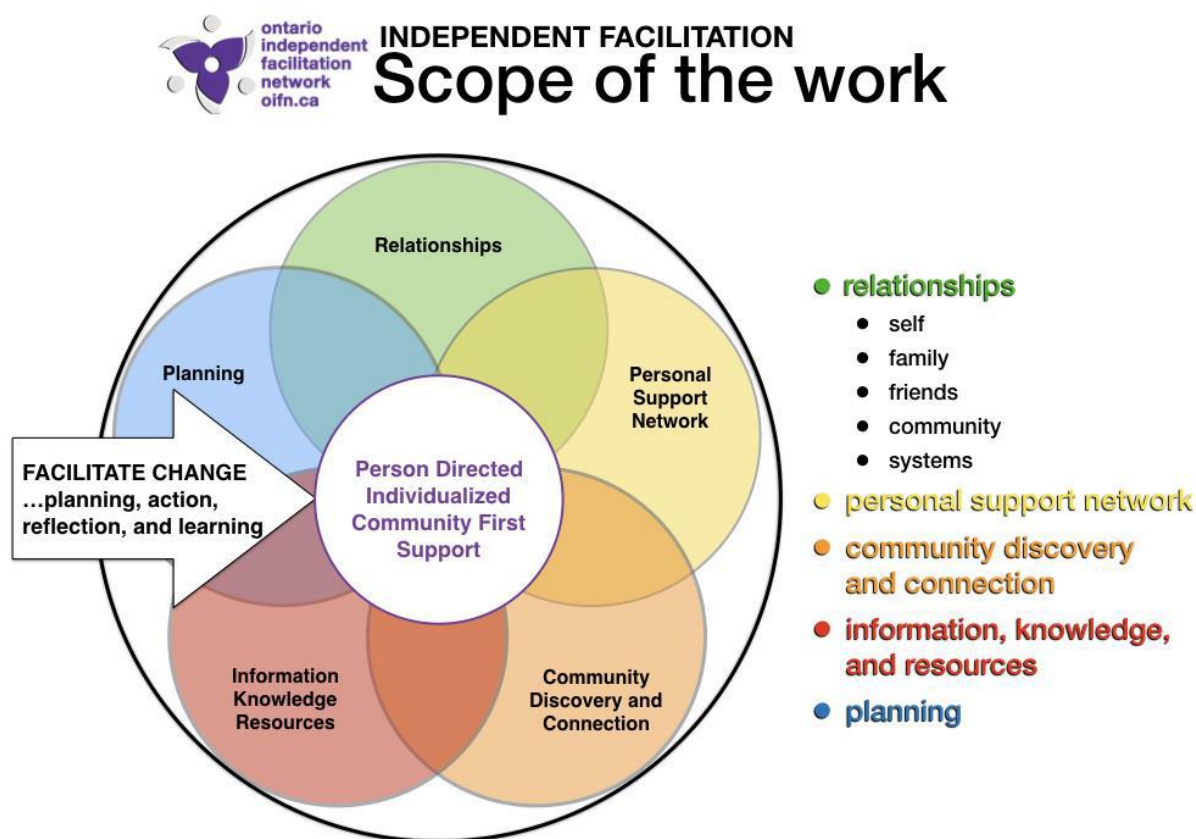
| | | Research Questions | |
|--------------------------------------|----------------------|---|---|
| | | What are the perceived experiences of transitioning to adulthood for people with disabilities and their families? | What role does independent facilitation have in transitioning to adulthood from the perspective of people with disabilities, their caregivers, and their IFs? |
| Interview Guide and Question Numbers | EADs Interview Guide | <p>2. Imagine you are back to when you were 17/18 years old, how was your experience in finishing school and planning to transition to adulthood?</p> <p>3. Did you, if any, receive help/support from your parents, family, friends, support workers, during your childhood? If so, please describe what kind of help or support they provide.</p> <p>4. Did you experience any challenges along the way of your journey to adulthood? If so, please describe them.</p> <p>5. How did you feel while trying to plan your transition to adulthood?</p> <p>6. What kinds of things are you doing now?</p> <p>7. From what you know now, if you could go back, would you change anything in regards to preparing for adulthood?</p> <p>8. Is there anything (i.e. supports, information, etc.) you wish you had while transitioning to adulthood?</p> <p>12. If you could describe your experience in transitioning to adulthood in one word. what would it be?</p> | <p>8. Please tell me about your independent facilitator.</p> <p>9. How did the independent facilitation service from Facilitation Organization, if used, helped or supported you during your transition?</p> <p>10. How do you feel about the provincial funding cuts to the independent facilitation service?</p> <p>11. What does independent facilitation mean to you?</p> |

| | | Research Questions | |
|---|---|---|---|
| | | What are the perceived experiences of transitioning to adulthood for people with disabilities and their families? | What role does independent facilitation have in transitioning to adulthood from the perspective of people with disabilities, their caregivers, and their IFs? |
| Interview Guide and Question Numbers | Caregiver/Support Person Interview Guide | <p>5. Please tell me about support your child received during childhood for his disability. What about during transition/currently?</p> <p>8. Please, tell me about your child's transition to adulthood.</p> <p>9. Where does your child currently live?</p> <p>10. Is your child currently working? Has he ever worked? Please discuss.</p> <p>11. What, if any, expectations or goals have you set for your child as an adult? Please describe them for me.</p> <p>12. Please describe any goals your child may have that you are aware of.</p> <p>13. How, if at all, does your community supports your child as an adult? Discuss.</p> | <p>13. How, if at all, does your community supports your child as an adult? Discuss.</p> <p>IFs Interview Guide</p> <p>4. What types of reasons do your clients tell you in why they use the IF services?</p> <p>5. What tasks do you typically complete for each of your clients?</p> <p>7. Thinking back to when you first started working with EAD, have you noticed, if any, changes in regard to your client's development, goal purpose, abilities etc.?</p> |
| | | | |

APPENDIX F**BEST JOURNEY TO ADULT LIFE (BJA MODEL)**

(Stewart et al., 2009)

APPENDIX G



(OIFN- Ontario Independent Facilitation Network, 2018)