A New Approach to Transition Planning for Transitional Aged Youth with Intellectual and

Developmental Disabilities

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Abstract

The current study was designed to gain a greater understanding of how transition planning is being done in the Niagara Region, as per the Integrated Transition Protocol, and to examine the barriers to the enactment of this protocol in relation to youth participation and implementation. Further, the study focused on uncovering whether youth were better included in their transition plans since the implementation of the protocol, and on discovering ways to better include youth in the transition process overall. Through a pragmatic qualitative research design informed by the theory of emerging adulthood and by a social model of disability, the perspectives of 14 professionals were explored through questionnaires, focus groups, and individual interviews. From the collected data, the following themes were found: (1) there continue to be barriers that hinder youth participation and the successful implementation of the protocol; (2) professionals feel youth participation is important; however, families continue to play the primary role during the transition process, despite a reported disconnection between the hopes and dreams of the families and the youth; (3) transition planning and practicing meaningful participation need to begin earlier; (4) the transition ends when the protocol ends so there is a gap between children's services and adult services, and the realities of adult services are unknown to many; (5) there are many benefits to integrated transition planning; (6) we must move past keeping youth "busy and safe" and ensure that they are participating in meaningful activities; and (7) it's a new process, but the right process. These themes are discussed in terms of their implications for the current transition policy in the Niagara Region and elsewhere in Ontario so that the voices and dreams of youth with developmental disabilities are included and respected during the transition process in hopes of improving their post high school outcomes and overall quality of life.

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Developmental Disabilities

In 2006, the Ministry of Community and Social Services of Ontario, Canada identified

the lack of support for youth transitioning out of high school and into adulthood as one of the

most significant gaps in the current support systems for people with developmental disabilities

(Mercer Delta Consulting, 2006). The study found that services for children and youth with

developmental disabilities had generally improved over the previous few years and that good

quality daytime support was available for these youths up until the age of 21; at 21 years of age

students could no longer attend school offered within the post-secondary system (Mercer Delta

Consulting, 2006). After young people reached age 21 their families often referred to

encountering "the cliff," a term coined to describe the dramatic decrease in the level of services

available despite the ongoing support needs that an individual with developmental disabilities

required (Mercer Delta Consulting, 2006, p. 13). Mercer Delta reported that this decrease in

supports often produced a rapid decrease in much of the progress made toward developing the

individual's independence and quality of life as many youths were left at home with "nothing to

do." (p. 14)

In response to this 2006 report, the Ontario Ministry of Children and Youth Services

(MCYS), the Ontario Ministry of Community and Social Services (MCSS), and the Ontario

Ministry of Education (EDU) issued a joint memo in 2013 explaining that they were working

together to establish protocols to promote effective planning and smooth transitions through a

single, integrated transition plan (Ontario Ministry of Community and Social Services, Ontario

Ministry of Children and Youth Services, & Ontario Ministry of Education, 2013). The

Ministries reported that the integrated transition planning process would lead to a single

transition plan to serve as a guide for "educational planning and help the young person transition from secondary school and child-centred services to adulthood" (Ontario Ministry of Community and Social Services, Ontario Ministry of Children and Youth Services, & Ontario Ministry of Education, 2013, p. 2). They further explained that each region would be responsible for developing protocols to guide transition planning, and that these protocols would describe the transition planning for each community. In response to this, in 2013 a Regional protocol was issued for the Hamilton-Niagara Region (Ontario Ministry of Children and Youth Services Ontario Ministry of Community and Social Services, & Ontario Ministry of Education, 2013) and was implemented in September 2014 (Ontario Ministry of Education, 2014).

To date, no research has been conducted on this new Regional protocol. The present study was designed not only to examine the new transition process, but also to gain a greater understanding of how transitional aged youth participate in their transition plans. The focus on youth participation is important. Participation in decisions regarding one's life is a fundamental human right, as outlined in the preamble to United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (UN Enable, 2006), and is a reoccurring theme in the Transition Planning Regional Protocol document (Ontario Ministry of Children and Youth Services, Ontario Ministry of Community and Social Services, & Ontario Ministry of Education, 2013).

In a previous preliminary study I conducted in the Niagara Region (McKay, 2015), I examined how the right to participate in life decisions, as set forth by the UNCRPD (2006), was being implemented for transitional aged youth with intellectual disabilities as they leave high school. The purpose of this study was to uncover if the right to participate was being respected during the transition process. This study involved semi-structured interviews with professionals who worked in the developmental service sector. The results of this small study found that (1)

youth were not always involved in their transition plans, (2) there were viable options after high school, (3) there were many barriers that hindered full participation of youth in the transition planning process, (4) professionals and parents were making decisions *for* and not *with* the transitional age youth, (5) transitional aged youth were not aware of their right to participate, (6) youth with disabilities deserved the same transition experience as youth without disabilities, (7) professionals were interested in including transitional age you in the transition process, but (8) different approaches needed to be developed to ensure that inclusion of youth in the process can occur. The study concluded that we must move past the question of whether youth are involved, and begin to examine how we can better involve youth in the transition process (McKay, 2015). There were many limitations to the aforementioned study, including a small sample size and the new protocol being in its infancy stages in the Niagara Region. As a result, the current study was designed to build on the previous research to gain a greater understanding of how transition planning is being done in the Niagara Region. The goal of the current study was to examine the barriers of the new transition planning protocol in relation to (1) youth participation, and (2) the implementation of the new Integrated Transition Planning Protocol. Further, the study was designed to uncover whether youth are better included in their transition plans since the development of the Integrated Transition Planning Protocol, and to discover ways to better include youth in their transition plans, if they are not currently active participants. Through questionnaires, focus groups, and individual interviews, the current study explored the perspectives of professionals who work with transitional aged youth in the Niagara Region.

Literature Review

The literature presented throughout this review was examined to explore the relevance of the current research study. First, the key concepts and terms used throughout this paper are

defined. Next, a review of the transition process in general is presented, followed by the specific challenges faced by youth with intellectual disabilities during their transition process. Then the current literature on the outcomes of transitional aged youth after they leave high school is explored, which leads to a discussion of what research has been deemed to be recommended practice in transition planning. The importance of youth participation in the transition process is explored and the literature on the roles of youth, families, and professionals during the transitional process are examined. To focus on youth participation, the concepts of self-determination and choice, as well as their relationship to participation, are reviewed, followed by a brief exploration of how youth participation has been shown to play a role in improving the quality of life for individuals with intellectual disabilities. This literature review then addresses the shift in transition protocols in Ontario, Canada over the past decade which led to that jurisdiction's most recent transition policy document. Specific focus has been directed toward the role of youth participation in the Niagara Regional Protocol, the location in which the study was conducted. The literature review concludes with a discussion of the importance of the current policy, and the gaps in the literature surrounding this policy.

Definitions

Developmental disability has been defined by The *Child and Family Services Act* (Ontario Ministry of Community and Social Services, 1990) as "a condition of mental impairment, present or occurring during a person's formative years, that is associated with limitations in adaptive behaviour" (p. 8). Put simply, it is an impairment in cognitive functioning that originates before adulthood and lasts throughout the lifetime. Intellectual disabilities have been characterized by three criteria: (1) significant limitations in intellectual functioning, (2) limitations in adaptive behaviors which compromise conceptual, social and practical skills, and

(3) appearance before the age of 18 (Werner, 2012, p. 2). The Ontario Ministry of Education

defines a developmental disability as a severe learning disorder that is characterized by:

>   (a) an inability to profit from a special education program for students with mild
>
>   intellectual disabilities because of slow intellectual development, (b) an ability to profit
>
>   from a special education program that is designed to accommodate slow intellectual
>
>   development, [and] (c) a limited potential for academic learning, independent social
>
>   adjustment, and economic self-support. (Ontario Ministry of Education, 1999, p. 13).

The Ontario Ministry of Education defines a (mild) intellectual disability as a learning disorder

that is characterized by

>   (a) an ability to profit educationally within a regular class with the aid of considerable
>
>   curriculum modification and supportive services, (b) an inability to profit educationally
>
>   within a regular class because of slow intellectual development, [and] (c) a potential for
>
>   academic learning, independent social adjustment and economic self-support. (Ontario
>
>   Ministry of Education, 1999, p.12)

As there is no one agreed upon definition of these terms, and the terms have often been used

interchangeably in the service delivery systems; throughout this research the term developmental

disability has been used as an umbrella term under which intellectual disability falls. The

Ministry documentation in Ontario, Canada, where the study took place, uses the term

developmental disability (Ontario Ministry of Children and Youth Services, Ontario Ministry of

Community and Social Services, & Ontario Ministry of Education, 2013); however, the vast

majority of this literature review has employed the term intellectual disabilities.

Transitional aged youth refers to any young person aged 14 years to 18 years who, under

any of the Ministry of Education, Ministry of Community and Social Service, and Ministry of

Children and Youth Services legislative frameworks, meets the definition of having a

developmental disability (Ontario Ministry of Community and Social Services, Ontario Ministry

of Children and Youth Services, & Ontario Ministry of Education, 2013). The Ministries define

the transition process as one that every young person with a developmental disability who

requests or will request adult developmental services upon reaching age 14 will have (Ontario

Ministry of Community and Social Services, Ontario Ministry of Children and Youth Services,

& Ontario Ministry of Education, 2013). The transition period has been identified as the time in

which youths begin to age-out of child-centered services, and require preparation for adult

services and supports. The transition plan represents a written plan that helps youth and their

families prepare for this transition from child to adult services and for successful integration into

community living in adulthood (Ontario Ministry of Community and Social Services, Ontario

Ministry of Children and Youth Services, 2011). A transition plan identifies the tasks that need

to be completed, the information that must be provided to achieve this transition successfully,

and the individuals who are responsible for completing each aspect of the planning process and

its implementation (Ontario Ministry of Community and Social Services, Ontario Ministry of

Children and Youth Services, 2011).

  The Ministries outlined that one of the key objectives of the integrated transition protocol

is to provide transitional aged youth, their families, and anyone deemed important to the young

person "with opportunities to actively participate in and contribute to transition planning"

(Ontario Ministry of Community and Social Services, Ontario Ministry of Children and Youth

Services, 2011, p. 8). Participation has been described as a continuum in which one has the right

to take part, to be present for, and to be consulted about decisions that affect one's life (Mitchell,

Franklin, Grego, & Bell, 2009).

The Transition Period

The transition period has often been described as the crucial task of moving from the protected life of a child to the "autonomous and independent life of an adult" (Dyke, Bourke, Llewellyn, & Leonard, 2013, p. 149). This period has been noted to be a challenging period for many adolescents, as youth are often forced to make critical decisions about their future that will influence the rest of their lives (Shogren & Plotner, 2012). The transitional period is a distinct time that occurs when youth are trying to find their place in the adult world. This period has been described as "the age of possibilities," as it is a time when an array of life directions remains possible (Arnett, 2000, p. 69). During this time, youth adopt new adult social roles that relate to independent living, employment, education, friendships, autonomy, and self-determination (Dyke et al., 2013). For most youth, the transition period is the time when they are most likely to be free to follow their own interests and desires, and are given increased independence and control over their lives (Arnett, 2000).

Unfortunately, these general descriptions of the transitional experience have not been found to represent the reality for many youth with disabilities. Research has described this period for youth with disabilities as a stressful experience, marked by long durations and uncertainty (Dyke et al., 2013). Many studies have suggested that the transition to adulthood is not easy for youth with disabilities, and that major key milestones, such as employment, financial independence, and romantic relationships, are never achieved (Keogh, Bernhelmer & Guthrie, 2004). At the very time when parents of youth without disabilities experience a reduction in their caregiver responsibilities, parents of youth with intellectual disabilities may lose the predictability of full-time care that results in an increase in their caregiving responsibilities (Pilnick, Clegg, Murphy & Almack, 2011). During this time, youth with

disabilities and their families must also learn to navigate the unfamiliar adult support system

based on eligibility, and adjust to the loss of the child supports they were once guaranteed

(Shogren & Plotner, 2012).

Life After High School – Outcomes

"If successful transition is measured by the standards of employment, viable social

connections, community participation and independent living, then an enormous discrepancy

exists between young people with disabilities and their non-disabled peers" (Salmon &

Kinnealey, 2007, p. 55). This sentiment is consistent throughout the literature, as the post-school

outcomes of youth with intellectual disabilities remain bleak. Recent reports on outcomes have

found that youth with intellectual disabilities are less likely to pursue post-secondary education,

to work, to live independently or to see friends at least weekly compared to youth with other

disabilities (Papay & Bambara, 2014; Shogren & Plotner, 2012).

In his analysis of the 2006 Participation and Activity Limitation Survey: Disability in

Canada (PALS), Crawford (2011) reported that only 15.5 percent of youth aged 15 to 24 who

had an intellectual disability had jobs, compared to 49.8 percent of their peers with other

disabilities, and 58.1 percent of the same age group without disabilities. The 2006 PALS report

further found that almost two-thirds (65.7 percent) of working age people with intellectual

disabilities had no formal educational accreditation, versus 25.1 percent of others with

disabilities and 18.8 percent of people without disabilities (Crawford, 2011). The study also

reported that individuals with intellectual disabilities were less likely than others with disabilities

to have taken work-related training, and that people with intellectual disabilities were about six

times more likely than others to have never been employed (Crawford, 2011). Furthermore, the

results showed that when persons with intellectual disabilities gained employment, the number of

hours they worked in a given week and the number of weeks worked in a year were lower than those of their disabled peers, ultimately leading to lower earnings compared to others with disabilities and about half the earnings of people without disabilities (Crawford, 2011).

A 2011 study conducted in the United States by Newman et al. (2011) reported similar results. They found that young adults with intellectual disabilities were less likely to be employed at the time of the interview and worked fewer hours per week on average than young adults with other disabilities (such as speech/language impairments, traumatic brain injuries, hearing or visual impairments, etc.). This same study also found that young adults with intellectual disabilities were less likely to have ever lived independently, and were less likely to see their friends at least once a week (Newman et al., 2011).

Best Practices

Best practices in transition refer to the components that are considered to be essential, as supported by research, in planning and providing support during the transition to adulthood (Papay & Bambara, 2014).   When examining five of the most recent comprehensive lists of best practices in transition planning either for youth with intellectual disabilities, or for youth with all disabilities, Papay and Bambara (2014) identified seven common best practices in transition planning: family involvement, individualized planning, instruction and experiences that prepare youth for employment, instruction and experiences that prepare youth for independent living, general education participation and inclusion with peers without disabilities, interagency involvement and collaboration, and youth involvement in transition planning and other strategies to develop self-determination. In their study, Papay and Bambara (2014) sought to examine whether the use of best practices predicted successful post school outcomes for youth with intellectual disabilities using data from the National Longitudinal Transition Study – 2 (NLTS2).

The NLTS2 was a longitudinal study conducted in the United States that followed youth with disabilities as they graduated from high school and began their adult lives. It involved a nationally representative sample of youth with disabilities aged 13 to 16 who were followed for 10 years, with data being collected every two years. Papay and Bambara's (2014) study used a sample of 490 youth with intellectual disabilities. They examined four outcomes: employment, post-secondary education, enjoyment of life, and social interactions at two time-points (up to 2 years and between 2 and 4 years out of high school). Using logistic regression, the authors found that although youth involvement was not a statistically significant predictor of any outcome, it was found to be practically significant in five of the analyses. These results were similar to those of Miceli (2008), who found that youth who were more involved in their transition planning were three times more likely to have taken a postsecondary education up to two years after high school, were five times more likely to be employed between two and four years out of high school, and were three times more likely to see friends at least weekly up to two years out of high school. Papay and Bambara (2014) further noted that there has been little research on the relationship between youth involvement and post school outcomes, and that this relationship needs to be explored further in future research.

Participation

Although the above research suggests a correlation between participation in the transitional process and outcomes, correlational research does not demonstrate causality. Other explanations for the correlational results could be that the youths who participated were more readily able to participate and hence more likely to achieve better outcomes. However, alternatively, the outcomes could also represent a rival hypothesis that the lack of discernable

outcomes from transitions could be the product of a lack of participation of the youth in their transition plans.

As noted earlier, participation is best understood on a continuum and is often simply defined as involvement in decisions (Mitchell, Franklin, Grego & Bell, 2009). Most research has suggested that participation consists of being an active participant in decisions relating to goal setting and services (Shrogen & Plotner, 2012). However, Hammel and her colleagues (2008) reported that participation, as described in a focus group of individuals with a variety of disabilities, was conceptualized as "a cluster of values" (p.1450). This cluster included active and meaningful engagement, choice and control, access and opportunity, personal and societal responsibilities, contributing to society, and having social connection, inclusion, and membership (Hammel et al., 2008).

The broader definition of participation as a cluster of values, as described by Hammel et al. (2008), has relevance for the current study as it expanded the understanding of the complexity of participation, and viewed participation during the transition process as a practice that does not simply end after the meeting has concluded. Instead, this definition clarified that participation is an ongoing process that enhances the involvement of persons with disabilities in their communities, and is of significant importance during the transition period when these individuals are preparing to become active community members.

Despite the importance of participation, research has shown that students with intellectual disabilities have higher levels of limited or no participation in their transition plans compared to students with other disabilities (Shogren & Plotner, 2012). Shogren and Plotner (2012) reported that 10 out of every 100 students with intellectual disabilities did not attend their transition planning meetings and that thirty-six percent of those who did attend did not participate.

Although it was found that 49.7 percent of participants provided "some input" in their transition

meetings, Shogren and Plotner (2012) found that only 3.3 percent of transitional aged youth

played a "leadership role" in their transition plans (p. 21). A study by Cooney (2002) concluded

that for most neurotypical graduating students the transition process is done *with* them, whereas

for students with intellectual disabilities the transition is done *to* them. Research has shown that

the current transition planning systems typically limit the opportunities for transitional aged

youth to become active participants in their lives, thereby violating the most fundamental human

rights we have as persons (Werner, 2012).   The following section will explore the roles of those

most likely to be involved in the transition process to gain a greater understanding of how each

person generally participates in the process.

Roles

Transition teams consist of school and adult service agency professionals, parents and

families, and youth with disabilities. Together, they each play a crucial role in the transition

process. However, it appears that these roles are often unbalanced and that too often the young

person is left out of the process (Cooney, 2002).

Schools and service providers.

Transition planning has occurred in the education system in Ontario, Canada for a

long time through the Identification, Placement, and Review Committee (IPRC) process.

The role of the IPRC is to (1) decide if a student should or should not be identified as

exceptional, (2) identify, according to the definitions provided by the Ministry of

Education, the areas of the student's exceptionality (i.e., mild intellectual disability vs.

developmental disability), (3) decide an appropriate placement for the student, and (4)

review the identification and placement at least once a year (Ontario Ministry of

Education, 2007). For most youth, this IPRC identification results in the creation and

implementation of an Individual Education Plan (IEP). An IEP is a plan developed for

students "in consultation with the parent" that includes:

> specific educational expectations; an outline of the special education program and
>
> services that will be received; a statement about the methods by which the
>
> student's progress will be reviewed; and, for students 14 years and older (except
>
> those identified as exceptional solely based on the basis of giftedness), a plan for
>
> transition to appropriate postsecondary school activities, such as work, further
>
> education, and community living. (Ontario Ministry of Education, 2007, *What is*
>
> *an IEP?).*

Professionals in the developmental services sector, along with the schools, play a primary

role in the transition process and often determine the options that are available to families and

students (Cooney, 2002). In a study by Cooney (2002) that explored the roles of youth, families,

and service providers during the transition period, the author concluded that professionals made

the initial decision regarding which options to present to youth and families based on eligibility,

skill level, and their best judgement, and then presented these limited choices to youth and

families. It was noted that the choices presented often required parents and transitional aged

youth to compromise their desired outcomes to fit with the options presented by professionals

and that if parents were reluctant to accept these options, they were told that it was up to them to

find new options and suitable placements (Cooney, 2002). Kaehne and Beyer (2014) also noted

that transition planning is often marked by low levels of choice for young people with

intellectual disabilities, and that most of the options presented suit services rather than users. A

lack of resources was also noted in a study by Werner (2012), who found that there were no

communication and visual aids to assist individuals to actively participate in their transition plans.

The study by Shrogen and Plotner (2012) reported results similar to those of Cooney (2002). In their study, they found that special education teachers were the most likely to be involved in transition plans, followed by parents and guardians, and lastly, the youth themselves. Park's (2008) study found that teachers often relied on the families of students with intellectual disabilities to relay their son's and daughter's interests and goals.

Park (2008) also found that a student's "cognitive and communicative limitations" were often the biggest barrier to their full participation in the transition process (p. 102). Special education teachers were quoted as saying that students with disabilities participate "to the extent that they are capable" (p. 102); this finding was echoed in the pilot study I conducted in 2015. However, one must be cautious of this type of thinking. A study by Laragy (2004) examined seven Australian transition programs for youth with disabilities and found that professionals still played a major role in choosing services, especially when youth and their families did not have the information needed to make an informed decision. This finding demonstrates that students' capabilities are often hindered by a lack of knowledge regarding availability of programming, and that the general assumption of cognitive and communicative limitations lead professionals to assume that a youth cannot fully participate. The researcher concluded that although the transition programs claimed to utilize the philosophy of self-determination and participation in decision making, all too often students were forced to conform to established and existing patterns of service delivery, and that service providers failed to provide flexible and individualized resources that allow students to participate in a meaningful way (Laragy, 2004).

A consistent finding throughout the literature was that family and youth participation were hindered by a lack of information available regarding process and services (Cooney, 2002; Laragy, 2004; Park, 2008). Parents reported that they did not know how the adult support services system functioned, and they were often uncertain about how they would fit in. Parents stated that one of the most troublesome experiences during the transition meetings was "having to learn the ins and outs of an unfamiliar system" (Cooney, 2002, p. 430). Teachers identified informing families about the transition process and the services as one of the most challenging but crucial tasks in supporting students with disabilities and their families during the transition period (Park, 2008). Teachers themselves noted that it was difficult to find the relevant information, and admitted that many families were still not aware of the process and services during the time of transition (Park, 2008). These findings are important as research has suggested that service providers play an even larger role in the transition process when families and youth do not have enough information to make their own choices (Laragy, 2004).

Families.

Despite previous research that has found that parents have low involvement in youth transition plans (Greene & Kochhar-Bryant, 2003), more current research has found that families are, in fact, actively involved (Davies & Beamish, 2009; Park, 2008). Davies and Beamish (2009), who reported high levels of participation in the transition planning process by parents, further noted, however, that these participating parents reported that their son or daughter with an intellectual disability participated only minimally. Similar research has reported that youth continue to be minimally involved, and that parents have a particularly strong voice in the decisions made about their child's future (Park, 2008).

The research supports the notion that outcomes for youth with intellectual disabilities are better when there is significant parental involvement in the transition process (Davies & Beamish, 2009; Dyke et al., 2013; Park, 2008); however, Laragy (2004) reported that the wishes of the parents of a young person with a disability may not always be the same as the wishes of the young person him/herself. This finding was also echoed in Park's (2008) study where a parent chose to send their child to a day program despite the child's interest in employment (Park, 2008). However, Cooney (2002) found that most parents do seek their children's input when planning future goals. Similarly, research has found that families and teachers/service providers may also have differing opinions (Carter, Brock & Trainor, 2014). Through an examination of teacher and parent assessments of the transition-related strengths and needs of 134 students with severe intellectual and developmental disabilities, Carter and colleagues found that the perceptions of teachers and parents regarding the transition-related strengths and needs of particular students were often very different. The researchers concluded that "it is important to assess the transition-related strengths and needs of students with severe disabilities from multiple perspectives because a single informant would likely provide an incomplete perspective" (Carter et al., 2014, p. 252).

Youth.

Inclusion in decision making of youth with intellectual disabilities regarding their transition planning has been a primary factor in the achievement of preferred post-school outcomes (Laragy, 2004). Despite this, the research has consistently reported that youth play the smallest role of all participants in their own transition planning (Cooney, 2002; Davies & Beamish, 2009; Dyke et al., 2013; Laragy, 2004; Park, 2008), even though transitional aged youth have been found to be able to articulate their post-graduation plans remarkably well

(Cooney, 2002). An extensive literature review by Cavet and Slopper (2004) concluded that given the right environment and supports, youth can make decisions. Research has demonstrated that children with disabilities want respect for their views (Cavet & Slopper, 2004) and to be recognized as being able to make their own choices, as illustrated by the following comment: "if they'd just let us, we'd do the right thing" (Cooney, 2002, p. 429).

A major concern that hinders youth participation during the transition process is the lack of choice available for persons with developmental disabilities. As noted by Weinkauf (2002), students from the special education system are often transitioned into a life of "limited choices and isolating opportunities" (p. 29). For example, a study by Griffin, McMillan and Hodapp (2010) found that compared to other students with disabilities, students with intellectual disabilities are less likely to be involved in job training, paid employment, and higher education. These students are also less likely to attain a high school graduation certificate, which often limits their choice of careers or post-graduation options (Crawford, 2011). Weinkauf (2002) expressed the disheartening fact that these students are denied an opportunity that is granted to hundreds of thousands of high school graduates each year, that of post-secondary education (Weinkauf, 2002).

Self-Determination

Although there are many definitions of self-determination, it is generally defined as the right and capacity of people to control and direct their lives (Wehmeyer & Gragoudas, 2004). Self-determination involves students understanding their interests, strengths, and weaknesses, and then using this information to identify, and later attain, their goals (Martin & Williams-Diehm, 2013). It is "the actions that enable one to act as the primary causal agent in one's life and to maintain or improve one's quality of life" (Wehmeyer, 2005, p. 117). For many years, it was believed that persons with intellectual disabilities were unable to become self-determined;

however, research findings have concluded that people with intellectual disabilities have the

capacity to control their lives in meaningful ways, if they are supported to do so (Foley, Dyke,

Girdler, Bourke, & Leonard, 2012). It is now agreed that self-determination plays a key role in

the transition process for youths with disabilities, and has been recognized as being best practice

since the 1990s (Wehmeyer & Gragoudas, 2004). The literature even suggests that self-

determination and the participation of young people in their transition plans are likely to result in

the young person achieving his or her goals (Laragy, 2004). For example, a study by Wehmeyer

and Schwartz (1997) measured the self-determination of students with mild intellectual

disabilities in the final year of high school using The Arc Self-Determination Scale, a 72 item

self-report scale that measures autonomy, self-regulation, psychical empowerment, and self-

realization (Wehmeyer & Kelcher, 1995). Using the National Consumer Survey (Jaskulski,

Metzler & Zierman, 1990) and the National Longitudinal Survey (Wagner, D'Amico, Marder,

Newman & Blackorby, 1992), Wehmeyer and Schwartz (1997) collected information on the

post-school outcomes of youth with a cognitive disability (described as mental retardation or

learning disability, with the mean IQ for the group being 77.31). Through a chi-square analysis,

the authors found that students who were more self-determined were more independent and more

likely to be employed for pay one year later, even when controlling for intelligence level.

Unfortunately, even when transition policies explicitly outlined the importance of self-

determination, parents and professionals, with the best of intentions, created a façade of

independence for adults with disabilities by allowing them to make trivial and even coerced

choices, claiming that this is self-determination (Ferguson & Ferguson, as cited in Cooney 2002).

Choice and Choosing

A central element in participation and self-determination is choice making (Agran, Storey, & Krupp, 2010; Hammel et al., 2008). It is suggested that those who are self-determined are able to make choices, to act on those choices, to experience the results of those choices, and then to make new choices (Agran et al., 2010). Historically, the right to make choices has been denied for individuals with intellectual disabilities; however, providing these individuals with opportunities to express their preferences, to make choices, and to act on those choices should be understood as a fundamental right (Agran et al., 2010). Typically, decisions have been determined by others for individuals with intellectual disabilities – that is, service providers and/or families and not the individuals themselves have made the decisions (Agran et al., 2010). This other-determination limits an individual's opportunity to practice decision-making and, as such, results in many persons with disabilities not knowing how to make choices (Agran et al., 2010) and the false assumption that individuals with intellectual and severe intellectual disabilities are unable make their own choices. However, research has shown that this population can in fact hold and express their views, and can make real choices when given the right environment (Cavet & Slopper, 2004). It has been argued that the more opportunity an individual has to make meaningful choices, the more control he or she will experience, and that increased control will result in higher self-determination (Agran et al., 2010).

Choice-making does not, however, mean total independence. For most neurotypical people, momentous and complex decisions, such as the decisions made during the transition period, are typically made with others providing assistance (Lotan & Ells, 2010). It is therefore not assumed that youth with intellectual disabilities should be making the transitional decisions on their own. Instead, the normative standard would be that the views, opinions, and choices of

youth with disabilities should be given the same respect as those of their non-disabled peers.

One could argue that it is just as important a choice to allow an individual to decide in what ways

and how much they want to be involved in their life decisions (Lotan & Ells, 2010). As noted by

Wehmeyer (2002), "being self-determined does not mean that one does everything for oneself"

(p. 59), nor does it mean that one must "independently make complex decisions or solve difficult

problems" (p. 58). Such misconceptions could result in practices that are contradictory to the

concepts of self-determination and participation.

Quality of Life

Quality of life measures have been used to evaluate transition outcomes for youth with

intellectual disabilities (Foley et al., 2012). This is because quality of life as a transition outcome

measures both conventional outcomes, such as employment, as well as subjective outcomes,

such as personal well-being, autonomy, and self-determination (Foley et al., 2012).

Quality of life has been defined as having eight core domains: interpersonal relations,

social inclusion, personal development, physical well-being, material well-being, emotional

well-being, rights, and self-determination (Neely-Barnes, Marcenko, & Weber, 2008). Research

has found that student involvement during the transition process results in increased positive

outcomes on a range of quality of life measures (Wehmeyer & Schwartz, 1998). Many

researchers have reported a positive relationship between participation, choice, self-

determination and quality of life. For example, DeJong (1983) argued that if people with

disabilities were given greater control over their services they would select the services that best

meet their needs, thereby improving their quality of life (as noted also in Neely-Barnes et al.,

2008). Similarly, Pilnick et al. (2011) argued that quality of life would improve if the barriers

that prevented people from being independent and making their own choices were removed. In

2005, Lachapelle and colleagues found that self-determination predicted greater quality of life in

persons with intellectual disabilities, a finding supporting Wehmeyer and Schwartz's (1998)

research that self-determination enhanced quality of life. Lachapelle and colleagues (2005)

evaluated the relationship between self-determination and quality of life of 182 adults with mild

intellectual disabilities in Canada, the United States, Belgium and France. Using both the Quality

of Life Questionnaire (QOL-Q; Schalock & Keith, 1993), and the adult version of The Arc's

Self-Determination Scale (Wehmeyer & Bolding 1999), discriminant function and correlational

analyses were conducted. The results suggested that, overall, self-determination and quality of

life were significantly correlated, and that self-determination contributes to enhanced quality of

life (Lachapelle et al., 2005). These findings further support the importance of participation

during the transition period.

It's Not Just Best Practice – It's a Human Right!

"Freedom to make one's own choices", "full and effective participation and inclusion in

society", "respect for inherent dignity [and] individual autonomy" – these are the guiding

principles of the United Nations Convention on the Human Rights of Persons with Disabilities

(UNCRPD) (UN Enable, 2006 Article 3, p. 6), a legally binding human rights document that

protects and promotes the rights of persons with disabilities. On March 11, 2010 Canada ratified

this convention and committed to uphold and protect the rights of persons with disabilities (UN

Enable, 2006). With this ratification, it was recognized that participation is not only best practice

but it is also a human right for all persons, including those with disabilities.

The UNCRPD not only encourages participation, but the committee that drafted the

Convention also upheld its own values as persons with disabilities were involved in the

development of the UNCRPD (Moritarity & Dew, 2011). Participation has been set forth as a

guiding principle of the UNCRPD and can be seen throughout its various Articles. This

fundamental human right was first expressed in Article 3, which outlines the general principles

of the UNCRPD.   It is later seen in Article 4.3, which notes that:

> In the development and implementation of legislation and policies to implement the
>
> present convention and in other decision-making processes concerning the issues relating
>
> to persons with disabilities, State Parties shall closely consult with and actively involve
>
> persons with disabilities, including children with disabilities. (UN Enable, 2006, para 1)

Article 7.3 also discusses participation, as it states that children with disabilities should have the

right to express their views on all matters affecting them, and that their views should be

considered (UN Enable, 2006). Article 21 explicitly outlines ways in which active participation

can be achieved by ensuring that persons with disabilities can "exercise the right to freedom of

expression and opinion, including the freedom to seek, receive, and impart information and ideas

on an equal basis with others and through all forms of communication of their choice" (UN

Enable, 2006, Article 21, para 1). Furthermore, Article 24, the right to education, advocates for

an inclusive education system that enables effective participation through social development

and life skills. Participation and inclusion can also be seen in Article 29, which focuses on

political and public rights, including the right to vote and to "effectively and fully participate in

political and public life on an equal basis with others" (para 2), and in Article 30, which

recognizes the right of persons with disabilities to participate in cultural life, recreation, leisure

and sport (UN Enable, 2010). Finally, Article 33 further stresses the importance of participation

by requiring State Parties to include persons with disabilities in the monitoring and

implementation of the Convention (Moritarity & Dew, 2011).

Understanding participation as a fundamental human right is important as it allows for the UNCRPD to be used as a tool to ensure that people with disabilities are given the chance to take control over, and to make decisions about, their own lives (Rooke, 2003). This is of special importance when applied to transitional aged youth, as the decisions being made at this life stage will often influence the rest of a youth's life.

Over 10 Years of Transition Policy in Ontario

In 2004, the government made a commitment to transform the developmental services in Ontario (Mercer Delta Consulting, 2006). The government sought consultation from people with developmental disabilities, their families, agencies, advocates, and members of the community in order to improve the developmental service sector (Mercer Delta Consulting, 2006). The goal of the consultation was to bring these groups together to provide valuable advice in order to "create a plan for a fair, accessible and sustainable system of community based supports" (Mercer Delta Consulting, 2006, p. 2). During the consultation, it become evident that the urgent needs of youth and families were not being addressed (Mercer Delta Consulting, 2006). Many families reported receiving limited supports and feeling as though they had "no choice" but to give up their efforts to take care of their adult sons and daughters at home. Families identified the transition across life stages as one of the "most urgent issues for discussion," revealing a strong need for improvement (Mercer Delta Consulting, 2006, p. 13). A major finding in the Mercer Delta paper was that individuals with developmental disabilities needed to participate in program planning to the fullest extent possible. They suggested that more inter-ministerial collaboration was needed, as families felt that the Ministry of Community and Social Services needed to work more closely with the Ministry of Education in planning transitions from school to adult supports (Mercer Delta Consulting, 2006). The report concluded that planning needed to begin earlier,

that better information needed to be provided, and that the system needed to proactively plan for the transition instead of responding to life change events as they occurred (Mercer Delta Consulting, 2006).

        The Provincial Transition Planning Framework. In 2011, the Ontario Ministry of Community and Social Services (MCSS) and the Ontario Ministry of Children and Youth Services (MCYS) came together to create a plan to improve the transition process for young people with developmental disabilities in Ontario (Ontario Ministry of Community and Social Services, Ontario Ministry of Children and Youth Services, 2011). The goal of the Ministries was to introduce a "Framework" and Regional Protocols to formalize transition planning and to ensure that transition planning began early (Ontario Ministry of Community and Social Services, Ontario Ministry of Children and Youth Services, 2011). The framework's key policies dictated that every transitional aged youth (as defined earlier) would receive a unique transition plan that would be based on their needs, program eligibility criteria, and available resources. The framework also noted that these plans would be guided by the young person's "interests, preferences, and priorities" (Ontario Ministry of Community and Social Services, Ontario Ministry of Children and Youth Services, 2011, p. 2). Within the Regional Protocols, the framework clearly defined planning processes and assigned responsibilities in an attempt to establish "transparent and consistent processes" (Ontario Ministry of Community and Social Services, Ontario Ministry of Children and Youth Services, 2011, p. 3). The goal was for people to know who was responsible for leading and supporting transition planning in their own communities (Ontario Ministry of Community and Social Services, Ontario Ministry of Children and Youth Services, 2011).

The Framework emphasized that transition planning protocols would incorporate best

practices for successful transitions, would begin planning early, and would allow opportunities

for youth and their families to actively participate in, and contribute to, the transition plan.

Within the new Framework it was outlined that transition planning would begin at age 14 or

earlier in order to provide youth with the information and support required for them to develop

the skills necessary to function as an adult and to ensure a smooth transition (Ontario Ministry of

Community and Social Services, Ontario Ministry of Children and Youth Services, 2011).   The

Framework called for the plan to be reviewed and updated at least annually and to identify

opportunities for youth to progressively increase their independence (Ontario Ministry of

Education, 2016).

Integrated transition planning. In 2013, it was recognized by the Ministries that

collaborative planning processes are expected in both the development of the Individual

Education Plans (IEPs) for students with developmental disabilities and in the 2011 *Transition*

Planning Framework (Clarke, Gitterman, & Carter-Whitney, 2013).   In light of this, a number of

school boards participated in the development of Regional protocols (Clarke et al., 2013).   This

collaboration resulted in the Ontario Ministries of Community and Social Services and of

Children and Youth Services announcing an addendum to the 2011 *Draft Provincial Transition*

Planning Framework: Transition Planning for Young People with Developmental Disabilities

(the 2011 document described above) to achieve integration with the Ministry of Education IEP

transition planning protocols.

The three Ministries, namely, the Ontario Ministry of Children and Youth Services, the

Ontario Ministry of Community and Social Services, and the Ontario Ministry of Education

(henceforth known as the "tri-Ministries") issued a joint memo on January 28, 2013, announcing

that they would work collaboratively and build on the 2011 transition planning practices in order

to facilitate a smooth and comprehensive transition experience. They continued by stating that it

was their goal to support "positive transition outcomes for each young person with a

developmental disability and their family/caregiver" by revising and building on the existing

regional protocols to create a process that would lead to a single integrated transition plan

(Clarke et al., 2013, p. 2.). The goal of the integrated transition planning process, which would

result in a single integrated transition plan, was for young people with developmental disabilities

to have one single plan that would "inform educational planning and help the young person

transition from secondary school and child-centered services to adulthood" (Ontario Ministry of

Community and Social Services, Ontario Ministry of Children and Youth Services, & Ontario

Ministry of Education, 2013, p. 1).

     The *tri-Ministry 2013-2014 Implementation Guide* defines a single integrated transition

plan as planning based on the identified needed steps that a young person must complete to attain

his or her goals from the time the plan begins, until the anticipated time of leaving school

(Ontario Ministry of Community and Social Services, Ontario Ministry of Children and Youth

Services, & Ontario Ministry of Education, 2013). It was further identified that the plan should

involve "school board officials, principals, teachers, students and their families, and others who

support the young person with a developmental disability such as community agency staff and

health care providers" (Ontario Ministry of Community and Social Services, Ontario Ministry of

Children and Youth Services, & Ontario Ministry of Education, 2013, p. 3). Within the plan

there should be goals for work and for further education and community living, and it should

reflect opportunities and resources that are available after the young person leaves high school.

It also identified the actions that should be taken to help a transitional aged youth to achieve their

goals, and identified the roles and responsibilities of the youth, the family, and "others" in

carrying out these actions (Ontario Ministry of Community and Social Services, Ontario

Ministry of Children and Youth Services, & Ontario Ministry of Education, 2013). The transition

plan would begin being developed at age 14 and would be reviewed and updated regularly as

part of the IEP planning process. In order to facilitate a smooth and coordinated transition, the

plan would be implemented "well before" the student left school (Ontario Ministry of

Community and Social Services, Ontario Ministry of Children and Youth Services, & Ontario

Ministry of Education, 2013, p. 3).

The role of the youth in the protocol. Although past research has identified that youth do

not often participate in their transition plans, the 2013-2014 *tri-Ministry Implementation Guide*

*(*Ontario Ministry of Community and Social Services, Ontario Ministry of Children and Youth

Services, & Ontario Ministry of Education, 2013), and the *Transition Planning Protocol and*

Procedures for Young People with Developmental Disabilities - Hamilton Niagara Region

Protocol (Ontario Ministry of Children and Youth Services, Ontario Ministry of Community and

Social Services, & Ontario Ministry of Education, 2013) acknowledged the importance of

providing youth with opportunities to participate. The remainder of this review will focus on the

Transition Planning Protocol and Procedures for Young People with Developmental Disabilities

- Hamilton Niagara Region Protocol (Ontario Ministry of Children and Youth Services, Ontario

Ministry of Community and Social Services, & Ontario Ministry of Education, 2013) (henceforth

known as the *Regional Protocol*) as the current research is being conducted in the Niagara

Region in Ontario, Canada.

Participation, self-determination, and choice were themes that were identified in the

Regional Protocol. For example, in the *Regional Protocol,* transition planning was described as

"a means for centering planning on the needs of the young adult and informing them of adult

service choices" (Ontario Ministry of Children and Youth Services ,Ontario Ministry of

Community and Social Services, & Ontario Ministry of Education, 2013, p. 9). Article 2.2 of

the *Regional Protocol* outlined that the planning process "must be conducted in a manner that is

respectful of the young person's autonomy", and Article 2.3 outlined that the plan must be

person-centered. Article 2.3 continues to state that youths should be involved in the planning

process, and "as much as possible", decisions about their care should be driven by their "needs,

preferences, interests, and strengths" (Ontario Ministry of Children and Youth Services , Ontario

Ministry of Community and Social Services, & Ontario Ministry of Education, 2013, p. 9).

Further, Article 2.3 discussed how the goal of the transition plan is to support a young person to

live in the community and to provide the youth with choices to support the development of self-

determination and self-advocacy (Ontario Ministry of Children and Youth Services ,Ontario

Ministry of Community and Social Services, & Ontario Ministry of Education, 2013). This

article also stated that information should be readily available for youth, and provided in

accessible locations and formats. Moreover, the transition meeting should include the

involvement of persons who are important to the young person, "as determined by the young

person" (Ontario Ministry of Children and Youth Services Ontario Ministry of Community and

Social Services, & Ontario Ministry of Education, 2013, p. 10). Article 2.3 concluded by

insisting that the plan should be implemented at a pace that takes the needs and preferences of

the young person into account, and that service decisions consider the least disruptive course of

action (Ontario Ministry of Children and Youth Services, Ontario Ministry of Community and

Social Services, & Ontario Ministry of Education, 2013).

Article 4.2 of the *Regional Protocol,* entitled "Youth", further emphasized the importance of participation by stating:

Young people's participation in decisions that affect them is valuable and has a range of positive outcomes for young people and those who engage with them. Consistent with Person Centered Planning Principles, the youth would ultimately decide who is a part of the planning team. The youth is responsible to express their preferences and opinions related to their needs, goals, interests, and desires, and following through with action steps as assigned to them. (Ontario Ministry of Children and Youth Services, Ontario Ministry of Community and Social Services& Ontario Ministry of Education, 2013, p. 15)

Implications for Authentic Youth Involvement in Planning

The literature, and this review, have clearly identified that despite years of research suggesting that youth play an important role in their transition process, they continue in many instances to play marginal roles in their transition plans. In light of the research presented throughout this literature review, it is important that the *Regional Protocol* be examined in order to better understand how policies can improve the participation of youth during the transition period. Although the *Regional Protocol* appears to be guided by the principles of youth participation, self-determination, and choice, it does not provide specific strategies to ensure that youth truly can be active participants in their transition plans. Although the *Protocol* claimed to be person-centered, concern has been raised that person-centered planning can become a paper exercise that can fail to actually increase independence, choice, and inclusion of transitional aged youth (Kaehne & Beyer, 2014).

It has been recognized for years that best practices in transition planning involve the active participation of youth during their transition meetings (Wehmeyer & Lawrence, 1995), and yet the recent literature discussed throughout this paper has led me to conclude that there remains a significant gap between policy and practice. It is not enough simply to say that youth should participate, that plans will be person-centered, and that transition plans will increase a youth's self-determination. Specific strategies, resources, and tools must not only be established, but also used to ensure that youth are actively involved in developing and implementing their transition plans and that their voices, perspectives, and goals are both acknowledged and respected.

Conclusion

In conclusion, the voices of youth with intellectual disabilities are often missing from their transition plans, and the outcomes of transition plans are less than ideal. It appears that despite policies and best practices that encourage transitional aged youth participation, participation continues to be a term that is easily thrown around but rarely operationalized. Although the new *Protocol* established in Ontario, Canada, appears hopeful, the question remains whether history will repeat itself, and youth will continue to be passive members of their transition planning teams. It is therefore the goal of the present study to examine ways to ensure that transitional aged youth are active participants in their transition planning process.

Researcher's Perspective

It is important that I now acknowledge my researcher perspective, as it influences all aspects of this study. I am currently a student in Applied Disability Studies at Brock University, and have a passion for working and advocating with individuals with intellectual disabilities.

Throughout my undergraduate degree, I was president of a charity and club called Best Buddies Brock University. The mission of the club was to create meaningful friendships between Brock students without intellectual disabilities and community members with intellectual disabilities. My experiences during this time led me to realize that these individuals were often not given the opportunities to make choices in their everyday lives despite their obvious ability to do so. During this same time, my cousin began his own transition from high school to adult life. This was a stressful time, and it quickly became obvious that the current system was failing my cousin. It concerned me that at the very time my cousin required additional supports, his choices were being limited. This led me to think about his future, and what possibilities existed. For me, his choices seemed endless. However, I was quickly brought back to reality during a dinner discussion in which my aunt revealed no plans has been established for my cousin after graduation. Throughout this discussion, it became obvious that the choices available were limited, not limitless, and that his transition plan was based on pre-established services, not his individualized needs. I began to wonder how involved my cousin truly was in his transition meeting. I also wondered how service providers ensured that his goals and interests were being met, as my cousin is non-verbal. These questions have led me to where I am today.

Methodology

Theoretical Framework

The current study was informed by the perspective offered by the theory of emerging adulthood because it recognizes the transition to adulthood as a distinct period in the life course that is in many ways different from the adolescence that comes before it and the young adulthood that follows it (Arnett, 2000). It is proposed that this is the age of identity exploration and the age

of possibilities (Arnett, 2007). This is important when examining the experiences of young

people with intellectual disabilities during this time period, as the same opportunities to make

life choices and decisions that are provided to neurotypical youth are not being made available

for transitioning students with intellectual disabilities.

　　　　The theory of emerging adulthood provides a way to interpret the experiences of young

people as it attempts to explain the experience of trying to find a place in the adult world (Arnett,

2007). The theory of emerging adulthood further recognizes the unique diversity of this time

period and even claims that it is defined by its heterogeneity (Arnett, 2000). It suggests that this

time period is when people are most likely to be free to follow their own interests and desires

(Arnett, 2000). When thinking of young people with intellectual disabilities in the context of this

theory of emerging adulthood it becomes a useful tool to understand how individuals attempt to

find independence and responsibilities. The diversity in the theory of emerging adulthood allows

us to examine the stories of these individuals not through the lens of their disabilities but,

instead, through a lens of a timeframe that is much different than any other time period in the

lifespan. It allows us to understand the complexity of this period in a young person's life and it

helps us to relate to the experiences that these young persons are going through.

　　　　In this thesis, a social model of disability studies lens was also employed. The social

model of disability views disability as a form of social oppression that is linked to issues of

equity, social justice, and human rights (Cameron & Moore, 2014). It is through a social model

of disability lens that it becomes clear that impairment and disability are not synonymous, but

rather it is the ways in which society "restricts [disabled persons] opportunities to participate in

mainstream economic and social activities" that cause an impairment to become a disability

(Oliver & Barnes, 2010, p. 548) The social model of disability bridges the gap between the

academy and the actuality of disabled people's lives, and aims to breakdown the societal barriers

that impede full participation (Cameron & Moore, 2014).   It also offers a distinct perspective

on how society excludes disabled people and how this exclusion can be challenged.   Further, a

social model of disability perspective allows for an examination of the societal barriers that

hinder persons with disabilities from being viewed as achieving adulthood status (Epp, 2003).

When used as a theoretical foundation, it allows us to understand the lack of participation and

involvement of transitional aged youth as a result of societal factors, not personal factors, and

provides us with insight on how to create change. Such an approach has the potential to be a key

influence on a variety of policies, including social policy, disability policy, and education policy

(Oliver & Barnes, 2010).

Purpose of the Study

        The goal of the current study was to examine the new Integrated Transition Planning

Process in the Niagara Region from the perspective of professionals who work with transitional

aged youth. The researcher sought to uncover what barriers hinder the effective implementation

and success of the transition protocol, and transition planning in general.   Further, it was hoped

that the study would explore how youth are currently involved in their transition plans, and

uncover how professionals could better include youth in their plans, if they were not currently

active participants. Through questionnaires, focus groups, and individual interviews, the

researcher sought to answer the following research questions: (1) What barriers hinder the active

participation of transitional aged youth with intellectual disabilities during their transition plans?

(2) What are ways to mitigate the barriers that are experienced when trying to authentically

include TAY in their transition plans? (3) What do community professionals see as missing

from the new transition process, specifically in regards to the role of the youth? (4) How can

professionals facilitate the active participation of transitional aged youth (TAY) during the

transition process? and (5) What would professionals like to know about the lived experiences of

youth and families during the transition process?

As previously noted, the current study emerged out of a previous research study (McKay,

2015) that examined how the right to participate in life decisions, as set forth by the UNCRPD

(2006), was being implemented for transitional aged youth with intellectual disabilities as they

leave high school.   There were many limitations to the previous study, including a small sample

size and the new protocol being in its infancy stages in the Niagara Region. As a result, the

current study was focused on building on the previous research in order to gain a greater

understanding of how transition planning was being done in the Niagara Region.

Given the recognized importance of including the voices of both families and youth, in

both the transition process and in research, the researcher had hoped to include these important

perspectives. The original goal of the current study was to move past the question "Are youth

involved?" and to work with professionals, families, and transitional aged youth to uncover and,

eventually, to create ways that youth could become active participants in their transition plans.

This goal was consistent with the new Integrated Transition Protocols, and with the current

direction of research, policy, and practice in the field. However, at the time of data collection for

the current study, the Transition Policy in the Niagara Region was still in the early stages of

implementation, and many families and youths were not yet benefiting from the new transition

policy. The goal of the integrated transition process is for each youth, ages 14 to 18 with a

developmental disability, to have a single, integrated transition plan that begins at 14 and is

updated annually to reflect the changing hopes, dreams, and circumstances of the youth. At the

time of recruitment, most youth referred for transition planning would have not begun the

transition planning process at age 14, due to a large number of youth being referred for planning and service limitations, and would have therefore not experienced the full range of potential benefits of the protocol. The researcher therefore concluded that it was neither ethical nor beneficial to speak with families and youth about a new transition policy that they had not yet fully experienced. The current study therefore examined only the perspectives of professionals who work with transitional aged youth. The implications of this are discussed in the limitations section of this study.

Research Design

This study was qualitative in orientation. Qualitative research is a broad approach to the study of social phenomena (Marshall & Rossman, 2016). Although there is no one agreed upon definition of qualitative research, it can be understood simply as social research that "is aimed at investigating the way in which people make sense of their ideas and experiences" (Savin-Baden & Major, 2013, p. 11). Although I was unable to ask about the personal experiences and perspectives of youth with developmental disabilities in the current study, I used a qualitative methodology to explore the ideas and experiences of the professionals and how they see youth participation during the transition process. Qualitative research is appropriate for the present study as the transition process is a complex issue that cannot be easily understood through quantitative research alone. It does not generally test for cause and effect, but rather seeks to learn about, describe, and explain an experience or situation from the perspectives of those involved (Savin-Baden & Major, 2013). Within quantitative research, researchers attempt to position themselves as objective outsiders and often ignore the biases they bring to the research. In contrast, qualitative researchers embrace and acknowledge their biases, and become important instruments in the research study (Savin-Baden & Major, 2013). There is no one way to

approach qualitative research, but rather one of its greatest benefits is its notion of choice and

variety of methods, approaches, and strategies (Savin-Baden & Major, 2013).

The current study is a pragmatic qualitative research study. Pragmatic qualitative

research is an approach that attempts to answer a given research question through the most

sensible and practical methods available (Savin-Baden & Major, 2013).   It is a philosophical

tradition that "asserts that truth may be interpreted in terms of the practical effects of what is

believed, and in particular, the usefulness of these effects" (Savin-Baden & Major, 2013, p. 60).

That is, pragmatic research is concentrated on the practicality or workability of the ideas or

principles. The purpose of pragmatic research is to link theory and practice and to focus on the

"what" and "how" of the research problem (e.g., in the current study, what are the barriers, how

can we better include youth). One benefit to using a pragmatic approach is that the researcher

chooses data collection and analysis methods that are most likely to provide insight into the

question being studied, without being constrained by one specific approach (Savin-Baden &

Major, 2013).

Participants

This study was focused on the perspectives of professionals who work with transitional

aged youth in the Niagara Region. As previously noted, the Integrated Transition Planning

Protocol is a tri-Ministry protocol that includes services supported by the Ministry of Education,

Ministry of Community and Social Services, and the Ministry of Children and Youth Services

(Ontario Ministry of Community and Social Services, Ontario Ministry of Children and Youth

Services, & Ontario Ministry of Education, 2013). This study, therefore, included participants

from each of the three Ministries in order to gain a holistic understanding of how professionals in

organizations that are supported by each Ministry implement the transition process, while

acknowledging that the transition process is a multidisciplinary approach to future planning for

youth with intellectual and developmental disabilities. The current sample was approximately

balanced with representation from participants who operated under each Ministry. In total, the

current study included the perspectives of 14 professionals who work with transitional aged

youth in the Niagara Region. Nine professionals participated in questionnaires, nine participants

participated in focus groups, and two professionals participated in individual interviews. It is

important to note that six of these professionals participated in two different data collection

methods (i.e. a questionnaire and a focus group). Including perspectives from the different

groups of professionals is consistent with the practices of a pragmatic research design, and

allowed for triangulation of perspectives to ensure accuracy and completeness in data collection.

A purposeful sampling strategy was used in order to recruit professionals who could

provide relevant information related to the TAY process in Niagara (Savin-Baden & Major,

2013). Participants were recruited through the Niagara Regional Committee on Transitional

Aged Youth and through that group to other professionals through a snowball sampling

technique. The Niagara Regional Transitional Aged Youth Committee consists of

representatives from a variety of agencies and schools that support transitional aged youth in the

Niagara Region. These individuals meet on a regular basis to discuss the procedures, obstacles,

and mandates of the transition policy and its implementation in Niagara. A snowball sampling

technique was also used in this study, where existing study participants recruited other

participants (Creswell, 2013). This technique was used as members of the Niagara Regional

Transitional Aged Youth Committee felt that their colleagues could provide additional insight

into the research and, therefore, they shared their recruitment packages with others. No

demographic information on participants is presented in this research in order to avoid the

possibility of any participants being identified in such a small professional community.

Procedures

      Data were collected through questionnaires, focus groups, and individual interviews.

      Recruitment. The researcher worked collaboratively with Contact Niagara for Children's

and Developmental Services (referred to as Contact Niagara in the rest of this document) , as this

agency plays a large role in the transition process in the Niagara Region. Contact Niagara is

responsible for organizing services for persons with intellectual disabilities in Niagara and acts

as the central registration point for young people requesting and requiring transition planning.

Contact Niagara professionals receive information from young persons, families, school boards,

and service providers who identify youth who require transition planning. When they receive this

information, they register the young person for transition planning and assist in identifying the

potential planning team members (Ontario Ministry of Children and Youth Services, Ontario

Ministry of Community and Social Services, & Ontario Ministry of Education, 2013). From

here, Contact Niagara completes an intake via telephone with the youth and/or guardian, and

then sends this intake to (1) the youth/guardian, (2) the Lead agency (the agency or school board

that brought the youth forward), and (3) the Planning agencies (the agencies or school board

involved with the youth who did not bring the youth forward). Contact Niagara also organizes

and leads the Niagara Regional Committee on Transitional Aged Youth meetings. For these

reasons, Contact Niagara was the gatekeeper for the current study (please see Appendix A).

      In February 2016, Contact Niagara distributed a questionnaire recruitment package via

email to members of the Niagara Regional Committee on Transitional Aged Youth. This

package included a letter of invitation inviting members to complete a brief questionnaire

(Appendix B), a consent form for the questionnaire (Appendix C), and the brief questionnaire (Appendix D).

The student researcher was later invited by Contact Niagara to attend a meeting of the Niagara Regional Committee on Transitional Aged Youth on April 5, 2016 to give a brief presentation on the study. The researcher distributed a recruitment package to committee members that included: (1) a letter of invitation inviting members to complete a brief questionnaire (Appendix B), (2) a consent form for the questionnaire (Appendix C), (3) the brief questionnaire (Appendix D), (4) a letter of invitation inviting members to participate in a one-hour focus group (Appendix E), and (5) the consent form for the focus group (Appendix F). This recruitment package provided committee members with the same recruitment material distributed in the email, as well as additional information on the focus groups. After the meeting, Contact Niagara distributed the recruitment packages again via email to the committee members. This was the same package that was distributed during the Niagara Regional Committee on Transitional Aged Youth meeting on April 5, 2016. This was done as committee members expressed an interest in having an electronic copy of the questionnaire and consent to complete and to pass on to colleagues. The recruitment material was distributed a total of three times: once via email prior to the recruitment presentation, once during the Niagara Regional Committee on Transitional Aged Youth meeting on April 5, 2016, and once after the Regional meeting.

During recruitment, the researcher emphasized that participants were not required to complete all aspects of the study. Participants could choose in which aspect they wished to participate. Further, participants were made aware that if they did not wish to participate in a focus group, but would like to participate in the study, an individual interview could be arranged.

Ethics. There were minimal ethical risks associated with the current study; however the following potential risks were identified: (1) participants feeling discomfort related to issues in the transition process with which they did not agree or about which they felt frustration, such as difficulties faced by youth and families with whom they work, and (2) the researcher was a volunteer at Contact Niagara, the partnering agency, which could have lead to employees of Contact Niagara feeling obligated to participate. Further, the Executive Director of Contact Niagara was also the chair of the Niagara Regional Committee on Transitional Aged Youth, and the researcher had previously attended committee meetings, which could cause committee members to feel that they must participate in the study. The faculty researchers also have a long history of professional work and research in the community of service providers for persons with intellectual and developmental disabilities in Niagara. It was possible that knowing the researchers may have encouraged some professionals to participate in the study; however, neither the faculty researchers nor the student researcher were in any position of employment authority in relation to potential community professional participants. Although both faculty researchers and the student researcher work in the field, and may have had prior contact with some or all of the individuals, no relationship that existed would coerce their participation or the research outcomes. The researcher also emphasized continuously to participants that participation was not mandatory, and that there would not be any consequences for not participating, or withdrawing from participating. The present study did not include persons who would be considered vulnerable, and therefore there were no ethical risks associated in this regard.

Despite the potential risks involved in the current study, the study provided professionals the chance to contribute to knowledge that could improve services for transitional aged youth.

Brock University Research Ethics Board clearance was granted for the present study (Appendix K).

Consent.

Professional questionnaires. All members of the Niagara Regional Committee on Transitional Aged Youth were provided with a consent form for the questionnaire via email (See Appendix C). If they chose to complete the questionnaire, they were asked to sign the consent and return it and the completed questionnaire to the researcher via email. As part of the consent form, professionals were made aware that this questionnaire would be used as part of an undergraduate's honours work as well as a master's thesis. The undergraduate student researcher, Cassidy Harm, had access to some of these data to use in a poster presentation for her undergraduate thesis course.

Professional focus group. Prior to the focus group, the researcher provided all members of the Niagara Regional Committee on Transitional Aged Youth with a copy of the consent form via email (see Appendix F). Those who chose to participate in the focus group were given a hard copy of the consent form prior to beginning the focus group. Each item was reviewed and all questions and concerns were answered. When the participants agreed to take part in the study, they signed the consent form and were once again reassured that their identity would remain confidential.

Data Collection.

Professionals.

A brief questionnaire (Appendix D) was distributed to members of the Niagara Regional Committee on Transitional Aged Youth in the winter of 2016. The purpose of the questionnaire

was to collect information about the challenges of inclusion in transition planning. Examples of questions include: *What barriers have you experienced when trying to include transitional aged youth?* and *Have you ever noticed a contrast between the wishes of the professional support team and the individual?* Nine questionnaires were returned to the researcher via email.

Two one-hour focus groups were conducted with professionals and service providers in the Niagara Region. A focus group is defined as "a gathering of a limited number of individuals, who through conversation with each other, provide information about a specific topic, issue or subject" (Savin-Baden & Major, 2013, pp. 374-375). Focus groups are commonly conducted in pragmatic research designs (Savin-Baden & Major, 2013). Focus groups were chosen as they are socially oriented and are often more relaxed than a one-to-one interview (Marshall & Rossman, 2016). This relaxed atmosphere often leads to natural forms of communication, including jokes, teasing and arguing, that are not often seen in other data collection methods (Savin-Baden & Major, 2013). Focus groups can encourage responsivity as one individual's comments often result in "a kind of chaining or cascading effect" (Savin-Baden & Major, 2013, p. 389). During the first focus group, which consisted of 7 professionals, the researcher introduced 6 questions and a research assistant served as a scribe (Appendix G). To ensure accuracy of the accounts, a voice recorder was also used. During the second focus group, which consisted of 2 professionals, the researcher introduced 14 questions (Appendix J). Two voice recorders were used in order to ensure accuracy of the accounts. It is important to note that the set of questions asked during the first focus group were different than the set of questions used during the second group (Appendix G & Appendix J). The implications and limitations of this will be discussed later; this occurred because of the shift of research focus previously discussed. Examples of questions asked during the first focus groups included: *If you could ask transitional aged youth*

any questions about their experience during the transition period, what would they be? and D*o*

you think youth and families experience the transition process in the same way? Examples of

questions asked during the second focus group included: *The Transition Planning Protocol*

Guiding Principles states that the planning process provides the person with choices to support

the development of self-determination and self-advocacy. (a) What choices are provided? (b)

How do you support this development? The questions asked during the second focus group were

the same as those asked during the individual interviews.

In addition to the two one-hour focus groups, two individual interviews were conducted

at the request of participants. The individual interviews followed the same protocol as the focus

groups, and participants were provided with a consent form for an individual interview

(Appendix H). The researcher introduced the 14 questions (Appendix J) and two voice recorders

were used to ensure accuracy. Examples of the questions asked during the individual interviews

were: *What do you think the role of the youth should be in a transition plan? From your*

experience, do you think this is typically done? (possible probe: please describe a typical

example of the role of youth in the process).

Organizational affiliations and length of service information are not reported to protect

the identity of participants who could be identifiable because they work in a relatively small

professional community.

Data Analysis

The information from the questionnaires was compiled on the computer. The questions

that yielded quantitative data, such as participants' perceived age of transitional aged youth,

were entered into an Excel Spreadsheet, and an average was calculated by taking the sum of the

number of years divided by the number of participants. The multiple-choice questions were also

entered into an Excel document, with a number 1 given for each item to which a participant responded with a check or answered yes. A percentage was then calculated by taking the total number of Yes answers for each option per question and dividing it by the number of participants. Dichotomous questions were also entered into an Excel document, and percentages were calculated by taking the total Yes answers to each question and dividing it by the number of participants.   Open-ended questions were organized by question, with each participant's answers being placed in a Word document under the corresponding question. These questions were then analyzed using thematic analysis. Similarly, the data from the focus groups and the individual interviews were transcribed and recorded on the computer in a Word document. These documents were then coded and analyzed using thematic analysis.

A preliminary deductive analysis of the data from Focus Group One was completed prior to any other data collection. From this preliminary analysis, it became clear that participants had identified that there were many barriers to the implementation of the Niagara protocol and inclusion of youth during their transition plans. Despite asking questions that pertained to the research question *What would professionals like to know about the lived experiences of youth and families during the transition process guided by the new protocol,* participants' responses focused on their experiences with the protocol and transition planning in general rather than the lived experience of the family and youth. As a result and based on this preliminary analysis, it was concluded that there were still many gaps in the current knowledge of the new Integrated Transition Process, and as a result, youth, and families may not have experienced the full benefits of the new protocol. This conclusion led to the decision to focus on the perspectives and experiences of professionals to gain a greater understanding of the new Integrated Transition Protocol As a result, a second set of questions was developed for use in Focus Group Two and

the Individual Interviews. The data from Focus Group One were included with the data from the

Questionnaires, Focus Group Two, and the Individual Interviews during the full analysis. The

preliminary analysis was used only to inform the decision to develop the new questions that

were used in Focus Group Two and the Individual Interviews. Once all the data were collected

and transcribed, they were analysed using thematic analysis. Thematic analysis is a useful and

flexible research tool that can provide "a rich, detailed, and complex account of data" (Braun &

Clarke, 2006, p. 78). It is widely used due to its ability to identify, analyze, and report patterns

of data (Braun & Clarke, 2006). It is defined as "the process of recovering the theme or themes

that are embodied and dramatized in the evolving meanings and imagery of the work" (Savin-

Baden & Major, p. 440). According to thematic analysis, the first step in the data analysis is to

become familiar with and immersed in the data by repeatedly reading the data and searching for

meanings and patterns (Braun & Clarke, 2006). For the current study, this was done by reading

the returned questionnaires individually, numerous times. First, deductive patterns were

highlighted within each questionnaire, and were then highlighted across questionnaires. Once

patterns were identified within and across all the questionnaires, the questionnaires were placed

aside and the same deductive analysis process was used with the focus group transcripts. The

transcript for Focus Group One was read numerous times, and patterns were highlighted and

noted within. Next, the transcript for Focus Group Two was read numerous times, and patterns

were highlighted and noted within. Once this was completed, patterns that emerged in both focus

groups were noted. The focus group transcripts and patterns were then placed aside. The same

process was used with the individual interviews where each interview was read individually

numerous times, patterns were highlighted and noted within each individual interview transcript.

Once this was completed, patterns across individual interviews were noted. Next, as per a

thematic analysis approach, codes were developed to organize the data into meaningful groups

(Braun & Clarke, 2006). These codes were developed by examining the highlighted patterns

within the different data collection methods. For example, patterns that were identified by

participants in the questionnaires were grouped together an appropriate descriptive code, such as

"age," was created. A similar pattern was later noted when examining the individual interview

data, and this pattern was therefore also coded as "age," however, these codes remained separate.

Once these codes were developed within each data collection method, the codes were compared

across methods and similar codes were grouped together. It is important to note that patterns did

not have to be present across all data collection methods to be developed into codes. From here,

the different codes were sorted into broader themes by examining the relationships between

codes, themes, and different levels of themes (Braun & Clarke, 2006). For example, the codes of

Youth, Families, and *Person Centred* were found to have a common theme of *Participation* and

have therefore been presented in this research as being a subtheme of Participation. Once themes

were identified, they were reviewed, modified, and defined, allowing for the development of a

rich description of the entire data set (Braun & Clarke, 2006).

A similar process was used to identify the inductive themes within the data. After coding

the deductive themes based on the questions asked, and previous ideas and concepts, it became

clear that there were also patterns within the data that were not simply responses to the specific

questions asked. These were issues raised by the participants. These patterns were highlighted

within the questionnaires, focus groups, and individual interviews, and then compared across the

questionnaires, focus groups, and individual interviews. Codes were then developed to organize

the data into meaningful groups by examining the highlighted patterns within, and then later,

across data collection methods. These codes were examined, and sorted into inductive themes and subthemes.

Results

These results are described, with representative quotations from participants, using the gender neutral "they" to protect the identity of participants. The data analysis produced seven major themes from both the deductive and inductive analyses. There were three major deductive themes that related to the research questions. These themes revolved around the barriers that impeded youth participation and transition planning in general, participation during the transition process, and the age at which transition planning begins. The four inductive themes included the transition ending when the protocol ends at age 18, the benefits of using an integrated approach to transition planning, moving past busy and safe and focusing on meaningful activities, and the new integrated process being the right process. First, the deductive themes will be reviewed, followed by the inductive themes.

Deductive Themes

Deductive themes are identified by coding and developing themes based on existing concepts or ideas (Fereday & Muir-Cochrane, 2006). The following themes were identified during the deductive analysis of the data: Barriers, Participation, and Age. Each theme then contained several subthemes. Each has been elaborated below.

Theme 1: Barriers.

 Analysis of the questionnaire, individual interview, and the focus group results revealed various barriers both to the participation of youth during their transition plans and to the implementation

of the new Integrated Transition Planning Protocol. Under the theme of *Barriers* the following

subthemes were identified.

       Youth's abilities. When asked what barriers service providers had experienced when

trying to include youth in their transition process, all participants who completed the

questionnaire indicated that the youth's ability to self-advocate was a major barrier that impeded

youth participation. Such a barrier was also noted by Participant One in the Individual Interviews

who stated that "[TAY] don't get to practice that self-advocacy.   I think that's something that is

missing in the protocol." Further, 66 percent and 78 percent of questionnaire participants

indicated that a youth's cognitive abilities and a youth's inability to effectively communicate,

respectively, were major barriers to the participation of youth during their transition meetings.

This finding was supported by both participants in Focus Group Two who noted that trying to

include a youth with limited communication in the transition process is "very hard. It really is

very hard." When asked how youth with limited communication were included in the transition

process, Participant One in the Individual Interviews noted that "I've had some students at the

table and basically they were there silent with their parent, and yeah, it's something that we need

to consider." Participant One in the Individual Interview went on to further discuss this

perceived limitation: "I had a young man… who could understand most of what went on but had

no verbal skills, and he couldn't indicate with eye gaze fast enough to keep up with the questions

in a typical meeting." When asked about how youth with limited communication participate

Participant Two in the Individual Interviews noted that "I would hope there would be someone

there to help them explain, unless of course it is the parent doing it, and the parent may not

always be very reflective of the youth's needs."

Despite these findings, 78 percent of participants in the questionnaire indicated that it was possible to determine what is authentically meaningful to the transitional aged youth. This was also reflected by both Focus Groups, and by the two participants in the Individual Interviews. For example, Participant Five in Focus Group One explained that…

> If you really listen, almost everyone communicates somewhat right? We worked with a young woman who didn't talk … and we'd go out with her – we'd walk in the park but there were times when there was just nothing. So, we were like – this is not enjoyable to you. Then we'd go on to the next thing and try something different each time but you'd return and visit the things that she liked – you don't stop trying.

Similarly, Participant Three in Focus Group One noted that "There's other small ways that [people] communicate that they're enjoying an experience or not." Participant One in Focus Group One explained that:

> I had a gentleman who was very similar to that [non-verbal], and it took a very long time – took me almost six months. I spent a lot of time going in and spending time with him in different environments and sort of picking up through his experiences of what he did, when he did it, who it did it with, and you could see what he liked and didn't like. A lot of conversations with different people who played an important role in his life. A very long process, but it can be done.

The Participants from Focus Group Two also noted strategies they used when a youth had limited communication, such as asking "people that know him really well or her really well" and "also talk[ing] about – how do you know she likes it? … So some of those questions – well she smiles, she's happy, she wants to go, she participates in it – so a lot of that non-verbal." Participant One in the Individual Interviews also noted a strategy when discussing the previous

example of the boy who could not follow via eye movements fast enough and explained that they "sat him down after [the meeting], and said 'okay, what do you think about this – here are your 2 choices." Participant One in the Individual Interviews further stressed the importance of "embedding those kinds of different things and visually reviewing things after, instead of just saying 'okay, we're done, see you in a year'."

Attitudinal barriers. Although not always explicitly stated by participants, a predominant theme from the current study was that societal attitudes and assumptions about disability were major barriers that hindered youth participation during the transition process. As noted by Participant Two of the Questionnaire, "community perceptions of people with developmental disabilities" is one barrier that hinders the transition process for youth. Although these attitudinal barriers are often unconscious to those who hold them, analysis of participants' responses made clear that the assumptions held about persons with disabilities by not only the community, but also by families and service providers, are often the biggest barriers to their participation. For example, as previously noted, all questionnaire participants expressed that a youth's cognitive abilities were a major barrier to their participation. Similarly, participants described finding it difficult to include youth with limited communication during the transition meetings, despite them potentially having other communicative strategies (i.e. eye gaze, as discussed by Participant One of the Individual Interviews). Although most participants agreed that it is possible to include youth with limited cognitive and/or communication skills in the transition process, the attitudes that it is "hard, very hard" (Participant One of Focus Group Two) and "a very long process" (Participant One in Focus Group One) are often bigger barriers than the limited skills themselves. Participant One of the Individual Interviews also discussed how at

times youth are unable to keep up with the meeting, and are not able to respond or identify their responses quickly enough. In this instance, the barrier is the societal expectation that communication and understanding should be immediate, rather than the youths' need for more time to process and communicate their thoughts.

Family perceptions of their disabled child's abilities were also noted a barriers, as explained by Participant Four of the Questionnaires who identified the following barrier to be particularly challenging "Families not ready to support their child to become a young adult with choices, rights and opportunities for growth." Participant One of Focus Group One felt similarly, and explained "… lot of parents don't see their son or daughter as a young adult" and followed up by explaining "sometimes families are that barrier between that person moving on – whether they want to move out of the house, or whether or not they want to learn how to take the bus to Toronto". Participant Four elaborated later on by explaining "… a lot of families take this leap to – well he needs 24-hour support – and I can tell you that probably 95% of the people I meet don't even come close to that."

Hegemonic norms also appear to be barriers that hinder youth participation. For example, Participant Two of Focus Group One explained

> We're recognizing that meetings don't work for most people. … Going for a walk with someone in a new location – you can learn so much about them. … it's about providing those different opportunities, and not just going – we're having a meeting and you go and you sit. When I first started I sat in a lot of Tim Hortons, and I don't know about you guys, but I don't sit in a lot of Tim Hortons any more.

Despite this recognition, other participants in the current study made reference to the typical meeting settings. For example, when explaining that plans must be person-centered, Participant

One of Focus Group Two noted "… we really have to engage the youth a little bit more in saying – this is your plan – who do you want sitting around the table" while later acknowledging that at times, youth are not able to sit through the entire transition meeting.

Families' desire for their youth to participate in typical activities, such as work, school, and volunteering also appeared to be a barrier. Participant Three of Focus Group One described sitting in a meeting where a service provider expressed that "for me it's really important to have a place to go Monday to Friday, 9 to 5, so therefore I think that's probably what your daughter would like". Participants in Focus Group One challenged this type of thinking and explained numerous times throughout the interview that youth "may not want to do those activities, or may not find them meaningful" and went on to further explain that everyone's definition of a meaningful day may be different.

Service limitations. Access to resources was also noted to be a barrier that impeded the active participation of youth, as noted by 78 percent of the Questionnaire participants. Similarly, 78 percent of questionnaire participants indicated that a lack of program availability was a major barrier. Fifty six percent of questionnaire participants noted challenges in communicating with other agencies and community partners to be a barrier, while 33 percent noted challenges in scheduling meetings to be a barrier.

Waitlists. Waitlists were identified as a major barrier to successful transition planning. Seventy eight percent of questionnaire participants identified that a lack of program/service availability was a major barrier to transition planning. For example, Participant Two in the Questionnaire noted that "children services end and adult services do not pick up where they left off, there is generally a waitlist for similar services" in their response to the question *list two barriers that you find particularly challenging*.

Participant Three in Focus Group One also touched on the frustrations that waitlists bring, and acknowledged that not only are there differences in child versus adult services, but also "if those services do exist in adult services, all of a sudden you're on a wait list for many years before you can get them. When they've just gotten off the children's waitlist and got them for a couple of years." Participant Two in Focus Group One further explained that there are not only longer waitlists for services, but also for funding, in their response:

> You start off with SSAH [Special Services at Home] as a child, and so the parents get
> used to that support, and then the child turns 18 and then you're on a wait list for Passport
> Funding and we don't know how long that's going to be because you guys don't really
> seem to need it – your child is fairly independent.

Participant One in the Individual Interviews expressed frustration with waitlists numerous times throughout the interview. For example, when asked *what emerges from a transition* meeting, Participant One in the Individual Interview answered "some agencies saying we have nothing to offer, we're just wait listing…and the waitlists are really frustrating for the parents." They later went on to explain that "it's not that I think they [service providers] don't give them self-advocacy, but if we're coming to a meeting in which they say you're on a waitlist for all of these services so we can't really talk about them because they're not really choices yet." When asked what they don't like about the transition process, Participant One in the Individual Interviews responded: "I find it frustrating that when we all sit at the table, some agencies just say 'well, we have a waitlist and we can't do anything right now.'."

Participant Two in the Individual Interviews did acknowledge the waitlists for services; however, this participant sees the transition process as an opportunity to find a solution to these waitlists. This was demonstrated in their statement "you've got this [TAY] plan that you've

worked on for the last 4 years and where can that be used right now while you're waiting for service."

Participants in the current study identified the following as barriers that impeded the successful implementation of the transition protocol, and the meaningful participation of youth during their transition plans: youths' abilities, service limitations, and waitlists. Participants felt that youths' abilities, particularly a youth's limited verbal communication abilities, presented a barrier to their participation during their meetings. Despite this finding, many participants acknowledged that there are ways to include youth with limited verbal communication abilities. Service limitations were also noted to be a barrier that impeded transition planning. Participants felt that there continues to be a lack of programming available, and that it is often difficult to communicate with other service providers and agencies. Waitlists were identified as a major barrier to transition planning, and to the successful inclusion of youth during transition plans. Participants felt that it was often difficult to plan during the transition process, as they felt there was nothing for youth to transition to. One Participant felt that the transition process was a good way to prepare for the recognized waitlists attached to adult Ministry funded services.

Theme 2: Participation

From Theme 2, Participation, there emerged the following subthemes: (1) *Different Perspectives*, including (1a) youths' and families' differing perspectives, (1b) youths' and service providers' differing perspectives, and (1c) families' and service providers' differing perspectives, (2) *Youth Participation,* (3) *Person-Centered Planning,* (4) *Family Participation*, and (5) *The Disconnect*.

Different perspectives. Although only 66 percent of questionnaire participants noted differing opinions among planning participants as a barrier to youth participation in the multiple-

choice section of the Questionnaire, further analysis of the data revealed that all questionnaire

participants noted that, at times, there were varying opinions between youth and families, youth

and service providers, and families and service providers.

      Youth and family differing perspectives. When questionnaire participants were asked

directly "do you see a contrast between the wishes of the family and the individual during the

transition process?", 89 percent of questionnaire participants indicated "Yes", they do see a

contrast between the wishes of the family and the individual. Similar results were seen in the

open-ended questions throughout the questionnaire. For example, when asked which barriers

were particularly challenging when including youth in their transition process, Participant Four

in the Questionnaire noted that a particularly challenging barrier was "families having different

goals and dreams for the child that their child does not want." This was echoed by Participant

Five in the Questionnaire, who noted that "Parents wanting one thing and the youth wanting

another" was a challenging barrier to including youth in their transition process. Participant Two

in the Questionnaire indicated that another barrier was "families' desire to have their child busy

every day versus the youths' desire to not be busy." Participant Two in the Questionnaire noted

that "often there is a disconnect" between the hopes and dreams of families and youth, and

further went on to say that "the individual may echo what their parents are saying but as they

learn to speak up for themselves, their wishes often do not coincide with their family's."

Participant Two in the Questionnaire later went on to explain that

        The definition of a meaningful day can be very different. Families tend to put

        meaning onto their loved one's day that is not actually meaningful. Families

        often want their loved ones to do typical activities such as work, school,

volunteering. Their loved ones may not want to do those activities, or may not

find them meaningful.

Participant Six in the Questionnaire responded "yes, often parents want to over-support youth or

have them 'busy' with activities that provide care and don't actually interest youth."

The different perspectives of youths, families, and service providers, were also

highlighted by the Participants in Focus Group One. For example, Participant One in Focus

Group One noted that

…a lot of parents don't see their son or daughter as a young adult. And they struggle

with allowing them personal growth to occur, and to encourage it and allow it to blossom,

and allowing them to fail. And I think that's one of the struggles that I have when I go in

and I offer support, because sometimes families are that barrier between that person

moving on – whether they want to move out of the house, or whether or not they want to

learn how to take the bus to Toronto, or whether or not they want to be friends with

someone maybe Mom and Dad doesn't like. But it's their choice not Mom and Dad's….

And I think Mom and Dad – they have a certain lifestyle in mind for their son or

daughter, but I mean in all reality, their son or daughter are going to be living – if they

don't have a full-time job – on financial assistance. They might not live in a really nice

place in town and they might not have the best apartment, but it's their lifestyle, not Mom

and Dad's.

Participant Four in Focus Group One also noted that

…you go into families who are tired and burnt out and they're not having those

conversations with their kids – the real conversations where they're sitting down and

really finding out – what are your dreams, what are your goals, what do you want.

Because so many families are just tired, and they feel as though they've been fighting. Participant Three of Focus Group One also explained that "it's a balance of trying to work with the families and understand the struggles that they go through and respect that – but at the same time having to be able to support their son or daughter in what they really want." Later, Participant Four of Focus Group One discussed many families want day programs for their child, and that

> Day programs are great – the parents say we'll drop Jimmy off at 9:00 and pick Jimmy
>
> up at 3:00 – but that's not what Jimmy wants. Jimmy wants to work and take the bus and
>
> do that kind of thing. And that's hard for parents – and sometimes it takes years – that
>
> the person is ready but you know… I bus trained a young woman for a year and a half,
>
> but really that last 8 months I bus trained her mom. And that's what I would say because
>
> she was fine, but I had to keep showing up at the spots and doing these kinds of things
>
> because it was the parent that was having a hard time with it.

Participant Two in Focus Group One suggested a strategy to ensure that the youth's perspective is always the first considered in the statement "share it with the youth, and then have them pass it on to the parents." This was echoed by Participant One in Focus Group One who suggested that we "start with talking to the youth first about what they want." Participant Two in Focus Group One echoed an earlier statement made by Participant Two in the Questionnaire when they explained that:

> A meaningful day for a person can be taught how to take the bus to the mall, have lunch
>
> at the mall with possibly meeting a friend or on their own – go to the Fairview Mall, go to
>
> the Y afterwards, doing something that is maybe an hour. [There is a] gardening group

right now running here and we're talking to the one gentleman's mom about how that

provides a meaningful day for him. He gets up, gets himself ready, watches wrestling or

whatever he does in the morning, gets on the bus, comes here, does gardening for an

hour, and then stays and has lunch for half an hour, and gets on the bus and goes home.

So that takes up about 4 hours of his day – so that is a meaningful day to him. And he's

so much happier than if he was at a program 9 to 5, because this is something he has

chosen, something he feels independent in doing… she's recognizing that having a

couple of those kinds of activities throughout the week provides a much more meaningful

day for him than coming to a day program, because he would be bored to tears in a day

program, but he's not ready for employment yet – or even volunteering for 4 or 5 hours –

that would just be way too much for him. So, it's recognizing, building all those little

transitions and making parents realize how big those are, how important they are, and

how much meaning it provides to a person.

Participant One in Focus Group One concluded this discussion by reiterating that "once again,

it's their [the TAY's] lifestyle, their life choices – not Mom and Dad's."

Participant One in Focus Group Two also noted that at times, there are different perspectives

between the wishes of the youth and their families. Participant One in Focus Group Two noted a

strategy for when these differing perspectives arise:

…we put it on the plan because we say to the individual that – everybody has a different

idea of what they'd like for you, so we're going to make a plan and then we'll talk to you

first and discuss it. And the thing is, even though Mom wants him to be in a full day

program, that can always be her want or what she thinks is best for him. But it's not her

plan. So we always have to go back to, and we're very careful about how we word things

so that everybody gets heard, but then it revolves around the goals that we have at the

end. And the goals obviously have to be about what the young person wants.

The responses above demonstrated that a particularly challenging barrier to ensuring youth are

active participants in their transition plans is that youth and families often have differing

perspectives. Participants explained how families want their youth to be "safe and busy," and

participate in activities that they themselves deem meaningful. Participants went on to explain

that at times youth have different definitions of what constitutes a meaningful day, and that their

vision for how they want to spend their days is quite different than that of their families.

Participants explained that it is at times difficult to balance the differing perspectives between

youth and families, but that in the end the goal of transition planning is to respect the goals of the

youth.

Youth and service provider differing perspectives. Questionnaire participants were asked

"Do you notice a contrast between the wishes of the professional team and the individual?" to

which 78 percent of participants responded "Yes." Service providers further noted that there are,

at times, disconnections between the perspectives of the professional team and the individual,

with Participant One in the Questionnaire noting that "historically, professional support was

about 'Health and Safety' first" and that "some professionals still see this as the #1 goal."

Participant Three in the Questionnaire further explained that "Professionals tend to promote what

they think is best for the person, particularly with youth because they are young." Participant

Seven in the Questionnaire noted that "yes" there are differing opinions because the "needs of

youth can be very complex and youth may disagree with the extent of support professionals feel

necessary to keep the youth/others safe/meet needs." When asked about the challenges in

inviting persons who are important to a youth to a TAY meeting, Participant Five in the

Questionnaire noted that a challenge is "the youth getting lost in the mix of 'professionals' who know what they should be doing and forgetting that it should be about what they [the youth] want to be doing."

Participants in Focus Group One also noted differences between the perspectives of service providers and youth. Participant Three in Focus Group One highlighted the importance of acknowledging the differences in their statement:

> It's pulling our values and what we think is right out of it, and it's very, very hard for people to do that. I sat in a meeting yesterday with someone who supports people and she said – well I know for me it's really important to have a place to go Monday to Friday, 9 to 5, so therefore I think that's probably what your daughter would like. And we have to pull back from those kinds of values and take ourselves out of it, and look at the person and see what they really want. And that's hard to do. It's hard to do because we do it sometimes without realizing we're doing it.

The responses from the Questionnaire highlighted the fact that service providers, often with the best intentions, try to promote services and options that they believe are best for the individual. However, at times the desires of service providers do not align with the desires of the youth who is transitioning. Participants stressed the importance of remembering that transition planning is about the youth and the youth's goals.

Family and service provider differing perspectives. When asked if families and professionals sometimes have different wishes for the transitional aged youth, 100 percent of participants indicated "Yes" families and professionals sometimes have different wishes for the youth. When asked about the differing perspectives between families and service providers, Participant Eight in the Questionnaire indicated that "often, they [families] want us [service

providers] to protect the youth and stop them from making decisions that are bad for them. The youth wants to exercise their right to make their own decisions."

Participants recognized that the wishes of the youth are often different than the wishes of their families, and of their service providers. Similarly, it was recognized that families and service providers also have differing perspectives at times. Participants felt that families and service providers, with the best intentions, place meaning on activities that often are not meaningful to a youth, and place a strong emphasis on the need to "protect" and keep youth "busy." Participants noted that youth may have a different definition of a meaningful day and may not want to always be busy, and that it is important to focus on what is meaningful to youth, while still respecting the concerns of families.

Youth participation. All Nine participants in the Questionnaire noted that youth are involved in their transition plans. These participants acknowledged the importance of youth participation in their written answers to the open-ended questions. For example, Participant Eight in the Questionnaire explained that you must "include youth in all meetings. Meeting without them is counterproductive and unfair." Participant Nine in the Questionnaire echoed this importance when they noted that we must "always involve the youth in the process. Involve them in discussions, always checking in with the youth asking for their input and feedback…never have a planning meeting without the youth present." Despite this recognized importance of including youth, when questionnaire participants were asked "*If you could ask transitional aged youth any questions about their experience during the transition process, what would they be?*" many participants asked questions about youth participation. For example, Participant One in the Questionnaire asked "Do people ask you what is important to you, what makes a good day, what your goals and dreams are? Do they get to know you? Are you a part of

the planning meetings? Do you have a say as to who attends a meeting? Do you think people

listened to you?" Participant Four in the Questionnaire asked "Did people listen to what you had

to say? Did you participate in the planning?", whereas Participant Seven in the Questionnaire

wondered "Did you feel heard?" and Participant Nine in the Questionnaire asked "Did you feel

that you were an active participant in the development of the plan? Did you feel that your

thoughts, opinions, and suggestions were listened to and were reflected in the plan?" These

responses demonstrate that although participants recognize the importance of youth participation,

they are uncertain about the degree to which youth feel heard, respected, and included.

Although 100 percent of participants in the Questionnaires noted that youth are involved

in their transition process, Participant One in Focus Group One explained that "…for some of the

people I've supported, they haven't been included in those transition meetings. It's Mom and

Dad, and the teacher and the principal and that's it…. he wasn't even there and he's saying – but

I didn't even do any of these meetings – that's not what I wanted." Participant One in Focus

Group One also acknowledged that youth may not always be involved, as seen in their statement

"I can personally tell you that I don't have a meeting about an individual unless that individual is

with me. And I have fought other agencies on this, and said nope, I won't be there if they're not

there, because why are we doing this." Participant Three in Focus Group One explained their

approach to including youth in meetings when they said

> … one of the biggest things I say is that you have the right to say no. If you don't want
>
> to do this, I'm not mad. And I know in my initial meetings … one of the things that
>
> comes out of my mouth is – when we work together, you're the boss. I'll listen to Mom
>
> and Dad, we'll take the information because they know you really well and I don't – but
>
> you're the boss. If you say no, it's no – we don't do that.

Participant One in Focus Group One also discussed a strategy to ensure that youth are participants in their transition plans when they explained:

> I think the important thing though with you saying that is having that person involved, and if they can only handle a 10 minute meeting and you need to have six 10 minute meetings, then have six 10 minute meetings. So, they understand that it's about them…. And 99% of the time, that individual, because you're making it positive, will sit through that entire meeting. But you have to let them know – this is about you, these are your life choices, so let's go, let's do it…you have to remember that it's not about us, it's about them.

Participants in Focus Group One also went on to further explain that participation doesn't end when goals have been identified. For example, Participant Five in Focus Group One explained that

> We don't just listen to them – okay, that's great to have those hopes and dreams, yay! We do something with it. Even if you have this great grandiose hope and dream that everyone is rolling their eyes at and going "that's not going to happen", it's what small steps can you take towards it, and we follow through. And then that makes a huge difference in getting to know the person and for families to open up to us and what really helps with that transition is that we actually do something with it, right. Show them what's out in the community and follow through.

Participant One in Focus Group One later stressed that participation doesn't end in their statement:

> …and then checking in with them once that's [their goal] been identified, and once again, person-centred – asking what is working and what is not working. That constant check-

in to make sure that they're…not going and having a job weaving something that they

dislike because they think that's where they should be and they have no other choice.

comes down to conversation.

The participants in Focus Group Two explained how they ensure youth are participants in

their transition plans throughout the focus group. For example, Participant One in Focus Group

Two explained that "if we can give them a little bit of what they're asking for in the plan, that

gives them that sense of – yes, I can do it." Participant Two in Focus Group Two went on to

further explain

> like if they want to go to college … that would be on the plan. If this is your goal to go to
>
> college, these are the little steps to call the college, look the program up, see if it's what
>
> you're looking for. So, it's those little steps to get to the big step.

Participant One in Focus Group Two echoed this when they stated

> or just like somebody wanting to get their license. They may not get their full license,
>
> but if they can get that book and start practicing – you know … sometimes you don't
>
> have to do the whole thing, but just being able to do part of it.

When asked what the role of the youth should be during the transition meetings, Participant Two

in Focus Group Two explained that youth should be "front and centre" and went on to explain

"when we sit at the table we always – like if the parent is talking – we always turn to the youth

and say – do you agree with that, what do you think? So they have a voice." Participant One in

Focus Group Two, however, did acknowledge that

> sometimes … youth are not always as involved as they should be. I think … it's just
>
> going to take some time for everybody to understand that it's not your plan,… – it's [the

youth's] plan. And we really have to engage the youth a little bit more in saying – this is

your plan – who do you want sitting around the table?

Participant Two recalled

I've been at plans that the parent has said they [the youth] don't think they're special

needs …they're not going to come because they're not special needs…. So, we go with

just the teacher, the parent and I have sat …we just do it without him. It's sad, I don't

like it, but sometimes just to complete that plan you have to move on.

Similarly, when asked if participants in Focus Group Two felt as if the conversations were still

dominated by others, rather than the individual, Participant Two responded "I still think it's other

dominated mostly", and Participant One responded

I do. … I've been to meetings where the individual isn't there, ones where they're just

there at the beginning, and I've been to ones where they've been there the whole time and

they're involved – but I find it's still a work in process.

Both participants in Focus Group Two also acknowledged that, at times, youth are unable to sit

in the entire transition meeting but that "sometimes too with those kids or young people, just

have them sit in on the good things that other people say, because we all benefit from that piece,

and then move on with your day" (Participant One, Focus Group Two). Participant One in Focus

Group Two also noted that they would like to hear more from the youth, and explained that

"we've never really reviewed the youth to say – okay, we've done this plan, how does it make

you feel? Do you feel like you are going to move forward in your life – which really makes a lot

of sense."

Participant One in the Individual Interviews had slightly different answers than those

above, and explained that "every meeting I've been to, the [youth] hasn't been there." They

went on to further explain that "I think that is something missing in the protocol- that the message is not strong enough that the kids should be at the table, and for the meetings I've been to, they have not." When asked "how do you ensure that the youth are able to express who they would like to be involved in their transition process" Participant One in the Individual Interviews responded

> …we let the family determine what that looks like, because we don't know who the aunts and uncles are, or if there is a significant family friend or pastor, or anybody, right? So, we say to the family, "you're invited to a TAY meeting – our staff will be there and you bring along whoever you would think needs to be there." But I don't think we specifically say "ask your son or daughter to say who needs to be there."

Participant Two in the Individual Interviews emphasized that an Integrated Transition Plan is "youth driven, family driven" and revolves around "what kind of things they [the youth] want to accomplish while they're still adolescents, and then beyond that." This Participant also emphasised that youth should be "front and centre in identifying what they want for the long term." They acknowledged that in order to ensure the hopes and dreams of youth are being met, we must "…touch base with the youth to say - How are we doing? Is this something that you want to continue doing? Are you liking this? Is this something you can see yourself doing for another period of time?" Once again, despite this acknowledged importance of youth participation, when asked whether this follow through to ensure the hopes and dreams of youth were being enacted, Participant Two in the Individual Interviews responded, "I would probably say it's not." Further, when asked if they believed youth are "front and centre" in their transition plans, Participant Two in the Individual Interviews noted that

…60-70 percent of the time, I do believe the process initiates this way. Like I think that's

the whole point of it, you sit there and you do want to hear all the perspectives and you

want the youth to be the centre of the planning team. So you do want to hear what

they've got to say. I think that as it plays out it's probably more restrictive and then

people sort of end up in stereotypical authoritarian type roles.

Later, Participant Two in the Individual Interviews went on to say, "I think the skeleton is there

in theory and is a good intention to plan, but I don't think it's drilling down enough to make sure

that youth is always the centre." When asked about the types of choices provided to youth,

Participant Two in the Individual Interviews explained that

the plan involves the step-by-step, the youth should be identifying – this makes sense, or

I like that or not, I don't want to do this, this isn't my choice – so they can advocate on

that level. Over the transitioning of the years to say this goal didn't work for me, I'd like

to try something else.

Participants in this study recognized the importance of youth participation during the

transition plans, and many acknowledged their attempts to include youth in the process.

However, participants agreed that despite knowing that youth should be "front and centre," youth

are not always active participants in their transition plans and, at times, do not even attend their

transition meetings.

Person Centered Planning. This approach to planning places the individual at the

center of the planning and is based on making determinations that the individual, with support

from family and friends (Ministry of Community and Social Services, 2013), has set as goals.

Almost all participants discussed Person Centered Planning in their responses, with most

acknowledging that this was a useful way to ensure that youth were active participants in their

transition plans. For example, in response to question 10 in the Questionnaire, which asked

participants "*How can service providers ensure that the focus is on the actual wishes of the*

individual and not a third party?" Participant Two in the Questionnaires responded "Using

Person Centered Planning can help keep the focus on the person. Taking time to really get to

know the person in places the person feels comfortable as well as trying new things. Having real

conversations and not questions/answer meetings with the person." Similarly, Participant Four in

the Questionnaire responded "Having an annual Person Centred Plan…Educate and inform the

young adult that it is all about them, and the goal has to be something they want and that they

[can] change or stop working on a goal at any time. Their voice is the most important."

Participant Six in the Questionnaire responded to the same question "Person Centered Planning

to determine best supports. This considers both what's important to the person as well as what's

important for them (health and safety)" and Participant Three in the Questionnaire stressed that

we must "remain person centred no matter what." When asked "*What could be*

changed/included to help reduce the barriers experienced during the transition process?"

Participant One in the Questionnaire suggested "the school system adapting a more Person-

Centred Approach with youth and families. Students being asked questions early on – what

makes you happy? What would you like to be one day? What scares you? Etc. One page profiles

and planning on a yearly basis."

      Specific reference to Person Centered Planning occurred only three times throughout

Focus Group One: once when Participant One commented "…and then checking in with them

once that's [their goals] been identified," and once again, "person-centred – asking what is

working and what is not working." In another instance, Participant One in Focus Group One also

explained that

We can come up with a plan for them, but there's no support to follow through on it.

You come up with this great person-centred plan, and well, there you go, go do it. Well,

who's going to do it? [There was] a man who had been living in a nursing home with his

parents and his parents died. And the nursing home was like – he's 40, what do we do

now? And his family was like – this is ridiculous – he's 40 and living in a nursing home.

But nobody ever put a plan into place for him.

Participant One from Focus Group Two discussed how they used the principles of

Person-Centred Planning, as recommended by the Ministry of Community and Social Services

(Ontario Ministry of Community and Social Services, 2013), when they are the Lead in the

transition meetings. Participant One elaborated that,

when we're the planners, we also do the person-centred plan… . We ask the same

[Person-Centered] questions, but everybody has a different idea of who this young person

is, so … we record all that information, and that's what goes on our integrated transition

plan. Then we have the meeting, and if we've missed anything or [professionals] want to

put anything extra into that plan, then we add it in at that time.

As previously noted, Participant One in the Individual Interviews did not feel that enough

emphasis was placed on the importance of youth participation in the transition protocol. In

response to this statement, I asked "Do you believe that the current transition planning principles

are consistent with the Person-Centred Plans?". This Participant responded

Not now. Even when I go to [some agencies], it depends on which [agency] is at the

table. Some say "can Johnny come in and join us?", and others say" we're just going to

meet right now get this done", if they're lead. So I think that's an area where we're very

weak, and we need to work on – and like I said, that's an area that kids need to practice

because if you don't give them the opportunity to practice it, they'll never be able to

understand what it's about. I've been in meetings where kids have come in – just one

meeting – and that [youth] was terrified.

Participant Two in the Individual Interviews also noted that "…the transitional aged youth

principles are similar – the desire to have people focus on what's right for them, that they're the

centre of any decision for their life."

Participants in the current study felt that using a Person-Centered approach during the

transition plans was one way to increase youth participation. They felt that using this approach

would ensure that youth are at the centre of the plans, and that their goals and wishes were

identified. Some participants noted that they already use Person-Centered planning during the

transition process, while others commented on the lack of follow through after a Person-Centered

plan was developed.

Family participation. Most of the participants in the current study acknowledged that

the family plays an important role in the transition process. For example, when participants in

the Questionnaires were asked "*If you could ask families any questions about their experience*

during the transition process, what would they be?" Participant One in the Questionnaire

wondered "Do you think you were heard?", Participant Four in the Questionnaires asked "Did

you find it useful? Did you learn anything new about your child? What did you think about the

transition process?", and Participant Seven in the Questionnaire asked: "Do you feel you

thoroughly understood processes/services – if not, how could this improve?" Participant Six in

the Questionnaires also acknowledged that although "the youth's opinion is central, it is

beneficial to include the family and let them know that service providers are also listening to

them." In their response to the question "*Do you think it is possible to determine what is*

authentically meaningful to a transitional aged youth?" Participant One in the Questionnaire also

acknowledged the importance of families noting that we must "support…families to really

communicate with their child, I feel [this] will make a difference when it comes to finding out

what a person really wants and desires."

In Focus Group One, participants discussed the struggles of families who are trying to

participate in the transition planning process. Participant Three in Focus Group One noted:

> Sometimes the parents themselves have disabilities or mental health problems, and the
>
> information goes home from the schools, but they don't follow up with it and then they
>
> lose school – so now what do we do? And they feel like they don't have any part in that
>
> transition process because they didn't really know that it existed.

Participant Four in Focus Group One later explained that "it's a balance of trying to work with

the families and understand the struggles that they go through and respect that – but at the same

time having to be able to support their son or daughter in what they really want and that kind of

thing, right." Further, Participant Four in Focus Group One recalled the following:

> I've said to parents recently – I'm here to support your son or daughter – I will consult
>
> with you because you need to be a part of the bigger picture - because at the end of the
>
> day it is their families that are there for them … it's about your son or daughter, and what
>
> they want and what they need.

Participant Three in Focus Group One also discussed "helping families think outside the box"

and acknowledged "that [the] knee-jerk reaction is Ministry funded supports [such as day

programs and sheltered workshops] – they [parents] always seem to go to that." Participants

discussed how families must also play an active role in the transition process, and advised that

families "start those connections as early as possible."

When completing a transition plan for youth who do not use verbal communication, Participant Two noted that they tend to take the information from "the parent." While Participants in Focus Group Two acknowledged the importance and role of family, they also made clear that the youth's perspective should be consulted at all times. Participant Two in Focus Group Two explained that "when we sit at the table we always – like if the parent is talking – we always turn to the youth and say – do you agree with that, what do you think."

When asked *What is a Single Integrated Transition Plan?* Participant One in the individual interviews responded: "For me it's about when agencies can gather at the table and each have their points of view recognized for the family – it's a family perspective." When later asked what the implications of doing this type of planning were, Participant One in the Individual Interviews explained that "it helps educate the parents." Participant One in the Individual Interviews later went on to explain that what emerges from a transition meeting can be quite frustrating, as seen in their statement

> …I think for families, I really feel for them, because when they look at that TAY letter that says that these are all the wonderful things we can do – so for them it's a magical thing – we're going to get all these people together at a table and you're going to say you can do summer camp, and you're going to say you can do employment, and you're going to say you can earn a credit in phys ed, and sometimes we just aren't there yet. And the wait lists are really frustrating for parents.

When asked *How do you ensure that the hopes and dreams of the youth are being met?* Participant One in the Individual Interviews explained that "every meeting I've been to, the student hasn't been there." They went on to explain how "for a variety of reasons, some of

which is the parent would prefer that they not be there because you're going to be talking about some pretty brutal things like level of functioning and abilities, and strengths as well, but still it can be a bit of a downer."

Participant Two in the Individual Interviews discussed how an Integrated Transition Plan "has to be youth driven, family driven" and explained that an advantage of starting the process at 14 was that "it allows us to see if there are services or supports that have not been included or that the parent wasn't aware of." In response to the question *How do you ensure that the youth are able to express who they would like to be involved in their transition process?* Participant Two in the Individual Interviews explained, similarly to Participant One in the Individual Interviews, that "I do ask the parents to start thinking about, you know, Pastor X or anyone else in the community who might be important to this youth." Participant One in the Individual Interviews went on to later explain that although we have made great strides in putting the youth's perspectives in the centre of the plans, they think that the plans are "still lead by a lot of adults involved in the youth's life."

An interesting finding emerged from this theme, as the role of the family differed between participants and appeared to be influenced by the Ministry that funds their programs. This finding will be discussed in greater detail in the discussion section of the paper. In general, participants acknowledged that families play an important role in the transition process, and some acknowledged that families continue to play the dominant role during the meetings, despite the recognized importance of having these plans be youth driven.

The disconnect. Participants felt that there was often a disconnection between the wishes of the youth and their families, one that wasn't always obvious at first. This was highlighted by Participant Two in the Questionnaire who explained that the disconnect "may not be apparent at

first. The individual may echo what their parents are saying but as they learn to speak up for themselves, their wishes do not often coincide with their families." Participant One in the Questionnaire also explained

> Families need more education in regards to their son/daughters from a very young age…supporting families to really communicate with their child, I feel, will make a difference when it comes to finding out what a person really wants and desires. The people we support will learn what it is like to answer questions based on how they feel, not how they want others to feel.

Participant Three in Focus Group One also explained that at times

> everything falls apart because people end up doing things they don't want to do. And then the parents are frustrated, the service providers are frustrated because they're like "well, they want to do that", and it's like "well no" – because that's not really what they wanted to do. They were pleasing you because that's what they're used to doing, and they're used to nodding and smiling and saying yes, that's okay – that's what Mom wants and I'm going to do it for Mom.

Participant Five in Focus Group One went on to further explain that

> that's just the model from school. We have a model student who sits there and you're good and you don't say anything so you're the model student. They're trained to be compliant and passive, and when you ask them what they want they really have no idea of that concept of their own rights and making their own decisions.

Participant One in Focus Group One also discussed how this need for approval transfers to the youths' interactions with service providers, in their statement:

and they look to us for approval, right? They're like – I want to do this – is that okay?

I'm like – I don't care, it's not my life. …so many people we support have been told

their whole lives what they can and cannot do, and then they come to us and we say that

you can do whatever the heck you want, but they don't know where to start. They don't

know what to say, what to do – and they're like -I want a job because that's what my

brother is doing…– they got a job, they got their G1, I want my G1. And when you make

them realize all of a sudden, they can take the bus they're like – I don't really need my

G1. I don't need to get a job because I have things that fulfill my life.

Participants acknowledged that, at times, youth and families appear to have the same

desires but that once youth learn how to self-advocate and participate in a meaningful way, their

hopes and wishes are much different than those of their families. Participants stressed the

importance of teaching these skills to youth, and allowing youth opportunities to practice their

skills.

Overall, participants explained that there are, at times, differing perspectives among all

involved in the transition planning process including youth and families, youth and service

providers, and families and service providers. Further, they felt that although youth participation

is important and that youth should be included in their transition plans, there are times when

youth do not attend transition meetings, and that transition plans continue to be dominated by

others (i.e. families or service providers) rather than by the youth. Person-Centered Planning

was suggested as one way to ensure youth are actively participating in their transition plans and

some participants noted that they are currently using a Person-Centered approach during their

meetings. Some concerns emerged related to the follow through on the Person-Centered plans.

Participants acknowledged that families play a crucial role during the transition process, and that

it is often difficult to balance the youths' wishes with the desire of parents to keep youth busy and safe. Participants further discussed that there is, at times, a disconnection between what the youth say they would like to do, and what they would actually like to do. Participants suggested that this occurs because the youth have not been provided with sufficient opportunities to learn, or practice, self-advocacy skills and meaningful participation.

Theme 3: Age

Most participants reported that transition planning should begin earlier than the currently mandated age of 14. Participants in the Questionnaire felt that beginning the transition process earlier could potentially reduce the barriers associated with youth currently not being active participants in their transition plans. For example, when asked how to reduce the barriers, Participant One in the Questionnaire responded: "students being asked questions early on…starting with this as soon as possible (I say before grade 9)." Participant Five in the Questionnaire echoed this answer in their responses to the same question, which read "earlier planning for what comes after high school." Participant Nine in the Questionnaire also felt that "We are starting the process at age 14 and at an age the youth are just starting high school and have to adapt to a lot of changes – a new peer group, a new school environment, new teachers." Participant Two in the Questionnaire also felt that we should be "educating families about how they can help prepare their youth for adulthood" and went on to explain that "this has to start at a young age." Participant One in the Questionnaire also felt that "if people were being asked at a young age what they really want and provided the same opportunities as other young people, they would learn about themselves and their confidence would be elevated." Participant One in Focus Group One also commented on the idea of starting to prepare for the transition at an earlier age and suggested

…families need to start those connections as early as possible. So, when they are in

grade 7, get them to maybe join some sort of club in the community, whether it's an art

class or a library class or some sort of organized sports. Get them to volunteer. So that

when their sons or daughters are growing up, at least they've got those connections,

they've built those relationships, and also the confidence right?

Participant Four in Focus Group One agreed with this and went on to later state

I think too that they need to start having these planning meetings for their children at a

much younger age, like it needs to start quickly where they're pulling in all the support –

whether it's neighbours, whether it's coaches and teachers and daycare. And having

everybody there together with of course the child in the middle of it. And start that

planning and thinking outside the box – how can we support – so by the time they get to

be 18 or 19 years old, there probably is a plan in place – because you know we change

over the years and things happen and people come and go in our lives, but at least there's

something there, and a vision.

When Focus Group One was asked *If you could design a new transition process, what would it look like?*, in their answers respondents emphasized their desire for the process to begin sooner. Participant Five in Focus Group One responded "Wow – start earlier. Start in SK and JK", to which Participant Two in Focus Group One added "I would start from birth!" and Participant Four in Focus Group One jokingly stated "in the delivery room!".

Unlike the Participants in Focus Group One, the Participants in Focus Group Two felt that starting the transition process at 14 was a good age. This was demonstrated in their responses "I think 14 is good. They're in high school" (Participant One Focus Group Two) and "Yes, I think it's a good age" (Participant Two Focus Group Two).

Participant One in the Individual Interviews also felt that the transition process should start earlier, as reflected in the response to the question *Are there steps that you feel should be taken so that we can increase youth participation and inclusion during the process?*

Well I'm wondering if we need to start before high school. So that kids that are in grades 7 and 8 start to be exposed… so that they can practice in a little bit more of a sheltered situation before they are thrown into the whole TAY thing.

Participant One in the Individual Interviews went on to later explain what changes they would make if they were to design a new transition process: "I think it should start younger…maybe 10, 11…because families need to start to think. They think, oh it's years before they graduate, but that comes so quickly and all of a sudden there's nothing in place."

Participant Two in the Individual Interviews also felt that the transition process should begin at an earlier age, as demonstrated in their response:

I think it should maybe begin a little bit younger because if they are 14 they are typically in grade 9 and that's an adjustment in of itself. Families are adjusting, the youth is adjusting and everything is new. I would hope that it happens in grade 8, so maybe not even an age, but a grade. So. grade 8 – there are some youth who are 14 in grade 8. So, then you have some kids in grade 8 and some kids in grade 9 and a totally different transition process just because of their age, you know like being in March versus October it impacts when they're planning is done. So. I would think grade 8 would be the best time.

In general, most participants felt that the transition planning process needed to begin earlier. Some noted that this would allow for more opportunities to practice participating,

whereas others commented on how this was already a stressful time in a youth's life and

beginning earlier may help to reduce this stress.

Inductive Themes

In addition to the three deductive themes discussed above, namely, (1) Barriers, (2)

Participation and (3) Age, the following themes were identified during the inductive analysis of

the data: (4) The Transition Ends when the Protocol Ends, (5) Benefits of an Integrated

Approach to Transition Planning, (6) Safe and Busy versus Meaningful, and (7) It's a New

Process but the Right Process. Inductive themes are themes that are identified from participants'

discussions and are not based on previous concepts or ideas (Fereday & Muir-Cochrane, 2006).

Each theme then contained several subthemes, as described below.

Theme 4: The transition ends when the protocol ends.

The following subthemes emerged under the theme of The Transition Ends when the

Protocol Ends: The Protocol ends at 18 – for some but not all Agencies, The Gap in Services and

Funding, and The Realities of Adult Services are Unknown to Many.

The protocol ends at 18 – for some but not all agencies. Although the TAY Protocol

in Niagara ends at age 18, 67% of participants in the Questionnaire felt that the term Transitional

Aged Youth encompasses youth up to age 30. Perhaps as a result of this arbitrary age cut off of

18, many participants expressed frustration with the TAY process being over when a youth turns

18. For example, Participant Two in Focus Group One explained that "[Adult services] can't

start [transition planning] until their [the youths'] last semester of school, when [service

providers] can meet them and start getting to know them." Participant Two of Focus Group Two

also commented on this and explained "right now we're discharging at 18 where the school can

keep them 'til 21 … [the school] can continue with them, and it's not cut off at 18, where

[agency's] is a final one [plan], just before their 18th birthday." Participant One in the Individual

Interviews also felt this gap and commented "a school board …can continue on until the students

are in their 21st year – so then [there is] … a little bit of a black hole there in the middle of it all,

where nothing happens." Later, Participant Two in the Individual Interviews commented:

> … [TAY] plans are not currently being looked at or considered, or they're just being
>
> passed around and by the time they become an adult it's just not information that's being
>
> used. I don't know if the parent or youth aren't fully aware of that.

In response, I asked *Can you elaborate a little bit on that? It sounds like from what you're*

saying that we're planning at 14, we go to about 18 with the planning and that's when the

protocol stops; therefore, that's when the planning stops? to which Participant Two in the

Individual Interviews responded:

> Yes, it's more around all those years of investing time and effort to say what does this
>
> person like or want, and then when you get to that age where they're no longer getting
>
> children's services all of that work is not being considered...

I then followed up with the question *What happens at 18 for youth*?, to which Participant Two in

the Individual Interviews responded that…

> they have to start from fresh right – with the Adult Developmental Services. The school,
>
> they can continue and the transition still happens... But beyond that all their Children's
>
> Services are gone and they have to start up again, and they may lack the formal supports
>
> so they need to look at what's informal.

Participants acknowledged that the Integrated Transition Protocol ends at age 18, and that

transition planning therefore also ends at age 18 for professionals who work under the Ministry

of Children and Youth Services. However, participants also acknowledged that those working

under the Ministry of Education continue transition planning until age 21, and that those working

under the Ministry of Community and Social Services do not begin transition planning until the

youth is at least 18 years of age. The implications of this will be discussed later in the

Discussion section of this paper.

  The gap in services and funding. A reoccurring theme throughout all data collection

methods was that despite the tri-Ministry Integrated Transition Protocol, there continues to be a

gap between child and adult services, and there is a need for smoother transitions between them.

  When asked if there was anyone missing in the current protocol, Participant Two in the

Questionnaire responded; "one agency that follows the youth from childhood to adulthood",

while Participant Five in the Questionnaire responded "more involvement from the agencies who

will be working with the youth after finishing school. Often, the agencies aren't included in the

planning process therefore when school ends its like starting all over." The "lack of transition

from children to adult services – children services end and adult services do not pick up where

they left off" was identified by Participant Two in the Questionnaire as a challenging barrier to

the transition process. Participant Six in the Questionnaire identified that there are "criteria for

agencies that limit them from supporting [youth] through transitions. As a result, youth

experience a gap in services and may be put at risk." Participant Eight in the Questionnaire

suggested

> some sort of transitional housing or program for youth 17 years old so that they can get a
>
> sense of what it really means to live on their own. The fact that people become adults on
>
> their 18th birthday and can walk away from all supports creates dangerous situations

because they don't have a chance to experience what it can be like while still having supports in place.

Participant Three in Focus Group One explained that "it's like there's a gap between adult services and children's services. The children's services just kind of end, and families go 'what do we do now?' Like everything that we've known up until now doesn't exist anymore in adult services." Participant Two in Focus Group One continued "every person that the family would have called for help can't help anymore." Participant Three in Focus Group One went on later to suggest

> …there needs to be less of a disconnect between children and adult services. I mean, even within Community Living they are two completely separate programs where they are children or they are adult, and they don't necessarily work together, right? It's almost like you get handed off from the children's worker and if there are adult family support workers, which some of them don't have anymore, they get handed to them, and that person who was with them all those years no longer has a role in their life. So, it almost would be good to see one agency where their one purpose of their program is to help with that whole transition. You're not going to get staff who are with you from maybe birth to 30, because staff don't actually stay that long, but there's some consistency in that it's one program that sees the expectation as an adult. I mean we see all these expectations, but if we were working in children services we wouldn't see necessarily all those all those long-term things that starting early have an effect on them. So, if you take people who are working with adults, and also help with, either partner them with children's services or something that their helping them

with those expectations and at different developmental stages where should

people be at and what expectations.

Focus Group Two also noted the gap in services. When asked *Do you believe*

there's anything missing from the current transition process?, Participant Two in Focus

Group Two responded "somebody at the other end," to which Participant One in Focus

Group Two added:

between the ages of 18 and 21. I think that can be one of the most difficult

because they're transitioning from high school, and the thing is, the high schools

do a great job in trying to connect them but I really think families need to have

that connector to other programs and things like that.

Participant Two in Focus Group Two went on to add "even the schools ask, after they turn 18,

who is going to attend the meeting if we have one next year regarding this child? Well we're

closed so – we're just kind of done." This led me to question *Are adult agencies involved in the*

transition plans; where the youth are transitioned to, are those people involved at all?."

Participant One in Focus Group Two explained that this would be the role of Developmental

Services Ontario (DSO), and Participant Two in Focus Group Two further elaborated that "the

DSO will only do referrals. They won't go to the schools and be part of these plans at 18 – they

just don't have the ability, they're too busy."

Participant One in the Individual Interviews also noted that DSO and other adult services

do not attend transition meetings and explained

I think there are some players who should be involved who say they can't – like DSO for

example. I do understand that they have just a few staff and there's a huge amount of

numbers, but if this is supposed to be a continuum, - if I was 17 years… and then I have

one day and it's my birthday – you're not a heck of a lot different the day before than the

day after. So, if they [youth] need us to facilitate all these things for them and help them

with their goals, why would we not do that as adults? So, I think there is a great big gap

there that I find scary … we have kind of a little bit of a black hole there in the middle of

it all, where nothing happens. So that's a bit scary for me, because if we are going to lose

a kid, it's around that age.

Participant One in the Individual Interviews also felt that "as soon as we hit that magical 16 ½

we're doing that application for the DSO and hopeful that it will be a yes, then nothing happens

after that. So is that really transitional planning?." They further suggested, similarly to others

throughout the study, that

maybe we need some kind of a coordinator or someone who does just that. Come to the

table – because parents have questions about that. When we're heading into adulthood

that is scary business. So, what does the future look like, are there group homes or

independent living situations or whatever that happens to be? How do I get support for

my medically fragile child as soon as they're adult and then I have 6 months of

nothingness? That is awful for a family.

They also made note that there is a need for "more immediacy" and explained

if this [the TAY process] works and we can get kids to 16 ½ knowing fully well that DSO

is coming, there should not be a gap. It should be ideally that you step out of your 18th

birthday into adult services, and there's no wait.

Participant Two in the Individual Interviews also felt that there was a gap between child and

adult services, and explained "I think we're still missing that hand-off and that connection, even

between the providers and the families." This Participant went on to further explain that

they [the youth] have to start fresh...with the Adult Developmental Services. The school,

they can continue and the transition still happens, the planning with the IEPs…but

beyond that all their children's services are gone and they have to start up again. Participant

Two in the Individual Interviews also felt, similarly to Participant One in the Individual

Interviews, that "when you have DSO involved at 16 and they're eligible for adult

developmental services, there's not a real connection with those access coordinators at 16, 18.

They don't get involved – they are missing from it." Participant Two in the Individual

Interviews also felt that the Transition Plan was a useful tool the DSO was missing out on. This

was demonstrated in their statement that "over time that plan, as it changes yearly, should evolve

into something that's a helpful tool for the DSO. And vice versa – the DSO has information that

they could be sharing."

Participants agreed that despite the mandated tri-Ministry Protocol, one Ministry in

particular was often missing from the transition meetings. Participants felt that the lack of

agency or persons supporting the youth throughout the transition (i.e., from before 18 until they

connect with adult services) resulted in a continued gap in services and support.

Realities of adult services. Many of the participants noted that there needs to be more

education for both families and service providers on the realities of adult services. When asked

What could be changed/included to help reduce the barriers experienced during the transition

process? Participant Two in the Questionnaire responded "more education for families about the

reality of adult supports", and Participant Three in the Questionnaires echoed this answer in their

response "early education of all parties involved of the reality of adult services." Participant

Eight in the Questionnaires also felt that "schools in particular are not always aware of what

supports are actually available for youth when they turn 18…the lack of knowledge of how the

adult system works causes a lot of problems during the transition process." Participant Two in

the Questionnaire felt similarly and noted the following barriers: "misinformation in the school

system about available supports and resources when school is done, families unprepared for the

reality of community life for their child."

Participant Two in Focus Group One also touched on the importance of educating others

on the reality of adult services:

> there are also the unrealistic expectations of the school system itself…people are like –
>
> you can go into a group home, you can go to a day program – but those services don't
>
> exist for adults, like any time soon.   Most of the times they are not the most appropriate
>
> service for that person, so I think that it's also that families aren't getting the right
>
> information early enough to help them make that transition because school, where they
>
> are relying on getting that information from, don't have the correct information. And are
>
> not totally interested in really getting it.

It is important to note that Participant One in Focus Group One followed up this comment,

explaining that this varies from school to school.

The uncertainty of adult services was also mentioned by Participant One in the Individual

Interviews, who questioned "…are there group homes or independent living situations or

whatever that happens to be? How do I get support for my medically fragile child as soon as

they're adult and then I have 6 months of nothingness?"

Participants expressed that there needs to be more education for families, educators, and

service providers about the realities of what services are available, and how services work once

youth transition to adult developmental services at age 18. Overall, participants expressed

frustration that there continues to be a gap in services and funding, and that there is a general

lack of understanding among families, schools and children's service providers about how adult developmental services work. Participants felt that Integrated Transition Planning ended at age 18 when the protocol ends, and when service providers who operate under the Ministry of Children and Youth Services guidelines are no longer able to be involved. Participants also acknowledged that those working under the Ministry of Education guidelines must continue to create transition plans, at times, alone, and that adult developmental services tend to not be involved during the transition process.

Theme 5: Benefits of an integrated approach to transition planning.

Although 56 percent of Questionnaire participants noted that a barrier to the transition process was related to challenges in communicating with other agencies and community partners, participants from Focus Group Two, and both Participant One and Participant Two in the Individual Interviews identified benefits of working collaboratively, as mandated by the Integrated Transition Protocol. One benefit was highlighted in Focus Group Two when Participant One in Focus Group Two commented "you know what's really nice? We're getting a nice connection with the schools, so we're getting to know a little bit more about what's going on at the schools, whereas before it was like we really didn't have that interaction." When asked what they liked about the new transition process, Participant Two in Focus Group Two explained "I like when all the community partners participate. It makes everybody feel good that everybody is there for that one child – and look how many support people that you have that is helping this goal."

Participant One in the Individual Interviews also noted that Integrated Transition Planning is different than previous protocols because in the past:

we didn't have the consistency that this forces us into…we've had some program leaders who work with this population…who are really good at making those connections in the community and involving…other organizations…and others aren't so skilled at that – they don't have the connections, they don't know who to call…so this makes it formalized and hopefully we can move forward with more plans.

Participant Two in the Individual Interviews explained that an Integrated Transition Plan is different than previous protocols because …

transition planning has happened in isolation with different agencies and school boards – they've all done their own thing – but they haven't actually talked to each other and sometimes there's probably duplication of work and resource, and lack of understanding of that person in different venues of their life. And so having that all come together in one room is where that brings it up to another level. So that's what I think has been helpful, versus the separate planning.

Participant Two in the Individual Interviews went on to explain that

you're not having a duplication of talking to different people, you're having the people that are most involved in the same room, so you're not having to explain to each one what this one said or that one said – so it's like everybody is there. I think that's very helpful and advantageous for the youth and the family. And also, when you have that kind of a scenario, it creates new ideas and new paths which may not have existed when you were dealing with the separate organizations. So it gives that opportunity for discussion that could potentially go in a direction that may not have gone and the youth is able to say – no, that didn't work for me or yes that sounds like a good idea. Or the parents can say – yes, that seems to suit our family.

When asked what they liked about the new transition protocol, Participant Two in the Individual

Interviews responded

> I think it's fabulous that we have one plan, that all the providers have agreed that even
>
> though they have a plan that exists on their own responsibility, that they are bringing one
>
> common plan so that that child that they go to one school or board, or if they move they
>
> always have the similar looking plan. So I think that's one of the greatest things and I
>
> think our community providers are pretty great – you know they'll inform each other if
>
> they need to meet or if things have escalated or changed, so there is a lot of
>
> communication there.

Participant Two in the Individual Interviews went on to explain how families feel about the

process, and explained that

> They [the families] feel, probably for one of the first times, that they have other people in
>
> the room that are focused on their son or daughter's life – not just for school or not just
>
> for community, but for the whole picture, and I think that's kind of a neat thing – that
>
> they are believing maybe in that system again.

Most participants agreed that a large benefit to the tri-Ministry Integrated Transition Protocol

was that it used a collaborative approach to transition planning. Participants felt that they were

making good connections with professionals who worked under different Ministry guidelines,

and felt that they were gaining a greater understanding of the various services, programs, and

supports available. Further, participants highlighted how this approach may benefit families, and

hypothesized that families may be more hopeful as a result of service providers coming together

to support their child.

Theme 6: Busy and Safe Versus Meaningful.

Some participants commented about the desires to have youth "safe and busy", versus the youths' desire to do something meaningful. Participant Eight in the Questionnaires identified this as a challenge, and noted "schools, FACS and families feel that youth need to be protected when they turn 18 and that their rights should be restricted so they cannot make decisions for themselves that we might think are unwise." Participant One in the Questionnaire explained that "families will lean on them keep him/her safe and busy. There is little discussion about what might be meaningful for the person, what is true quality and allowing a person to have choice." Participant Three went on to further explain "care, control and protection. Families want a youth protected and cared for often by trying to control decisions which is detrimental to the person, relationships, and personal growth." Participant Five in the Questionnaire also felt that "very often the family wants the person to be out and busy doing things regardless of what that looks like", and Participant Six in the Questionnaire felt that "often parents want to over support youth or have them 'busy' with activities that provide care and don't actually interest the youth." Participant One in the Questionnaire also explained that this mindset is not unique to families, but that "historically, professionals' support was about health and safety first. Some professionals still see this as the #1 goal."

Participant Four in Focus Group One also commented on this idea of safe versus meaningful, and noted

> they [families] want their kids at the end of the day to be safe. It's all about safety, so a lot of families take this leap to – well he needs 24 hour support – and I can tell you that probably 95% of the people I meet don't even come close to that.

Participants acknowledged that families often felt that keeping their child safe and busy was an important factor when planning for the future. Participants discussed how some youth do not wish to be busy at all times, and that their definition of a meaningful day may be different than that of their families or service providers.

Theme 7: It's a New Process – But It's the Right Process.

Participants in the current study acknowledged that this collaborative approach to transition planning is new, but that they are getting better at it and find it an effective way to plan. When asked if they could design a new transition process, the participants in Focus Group Two both felt that they liked the current transition process, as demonstrated by Participant One in Focus Group Two's response: "you know what – I like it. I think we're finally getting our heads around it. Can we tweak it down the road? Absolutely. But right now, I think we all need to get our heads around doing this, and doing this really well." When asked what they like about the current transition process, Participant One from Focus Group Two responded "I love it when a plan goes really well, and that young person – you finish at age 18 and they've got a plan that is going to move them along the system" and Participant Two from Focus Group Two replied

I like when all the community partners participate. It makes everybody feel good that

everybody is there for that one child – and look how many support people that you have

that is helping this goal. And that's what I like about it – the more involved, the better.

Participant One in the Individual Interviews also acknowledged that this is a new process, in their comment "We're really in the early stages. I mean this is only about the 3rd year that we've been going on. The numbers are getting bigger which is a good thing as we move forward." Participant One in the Individual Interviews was also asked *What do you like about the new transition process?* to which they responded

I like the fact that parents have opportunities that they never had before. I've been [working with youth] for [many] years and I've worked with families who've had no services until they graduated and then there was a big explosion – "what am I going to do – they're at home?" Even though we've tried to say try this, try that, I'll help you with this, I'll make a phone call – it just never happened. So, for this to be really formalized is important for them.

Participant Two in the Individual Interviews was also asked how they would design a new transition process, to which they responded

Wow – that's crazy. I don't know – we've worked really hard at this one. I'm pretty okay with it. I think it's always a work in progress. So, would I design a new one? Unless you have all people, who are involved with people with disabilities in one organization, it's hard to look at another way to do it. This is probably the best way to do it right now, but again, just bringing that youth into the middle of anything that needs to be done.

When asked what they liked about the current transition process, Participant Two in the Individual Interviews responded

I think it's fabulous that we have one plan, that all the providers have agreed that even though they have a plan that exists on their own responsibility, that they are bringing one common plan so that that child that they go to one school or board, or if they move they always have the similar looking plan. So, I think that's one of the greatest things and I think our community providers are pretty great – you know they'll inform each other if they need to meet or if things have escalated or changed, so there is a lot of communication there.

Participants discussed how Integrated Transition Planning and the tri-Ministry Transition Protocol are new processes, that they are now just getting comfortable with. Despite this, participants truly felt that this approach to transition planning was beneficial for youth, families, and service providers. Overall, participants in the current study are happy with the new process.

Discussion

The current study was designed to gain a greater understanding of how the new transition planning protocol is being used in the Niagara Region, and to examine the barriers to (1) youth participation and (2) implementation. Further, the study was designed to uncover whether youth were better included in their transition plans since the implementation of the Integrated Transition Planning Protocol, and to discover ways to better include youth in their transition plans, if they were not currently active participants. Through questionnaires, focus groups, and individual interviews, the study explored the perspectives of professionals who work with transitional aged youth in the Niagara Region. This study was able to obtain the opinions of professionals in Niagara who were mandated under the tri-Ministry protocol mandated by the Ontario Ministries of Children and Youth Services, Education, and Community and Social Services. From the collected data, the following major themes were identified: (1) there continue to be barriers that hinder youth participation and the successful implementation of the protocol; (2) professionals feel youth participation is important, but families continue to play the primary role during the transition process, despite a reported disconnection between the hopes and dreams of the families and the youth; (3) transition planning and practicing meaningful participation need to begin earlier; (4) the transition ends when the protocol ends and there is a gap between child services and adult services which is not being addressed currently; and the realities of adult services are unknown to many educators, children's service providers, and

youth; (5) there are many benefits to integrated transition planning; (6) we must move past

programs that focus on keeping youth "busy and safe" and start ensuring that youth are

participating in activities that are meaningful to them post-high school graduation; and (7) the

current Integrated Transition Planning Process is a new process, but it is the right process. These

themes will be explained in greater detail throughout the remainder of this section.

Various barriers to transition planning in general, and youth participation during the

transition process specifically, were found in the current study and have been well supported

throughout the transition literature. The current study identified the following three barriers: (1)

youth's abilities, (2) service limitations, including waitlists, and (3) attitudinal barriers. It is

important to note that despite the current study only highlighting three barriers, other barriers

were noted by some participants and have been supported by literature. Youths' abilities have

often been cited as a barrier that hinders their full participation during the transition process. For

example, in Park's (2008) study, teachers felt that common barriers to participation and

involvement in the development of goals and participation during the transition process were the

cognitive and communication limitations of some youth. Similar findings were found in the

Carter and colleagues (2014) study that examined teacher and parent perspectives of the

strengths and needs of 134 youth with severe intellectual and developmental disabilities during

the transition process. This study found that although students with severe disabilities were

perceived to have a range of strengths related to the transition process, many of the teachers who

participated in the study noted items, such as "has needed speaking skills – may include sign

language or alternative/augmentative communication" and "performs various indoor leisure

activities" as *not appropriate* (p. 253). The researchers explained that the option *not appropriate*

was used to indicate if a rater considered an item to be an "inappropriate area of planning for the

focus student" (Carter et al., 2014, p. 248). The researchers clearly stated that "it is possible that some teachers may perceive that basic social, communication and recreational skills are not attainable for some students" and further stressed the importance of expectations for this population (Carter et al., 2014, p. 253). However, research supports that despite the perception of youths' abilities being a barrier to their active participation in the transition process, those with severe disabilities and limited communication can participate in their transition plans in a meaningful way (Cavet and Slopper, 2004). An important conclusion was made in the study by Cooney (2002) who found that transitional aged youth with intellectual disabilities not only had hopes and dreams for their future, but they were also able to articulate these aspirations, given the proper supports. Based on the findings of this past literature when compared to the identified barrier of youth abilities in this study, it becomes clear that it is not, in fact, the limitations of youth that hinder their participation, but rather the unconscious attitudes and assumptions of others, and of society, that do not allow for alternative ways to support them to participate in meaningful ways. This finding was supported by Laragy (2004), who also found that students were often forced to conform to pre-existing patterns of service delivery that did not allow for flexible and individualized resources that could support students to participate in meaningful ways. In general, it can be concluded that is the *assumption* of cognitive and communicative limitations that often lead professionals to assume that a youth cannot fully participate, rather than the limitation itself. This finding will be discussed further later in the discussion section of this paper.

Service limitations, which included a lack of programme availability and difficulty communicating with other service providers and agencies, were also discussed in the current study and supported in the literature. For example, Weinkauf (2002) noted a lack of post-

secondary school options for youth with disabilities whereas Griffin and colleagues (2010)

argued that the limited opportunities for participation and autonomy for persons with intellectual

disabilities (ID) during the transition process are due to a lack of services, information, and

funding availability. Similarly, in a previous study (McKay, 2015), I found that there was a

general lack of understanding of who does what during the transition process. Although this

barrier was not explicitly noted in the current study, one could hypothesize that this may be one

reason why participants noted it was at times difficult to communicate with other professionals

during the transition process. As noted by Park (2008), the transition process requires

involvement of a variety of professionals from many different disciplines. Therefore, the

collaboration among all parties is essential, and it is critical that professionals understand not

only the transition process and services available, but also each other's roles and responsibilities

in the process (Greene & Kochhar-Bryant, 2003).   It should be noted that using an integrated

approach to transition planning requires a great deal of time and resources, and places increased

demands on already overworked professionals. The barrier of service limitations, that may be a

key contributor to the inability to conduct transition meetings in a way that would support youth

with developmental disabilities to be meaningfully included, pertains to the extensive time

commitment required for this to be done, with the responsibility for this adding to the already

large workloads of the professionals involved in the process.

Service limitations also included the theme of waitlists. Waitlists were identified as a

major barrier to transition planning and the successful inclusion of youth during transition plans.

Participants felt that it was often difficult to plan during the transition process, as there was

nothing for youth to transition to. Unfortunately, long waitlists and a lack of Ministry funded

services, such as day programs, group homes, and supported employment options, or Ministry

funding, such as individualized Passport Funding, are well recognized as being major barriers in

the adult developmental service sector, with the Ombudsman's report in 2016 noting that "many

[families] were discouraged by interminable waitlist delays and desperate for help" (Dubé, 2016,

p. 1). The Passport Program, which distributes individualized Passport Funding, is "the

Ministry's primary program for direct funding of supports and services" in the adult

developmental services sector (Dubé, 2016, p. 21). Passport funds enable adults with

developmental disabilities to participate "in community classes and recreational programs,

develop work, volunteer, and daily life skills, hire a support worker, create a life plan, and access

temporary respite for their caregivers" (Dubé, 2016, p. 21). However, "passport funding is

limited by a specific annual budget" and "once the funds for any given year are distributed, other

eligible applicants are placed on a waitlist" (Dubé, 2016, p. 22). As noted in the Ombudsman's

report, in March 2012 there were 3,700 individuals waiting for Passport Funding and as of

December 2015 there were 14,402 individuals waiting for Passport Funding (Dubé, 2016). The

Ombudsman also identified that it is important to note that the existence of an integrated

transition plan, and of the tri-Ministry protocol in Ontario, "does not guarantee an individual

access to services and supports at age 18" and that "many transitions to the adult system result in

long waitlists for services and supports" (Dubé, 2016, p. 24). With this knowledge, it is

important to begin to break free of planning for these Ministry funded services, especially for

youth who are deemed "low needs", as waitlists for many of these services and funding are based

on "a prioritization of individuals, from those most in need down to those with very low needs"

rather than a first-come first-serve basis (Dubé, 2016, p. 28). As noted by one participant in the

current study, the transition process is a good way to prepare youth and families for the

recognized waitlists attached to adult Ministry funded services.

It is my belief that when utilized well, this transition process may provide opportunities for youth with disabilities to become more involved in their communities, to build natural, non-paid supports, and to participate in activities that they themselves have deemed meaningful. In turn, it is my belief that this will improve the quality of life of many youth with developmental disabilities. Although I do recognize that this is not a simple task, and that in the interim this may result in more work and a need for more resources, one can hypothesize that if youth with disabilities are relying less on Ministry funded services and supports when they turn 18 as a result of their natural supports created during the transition process, such an approach will result in less work and fewer resources throughout the remainder of the life course.

A critical aspect of adopting such an approach is that youth must be active participants during their transition plans. The importance of youth participation was noted by most participants in the current study; however, despite this, families continued to play the primary role during the transition process. This finding is unfortunate, as there was a reported disconnection at times between the hopes and dreams of the families, and of the youth. Youth not being active participants during their transition plans is well supported in the literature. For example, Cooney (2002) noted that transitional aged youth are often only partially involved in the transition process, and at times are left out of the process completely. Similarly, numerous studies have found that the decisions about where an individual with an ID will work, learn, live, and spend their day are often made by people other than the individual themselves (Cooney, 2002; Stancliffe et al., 2011; Timmons et al., 2011). Despite this finding, both the participants in the current study and participants in other studies have agreed that in order for transitions to be successful, the youths have to be the ones making the decisions (Laragy, 2004).

One potential reason that youth are not meaningfully participating in their transition process is that they have not been provided with opportunities to practice meaningful participation and decision making. This is seen clearly throughout the current study, as the focus of who the transition process is for is different depending on which Ministry the participant operates under. For example, the hopes, feelings, and role of the family during the transition process were often discussed when speaking with participants who operated under the Ministry of Education, who supports youth up to age 21, and Ministry of Children and Youth Services, who serve youth up to the age of 18; whereas a very strong emphasis was placed on the youths' hopes, dreams, and voice when speaking with participants who operated under the Ministry of Community of Social Services (MCSS), who support people ages 18 and older. Participants operating under the umbrella of MCSS discussed in the current study that although it may appear at first that youth have the same hopes and dreams as their family, once a youth learns how to self-advocate, their dreams often do not coincide with those of their loved ones. It was recognized in this study that many families continue to place a strong emphasis on keeping their youth "safe and busy" rather than involved in activities that are meaningful to the person. It can be hypothesized that this is why transition plans continue to revolve around Ministry funded services, such as day programs, which offer most families a place for their adult son or daughter to go for the majority of the day, most days of the week.

These findings are important, and supported by studies such as Cooney's (2002) research that have found that transitional aged youth with disabilities not only have hopes and dreams for their future, but they also are able to articulate these aspirations with appropriate support. In Cooney's study, young adults voiced their desire for paid work, for a place of their own, and for freedom to choose how to live their lives. Despite a clear ability to make decisions about their

future, many of the youth noted that they were not given the independence they hoped for in

adulthood, with one individual even discussing his frustration with the fact that his mother and

teacher chose where he would be working (Cooney, 2002). Cooney (2002) went on to explain

that it appears that the current systems only provide a façade of active participation and

autonomy by providing youth with "trivial, secondary, or coerced choices" (p. 432).

One potential way to combat these findings is by beginning the transition planning

process and this integrated approach at an earlier age, and throughout all major life transitions.

We must also begin to provide children with disabilities with the opportunity to make small,

meaningful choices from an early age, so that youth have practiced making decisions prior to the

large decision of how to spend their days post high school graduation.

As noted, the transition process ends when the protocol ends at age 18, and there

continues to be a gap between child developmental services and adult developmental services.

The Ombudsman's report explained that

> the transition from adolescence to adulthood for those with developmental disabilities
>
> and their families is marked by a significant shift in available services and supports. At
>
> 18 years of age, access to the Special Services at Home supports ends and individuals
>
> may apply for Ontario Disability Support Program benefits. Individuals who were
>
> receiving services and programming through the Ministry of Children and Youth
>
> Services no longer qualify for children's supports, and must apply for them through local
>
> Developmental Services Ontario offices. (Dubé, 2016, p. 23)

In addition to this gap in services, as noted by participants in the current study and in

previous research, the realities of adult services are unknown to many educators, children's

service providers, families and youth. Although eligibility for adult developmental services (also

known as Developmental Services Ontario, or DSO) is determined at age 16, there is little

involvement from these adult services until the youth has aged out of child services at age 18,

and the Integrated Transition Process has ended. As a result, the wide range of services that may

be available to a youth after their 18th birthday is unknown until after their transition plans have

been completed. Therefore, another potential barrier that hinders youths' abilities to

meaningfully participate is that they are unaware of what options are available to them. This

finding is well recognized in the transition research with Laragy (2004) arguing that it is difficult

to make decisions when a person does not have knowledge about their choices. Similar studies

noted that opportunities for full participation in the transition process are limited because

supports and information needed to guide people with disabilities through the transition are hard

to find (Cooney, 2002; Laragy, 2004; Park, 2008). The importance of knowledge was

highlighted by the teachers in Park's (2008) study who said that presenting information about the

transition process and services was one of the most crucial, yet challenging, tasks in supporting

students with disabilities during the transition period.

The current framework for transition planning utilizes an integrated, or collaborative,

approach, which has been well documented as an effective strategy and best practice in transition

planning) (Kohler & Field, 2003; as cited in Papay & Bambara, 2014). Participants in the

current study felt that there were many benefits to utilizing this kind of approach, such as making

strong connections with other professionals who worked under different Ministry guidelines, and

felt that they were gaining a greater understanding of the various services, programs, and

supports available. Further, participants felt that this approach was very beneficial to families,

and suggested that families may feel better supported, and perhaps have even re-gained faith in

the current support system because of such an approach.

It is important to comment that the Integrated Transition Planning Process is a new process throughout Ontario, Canada and that the Niagara Region has done a very good job of adopting the protocol and implementing it throughout the Region. Participants in this study highlighted the importance of such a protocol, and discussed how they truly felt that this was the best way to help youth transition into adulthood. Participants have embraced the Protocol and are working hard to ensure that all youth with disabilities in the Niagara Region are supported through their transitions. Although participants noted that the Protocol is not yet perfect, they did express hope for future transition planning as they become more comfortable with the process.

Connection to Theory and Literature

The theory of emerging adulthood was used during the analysis of the data as it allowed for a baseline, or comparison, of how this unique time in a youth's life is experienced by youth without compared to youth with developmental disabilities. As explained, for youth without disabilities, this period is characterized as being a time of exploration and endless possibilities (Arnett, 2007). Despite this, it was recognized in the current study that this identity exploration and numerous possibilities were not presented to transitional aged youth with disabilities. Youth without developmental disabilities, just like youth with developmental disabilities, are attempting to find their place in the adult world during this distinct time in their lives. The theory of emerging adulthood allowed for the recognition that this process is much longer, and much less successful for youth with disabilities. It was made obvious that while most youth are trying to find independence and responsibility during this time frame, youth with disabilities continue to be viewed as children who require protecting, and are therefore not provided with opportunities to gain autonomy. The theory of emerging adulthood allowed for a close examination of this

very distinct time period in a youth's life, and made obvious that despite age similarities, the

experiences of youth with and without disabilities was much different as a result of the

attitudinal barriers highlighted by the social model of disability.

The theory of a social model of disability informed much of this analysis. A social model

of disability promotes a human rights perspective, and emphasizes that persons with disabilities

have the right to make choices about their lives (Oliver & Barnes, 2010). It acknowledges that

persons with disabilities are rights-bearing citizens and therefore are entitled to the same choices

and opportunities as non-disabled citizens. In the current study, it was identified that youth are

not provided with the same opportunities as their non-disabled peers to practice participation and

choice making, and that this hindered their ability to participate meaningfully during their

transition plans. An important part of the social model of disability is recognizing that disability

is a result of societal oppression which views persons with disabilities as eternal children who

are dependent and in need of protection (Epp, 2003). These themes emerged throughout the

current study, as participants often felt that they needed to keep youth safe, rather than allow

them to make potentially poor choices. And yet, it is important to note that most of us have

made poor choices at one time in our lives, and that these poor choices shape us, teach us, and

allow us to grow. A social model of disability also attempts to break down the societal barriers

that impede the participation of persons with disabilities in their communities, and in their lives.

In the current study, a youth's perceived limited cognitive abilities were noted as a barrier that

impeded their participation during the transition process. From a social model perspective, it is

not the limited cognitive abilities of youth that is the barrier to their participation, but rather, the

assumption that limited cognitive abilities render youth incapable of participating. This social

model perspective was highlighted by the result that found that attitudes and assumptions about

disability were significant barriers to youth participation during the transition process. Applying a social model of disability to the current research is important, because at the time of the transition period, youth will have gone years living in a world that is oppressive for persons with disabilities where they have had to face attitudes, comments, and barriers that have made their impairment a disability (Oliver & Barnes, 2010). As a result of this oppression, it is likely that these youths have been provided with limited choices, and have been denied opportunities and activities based on their impairment (Oliver & Barnes, 2010). It is naïve to think that this has not impacted a youth's worldview, and that youth do not internalize this oppression. As a result, I suspect that youth are unaware of the opportunities that are available to them, and that youth may often feel that the opportunities that their non-disabled peers have are not universal, and are not available to them. Overall, a social model of disability highlights a distinction between impairment and disability, with the latter being a result of often unconscious societal attitudes (Oliver & Barnes, 2010). Using a social model of disability approach to highlight this oppression is important, as it creates an opportunity for discussion that may challenge these unconscious assumptions and beliefs and create an environment in which youth can become active participants in their transition plans, and make meaningful choices about how they would like to spend their days after high school graduation.

As the current study unfolded, a critical disability perspective emerged that was not previously discussed, although it has some connection to the social model of disability. I began asking myself many questions: Why does this binary between childhood and adulthood exist? What constitutes childhood and adulthood? And why is there such a distinction between the two? Why is obtaining employment and/ or full-time programming defined as a successful transition? Does meeting the milestones of employment and independent living guarantee inclusion, or

would persons with developmental disabilities continue to be in, rather than part of, the community (Hall, 2010). Who has deemed employment meaningful for all persons? Is participation during the transition process defined for youth with developmental disabilities? Are they truly active participations, or rather, are they provided with a tokenistic role that provides the illusion that plans are Person-Centered and youth driven? I also questioned whether youth were truly participants in their transition plans, or if they were rather provided with tokenistic roles that provided the illusion that these plans were Person-Centered and youth driven. Being unable to bring this critical lens into the analysis is one limitation of the study, and should be explored further in future research.

Recommendations for research

As the current study occurred during a time when the transition process in the Niagara Region was still evolving, it is recommended that future studies continue to explore how transition planning is being done in the Niagara Region, with a specific emphasis being placed on youth participation during the process. Future research should also include the perspectives of families and youth, as their perspectives are noticeably missing in the current study, and in the transition literature in general. Particularly, a strong focus should be placed on how families and youth experience the transition process. Similarly, an in-depth look at how youth participate, and how we can ensure that youth are active participants in their transition plans, would enhance the current transition literature. Using a critical disability studies perspective will also help to enhance the current research, as such a perspective has not yet been well documented in the transition literature and may therefore offer new insight.

Recommendations for Practice and Policy

The findings in the current study have implications for future practice and policy. For example, an important finding in the current study was that despite the Protocol being deemed a tri-Ministry Protocol, the Ministry of Community and Social Services is noticeably missing from most of the transition planning process. This lack of a connection to where the youth will be transitioning results in a gap in services, and an inability to plan, as the services available once a youth turns 18 are unknown to many currently involved in the planning process. It is therefore recommended that youth who are deemed eligible for Developmental Services Ontario (DSO) prior to the age of 18 have a representative from the adult services attend at least one transition meeting before the youth's 18th birthday in order to facilitate a smoother transition.

Participants in the current study felt that transition planning should begin earlier, in hopes of providing youth with more opportunities to practice being meaningful participants in their lives. Many will agree that youth go through numerous transitions during their lifetime, including the transition from home to day care or kindergarten, from kindergarten to grade school, and from grade school to high school. Applying an integrated approach throughout the lifespan and all transitions may be one way to help youth practice being meaningful participants in their plans. It may also help families to connect to services at a younger age, and to gain more support from and knowledge about the current support system. Having an integrated approach from a young age may also help to foster stronger relationships between the schools and the community agencies, creating a sense of shared resources and responsibility which, in turn, may lead to creative thinking and unique plans that cater to individuals' hopes, dreams, and needs.

Further, although I recognize the importance of keeping youth safe, I feel that this current study highlights the need to provide youth with opportunities to make choices and to fail, while

they still have a safety net in place. Identifying a youth's goals or interests from a young age

allows for exploration of whether that is something the youth truly would like to do. For

example, if a youth identifies in grade 8 or 9 that they love animals and would like to be a vet or

work with animals, perhaps the school and/or community could take a group of like-minded

youths to volunteer at an animal shelter once a week. If the youth continues to enjoy this

experience, the support from teachers and community could be gradually faded out during their 4

years of high school, as the youth become more confident in their role at the shelter, and as

natural supports (e.g., the staff at the shelter) become more comfortable with the youth.

Creating community connections and supports, and placing less emphasis on Ministry

funded services such as day programs and group homes, and more emphasis on what is

meaningful to the youth is another recommendation for future policy. It is well recognized that

there are not enough Ministry funded services, and that many of these services have long

waitlists. It is therefore recommended that the transition process be used as a tool to plan for this

gap in services, and to think uniquely about what other opportunities are available to youth with

intellectual and developmental disabilities outside of these Ministry funded services.

Limitations

A major limitation of the current study is that the perspectives of both the youth and their

families are noticeably missing, despite a focus on youth participation. As previously discussed,

the Integrated Transition Process is new in the Niagara Region, and has only been well

recognized and adopted for a little under 3 years. During the initial phases of this study, the

process was new and most youth and families were not yet receiving its full benefits. Therefore,

it felt unethical and invalid to discuss a process that youth may have not yet been receiving. As a

result, youth and families were not interviewed and their perspectives were not included in this

study. This is a major limitation, as youth and parents may feel differently about the process

than service providers, and may have greater insights on how to help facilitate meaningful

participation for other persons with disabilities. This led to a further limitation of the current

study, which was that the focus of the research changed half way through the data collection

process and, therefore, the questions from the first focus group were different than the questions

asked in focus group two and in the individual interviews. Although themes were still found

across the two different sets of questions, it is important to note that this was a major limitation.

Another limitation previously discussed is that a critical disability perspective was not

used although it may have benefited the analysis. It is recommended that future research apply

such a theoretical framework to help develop ways to improve the transition process and overall

quality of life for youth and their families. It is hypothesized that a critical disability studies

perspective may allow for opportunities to challenge hegemonic norms, such as the assumption

that all persons want to obtain employment and independent living status, that usually guide

transition planning. Challenging these norms may allow for more open discussions and

opportunities for youth to explore alternative spaces where they feel a sense of belonging.

Conclusion

In conclusion, the transition to adulthood is a stressful time for all young persons, but

especially for youth with developmental disabilities and their families. In an attempt to combat

the well documented negative experiences and outcomes associated with the transition process for

youth with developmental disabilities, the Ontario Ministry of Children and Youth Services, the

Ontario Ministry of Community and Social Services, and the Ontario Ministry of Education

worked together to create the tri-Ministry Integrated Transition Protocol, which has been adopted

and implemented in the Niagara Region since 2014. Overall, the current study, through

questionnaires, focus groups, and individual interviews with 14 professionals working in the Niagara Region under all three ministries (MCYS, MCSS, EDU), concluded that the Integrated Transition Process is a good process that is well supported by the professionals who are implementing it, but that there continue to be obstacles in the way we currently plan for a youth's transition that must be rectified.

The current study found that although the importance of youth participation is recognized in the Integrated Protocol, in research, and by service providers, youth continue to play a back-seat role during the development of their transition plans, with families playing the primary role, despite reported disconnects between their respective desires. Further, it was found that, in general, transition planning continues to focus on planning for Ministry funded services, rather than community-based, natural supports, and that this results in many barriers such as a lack of program availability and waitlists, continuing to impede successful transitions to adulthood. This study also found that youth need to begin practicing decision making and participation earlier so that they can be better self-advocates during their transition meetings. Further, it suggests that it is no longer enough to keep youth "safe and busy" and emphasized placing a stronger focus on determining what is meaningful for a youth so that they can live happier, fuller lives. An important conclusion made from this research is that it would be very helpful if adult developmental services, such as DSO that is funded through the Ministry of Community and Social Services, were able to participate in the transition process in order to mediate some of the barriers found in the current study (such as not knowing what services are available once a youth turns 18).

Overall, the current study is important as it is one of the first studies to examine the Integrated Transition Process in the Niagara Region of Ontario, Canada, and therefore offers a

variety of insights into how transition planning is being done in this region, how it can be improved, and how other areas in Ontario can help youth and families during the transition process.

References

Agran, M., Storey, K., Krupp, M. (2010). Choosing and choice making are not the same: Asking
"what do you want for lunch?" is not self-determination. *Journal of Vocational
Rehabilitation, 33*, 77-88.

Arnett, J. J. (2000). Emerging adulthood: A theory of development from the late teens through
the twenties. *American Psychologist, 55*, 469-80

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in
Psychology, 3,* 77-101.

Cameron, C. & Moore, M. (2014). Disability studies. In C. Cameron (Eds.), *Disability studies: A
student's guide* (37-39). Thousand Oaks, CA: Sage.

Carter, E., Brock, M., Trainor, A. (2014). Transition assessment and planning for youth with
severe intellectual and developmental disabilities. *The Journal of Special Education,
47*(4), 245-255.

Cavet, J. & Sloper, P. (2004). Participation of disabled children in individual decisions about
their lives and in public decisions about service development. *Children and Society, 18,*
279-290.

Clark, G., Gitterman, A., & Carter-Whitney, D. (2013). *Integrated transition planning for young
people with developmental disabilities.* Memorandum. Retrieved from
http://www.edu.gov.on.ca/eng/policyfunding/memos/jan2013/TransitionPlanDevelop.pdf

Cooney, B. (2002). Exploring perspectives on transition of youth with disabilities: Voice of
young adults, parents, and professionals. *Mental Retardation, 40*(6), 425-435.

Crawford, C. (2011). *The employment of people with intellectual disabilities in Canada: A statistical profile*. Toronto, ON: Institute for Research and Development on Inclusion and Society (IRIS).

Creswell, J. (2013). *Qualitative inquiry and research design.* Thousand Oaks, California: Sage Publications, Inc.

Davies, D. M., & Beamish, W. (2009). Transition from school for young adults with intellectual disability: Parental perspectives on "life as an adjustment." *Journal of Intellectual and Developmental Disability, 34*(3), 248-257.

Dubé, P. (2016). *Nowhere to turn: Investigation into the Ministry of Community and Social Services' response to situations of crisis involving adults with developmental disabilities.* Ombudsman Ontario. Retrieved from

https://www.ombudsman.on.ca/Files/sitemedia/Documents/NTT-Final-EN-w-cover.pdf

Dyke, P., Bourke, J., Llewellyn, G., & Leonard, H. (2013). The experience of mothers of young adults with an intellectual disability transitioning from secondary school to adult life. *Journal of Intellectual & Developmental Disability, 38*(2), 149-162.

Epp, T. (2003). (Re)claiming adulthood: Learning disabilities and social policy in Ontario. *Disability Studies Quarterly, 23* (2), 88-100.

Fereday, J & Muir-Cochrane, E. (2006). Demonstrating rigor using thematic analysis: A hybrid approach of inductive an deductive coding and theme development. *International Journal of Qualitative Methods, 5*(1), 1-11.

Foley, K. R., Dyke, P., Girdler, S., & Leonard, H. (2012). Young adults with intellectual disabilities transitioning from school to post-school: A literature review framed within the ICF. *Disability and Rehabilitation, 34(20)*, 1747-1764.

Greene, G., & Kochhar-Bryant, C. A. (Eds.). (2003). *Pathways to successful transition for youth with disabilities*. Upper Saddle River, NJ: Pearson Education, Inc.

Griffin, M., McMillan, E., & Hodapp, R. (2010). Family perspectives on post-secondary education for students with intellectual disabilities. Education and Training in Autism & Developmental Disabilities, 45(3), 339-346.

Hall, E. (2010). Spaces of social inclusion and belonging for people with intellectual disabilities. *Journal of Intellectual Disability Research, 54*(1), 48-57

Hammel, J., Magasi, S., Heinemann, A., Whiteneck, G., Bogner, J., & Rodriguez, E. (2008). What does participation mean? An insider perspective from people with disabilities. *Journal of Disability and Rehabilitation, 30(19)*, 1445-1460.

Kaehne, A., & Beyer, S. (2014). Person-centered reviews as mechanism for planning the post-school transition of young people with intellectual disabilities. *Journal of Intellectual Disability Research, 58(7),* 603-613.

Keogh, B., Bernheimer, L., & Guthrie, D. (2004). Children with developmental delays twenty years later: Where are they? How are they? *American Journal on Mental Retardation, 109*(3), 219-230.

Lachapelle, Y., Wehmeyer, M. L., Haelewyck, M.-C., Courbois, Y., Keith, K. D., Schalock, R., …Walsh, P.N. (2005). The relationship between quality of life and self-determination: An international study. *Journal of Intellectual Disability Research, 49*(10), 740-744.

Laragy, C. (2004). Self-determination within Australian school transition programmes for students with a disability. *Journal of Disability & Society, 19*(5), 519-530.

Lotan, G., & Ells, C. (2010). Adults with intellectual and developmental disabilities and

participation in decision making: ethical considerations for professional-client practice. *Intellectual and Developmental Disabilities, 48*(2), 112-125.

Marshall, C., & Rossman, G. B. (2016). *Qualitative research design* (6th ed.). Thousand Oaks, CA: Sage.

Martin, J., & Williams-Diehm, K. (2013). Student engagement and leadership of the transition planning process. *Career Development and Transition for Exceptional Individuals, 36(1),* 43-50.

McKay, K. (2015*). "It can't just be something that is talked about for somebody": The right to participate for transitional aged youth with intellectual disabilities* (Unpublished undergraduate dissertation). Brock University, St. Catharines.

Mercer Delta Consulting. (2006). *Summary report: Consultation on transforming supports in Ontario for people who have a developmental disability*. Toronto: Ministry of Community and Social Services.

Miceli, M. (2008). *The associations among youth characteristics, secondary school experiences, and enrollment in two- and four-year colleges among youth with disabilities* (Unpublished doctoral dissertation). University of Maryland, Baltimore.

Mitchell, W., Franklin, A., Grego, V., & Bell, M. (2009). Working with children with learning disabilities and/or who communicate non-verbally: Research experiences and their implications for social work education, increased participation and social inclusion. *Social Work Education, 28*(3), 309-324.

Moriarity, L. & Dew, K. (2011). The United Nations convention on the rights of persons with

    disabilities and participation in Aotearoa New Zealand. *Journal of Disability & Society,*

    26(6), 683-697.

Neely-Barnes, S., Marcenko, M., & Weber, L. (2008). Does choice influence quality of life for

    people with mild intellectual disabilities? *Journal of Intellectual and Developmental*

    Disabilities, 46(1), 12-26.

Newman, L., Wagner, M., Knokey, A. M., Marder, C., Nagle, K., Shaver, D…., and Schwarting,

    M. (2011). *The post-uigh school outcomes of young adults with disabilities up to 8 years*

    after high school. A report from the national longitudinal transition study-2 (NLTS2)

    (NCSER 2011-3005). Menlo Park, CA: SRI International.

Oliver, M. & Barnes, C. (2010). Disability studies, disabled people and the struggle for

    inclusion. *British Journal of Sociology of Education, 31*(5), 547-560.

Ontario Ministry of Children and Youth Services, Ontario Ministry of Community and Social

    Services, Ontario Ministry of Education. (2013). *Transition planning protocol and*

    procedures for young people with developmental disabilities, Hamilton/Niagara Region.

    Toronto, ON: Authors.Copy in possession of Contact Niagara.

Ontario Ministry of Community and Social Services, Ontario Ministry of Children and Youth

    Services, & Ontario Ministry of Education (2013). *Integrated transition planning for*

    young people with developmental disabilities 2013-2014: tri-Ministry implementation

    guide. Retrieved from:

    http://www.ocdsb.ca/calendar/AGENDA%20DOCS/2013%20DOCS/October%202013/S

    EAC%2023%20October/06a%20Transition%20Protocol.pdf

Ontario Ministry of Community and Social Services. (1990). Child and Family Services Act,

      R.S.O. c. C. 11. Retrieved from: https://www.ontario.ca/laws/statute/90c11

Ontario Ministry of Community and Social Services, Ontario Ministry of Children and Youth

      Services (2011). *Provincial transition planning framework: Transition planning for*

      young people with developmental disabilities. Retrieved from:

      http://coordinatedaccess.ca/wp-content/uploads/2015/07/Transition-Planning-

      Framework-Final-English.pdf

Ontario Ministry of Education (1999). Categories of exceptionality and definitions. Retrieved

      from: http://www.peelschools.org/parents/specialed/sep/documents/B7categories.pdf

Ontario Ministry of Education (2007). *Highlights of Regulation 181/98.* Retrieved from:

      http://www.edu.gov.on.ca/eng/general/elemsec/speced/hilites.html

Ontario Ministry of Education (2014). *Special Education Update*. Retrieved from:

      http://www2.edu.gov.on.ca.../SpecialEd_Update2014.pdf

Ontario Ministry of Education (2016). *Ministry of Education Special Education Update:*

      Integrated Transition Planning for Young People with Developmental Disability.

      Retrieved from:

      http://www.edu.gov.on.ca/eng/general/elemsec/speced/special_ed_update.html#_Toc445

      455685

Papay, C., & Bambara, L. (2014). Best practices in transition to adult life for youth with

      intellectual disabilities. *Career Development and Transition for Exceptional Individuals,*

      37(3), 136-148.

Park, Y. (2008). Transition services for high school students with disabilities: Perspectives of

      special education teachers. *Exceptionality Education Canada, 18*(3), 95-111.

Pilnick, A., Clegg, J., Murphy, E., & Almack, K. (2011). 'Just being selfish for my own sake…':

> Balancing the views of young adults with intellectual disabilities and their carers in

> transition planning. *The Sociological Review, 59(2),* 303-323.

Rooke, J. (2003). Reaching one's potential: A discussion of individual human rights and people

> with developmental disabilities in Canada. *Journal on Developmental Disabilities, 10*(2),

> 15-24.

Savin-Baden, M. & Major, C. H. (2013). *Qualitative research: The essential guide to theory and*

> *practice*. New York, NY: Routledge

Salmon, N., & Kinnealey, M. (2007). Paving rough roads: Transitions to life beyond the

> classroom as experienced by students with disabilities and their families. *Exceptionality*

> *Education Canada, 17*(1), 53-84

Schalock R. L. & Keith K. D. (1993). Quality of Life Questionnaire. IDS Publishers,

> Worthington, OH.

Shogren, K., & Plotner, A. (2012). Transition planning for students with intellectual disabilities,

> autism, or other disabilities: Data from the National Longitudinal Transition Study-2.

> *Intellectual and Developmental Disabilities, 50*(1), 16-30.

Stancliffe, R.J., Lakin, K.C., Larson, S., Engler, J., Taub, S., & Fortune, J. (2011). Choice of

> living arrangements. *Journal of Intellectual Disability Research, 55*(8), 746-762.

Timmons, J., Hall, A., Bose, J., Wolfe, A., & Winsor, J. (2011). Choosing employment:

> Factorsthat impact employment decisionsfor individuals with intellectual disability.

> Intellectual and Developmental Disabilities 49 (4):285–299.

UN Enable. (2006). *United Nations convention on the rights of persons with disabilities.*

Retrieved on January 2, 2016, from:

http://www.un.org/disabilities/default.asp?navid=15&pid=150

Wagner, M., D'Amico, R., Marder, C., Newman, L., & Blackorby, J. (1992). What happens

next? Trends in postschool outcomes of youth with disabilities. Menlo Park, CA; SRI

International. (ERIC Document Reproduction Service No. ED 356 603).

Werner, S. (2012). Individuals with intellectual disabilities: A review of the literature on

decision-making since the Convention on the Rights of People with Disabilities (CRPD).

Public Health Reviews, 34(2), 1-28.

Wehmeyer, M. L. (2002). The confluence of person-centered planning and self-determination. In

S. Holburn & P. M. Vietze (Eds.), *Person-centered planning: Research, practice and

future directions* (pp. 51–69). Baltimore: Brookes.

Wehmeyer, M. (2005). Self-determination and individuals with severe disabilities: Re-examining

meanings and misinterpretations. *Research and Practice for Persons with Severe

Disabilities, 30(3)*, 113-120.

Wehmeyer M. & Bolding N. (1999) Self-determination across living and working environments:

a matched samples study of adults with mental retardation. Mental Retardation 37, 353–

63.

Wehmeyer, M. & Gragoudas, S. (2004). Centers for independent living and transition-age youth:

Empowerment and self-determination. *Journal of Vocational Rehabilitation, 20,*53-58.

Wehmeyer, M. & Kelcher, K. (1995). *The Arc's Self-Determination Scale-Adolescent Version*.

Retrieved from http://www.thearc.org/document.doc?id=3670

Wehmeyer, M. & Lawrence, M. (1995). Whose future is it anyway? Promoting student

      involvement in transition planning. *Career Development for Exceptional Individuals,*

      *18(2),*69-83.

Wehmeyer, M. & Schwartz, M. (1997). Self-determination and positive adult outcomes: a

      follow-up study of youth with mental retardation or learning disabilities. *Journal of*

      Exceptional Children, 63, 245-255.

Wehmeyer, M. & Schwartz, M. (1998). The self-determination focus of transition goals for

      students with mental retardation. *Career Development for Exceptional Individuals, 21,*

      75-86.

Weinkauf, T. (2002). College and university? You've got to be kidding: Inclusive post-

      secondary education for adults with intellectual disabilities. Crossing Boundaries – An

      Interdisciplinary Journal, 1(2), 28-37.

Appendix A

Letter of Permission Contact Niagara

Contact NIAGARA

July 18, 2017

To Whom It May Concern,

On behalf of Contact Niagara, I would like to acknowledge the collaboration between Brock University Masters Student Katie McKay and Contact Niagara, with respect to the examination of the Transitional Age Youth Process. Please consider this our consent to the use of our Organization's name (*Contact Niagara for Children's and Developmental Services*) in Ms. McKay's thesis, and in any publications and presentation related to this research. This consent is provided on the understanding that Ms. McKay would first consult with the Executive Director of Contact Niagara, should there be any reason to believe any reference would put Contact Niagara, or it's clients, at-risk in any way.

Thank you again for this wonderful opportunity. If you have any questions or concerns, please do not hesitate to contact me as indicated below.

Sincerely,

Nadine Wallace
Executive Director
Contact Niagara for
Children's and Developmental Services and
Co-ordinator of the Independent Review Mechanism
for the Autism Intervention Program
nadine@contactniagara.org
905-684-3407 extension 7233
1-800-933-3617 extension 7233

Appendix B

Letter of Invitation Questionnaire

Date: February 13, 2016

Title of Study: A New Approach to Transition Planning for Transitional Aged Youth with Intellectual Disabilities

Principal Investigators: Dr. Frances Owen, [Principal Investigator], Dr. Dorothy Griffiths [Principal Investigator], Child and Youth Studies, Brock University

Student Principal Investigator: Katie McKay, MA Candidate, Centre for Applied Disabilities Studies, Brock University

Co-Investigator: Cassidy Harm, Honours Thesis student, Department of Child and Youth Studies, Brock University

Research Collaborators: Contact Niagara

We invite you to participate in a research project entitled **A New Approach to Transition Planning for Transitional Aged Youth with Intellectual Disabilities.** This project is focused on investigating the transition process for transitional aged youth with intellectual disabilities from the perspective of professionals working in the field of developmental disabilities in the Niagara Region.

Should you choose to participate, you will be asked to complete a brief questionnaire about participation in planning for transitional aged youth with intellectual disabilities and the new Integrated Transition Planning Protocol.

The questionnaire will take approximately 15 minutes to complete.

If you have any pertinent questions about your rights as a research participant, please contact the Brock University Research Ethics Officer (905 688-5550 ext 3035)

If you have any questions, please feel free to contact me (see below for contact information).

Thank you,

Frances Owen, Ph.D., C. Psych.   Katie McKay

Principal Investigator   Principal Student Investigator

(905) 688-5550, 4807   (905) 688-5550, 5467

fowen@brocku.ca   km11fp@brocku.ca

Dorothy Griffiths, CM, O.Ont., Ph.D.   Cassidy Harm

Principal Investigator   Co-Investigator

(905) 688-5550, 4069   (905) 688-5550, 5467

dgriffiths@brocku.ca   ch11oe@brocku.ca

This study has been reviewed and received ethics clearance through Brock University's Research Ethics Board [File # 15-104].

Appendix C

Consent for Questionnaire

Date: February 13, 2016

Title of Study: A New Approach to Transition Planning for Transitional Aged Youth with Intellectual Disabilities

Researchers: Dorothy Griffiths, CM, O.Ont., Ph.D., Dept. of Child and Youth Studies and Frances Owen, Ph.D., C. Psych., Dept. of Child and Youth Studies

Student Researcher: Katie McKay, MA Candidate, Centre for Applied Disabilities Studies

Co-Investigator: Cassidy Harm, Honours Thesis Student, Dept. of Child and Youth Studies

Research Collaborators: Contact Niagara

Name of Participant: (Please print) _____

Purpose

I am being invited to participate in a study that involves research. The purpose of this study is to gain a greater understanding of the transition process for transitional aged youth with intellectual disabilities from the perspective of professionals working in the field of developmental disabilities in the Niagara Region.. I understand that this study is being conducted as part of an undergraduate honours thesis and a master's thesis. I understand that my participation includes completing a questionnaire and returning it to the researchers, Katie McKay or Cassidy Harm.

In the questionnaire, I will be answering questions about participation in planning regarding transitional aged youth, and the new integrated transitional planning protocol.

Participation

I understand that there will be no payment for my participation in this study. I understand that, for myself, the risks involved in participating in this study are only minimal (e.g., psychological discomfort in discussing the difficulties that may be faced by transitional aged youth and their families. I understand that Contact Niagara is the partnering agency in this study. I also understand that the executive director of Contact Niagara is the chair of the Niagara Regional Transitional Aged Youth Committee. I understand that any information I provide for the purpose of this study will be treated with confidentiality. Access to this data will be restricted to the principal investigators, principal student investigators, and research

assistants. My decision to participate, not participate, or to withdraw will not affect my standing in the workplace

Confidentiality

All information I provide will be kept strictly confidential. However, if during the course of my participation in the study I tell you that a minor I support in my work has been abused or will be abused I understand you will have to report this to the appropriate authorities using my name. I understand that, for ethical reasons, you may breach confidentiality if I make a serious threat to harm myself or someone else. I also understand that you will have to breach confidentiality if you receive a subpoena for your records.

Data

The information I give you will be aggregated with the information you get from other study participants. My name will not be associated with my comments in this aggregate information. Consents, with identifiers and addresses, will be kept securely in a locked file in the laboratory in the Lifespan building 511H.. The identifier on the interview form will just note that the person was a professional and all interviews will be numbered. No personal identifiers will be present in the data. All records will be disposed of 2 years after the study has been completed.

Publication/Use of Results

I understand that the information I give you will be part of (1) an undergraduate honours thesis, and (2) a larger Master's study that will examine the lived experiences of transitional aged youth with developmental disabilities and their families as they undergo the Transitional Aged Youth Process in the Niagara Region. The information I provide today will be used as the basis for developing interview questions for this larger study, and will aid in the development of a tool kit for professionals to use with youth during the transition process. The researchers, Katie McKay, and Cassidy Harm and their supervisors, Dorothy Griffiths and Frances Owen, will have access to this information.

- The results of this study will be discussed at annual symposia and presented at academic and community focused conferences.
- The findings of this study may be published in book form for academic and general audiences, in refereed journals, and as fact sheets.
- The results will be presented in aggregated form

Please check each box you consent to:

[   ] Yes, I understand the general nature of this study and my involvement in it.
[   ] You may publish articles and books, and make professional and public presentations using the information that all the people who helped in the study give you.

[   ] I agree to participate in this study and I understand that I may withdraw from this study at any time.

[   ] I give permission for you to reanalyse my data from this study as part of a larger study which will lead to the development of a toolkit for professionals to use with youth during the transition process

[   ]   I give permission for you to contact me to ask if I would be interested in participating in future studies on transitional aged youth

I agree to participate in this study described above. I have made this decision based on the information I have read in the Informed Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time. I understand that by submitting the questionnaire, I am offering my consent to participate.

Please check each box that applies

[   ] I would like to receive a copy of the results of the study

     [   ] Email: _____   [   ] Surface Mail: _____

[   ] I would not like to receive a copy of the results of the study

Contact Information and Ethics Clearance
This study has been reviewed and has received ethics clearance from the Brock Research Ethics Board. (File # 15-104)

If I have any questions or concerns about my participation in the study, I may contact Dorothy Griffiths at (905) 688-5550 ext. 4069 or Frances Owen at (905) 688-5550, 4807 or the Brock University Research Ethics Officer in the Office of Research Services at (905) 688-5550, 3035, or by email at reb@brocku.ca.

Thank you for your help!

Please take one copy of this form with you for further reference.

I have fully explained the procedures of this study to the above volunteer.

Researcher Signature_____Date _____

Appendix D

Questionnaire

A New Approach to Transition Planning for Transitional Aged Youth with Intellectual Disabilities: A Questionnaire

1. How many years have you worked with transitional aged youth?

_____ years

2. What age would you use to define transitional aged youth?

_____ years old

3. Describe your role in the transition process:

4. What barriers have you experienced when trying to include transitional aged youth (check all that apply):

☐ youths' ability to self-advocate

☐ youths' cognitive abilities

☐ youths' inability to effectively communicate

☐ access to resources

☐ lack of programming available

☐ challenges in communicating with other agencies/ community partners

☐ challenges in scheduling meetings

☐ differing opinions

☐ other

5a. List two barriers that you find to be particularly challenging when including transitional aged youth:

_____   _____

5b. What could be changed/included to help reduce the barriers experienced during the transition process?

6. When you are supporting a transitional aged youth, who is generally involved in the transition process (check all that apply):

☐ youth

☐ youth's parents

☐ teachers

☐ peers

☐ siblings

☐ agency representatives (please specify): _____

☐ other (please specify): _____

7a. Do you think there is anyone currently missing from the transition process? If so, who?

7b. Are there any particular challenges or problems that you could predict emerging when trying to invite others into the transition process, if so what are they?

8a. Do you think it is possible to determine what is authentically meaningful to a transitional aged youth in all circumstances – i.e someone who has limited communication?

8b. How might service providers support individuals to express what is meaningful to them?

9a . Do you see a contrast between the wishes of the family and the individual during the transition process? If so, what is the nature of the difference?

9b. Have you ever noticed a contrast between the wishes of the professional support team and the individual?

9c. Do families and professionals sometimes have different wishes for the transitional aged youth?

10. How can service providers ensure that the focus is on the actual wishes of the individual and not a third party?

11. If you could ask transitional aged youth any questions about their experience during the transition process, what would they be?

12. If you could ask families any questions about their experience during the transition process, what would they be?

Appendix E

Letter of Invitation for Focus Groups

Date: February 13, 2016

Title of Study: A New Approach to Transition Planning for Transitional Aged Youth with Intellectual Disabilities

Principal Investigators: Frances Owen, Ph.D., C. Psych. [Principal Investigator], Dorothy Griffiths, CM, O.Ont., Ph.D., Dept. of Child and Youth Studies [Principal Investigator], Child and Youth Studies, Brock University

Student Principal Investigator: Katie McKay, MA Candidate, Centre for Applied Disabilities Studies, Brock University

Co-Investigator: Cassidy Harm, Honors Thesis student, Department of Child and Youth Studies, Brock University

Research Collaborators: Contact Niagara

We invite you to participate in a research project entitled **A New Approach to Transition Planning for Transitional Aged Youth with Intellectual Disabilities.** This project is focused on exploring the transition process for transitional aged youth with intellectual disabilities from the perspective of professionals working in the field of developmental disabilities in the Niagara Region.

Should you choose to participate, you will be asked to be part of a focus group that will be asked questions about the new Integrated Transition Planning Protocol for Transitional Aged Youth with intellectual disabilities. The purpose of the focus group will be to gain a greater understanding of what professionals would like to know about the lived experiences of youth and families during the transition process. The data from this focus group will be used as part of (1) an undergraduate honours thesis, and (2) a larger study that includes a master's thesis, that will lead to the development of a toolkit for professionals to use to better include youth during the transition process.

The expected duration of the focus is one hour and will be audio recorded. Should you not wish to participate in a focus group, but would like to participate in the study, individual interviews (either face-to-face, or via telephone) may be completed.

If you would like to participate in either a focus group, or an individual interview, please contact Katie McKay, the principal student investigator, at km11fp@brocku.ca to arrange a date and time.

If you have any pertinent questions about your rights as a research participant, please contact the Brock University Research Ethics Officer (905 688-5550 ext 3035, reb@brocku.ca)

If you have any questions, please feel free to contact me (see below for contact information).

Thank you,

Frances Owen, Ph.D., C. Psych.   Katie McKay

Principal Investigator   Principal Student Investigator

(905) 688-5550, 4807   (905) 688-5550, 5467

fowen@brocku.ca   km11fp@brocku.ca

Dorothy Griffiths, CM, O.Ont., Ph.D.   Cassidy Harm

Principal Investigator   Co-Investigator

(905) 688-5550, 4069   (905) 688-5550, 5467

dgriffiths@brocku.ca   ch11oe@brocku.ca

This study has been reviewed and received ethics clearance through Brock University's Research Ethics Board [File # REB #15-104].

Appendix F

Consent Focus Groups

Date: February 13, 2016
Title of Study: A New Approach to Transition Planning for Transitional Aged Youth with Intellectual Disabilities
Researchers: Frances Owen, Ph.D., C. Psych., Dept. of Child and Youth Studies; Dorothy Griffiths, CM, O.Ont., Ph.D., Dept. of Child and Youth Studies
Student Researcher: Katie McKay, MA Candidate, Centre for Applied Disabilities Studies
Co-Investigator: Cassidy Harm, Honours Thesis Student, Dept. of Child and Youth Studies
Research Collaborators: Contact Niagara

Name of Participant: (Please print) _____

Purpose

I understand that the purpose of this research project in which I have agreed to participate is to gain a greater understanding of the transition process for transitional aged youth with intellectual disabilities from the perspective of professionals working in the field of developmental disabilities in the Niagara Region.   I understand that this study is being conducted as part of a master's thesis. I understand that my participation includes participating in a one-hour focus group session with the student researcher, Katie McKay, her faculty supervisor, and other professionals who chose to participate. During the focus group, I will be answering questions about participation in planning regarding transitional aged youth, and the new integrated protocol. I also understand that the student researcher who conduct the interviews will write down and audio record the focus group session. I understand that my participation in this study is voluntary

Participation

I understand that there will be no payment for my participation in this study. I understand that, for myself, the risks involved in participating in this study are only minimal (e.g., psychological discomfort in discussing the difficulties that may be faced by transitional aged youth and their families). I understand that others who have attended the Niagara Regional Committee on Transitional Aged Youth meeting will be invited to participate in the focus group. I understand that Contact Niagara is the partnering agency in this study. I also understand that the executive director of Contact Niagara is the chair of the Niagara Regional Transitional Aged Youth Committee. I understand that Nadine, the executive director of Contact Niagara, and the chair of the Niagara Regional Transitional Aged Youth committee, will not have access to raw data or identifiers. However, I understand that my participation in this study is completely voluntary. I may decline to answer any questions or to participate in any component of the study

Confidentiality

All information I provide will be considered confidential and grouped with responses from other

participants. I understand that confidentiality cannot be guaranteed because the researchers cannot control potential disclosure from other participants. I understand that the researchers will ask for me and all focus group participants to respect our fellow participants and to keep confidential all information that could identify other participants, their comments or any additional information that is shared during the focus group. However, if any information is shared about a minor who has been abused or will be abused the researchers will have to report this to the appropriate authorities and disclose the participants name(s). I understand that, for ethical reasons, you may breach confidentiality if I make a serious threat to harm myself or someone else. I also understand that you will have to breach confidentiality if you receive a subpoena for your records.

Data

The information I give you will be aggregated with the information you get from other study participants. My name will not be associated with my comments in this aggregate information. Consents, with identifiers and addresses, will be kept securely in a locked file in the laboratory in the Lifespan building 511H. The interview transcripts and audio recordings will be maintained in a separate file in the same lab. The identifier on the interview form will just note that the person was a professional and all interviews will be numbered. No personal identifiers will be present in the data. All records will be disposed of 2 years after the study has been completed. Notes will be shredded, audio and data files will be deleted after transcription.

In the event that I wish to discontinue my participation in this focus group I may do so without facing penalty. However I understand that although I may withdraw my participation during the focus group, due to the nature of focus groups it is not possible to separate an individual participant's data and therefore all data I have given up to the point of my withdrawal will be included in the research.

Publication/Use of Results
I understand that the information I give you will be part of a master's study that will examine Transitional Aged Youth Process in the Niagara Region.. The researcher, Katie McKay and her supervisors, Dorothy Griffiths and Frances Owen, will have access to this information.

- The results of this study will be discussed at annual symposia and presented at academic and community focused conferences.
- The findings of this study may be published in book form for academic and general audiences, in refereed journals, and as fact sheets.

The results will be presented in aggregated form Please check each box you consent to:

[   ] Yes, I understand the general nature of this study and my involvement in it.
[   ] You may publish articles and books, and make professional and public presentations using the information that all the people who helped in the study give you.
[   ] I agree to participate in this study and I understand that I may withdraw from this study at any time.
[   ] I give permission for you to reanalyse my data from this study as part of a larger study which will lead to the development of a toolkit for professionals to use with youth during the transition process
[   ] I give permission for you to contact me to ask if I would be interested in participating in future studies on transitional aged youth

Participant Signature_____Date _____

Please check each box that applies:

[   ] I would like to receive a copy of the results of the study
        [   ] Email: _____
        [   ] Surface Mail: _____
[   ] I would not like to receive a copy of the results of the study

Contact Information and Ethics Clearance
This study has been reviewed and has received ethics clearance from the Brock Research Ethics Board. (File # 15-104)

If I have any questions or concerns about my participation in the study, I may contact Dorothy Griffiths at (905) 688-5550 ext. 4069 or Frances Owen at (905) 688-5550, 4807 or the Brock University Research Ethics Officer in the Office of Research Services at (905) 688-5550, 3035, or by email at reb@brocku.ca.

Thank you for your help!

Please take one copy of this form with you for further reference.

I have fully explained the procedures of this study to the above volunteer.

Researcher Signature_____Date _____

Appendix G

Focus Group One Questions

Phase 1:

Introduction: We are seeking the advice of the Transitional Aged Youth Committee about questions that you think we should include as we plan to interview TAY and their families about the TAY experience. Ultimately we are hoping to use the information we get from this TAY research project to create a toolkit that will help TAY and their families.

Research Question: What would professionals like to know about the lived experiences of youth and families during the transition process guided by the new protocol?

1) Do you feel that you have a good understanding of how youth experience the transition process?
    a. How could you gain a greater understanding of their experiences?
    b. What about their experience is important for professionals to know?
    c. What about the transition process would you like to know more about from a youth's perspective?
2) If you could ask transitional aged youth any questions about their experience during the transition period, what would they be?
3) Do you feel that you have a good understanding of how families experience the transition process?
    a. How could you gain a greater understanding of their experiences?
    b. What about their experience is important for professionals to know?
    c. What about the transition process you would like to know more about from a family's perspective?
4) If you could ask families any questions about their experience during the transition period, what would they be?
5) Do you think youth and families experience the transition process in the same way?
6) Do you think it is important for professionals to understand how families and youth experience the transition process?
    a. Why?
        Or
    b. Why not?

Appendix H

Letter of Invitation Individual Interview

Title of Study: A New Approach to Transition Planning for Transitional Aged Youth with Intellectual Disabilities

Principal Investigators: Dr. Frances Owen, [Principal Investigator], Dr. Dorothy Griffiths [Principal Investigator], Child and Youth Studies, Brock University

Student Principal Investigator: Katie McKay, MA Applied Disabilities Studies, Brock University

We invite you to participate in a research project entitled **A New Approach to Transition Planning for Transitional Aged Youth with Intellectual Disabilities.** This project is interested in understanding the transition from the perspective of transitional aged youth with developmental disabilities and their families. Should you choose to participate, you will be asked to complete a one- hour semi-structured interview about the new Integrated Transition Planning Protocol for transitional aged youth with intellectual disabilities.

The expected duration of the semi-structured interview is one hour and all interviews will be audio recorded.

If you have any pertinent questions about your rights as a research participant, please contact the Brock University Research Ethics Officer (905 688-5550 ext 3035, reb@brocku.ca)

If you would like to participate in the study or would like more information on the study, please contact the Principal Student Investigator, Katie McKay, either by email at km11fp@brocku.ca, by phone (905) 688-5550 ext. 5467, or by mailing this signed letter of invitation to Katie at Contact Niagara in the pre-stamped envelope provided.

Thank you,

Frances Owen, Ph.D., C. Psych.   Katie McKay

Principal Investigator   Principal Student Investigator

(905) 688-5550, 4807   (905) 688-5550, 5467

fowen@brocku.ca   km11fp@brocku.ca

Dorothy Griffiths, CM, O.Ont., Ph.D.

Principal Investigator

(905) 688-5550, 4069

dgriffiths@brocku.ca

Appendix I

Consent for Individual Interview

Date:

Title of Study: A New Approach to Transition Planning for Transitional Aged Youth with Intellectual Disabilities

Researchers: Frances Owen, Ph.D., C. Psych., Dept. of Child and Youth Studies; Dorothy Griffiths, CM, O.Ont., Ph.D., Dept. of Child and Youth Studies

Student Researcher: Katie McKay, MA Candidate, Centre for Applied Disabilities Studies

Research Collaborators: Contact Niagara

Name of Participant: (Please print) _____

Purpose

I understand that the purpose of this research project in which I have agreed to participate is to gain a greater understanding of the transition process for transitional aged youth with intellectual disabilities from the perspective of transitional aged youth with developmental disabilities and their families in the Niagara Region. I understand that this study is being conducted as part of a master's thesis. I understand that my participation includes participating in a one hour semi-structured interview with the student researcher, Katie McKay, during which I will be answering questions about human rights and participation in planning regarding transitional aged youth. I acknowledge that these interviews will be conducted at a lab at Brock University or at a community agency office. If a face-to-face interview is not possible, I also acknowledge that a telephone interview may take place. I also understand that the student researcher who conducts the interviews will write down and audio record my responses to semi-structured interview questions. I understand that my participation in this study is voluntary and that I may withdraw from the study at any time and for any reason without penalty before the data have analyzed.

Participation

I understand that there will be no payment for my participation in this study. I understand that the risks involved in participating in this study are only minimal (e.g., psychological discomfort in discussing the difficulties that may be faced by transitional aged youth and their families). I understand that Contact Niagara is the partnering agency in this study. I understand that any information I provide for the purpose

of this study will be treated with confidentiality. Access to this data will be restricted to the principal investigators, principal student investigators, and research assistants.

Confidentiality

I understand that all my personal data will be kept strictly confidential. However, if during the course of my participation in the study I tell you that a minor has been abused or will be abused you will have to report this to the appropriate authorities using my name. I understand that, for ethical reasons, you may breach confidentiality if I make a serious threat to harm myself or someone else. I also understand that you will have to breach confidentiality if you receive a subpoena for your records.

Data

The information I give you will be aggregated with the information you get from other study participants. My name will not be associated with my comments in this aggregate information. Consents, with identifiers and addresses, will be kept securely in a locked file in the laboratory in the Lifespan building 511H. The interview transcripts and audio recordings will be maintained in a separate file in the same lab. The identifier on the interview form will just note that the person was a professional, and all interviews will be numbered. No personal identifiers will be present in the data. All records will be disposed of 2 years after the study has been completed. Notes will be shredded, audio and data files will be deleted after transcription

In the event that I wish to withdraw my participation from this study before data have been aggregated, I understand that my data will be disposed of via shredder and that my audio recording will be deleted. I understand that there will be no consequences for withdrawing.

I understand that the information I give you will be part of a master's study that will examine Transitional Aged Youth Process in the Niagara Region.. The researcher, Katie McKay and her supervisors, Dorothy Griffiths and Frances Owen, will have access to this information.

Please check each box you consent to:

[   ] You may publish articles and books, and make professional and public presentations using the information that all the people who helped in the study give you.

[   ] Yes, I understand the general nature of this study and my involvement in it.

[   ] I agree to participate in this study and I understand that I may withdraw from this study at any time without penalty.

[   ] I give permission for you to contact me to ask if I would be interested in participating in future studies on transitional aged youth

Participant Signature_____Date _____

Please check each box that applies

[   ] I would like to receive a copy of the results of the study

      [   ] Email: _____

      [   ] Surface Mail: _____

[   ] I would not like to receive a copy of the results of the study

This study has been reviewed and has received ethics clearance from the Brock Research Ethics Board. (File # 15-104)

If I have any questions or concerns about my participation in the study, I may contact Dorothy Griffiths at (905) 688-5550 ext. 4069 or Frances Owen at (905) 688-5550, 4807 or the Brock University Research Ethics Officer in the Office of Research Services at (905) 688-5550, 3035, or by email at reb@brocku.ca.

Thank you for your help!

Please take one copy of this form with you for further reference.

I have fully explained the procedures of this study to the above volunteer.

Researcher Signature_____Date _____

Appendix J

Individual Interview Questions

1) As of September 2014, an Integrated Transition Planning protocol has been mandated. As part of the protocol, the Ministry of Children and Youth Services, the Ministry of Community and Social Services, and the Ministry of Education must work together to establish a single integrated transition plan.
   a) What is a single integrated transition plan?
   b) How has this new protocol changed the transition process?
   c) What are the implications of doing this type of planning? (possible probes: for TAY, for their families, for professionals in different service sectors)
2) The Integrated Transition Planning protocol now mandates that transition planning begin at age 14.
   a) Do you think this is a good age to begin the planning process? (possible probe- What do you think is the optimal age at which to begin this planning?
   b) What are the advantages of beginning the transition process at 14?
   c) What are the disadvantages of beginning the transition process at 14?
3) According to the Transition Planning Protocol Guiding Principles, the integrated transition plan should operate under the same principles as Person Centered Planning Principles
   a) What are Person Centered Planning Principles?
   b) Do you believe the current transition planning principles are consistent with these principles?
      i. If yes, how?
      ii. If no, how not?
4) Have you participated in a transition plan using the new protocol from start to finish?
   If answer is yes, then say "I would like to go through that process with you to get an idea what is involved by asking you some questions about your experience"

      i. How is it initiated?
      ii. Who takes responsibility for hosting the transition meeting?
          1. How is this decided?
      iii. What does a transition meeting involve?
      iv. What emerges from the transition meeting?
      v. What is done after the meeting?
      vi. How do you ensure that the hopes and dreams of the youth are being met?
      vii. What happens if the desires of the youth are unrealistic or cannot be met?
   If answer was No, then ask " From your understanding of the process, what do you think it should look like?"

5) What do you think the role of the youth should be in a transition plan? From your experience, do you think this is typically done? (possible probe: please describe a typical example of the role of youth in the process.)

6) The Transition Planning Protocol Guiding Principles states that "the planning process provides the person with choices to support the development of self-determination and self-advocacy"
    a) What choices are provided?
    b) How do you support this development?

7) The Transition Planning Protocol Guiding Principles also state that "Transition Planning includes the involvement of people who are important to the young person, as determined by the young person"
    a) How do you ensure that the youth is able to express who they would like involved in their transition process?
    b) Who invites these important people?

8) What steps are taken to include youth in the transition process? Are there other steps you feel should be taken to increase inclusion?

9) Are there any specific tools/resources used to include youth in the transition process?
    a) If yes, say "could you please explain them?"
    b) If no, say "what tools/resources would/could be helpful?"

10) How do youth who do not use verbal communication or who have limited verbal communication participate in the transition process?
    a) Can you recommend any changes, tools, or strategies to better include youth who do not communicate verbally?

11) During the transition process, what is the role of the …?
    a) Family
    b) School
    c) Community organization
    d) Other?

12) Are you happy with the current transition process?
    a) What do you like about the current transition process?
    b) What do you dislike about the current transition process?

13) If you could design a new transition process, what would it look like?

14) Do you believe there is anything missing from the current transition process?
    a) If so, what?
    b) How could we include this?

Appendix K

REB Clearance

Brock University

Research Ethics Office Tel:
905-688-5550 ext. 3035

Email: reb@brocku.ca

Social Science Research Ethics Board

Certificate of Ethics Clearance for Human Participant Research

DATE:	2/4/2016		
PRINCIPAL INVESTIGATOR:	OWEN, Frances - Child and Youth Studies		
FILE:	15-104 – OWEN		
TYPE:	Masters Thesis/Project Undergraduate	STUDENT:	Katie McKay Cassidy Harm
		SUPERVISOR:	Frances Owen and Dorothy Griffiths
TITLE:	A New Approach to Transition Planning for Transitional Aged Youth with Intellectual Disabilities.		

ETHICS CLEARANCE GRANTED

Type of Clearance: NEW   Expiry Date: 2/28/2017

The Brock University Social Science Research Ethics Board has reviewed the above named research proposal and considers the procedures, as described by the applicant, to conform to the University's ethical standards and the Tri-Council Policy Statement. Clearance granted from 2/4/2016 to 2/28/2017.

The Tri-Council Policy Statement requires that ongoing research be monitored by, at a minimum, an annual report. Should your project extend beyond the expiry date, you are required to submit a Renewal form before 2/28/2017. Continued clearance is contingent on timely submission of reports.

To comply with the Tri-Council Policy Statement, you must also submit a final report upon completion of your project. All report forms can be found on the Research Ethics web page at http://www.brocku.ca/research/policies-and-forms/research-forms.

In addition, throughout your research, you must report promptly to the REB:

a)   Changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
b)   All adverse and/or unanticipated experiences or events that may have real or potential unfavourable implications for participants;
c)   New information that may adversely affect the safety of the participants or the conduct of the study;
d)   Any changes in your source of funding or new funding to a previously unfunded project.

We wish you success with your research.

Approved: _K Maich_____

              Kimberly Maich, Chair
              Social Science Research Ethics Board

Note: Brock University is accountable for the research carried out in its own jurisdiction or under its auspices and may refuse certain research even though the REB has found it ethically acceptable.

         If research participants are in the care of a health facility, at a school, or other institution or community organization, it is the responsibility of the Principal Investigator to ensure that the ethical guidelines and clearance of those facilities or institutions are obtained and filed with the REB prior to the initiation of research at that site.