

A New Approach to Transition Planning for Transitional Aged Youth With Intellectual and Developmental Disabilities

Abstract

The current study examined transition planning in the Niagara Region in Ontario, Canada, as per the protocol for integrated transition planning for young people with developmental disabilities, and the barriers to the enactment of this protocol in relation to youth participation and implementation. Further, the study focused on whether youth were better included in their transition plans since the implementation of the protocol, and ways to better include youth in the transition process. 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; (3) transition planning should begin earlier and continue into adult services to reduce the gap between children's services and adult services; (4) we must move past keeping youth "busy and safe" and ensure that they are participating in meaningful activities; and (5) integrated transition planning is a new process but it is the right process that has many benefits.¹

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

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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, 2013b). 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, 2013a, p. 2). They further explained that each region in the province 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, 2013b) 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 to examine implementation of the new transition process. In particular, the intention was to gain a greater understanding of how transitional aged youth participate in their transition plans, whether they are better included since the initiation of the Plan, and to discover ways to better include youth in their plan, if they are not currently involved.

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 (UN) Convention on the Rights of Persons with Disabilities (United Nations General Assembly, 2007) 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, 2013b). 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 in Ontario, Canada.

Literature Review

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). 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 youths with disabilities. Research has described this period for youth with disabilities as a stressful experience, that is filled with uncertainty for a long time (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; Newman et al. (2011). 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, resulting 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 that they were once guaranteed (Shogren & Plotner, 2012).

“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 shown 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). This 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 each week and the number of weeks worked in a year were

lower than those of their peers with other disabilities, 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 comparable results. They found that young adults with intellectual disabilities were less likely to be employed at the time of the study 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). The focus of transition planning has been on improving these outcomes.

Inclusion in decision making by 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). Research has demonstrated that children with disabilities want respect for their views (Cavet & Sloper, 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).

Although past research has identified that youth do not often participate in their transition plans, the Integrated Transition Protocols being examined in this study, 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, 2013a), and the *Transition Planning Protocol and Procedures for Young People with Developmental Disabilities – Hamilton Niagara Region Protocol* (here forth known as the *Regional Protocol*) (Ontario Ministry of Children and Youth Services, Ontario

Ministry of Community and Social Services, & Ontario Ministry of Education, 2013b) acknowledged the importance of providing youth with opportunities to participate. Participation, self-determination, and choice were themes that were identified in the *Regional Protocol*. For example, in the *Regional Protocol*, Article 2.3 outlined that the plan must be person-centred and continues to state that youth 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, 2013b, 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 their self-determination and self-advocacy (Ontario Ministry of Children and Youth Services, Ontario Ministry of Community and Social Services, & Ontario Ministry of Education, 2013b). 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” and went on to further note that “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, 2013b, p. 15).

The literature reviewed here clearly identifies that, despite years of research suggesting that they play an important role in their transition process, youth continue in many instances to play marginal roles in their transition plans. In light of this, 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 *Protocol* claims to be guided by the principles of youth participation, self-determination, and choice, and appears to be person-centred, concern has been raised that person-centred planning can become a paper

exercise that can fail to increase independence, choice, and inclusion of transitional aged youth (Kaehne & Beyer, 2014). 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.

Materials and Methods

Purpose of the Study

The goal of the 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 specific foci were on the examination of the experience of youth and families during the transition process, how youth are currently involved in their transition plans, what barriers hinder the effective implementation and success of the transition protocol and transition planning in general, and how professionals could better include youth in their plans.

Research Design

This study employed a pragmatic qualitative research design that was informed by the theory of emerging adulthood and by a social model of disability. The combination of these theories allowed for an in-depth examination of this important transition period. It is a distinct time in the lifespan that can be especially challenging for youth with developmental disabilities who are often marginalized, oppressed and considered to not fully reach “adult” status.

Participants

This study was focused on the perspectives of professionals who work with transitional aged youth in the Niagara Region. It included participants from each of the three Ministries involved in the Integrated Transition Planning Protocol in order to gain a holistic understanding of how professionals in organizations that are supported by each of the three Ministries implement the transition process, while acknowledging that the transition process is a multidisciplinary approach to future plan-

ning for youth with intellectual and developmental disabilities. The current sample was approximately balanced with representation from participants who operated under each Ministry. Detailed descriptions of participants are not provided for confidentiality reasons. 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 using a snowball sampling technique (Creswell, 2013). 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. 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

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 key 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 distributed recruitment packages to members of the Niagara Regional Committee on Transitional Aged Youth. The recruitment material was distributed three times: once via email prior to the recruitment presentation, once during the Niagara Regional Committee on Transitional Aged Youth meeting, and once after the Regional meeting.

Three data collection methods were used: questionnaires, focus groups, and individual interviews. 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. The first focus group consisted of seven professionals, while the second focus group consisted of two professionals. It is important to note that the set of questions asked during the first focus group was different than the set of questions used during the second group. This occurred as a result of a shift in research focus. 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 *Do 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?* Two individual interviews were conducted at the request of participants. The questions asked during the individual interviews were the same as those asked during the second focus group.

A preliminary thematic deductive analysis of the data from Focus Group One was completed prior to any other data collection. During this analysis, the transcript of the focus group was read numerous times, and coded for patterns and then for themes. 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 foci, participants' responses focused on their experiences with the protocol and transition planning in general rather than the lived experience of the family and youth who went through the process. 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 that youth and their 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 analyzed using thematic analysis (Braun & Clarke, 2006).

Results

From the collected data, five major themes were identified. These themes can be best described as being either deductive or inductive. Deductive themes are identified by coding and developing themes based on existing concepts or ideas (Fereday & Muir-Cochrane, 2006). Inductive themes are themes that are identified from participants' discussions and are not based on previous concepts or ideas (Fereday & Muir-Cochrane, 2006).

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 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. Sixty-six 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. When asked how youth with limited communication were included in the transition process, a participant 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." That participant 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."

Attitudinal barriers. A predominant theme was that societal attitudes and assumptions about disability were major barriers that hindered youth participation during the transition process. As noted by a participant in 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. Another Questionnaire participant identified the following barrier to be particularly challenging: "Families [are] not ready to support their child to become a young adult with choices, rights and opportunities for growth." A Focus Group participant 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."

Service limitations. Access to resources was also noted to be a barrier that impeded the active participation of youth, as noted by 78 percent

Table 1. Barriers to Youth Participation in the Planning Process

Barrier	% of Participants Who Noted Barrier
Access to Resources	78%
Lack of Programming Available	78%
Challenges in Communicating with Other Agencies/Community Partners	56%
Challenges in Scheduling Meetings	33%

of the Questionnaire participants (see Table 1). Similarly, 56 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 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, a participant 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.” A participant 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 four years and where can that be used right now while you’re waiting for service.”

Theme 2: Participation

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

Different perspectives. Sixty six percent of Questionnaire participants noted differing opinions among planning participants as a barrier to youth participation. This included differences between the wishes of youth and families, youth and service providers, and families

and service providers. For example, when asked which barriers were particularly challenging when including youth in their transition process, a participant in the Questionnaire referred to “families having different goals and dreams for the child that their child does not want.” This was echoed by another Questionnaire participant, who noted “Parents wanting one thing and the youth wanting another” as being a barrier to including youth in their transition process. Participants in the Focus Groups also described differences between the perspectives of service providers and youth. One participant explained, “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.”

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 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 and acknowledged the importance of their participation. However, a participant in the Focus Groups 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.” A participant in the Individual Interviews echoed this statement, 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."

Person Centred Planning. Almost all participants discussed Person Centred 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, a participant in the Questionnaires responded, "Using Person Centred 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." Similarly, another Questionnaire participant 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." When asked, "*What could be changed/included to help reduce the barriers experienced during the transition process?*" a participant 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."

Family participation. Most of the participants in the current study acknowledged that the family plays an important role in the transition process. A participant in the Questionnaires 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?*" another participant 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."

The disconnect. Participants felt that there was often a disconnection between the wishes of the youth and their families. This was high-

lighted by a participant 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'." 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. This was noted by a participant in the Questionnaire who explained, "supporting families to really communicate with their child... 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." Participants stressed the importance of teaching these skills to youth, and allowing youth opportunities to practice their skills.

Theme 3: The Transition Begins and Ends With the Protocol

The following subthemes emerged under the theme of The Transition Begins and Ends with the Protocol: *Age, 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.*

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, a participant in the Questionnaire responded: "students being asked questions early on...starting with this as soon as possible (I say before Grade 9)." Another participant echoed this answer in their response to the same question, suggesting, "earlier planning for what comes after high school." Another participant reflected on the stresses already facing youth when they enter high school and also start planning for the end of school: "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.” Questionnaire participants 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.” Further, participants 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.”

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. Many participants expressed frustration with the TAY process ending when a youth turns 18. As one participant 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 [by adult services]. I don’t know if the parent or youth aren’t fully aware of that.”

When asked, *What happens at 18 for youth?*, the participant responded that “they have to start from fresh right – with the Adult Developmental Services...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.”

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, Participants in the Questionnaire responded, “one agency that follows the youth from childhood to adulthood,” and “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.” Focus Group

participants explained, “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.” Another Focus Group participant continued, “every person that the family would have called for help can’t help anymore,” while another 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.” A follow up question then was asked about whether adult agencies to which youth will be transitioned are involved in the transition plans. A participant in the Focus Group explained that this would be the role of Developmental Services Ontario (DSO), and another participant in the Focus Group 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.”

Realities of adult services. Many of the participants noted that there needs to be more education for both families and service providers about the realities of adult services. When asked what could be changed/included to help reduce the barriers experienced during the transition process, participants in the Questionnaire suggested, “more education for families about the reality of adult supports,” and “early education of all parties involved of the reality of adult services.” Questionnaire participants 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” 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.”

Theme 4: 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. Participants in the Questionnaire explained

that “families will lean on them [to] 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.” Participants 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.” Questionnaire participants also felt that “very often the family wants the person to be out and busy doing things regardless of what that looks like,” and that “often parents want to over support youth or have them ‘busy’ with activities that provide care and don’t actually interest the youth.” Participants 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.”

Theme 5: 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 the Focus Groups felt that they liked the current transition process, as in the 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, a Focus Group participant 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,” while another 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.”

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 the Focus Groups and both the Individual Interviews identified benefits of working collaboratively, as mandated by the Integrated Transition Protocol. One benefit was highlighted in a Focus Group when a participant 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.”

Discussion

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 that 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 families and youth; (3) the transition begins and ends with the planning protocol and there is a gap between child services and adult services which is not being addressed currently; (4) there is a need to move past programs that focus on keeping youth “busy and safe” and to start ensuring that youth are participating in activities that are meaningful to them after high school graduation; and (5) the current Integrated Transition Planning Process is a new process, but it is the right process and there are many benefits to integrated transition planning.

Many of the themes identified during this study are supported in the literature. For example, various barriers to transition planning and youth participation during the transition process, were found in the current study and have been well supported throughout the transition literature. Three key barriers identified by participants in this study were: (1) youths’ abilities, (2) service limitations, including waitlists, and (3) attitudinal barriers. It is important to note that despite the current study only highlight-

ing three barriers, others were noted by some participants and have been supported by the literature. The three presented in this study are key barriers as they were noted across all data collection methods, and in other research studies. Youths' abilities have often been cited as a factor that hinders their full participation during the transition process. For example, in Park's (2008) study, teachers felt that common impediments to participation and involvement in the development of goals and participation during the transition process were the cognitive and communication limitations of some youth. However, research supports that despite the perception of youths' abilities being a limitation 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 & Sloper, 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 futures, but they also were 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 meaningfully. 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 them to participate in meaningful ways. In general, it can be concluded that it is the *assumption* of cognitive and communicative limitation that often lead professionals to assume that a youth cannot fully participate, rather than the limitation itself.

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, Weinkauff (2002) noted a lack of post-secondary school options for youth with disabilities, whereas Griffin, McMillan, and Hodapp (2010) argued that the limited oppor-

tunities 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. The barrier of service limitations identified by interviewees in this study, may be a key contributor to the inability to conduct transition meetings in a way that would support meaningful inclusion of youth with developmental disabilities. There is an extensive time commitment required to engage youth in these meetings which is difficult for professionals to provide given their already large workloads associated with the process.

Service limitations also included 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 were no services to which youth could transition. 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). 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. This will improve the quality of life of many youth with developmental disabilities. Although this is not a simple task, and in the interim 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 the natural supports created during the transition process, such an approach will result in less work and fewer resources throughout the remainder of their life course.

A critical aspect of adopting such an approach is that youth must be active participants during their transition planning. The importance of youth participation was noted by most par-

ticipants 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, Hall, Bose, Wolfe, & Winsor, 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 youth have to be the ones making the decisions (Laragy, 2004).

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 have 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 difficult 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.

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 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 own lives. Many will agree that youth go through numerous transitions during their lifetime, including the transition from home to daycare 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, despite the recognized importance of keeping youth safe, the 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 what the youth truly would like to do.

Creating community connections and supports while 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 more broadly about what other opportunities are available to youth with intellectual and developmental disabilities outside of these Ministry funded services. As part of the TAY process, it is recommended that natural community supports, such as local businesses and community resources, be explored, fostered, and encouraged from the start in order to help create new informal supports for youth with developmental disabilities.

Limitations

A limitation of the current study is that the perspectives of both the youth and their families are missing, despite a focus on youth participation. 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. Despite this being identified as a limitation, it is important to note that the professionals who participated in this study have a wealth of knowledge and experience. Whereas families and youth could speak to their individual experiences navigating the transition process, the professionals in this study were able to speak to a variety of experiences and cases, providing an overview of the current transition process. Similarly, many of the professional participants would have experienced both previous transition processes, and could therefore compare past experiences and processes to the current protocol being examined. A further limitation of the current study was that the focus of the research changed halfway through the data collection process and, therefore, the questions from the first focus group were different than the ques-

tions asked in focus group two and in the individual interviews. In addition, having only two participants in focus group two was noted as a barrier. 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 is that a critical disability perspective was not used during the framing of the questions, or during the data analysis, although it may have benefited this study. Types of questions that could have emerged from a critical disability studies perspective include: why does this binary between childhood and adulthood exist?; 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 will persons with developmental disabilities continue to be in, rather than fully a part of the community? (Hall, 2010). Using a critical approach and asking these types of questions could have challenged the hegemonic norms that often guide transition planning, such as the perception of employment and independent living as universally optimal outcomes. It is only by challenging these norms that we can move past them and create opportunities for youth to express what they want and participate in activities that are meaningful to them. 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 by allowing for more open discussions and opportunities for youth to explore alternative spaces where they feel a sense of authentic belonging (Hall, 2010).

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 Ministries of Children and Youth Services, Community and Social Services, and 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 participants in the current study concluded that the

Integrated Transition Process is a good one 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 disconnection 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. This results in many barriers such as a lack of program availability and waitlists, which continues to impede successful transitions to adulthood. Youth need to begin practicing decision-making and participation in planning earlier so that they can be better self-advocates during their transition meetings. Participants suggested 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 planning process in order to mediate some of the barriers found in the current study.

Key Messages From This Article

People with Disabilities. You have the right to be included in your transition plan. You have the right to let people know what your hopes, dreams, and goals are, and to have those hopes, dreams and goals respected.

Professionals. It is important to remember that transition plans are about the youth's goals, hopes and dreams. We must move past the central focus on ministry-funded services only and begin thinking also about the development of meaningful community relationships and connections to ensure that youth are living the lives they want to live.

Policymakers. Despite the Protocol being deemed to be tri-Ministerial, 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 high school planning process. It is recommended that youth who are deemed eligible for Developmental Services Ontario (DSO) before their 18th birthday have a representative from the adult services attend at least one transition meeting.

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