Journal on Developmental Disabilities
Le journal sur les handicaps du développement

JoDD

La publication officielle de l'association ontarienne sur les handicaps du développement
The official publication of the Ontario Association on Developmental Disabilitites

Transitional Aged Youth

Volume 24, Number 1 2019

Ontario Association on
Developmental Disabilities

Journal on Developmental Disabilities / Le journal sur les handicaps du développement
published by the Ontario Association on Developmental Disabilities, Toronto, ON

ISSN 1917-7909 (Online)   ISSN 1188-9136 (Print)

Cover Image: “Three Shades of Me” (2019) by Conrod Skyers

Medium: Acrylic on Canvas

Conrod says, “The painting depicts me over time and my Jamaican roots. I find it very difficult to talk about my past and don’t like reliving it. Creative Village Studio saved my life. I threw myself into art so I wouldn’t get in to trouble. I am proud of my work and I am an artist.”

Special thanks to Creative Village Studio, a community-based art studio in the heart of Islington Village, operated by Community Living Toronto.

Journal on Developmental Disabilities
Le journal sur les handicaps du développement
JoDD
Volume 24, Number 1, 2019

Table of Contents

Introduction

Articles

Journal On Developmental Disabilities

Volume 24, Number 1, 2019

Journal on Developmental Disabilities
Le journal sur les handicaps du développement
JoDD
Volume 24, Number 1, 2019

Transitional Aged Youth: Navigating Planning Across Systems

Authors

Anne Readhead,[1]
Lisa Whittingham,[1]
Katie McKay,[2]
Courtney Bishop,[1]
Frances Owen[1]

[1] Department of Child and Youth Studies, Brock University, St. Catharines, ON

[2] Contact Niagara for Children's and Developmental Services, St. Catharines, ON

Correspondence

areadhead@brocku.ca

Keywords

transitional aged youth, developmental disabilities, person-centred/person-directed planning, coordinated transition planning

Abstract

For youth who have intellectual/developmental disabilities, the transition following high school from services directed to children and youth to services intended for adults can be daunting. However, since 2013 the Ontario government along with educational and community-based services have focused on the development and implementation of multisectoral coordinated planning processes to facilitate this change during the high school years. This article describes the nature of the youth to adult transition and some of the planning processes used to support them. Notions of social inclusion, quality of life, and youth-centred approaches with the ministerial adoption of these approaches are discussed. It also introduces the articles in this special issue that explore the transition process itself and the experiences of youth and their families.

The transition to adulthood for an adolescent with an intellectual/developmental disability (I/DD) presents the potential for new opportunities in their daily activities and relationships; however, it also can lead to the displacement of familiar social support networks, such as those associated with school and children's services, in addition to the challenge of adjustment to an entirely different system of service provision for adults. This phase of life represents a time of uncertainty and complexity as the young person plans for post-secondary education, employment, community networking and/or alternative living options. The articles in this special issue highlight and describe the nature of this transition, the experiences of youth and their families, and the changes to the transitional aged youth (TAY) planning processes in Ontario, Canada that were initiated in 2013 and that continue to evolve.

Transition for Young People With I/DD

As Wehmeyer and Webb (2012) explain "[t]he concept of transition implies movement and change" (p. 3). For neurotypical youth, the benchmarks of a "successful adult life" are demonstrated by graduating from high school, participating in college and/or university, finding employment, and living independently. In addition to these typical benchmarks, for young people with I/DD the focus of transitioning tends to be further complicated by the requirement that they shift from services for children/youth to those that are directed to adults with disabilities (Hurd, Evans, & Renwick, 2018). As described in Katie McKay's article in this issue, this is a significant transition to an entirely different service system when youth reach the age of 18. Historically, there were limited options available for youth with I/DD as they transitioned into adult services. Currently, while the opportunities for social inclusion remain restricted, innovative attempts are being made including individualized goals and supports to access social networks, public services and/or community activities. More specifically, the tenets of social inclusion have expanded to incorporate a focus on developing natural supports and diverse relationships within the community and on providing opportunities for inclusive interactions and engaging participation. These opportunities include different forms of postsecondary education, employment and participation in community activities such as recreational clubs. The article by Readhead, Whittingham, McKay, Bishop, Owen and Hope in this issue discusses some of these options and the ways in which youth can be supported to participate in them. Jo Anne Nugent's article describes an innovative culinary college training program that is preparing youth for entry into the world of work. This kind of social inclusion is a component of an individual's well-being and human rights (Simplican, Leader, Kosciulek, & Leahy, 2015).

Notions of social inclusion are constantly changing. Simplican and colleagues (2015) have made the point that a clear understanding of social inclusion is impeded by the lack of a common definition of the concept. This tends to contribute to communication difficulties concerning the nature of social inclusion among stakeholders, including the individuals with disabilities, their family members, professional supporters, and the policymakers who influence them. For example, as definitions have evolved so too has the understanding of social inclusion as "not only a personal issue, but also an issue of civil rights, equality and economics" (Simplican et al., 2015, p. 22). Simplican and colleagues have developed a nuanced definition of social inclusion that focuses on the interaction of interpersonal relationships and community participation. They have developed a broad ecological framework that examines what they refer to as "enabling and disabling conditions" (p. 26) on the individual, interpersonal, organizational, community, and socio-political levels that support or inhibit social inclusion. For example, the relationships between family members and service staff can either facilitate or impede an individual's motivation and goal setting, and the nature of these interactions can, in turn, be affected by the larger organizational culture of the services with which the individual is involved. The quality of life for youth who are transitioning out of school is often contingent on their access to social services that provide individualized service, empowerment, self-determination, inclusion and opportunities to experience equitable rights (Gomez, Verdugo, Arias, Navas, & Schalock, 2013).

Teams supporting youth with I/DD in the process of transition planning should focus on the opportunities and supports necessary to optimize a youth's quality of life. However, it is essential that they ensure that there is balance, so the complexity of the youth's needs does not overshadow the importance of ensuring that the planning is based on the decision-making, engagement and self-determination of the youth themselves. A person-centred approach is a critical mechanism to facilitate an authentic and meaningful planning process for youth and their families (Kaehne & Beyer, 2014). The articles in this issue emphasize the central importance of an individualized approach to planning for all transitional aged youth.

Person-Centred Planning and Person-Directed Planning

Research in the United Kingdom has argued that Person-Centred Planning (PCP) does not resolve the complex structural issues of service delivery. However, it is discussed that it is important to not lose sight of the research that illustrates that PCP "…may open up opportunities to users for increased participation in the transition process itself, formulate more adequate post-school destinations based on needs and abilities of the young person and articulate clear goals for support and intervention" (Kaehne & Beyer, 2014, p. 604) where planning *for* becomes planning *with* the person. The PCP approach promotes values and strategies that scaffold towards Person-Directed Planning (PDP), an extension of the PCP process where planning *with* becomes planning *by* the young person (Martin, Grandia, Ouellette-Kuntz, & Cobigo, 2016).

Current research in Ontario by Martin et al. (2016) focused on the processes that are necessary to support PDP. They suggested that planning should focus on the youth as the most important participant in the development of the transition plan. Furthermore, they suggested that the process should endorse the importance of the young person setting goals that are supported by family/community/service providers, and that such goals value and promote the young person's self-determination in decision-making. Finally, they suggested that communication within the planning process should also foster collaboration among essential social networks that empower the young person. The effectiveness of the PDP approach hinges on having "the right people with the right attitudes engaging in the right actions" (Martin et al., 2016, p. 552). In order for planning to be successful, such as supporting "person-directed living" (p. 554), the service system must enact a planning process that ensures that the right people are on the planning team. These should be people who are chosen by the young person and who know the person, and should include "natural supports." (p. 554). In addition, the people included on the planning team should commit to a PDP approach and be flexible in response to the youth's decision-making power. The relationship between the young person with I/DD and the other members of the planning process is key, as the planning team members work collaboratively with the young person as an active planning member.

In addition to having the correct people participating in the transition planning, Cooper-Duffy and Eaker (2017) suggested that it is also important to have a strong support system to carry-out the transition planning process. The team should be founded on collaborative action and cooperative participation with a shared focus on goal setting, clearly designated roles and responsibilities, a smooth pathway to outcome attainment, the presence of social networking, group problem-solving and ongoing follow-up (Cooper-Duffy & Eaker, 2017). Noonan, Erickson and Morningstar (2013) described interagency collaboration as a predictor of positive outcomes for youth after high school. The implementation of cooperative planning and interagency collaboration among service providers, youth and their families assists in building a pathway to navigating the complex and challenging service systems leading to a more successful transition experience (Leonard et al., 2016). A promising model that reflects this integrated approach is the Ontario tri-sector collaborative transitional aged youth planning process that is described in Katie McKay's article in this issue. In addition, the article by Coons-Harding, Azulai and McFarlane describes planning tools from across Canada that focus on transition planning with youth who have fetal alcohol spectrum disorder. In Ontario, the transition process leads into adult services that are governed by updated legislation focused on social inclusion.

In 2008 the Ontario Ministry of Community and Social Services, responsible for adult developmental services, released the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act* (Ontario Government, 2008, SIPDDA) which replaced the 35-year-old *Developmental Services Act* (1974). Some of the key changes that the SIPDDA brought forward included a new definition of *developmental disability* and changes to the requirements that agencies, funded by that ministry, provide services and supports that follow guidelines for Quality Assurance Measures, which include a focus on person-directed planning. The Ontario government's vision for developmental services transformation was based on the concept of *citizenship* as one of its key underlying tenets for moving towards the social inclusion of persons with I/DD "to live as independently as possible in the community and [developmental services] to support their full inclusion in all aspects of society" (Ontario Ministry of Community and Social Services, 2013, p. 6). Further movement toward inclusion was reflected in the 2015 Government of Ontario announcement that provincially funded sheltered workshops would be closing. Barbara Simmons, then Director of Community Supports Policy Branch for the Ministry of Community and Social Services in Ontario, promised that sheltered workshops would be replaced gradually by agencies that would help persons with I/DD to find jobs, volunteer work, and other activities in the community so that no one would be left without services (Welsh, 2015).

With the new transition framework in place, the question still remains – where will youth with I/DD transition to once they leave high school? The 2013 Ontario tri-ministry protocol (Ontario Ministry of Community and Social Services, Ontario Ministry of Children and Youth Services, & Ontario Ministry of Education, 2013) states that the plan should reflect the opportunities and resources that are available to the young person once they leave high school; however, for many youth with I/DD these opportunities are unknown and, at times, even nonexistent. For youth without disabilities, the range of available options is somewhat clearer and often prescribed; however, for youth with I/DD, there remain numerous barriers limiting their opportunities and hindering attainment of their desired transition plan outcomes.

About This Special Issue

It is clear that the transition into adulthood is marked by many changes in roles, responsibilities, and environments (Glidden, Ludwig, & Grien, 2012). For many individuals with I/DD and their families, this can be a trying time due to challenges such as changes to funding and supports, long waitlists, and a lack of services. The purpose of this special issue is to examine these and other barriers, in addition to the creative processes and alternative options that have emerged to improve the quality of life outcomes for those who are transitioning into adult services and adult community life.

The articles that follow reflect a diverse range of perspectives on this complex process. While several focus on the transition of youth from an educational setting to a vocational or post-secondary educational setting, others focus on the strengths and resilience, and the tensions and challenges that youth, parents, and formal support networks experience especially for youth who are leaving the foster care system and for those who have fetal alcohol spectrum disorder. The first two articles examine the planning process itself. *What's Next? Post Secondary Planning for Youth With I/DD* by Anne Readhead, Lisa Whittingham, Katie McKay, Courtney Bishop, and Jennifer Hope, examines how individualized secondary school planning with access to cooperative and experiential learning opportunities can help youth to gain experience that builds their skills and community connections. These may inform their planning decisions as they move into post-secondary training or education, or into a job. The authors examine the options and supports that young adults may have as they leave high school in addition to the barriers they may face in realizing their goals as they relate to various employment models.

Katie McKay's article, *A New Approach to Transition Planning for Transitional Aged Youth With Intellectual and Developmental Disabilities*, explores the initial steps in the implementation of transition planning in the Niagara Region of Ontario. Her particular focus is on the extent to which youth are engaged actively in planning their transitions. Because her data were collected very early in this new process, she relied on professionals who had experience with the previous planning procedures and the new regional protocol. The author provides a clear description of this innovative transition planning protocol, the barriers to youth involvement in the planning process and suggestions for improving their participation and the outcomes for transitional aged youth with developmental disabilities.

The third article describes an innovative post-secondary culinary training program that grew out of a partnership between Humber College and Christian Horizons. Jo Anne Nugent describes this program in her article *A Better Slice of Life – The Culinary Training program: Creating a Pathway to Employment for Adults with Developmental Disabilities*. Christian Horizons provides support staff to assist the Humber College culinary instructor during lab-based instruction and the agency also finds commercial kitchen placements for the students and provides staff support to assist them. The author reports that the program had a 100% retention rate with an 83% employment rate after its first two years of operation. The article not only includes descriptions of the students' gains in professional skills, self-esteem, and confidence, but also the factors contributing to the success of the partnership and plans for future program development are also described.

The fourth article, *System Kids: Transition Aged Youth from Foster Care to Developmental Series* by Sue Hutton, Kevin John Head, Sarah Lyttle, Jordyn, Noah Kenneally and Maja Rehou, combines the innovative use of art, interviews with the youth and staff, and background literature to describe the experiences of three young adults who faced rights violations in the various systems involved in their lives. Their powerful stories remind us of the importance of ensuring that youth are able to genuinely participate in the transition process and to tell their own stories.

The final two articles focus on youth with fetal alcohol spectrum disorder and the unique challenges faced by these individuals leaving secondary school. In *"Well Where's He Supposed to Live?": Experiences of Adoptive Parents of Emerging Adult Children With Fetal Alcohol Spectrum Disorder in Ontario,* Jenna Pepper, Shelley Watson, and Kelly Coons-Harding describe the unique challenges that parents of youth with fetal alcohol spectrum disorder (FASD) face in transition planning. These parents describe the tensions of having a child with a developmental disability when they are not able to find effective or knowledgeable support services, and the threat of negative outcomes they face when good transition planning does not occur.

In contrast, in *State-of-the-Art Transition Planning Tools for Youth With Fetal Alcohol Spectrum Disorder in Canada,* co-authors Kelly Coons-Harding, Anna Azulai, and Audrey McFarlane provide a systematic review of the literature and resources for transition planning involving youth with FASD. They highlight the work being done across Canada to develop transition programs, processes, and resources to assist persons with FASD and their families that will facilitate the transition to adulthood successfully. This article emphasizes the importance of interdependence and early planning when preparing for a youth's future.

Taken as a whole, the articles in this issue aim to challenge any notion that there is a single pathway for young people to transition successfully into adult services. Instead they examine a range of options that may be available to youth as well as the systemic factors that may be barriers or facilitators on this journey.

Key Messages From This Article

People with disabilities. When you turn 14 years old, you have the right to be involved in planning what you want to do after high school. Your family, teachers and people from support agencies will help you to make this plan.

Professionals. Developing transition plans with youth who are anticipating what they will do after high school requires cross-sectoral cooperation and coordination to ensure the development of a single person-directed plan.

Policymakers. While the move to cross-sectoral planning with transitional aged youth offers much promise, for many the need for more employment, education and community support options remains a barrier to realization of these plans.

References

Cooper-Duffy, K., & Eaker, K. (2017). Effective team practices: Interprofessional contributions to communication issues with a parent's perspective. *American Journal of Speech-Language Pathology, 26,* 181–192. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/28514473

Glidden, L. M., Ludwig, J. A., & Grein, K. A. (2012). Transitions to adulthood: De-construction and re-construction. *International Journal of Research in Developmental Disabilities, 43,* 220–248.

Gomez, L., Verdugo, M., Arias, B., Navas, P., & Schalock, R. (2013). The developmental and use of Provider Profiles at the organizational and systems level. *Evaluation and Program Planning*, *40*, 17–26. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/23728204

Hurd, C., Evans, C., & Renwick, R. (2018). Having friends is like having marshmallows: Perspectives of transition-aged youths with intellectual and developmental disabilities on friendship. *Journal on Applied Research in Intellectual Disabilities*, *31*, 1186–1196. doi:10.1111/jar.12493

Kaehne, A. & Beyer, S. (2014). Person-centred reviews as a mechanism for planning the post-school transition of young people with intellectual disability. *Journal of Intellectual Disability Research*, *58*,603–613. doi:10.1111/jir.12058

Leonard, H., Foley, K., Pikora, T., Bourke, J., Wong, K., McPherson, L … Downs, J. (2016). Transition to adulthood for young people with intellectual disability: The experiences of their families. *European*

Child and Adolescent Psychiatry, *25*, 1369–1381. doi:10.1007/s00787-016-0853-2

Martin, L., Grandia, P., Ouellette-Kuntz, H., & Cobigo, V. (2016). From framework to practice: Person-directed planning in the real world. *Journal of Applied Research in Intellectual Disabilities*, *29*, 552–565. doi:10.1111/jar.12214

Noonan, P., Erickson, A., & Morningstar, M. (2013). Effects of community transition teams on interagency collaboration for school and adult agency staff. *Hammill Institute on Disabilities*, 36, 96–104. doi:10.1177/2165143412451119

Ontario Government. (2008). *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act*, 2008, S.O. 2008, c.14. Retrieved from https://www.ontario.ca/laws/statute/08s14

Ontario Ministry of Community and Social Services (2013). *Person-directed planning and facilitation guide*. Retrieved from https://www.mcss.gov.on.ca/documents/en/mcss/publications/developmental/Person_DirectedPlanning.pdf

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/SEAC%2023%20October/06a%20Transition%20Protocol.pdf

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

Wehmeyer, M., & Webb, K. (2012). *Handbook of adolescent transition education for youth with disabilities*. New York, NY: Routledge.

Welsh, M. (2015, November 29). Ontario's sheltered workshops to close forever. *Toronto Star.* Retrieved from http://www.thestar.com/news/canada/2015/11/29/ontarios-sheltered-workshops-to-close-forever.html

Journal on Developmental Disabilities
Le journal sur les handicaps du développement
JoDD
Volume 24, Number 1, 2019

How This Special Issue Was Developed: A Note From the Guest Editors

Authors

Donato Tarulli,
Frances Owen,
Dorothy Griffiths

Department of Child
and Youth Studies,
Brock University,
St. Catharines, ON

Correspondence

dtarulli@brocku.ca

Keywords

transitional aged youth planning

The inspiration for this special issue was Katie McKay's master's thesis in the Department of Applied Disability Studies at Brock University. Her work focused on the initial stages of Niagara's approach to enacting tri-sector integrated transitional aged youth planning that was developed in response to a 2013 Ministry of Community and Social Services, Ministry of Ministry of Education and Ministry Children and Youth Services memo on this topic. These provincial and regional initiatives prompted us to suggest that it deserved the attention that a special issue could provide.

In addition to Katie McKay, we encouraged several other authors to submit articles on their work areas related to transitional aged youth. Anne Readhead, Lisa Whittingham, Courtney Bishop and Jennifer Hope have been involved in research projects on postsecondary skills training and supported entrepreneurship with a particular focus on the innovative model used at Common Ground Co-operative in Toronto. The first three of these authors and Katie McKay also were asked to become involved in the development of the introductory article to this special issue. Jo Anne Nugent was similarly encouraged to submit her work on a postsecondary culinary training model that is a partnership between Humber College and Christian Horizons. Sue Hutton was encouraged to contribute an article on the ARCH Disability Law Centre's Respecting Rights project that provides education about decision-making rights to persons who have developmental disabilities and those who support them. The co-authors of that paper, Kevin John Head, Sarah Lyttle, Jordyn, Noah Kenneally and Maja Rehou, include three self-advocates who attended Respecting Rights workshops and met to discuss issues they had experienced with decision-making in the foster care system and in adult developmental services. Their paper reflects these issues.

Lead authors Kelly Coons-Harding and Jenna Pepper and their respective teams responded to the call for papers for this special issue. Kelly Coons-Harding and her colleagues, Anna Azulai and Audrey McFarlane, all are affiliated with the Canada FASD Research Network that was contracted by the Government of Alberta to explore best practices in the transition of youth who have FASD to adult service supports. The paper by Jenna Pepper and her colleagues, Shelley Watson and Kelly Coons-Harding, is based on Jenna Pepper's master's thesis at Laurentian University that focused on the experiences of families who adopt children with FASD.

We are delighted that this special issue includes work by both new and established researchers who explore issues ranging from the personal experiences of youth leaving the foster care system and parents of children with fetal alcohol spectrum disorder, to the educational, structural and systemic changes being made to scaffold the transition that young people with developmental disabilities face as they leave high school. Their research illuminates concerns and suggests ways forward in an increasingly complex service environment.

Journal on Developmental Disabilities
Le journal sur les handicaps du développement
JoDD
Volume 24, Number 1, 2019

What's Next? Post-Secondary Planning for Youth With Intellectual and/or Developmental Disabilities

Authors

Anne Readhead,[1]
Lisa Whittingham,[1]
Katie McKay,[2]
Courtney Bishop,[1]
Jennifer Hope[3]

[1] Department of Child and Youth Studies,
Brock University,
St. Catharines, ON

[2] Contact Niagara for Children's and Developmental Services
St. Catharines, ON

[3] Common Ground Co-operative
Toronto, ON

Correspondence

areadhead@brocku.ca

Keywords

transitional aged youth,
developmental disability,
coordinated transition planning,
employment

Abstract

Youth with intellectual and/or developmental disabilities (I/DD) have an increasing range of post-secondary training, education and employment options when they transition out of high school. This article describes pathways that youth who are interested in employment may take and the supports and processes necessary to help them to move toward their goal. Innovative approaches to skills training for transitional aged youth (TAY) and emerging models of employment and entrepreneurship are described. Unemployment and underemployment of youth and barriers to employment are reviewed. The central role of early individualized planning, experiential learning opportunities, ongoing coordinated mentorship, advocacy and support are discussed.

Introduction

The primary goal of secondary education is to provide students with the skills and experience necessary to live a meaningful and fulfilling adult life. Central to that goal is preparing students, with or without disabilities, for the world of work (Wehman, Chan, Ditchman, & Kang, 2014). However, youth unemployment is a concern. "The world's population of youth aged 15–24 reached 1.2 million in 2010 and, in that year, youth were three times as likely to be unemployed" (United Nations Educational, Scientific and Cultural Organization [UNESCO], 2012, as cited in DeLuca, Godden, Hutchinson, & Versnel, 2015, p. 183). Youth with intellectual and/or developmental disabilities (I/DD) are at an even higher risk for unemployment than their typically developing peers (Dague, 2012). In his Institute for Research and Inclusion in Society report, Crawford (2011) reported that, in Canada, only 15.5% of youth with I/DD aged 15–24 years were employed, while 49.8% of youth with other disabilities and 58.1% of youth without disabilities were employed (Crawford, 2011). Factors that contribute to this risk for unemployment include their insufficient competency in both educational and work-related skills (United Nations Educational, Scientific and Cultural Organization [UNESCO], 2012, as cited in DeLuca, Godden, Hutchinson, & Versnel, 2015).

In the hope of closing this gap, a number of new youth employment options have been recognized as supporting both community inclusion and inclusive employment for youth with I/DD (Lysaght, Cobigo & Hamilton, 2012). The purpose of this article is to examine the various pathways to employment for transitional aged youth (TAY) with I/DD for whom this is a chosen life goal. These pathways are illustrated in a descriptive model that includes pathways from secondary education through post-secondary education (PSE) and/or pre-employment training to various employment options. Barriers that can be encountered at each stage and supports that are necessary for youth to achieve the education, training and jobs to which they aspire are also described. Achieving employment goals begins with early person-centred and person-directed planning during the secondary school years and the provision of appropriate individualized supports through post-secondary training and employment.

Transition Planning During High School

There is an ample amount of research demonstrating the efficacy of work-related skill development programs for youth during their secondary education (Benz, Lindstrom, & Yovanoff, 2000; Corbett, Clark, & Blank, 2002). These programs are a part of the employment planning process that takes place during the high school years and play a significant role in favourable post-school employment outcomes in employment and independent living. For TAY in Ontario, Canada, the employment planning process is intertwined with each student's Individual Education Plan and supplemented with co-operative education and experiential learning opportunities. As illustrated in Figure 1, students may face barriers to employment-focused training during high school if they have limited community pre-employment or employment options available to them in the community. Other barriers include inadequate information being provided about career choices that may be available to them. If they do have work opportunities, they may have work supervisors or mentors who do not have the training necessary to prepare them to provide appropriate and individualized supports for high school students who had I/DD. These barriers can be mitigated by coordinated cross-sectoral transitional planning, Individual Education Plans, and consistent planning procedures that optimize youth participation in decision making and that include high school training that focuses on skill development. These factors can lead to successful entry to post-secondary education and/or pre-employment training with eventual achievement of employment goals.

Individual Education Plan. In Ontario, Canada, the Individual Education Plan (IEP) process was developed by the Ministry of Education, in accordance with the Education Act (Section 1) and the Human Rights Code (Ontario Human Rights Code, s. 17(2)) (Ontario Ministry of Education, 2004). It is a province-wide, mandatory process for all students who have been identified as requiring additional supports by a school board Identification, Placement and Review Committee (IPRC).

The primary goal of the IEP is to provide educators with a consistent approach to developing individualized plans that meet the needs of the individual students and their long-term goals (Ontario Ministry of Education, 2004). The plan itself is "predominantly comprised of a description of a student's 'exceptionality,' a summary of their program and services, an explanation of goals and expectations, and an outline of how their progress will be monitored" (Boyd, Ng, & Schryer, 2015, p. 1538). With collaboration from youth themselves, their families, professionals and surrounding communities, an IEP can be developed to create opportunities for youth to develop the skills they require for employment and independence in a variety of settings, including school, the community, and the home (Davies & Beamish, 2009; Dyke, Bourke, Llewellyn & Leonard, 2013). Although great efforts have been made to provide individuals with I/DD with an education that will prepare them for life after high school, research on outcomes suggests that many of these students are less likely than students with other disabilities to aspire to attend PSE or to obtain competitive employment and are more likely to work in sheltered workshops or supported employment (Grigal, Hart & Migliore, 2011).

As a general planning process protocol, the IEP, as it is developed, does not direct the process toward any specific outcome, such as employment. Additionally, the documents that support the IEP are loosely structured and leave room for interpretation. Furthermore, with many people involved in the process, there is a risk of others' interests being placed above those of the individual (Boyd et al., 2015). Without specific guide-

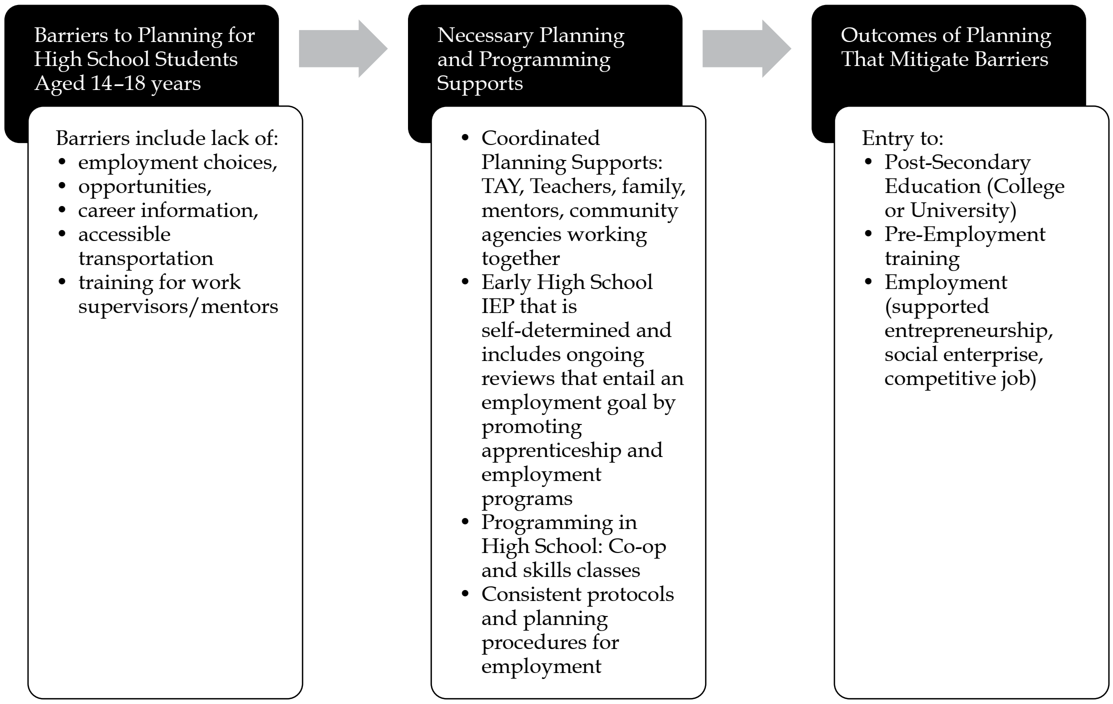

Figure 1. Supports and program options necessary to mitigate barriers to achieve successful outcomes for transitional aged youth during high school

lines or mandates focused on employment, many of those involved in this process may not plan for employment or explore the potential career pathways with the TAY they are supporting. This concern was supported by the Initial Report of the Ontario Government's Partnership Council on Employment Opportunities for People with Disabilities (2016) that suggested that the IEP process should include a focus on employment. Additionally, recommendations were made to recognize the importance of early work engagement and the availability of co-operative programs for youth with disabilities in the secondary education system.

Planning procedures. While there appear to be no universally accepted guidelines for transition planning with a specific focus on employment, there is a growing collection of transition planning protocols, handbooks, and resources available throughout Canada to help youth, families, and service providers to navigate the transition from child services to adult services (e.g., Healthy Child Manitoba, 2008; British Columbia Ministry of Children and Family Development, n.d.; Roebuck & MacLeod, 2006; Saskatchewan Association for Community Living, 2012). In Ontario, the Ontario Ministries of Education, Community and Social Services, and Child and Youth Services developed a tri-ministry transition protocol that outlines the roles and responsibilities of children's service providers, the school, and adult developmental services in developing a transition plan beginning when students reach age 14 years. As a general planning process protocol it does not direct the process toward any specific outcome, however it does specify that the transition plan will identify:

> goals for work, further education, and community living that reflect actual opportunities and resources that are likely to be available after the young person with a developmental disability leaves school and are likely to be achievable by the young person, given appropriate supports (Ontario Ministry of Community and Social Services, Ontario Ministry of Children and Youth Services, & Ontario Ministry of Education, 2013, p. 8).

Handbooks and protocols outline various best practices for transition plans, such as the use of a person-centred approach, collaboration, and early planning. However, the focus of many of these documents does not address specific employment planning and preparation guidelines. For instance, employment preparation programs, such as the cooperative education and experiential learning program, are rarely mentioned in these documents. There is also little mention of other employment preparation strategies, such as volunteering or career assessments that may help youth to gain a greater understanding of their interests, skills, and potential career options.

An individualized planning approach that includes a focus on specific preparation for employment options is required during the secondary school years. This is supported by research that highlights employment as a primary goal for many youth with disabilities (McConkey 2005 as cited in Crawford, 2012), studies supporting the efficacy of work-related planning during the secondary school transition (Hart, Mele-McCarthy, Pasternack, Zimbrich, & Parker, 2004) and evidence of poor post-secondary employment outcomes for youth with I/DD.

Transition planning that includes a focus on employment options could have the potential to eliminate many of the barriers to eventual employment. This planning should include youth, families, teachers, developmental service workers, community and transfer payment agencies that oversee the distribution of government funds to program recipients, and the greater community, such as local businesses, in keeping with the Ontario tri-ministry transition protocol. Comprehensive plans that outline a youth's interests, goals, and skills should be created, and opportunities to explore specific career options and to build employment skills should be outlined in these plans. Transportation and accessibility accommodations should also be included as these factors can present barriers to the post-school success of youth with disabilities. Information about all employment programs, both within the school and the community, should be given to families during the first transition meeting so that the employment planning process can begin early. These guidelines should be included in the transition protocols and handbooks that are already available and that continue to be developed.

The current protocols and resources that are available are a good starting point for improving the post-school outcomes of youth with disabilities, however placing a stronger emphasis on employer connections, employment exploration and work skill development experience during high school may help youth to achieve meaningful employment.

Cooperative education and experiential learning. Research has demonstrated that early work-related programs during high school, such as school-sponsored work experiences, vocational education enrolment, and after-school jobs, contribute to more favourable post-school employment outcomes for youth (Benz et al., 2000; Corbett et al., 2002; Landmark, Ju & Zhang, 2010). A number of options are provided to students attending Ontario secondary schools including: career talks/classroom visits, career fairs/career days, workplace tours, job shadowing and job twinning, work experience, mentoring, project-based learning, co-operative education, specialist high skills majors, school-work transitions, and the Ontario Youth Apprenticeship Program (Ontario Ministry of Education, 2000). A description of these programs can be found in this document that outlines the details of each program's key elements. While these programs are not developed specifically for individuals with I/DD, the Ontario Ministry of Education (2000) does state that these programs can "assist all students, including exceptional students, who are bound for university, college, apprenticeship, or the workplace, in making career decisions as well as in developing the knowledge, skills, and attitudes that are essential in today's society" (p. 6).

Although there is much evidence of the use of early work-related programs to improve post-secondary outcomes, the participation of youth with disabilities in these programs has been described as "generally uneven and fairly limited" (Carter, Trainor, Cakiroglu, Swedeen, & Owens, 2010, p. 19). In a study conducted by Carter et al. (2010) in the US, over half of the schools interviewed reported that students with disabilities participated in some form of short-term, work-related employment training (such as career or job counselling, career interest and aptitude assessments, tours of local businesses, and job fairs). However, fewer students were involved in cooperative education programs in an unpaid, supported work environment. These findings were representative of the activities offered by the school, with more schools providing short-term, indirect programs than long-term cooperative or work-based experiences. Furthermore, it was noted that students with severe disabilities or emotional or behavioural disorders were much less likely to be involved in any type of additional work-related skill development programs (Carter et al., 2010). Despite findings that suggest the need for, and the increased availability of, early work-related programs, the post-school outcomes experienced by youth with I/DD remain quite bleak, and suggest that "too many youths with disabilities are exiting school without the skills, attitudes, experiences, and linkages that will launch them successfully to the world of work and/or inform their career paths" (Carter, et al., 2010, p. 14).

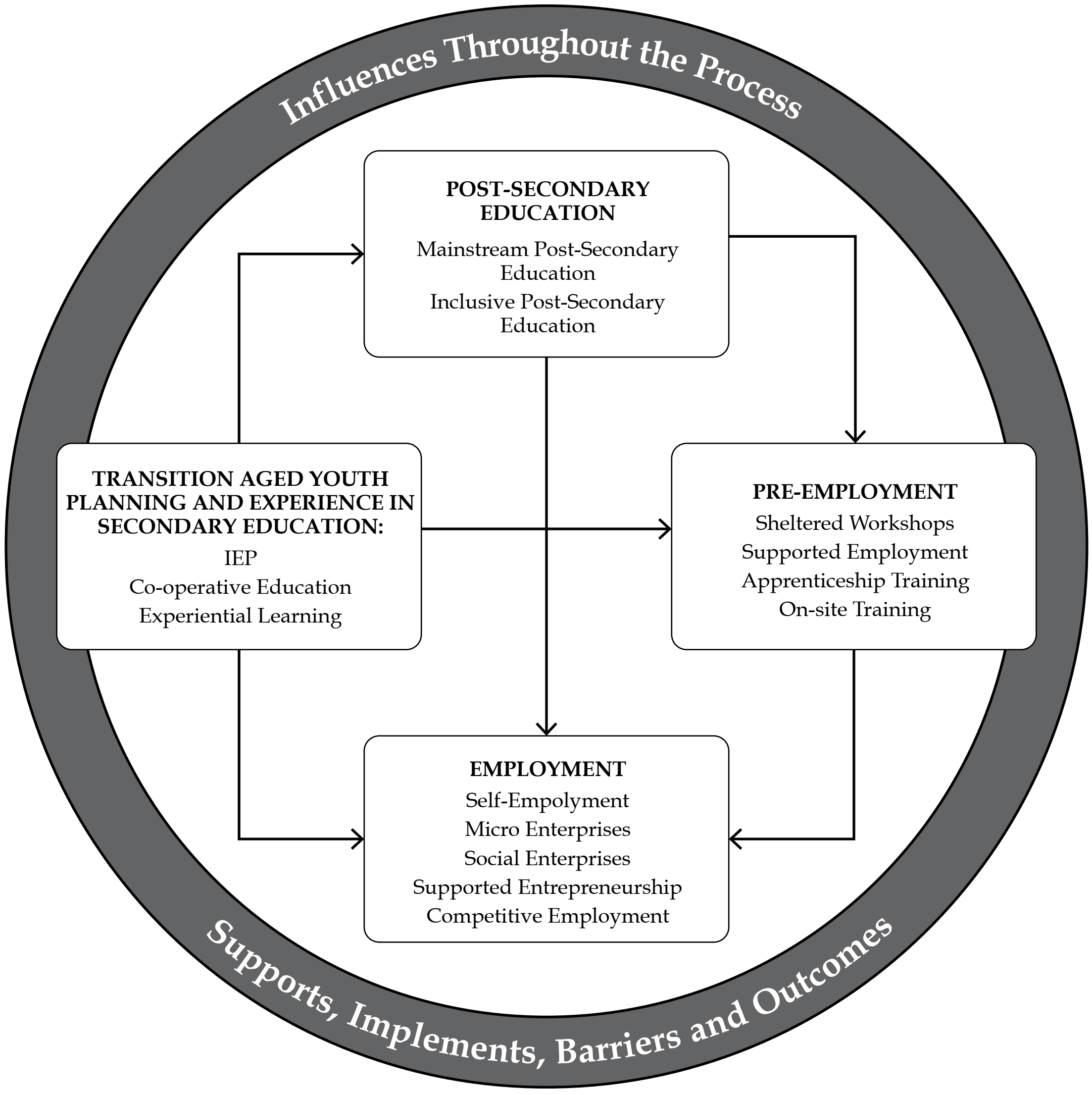

Figure 2. *Pathways to employment from secondary education can be directly to employment or through post-secondary and/or pre-employment options*

Post-Secondary Programs and Pre-Employment Training

Increasingly, students with I/DD are exploring the academic, social, workforce and community aspects of life after they leave high school (Mock & Love, 2012). As illustrated in Figure 2, due to changes in the public perception of disability and legislation that promotes inclusion, persons with I/DD are now able to pursue post-secondary education or to find pre-employment training, such as apprenticeship, that is similar to what is available to their typically developing peers (Bruce, 2011). Figure 2 illustrates how students with I/DD who pursue PSE have two possible avenues; they can enter a mainstream post-secondary program based on their interests (e.g., computer programming or culinary training) or they can enter an inclusive post-secondary education (IPSE) program that is designed for persons with disabilities. From there they may move into a pre-employment program or directly into a job.

Mainstream post-secondary education options. Ideally, students entering mainstream post-secondary programs attend courses with their typically developing peers; however, they receive course accommodations (e.g., extensions on due dates) and modifications (e.g., alternative forms of course materials) that increase the likelihood of their success (Harrison & Holmes, 2013). While these accommodations and modifications may be enough for students with learning disabilities (e.g., dyslexia), post-secondary administrators recognize that they are unprepared to support persons with I/DD. For example, Harrison & Holmes (2013) surveyed the heads of Disability Services Offices at Ontario post-secondary institutions (both college and university) regarding their accommodations and modifications for students with mild I/DD and their accompanying success rates. The results indicated that neither college nor university programs were willing to make modifications to admission requirements; however, colleges were more willing to make in-class accommodations for students with I/DD than were university programs. Finally, they found that disability services offices' administrators estimated that fewer than half of students with I/DD graduated from post-secondary education. Given these barriers, it is not surprising that Grigal et al. (2011) found that only 11% of high school IEPs identified mainstream PSE as a goal.

Individualized post-secondary education options. Since the 1990s, Canadian colleges have focused on developing IPSE programs that provide opportunities for persons with I/DD. In terms of format, these programs range from inclusive individualized support to segregated classes (Bruce, 2011). In Ontario, many colleges have started to offer Community Integration through Co-operative Education (CICE) programs. Typically, these programs offer a hybrid model that combines life skills training with mainstream academic classes, based on student interest and support in response to the students' needs. In addition, students often participate in several co-operative placements that allow them to further develop workplace skills (Bruce, 2011).

Despite the academic accommodations made in CICE programs, transitions to employment for CICE students remain limited when compared to their peers who attend mainstream PSE programs. For example, Durham College (n.d.) reported that CICE graduates were less likely than mainstream students to find general employment (i.e., 71% employed compared to the 84% college total), and even less likely to find employment related to their area of interest (i.e., 14% working in related field compared to the 55% college total).

In addition, a variety of outcomes have been reported for the longitudinal employment outcomes of students who participated in IPSE programs. One study showed that after completing a PSE program, 37% of the students with I/DD were employed and 66% were doing volunteer work. Of the participants who were working, 100% were not employed in their desired field (Butler, Sheppard-Jones, Whaley, Harrison & Osness, 2016). However, there is some evidence that youth with more severe intellectual disabilities who completed PSE showed significantly increased participation in competitive versus sheltered workshop employment (Hart, Zimbrichj & Ghilori, 2001). Therefore, although IPSE programs appear to influence the ability of some persons with I/DD to secure employment, it tends not to be in their preferred field of interest.

Further research regarding the PSE programs and their impact on employment is needed. Petcu, Chezan and Van Horn (2015) identified that "as more and more students with I/DD attend PSE programs, research also needs to concentrate on examining the assessment procedures implemented by these programs to assess and monitor student progress and program effectiveness" (p. 371). Moreover, McEathron, Beuhring, Maynard, and Mavis (2015) determined that there needed to be a better understanding of the intersection among educational or program support, agency support, family support and financial or funding support.

Other pre-employment service options. An alternative or additional option for PSE students is to enrol in pre-employment services, which seek to provide students with a range of opportunities including workshops, vocational training, and on-site job-coaching (Canadian Association for Community Living, 2011). Although the range of pre-employment services is extensive, they all strive to provide on-site job-coaching to facilitate the development of both job-specific skills and other "soft-skills" (i.e., social skills) that are desired by employers (Butcher & Wilton, 2008; Canadian Association for Community Living, 2011). Two of the more common pre-employment options available for these students are employment supports, that may include various forms of training, and in jurisdictions where they are still operational, other youth may participate in sheltered workshops. As shown in Figure 2, youth may access these programs directly after leaving high school or they may participate in supported employment and work training programs after attending post-secondary programs.

Sheltered workshops. Sheltered workshops provide work activity in a segregated environment with stipend pay. Work sites tend to focus on simple assembly tasks with support provided by trained support workers. Although the intention is to provide students with the necessary training to find placements in the mainstream workforce, many sheltered workshop participants do not obtain outside paid employment (Canadian Association for Community Living, 2011; Hart et al., 2001; Parmenter, 2011). However, there is evidence that the movement away from sheltered workshops to a focus on community-based employment, while it can be challenging, "can result in new and fulfilling experiences for participants" (Dague, 2012, p. 10). The cessation of Ontario government funding of sheltered workshops was announced in 2015 (Welsh, 2015).

Employment supports. Employment supports are temporary on-site trainings that increase the likelihood a person with I/DD is able to secure and maintain competitive employment. These services are located in an integrated environment with paid wages, individualized supports and on-the-job training that matches the person's interests (Butcher & Wilton, 2008). During transition planning, youth with I/DD and their support teams are more likely to identify employment support programs as a desired trajectory for employment than post-secondary education. For example, Grigal and colleagues (2011) found that employment support was the goal in 45% of student IEPs. The shift from sheltered workshops to employment support programs reflects the desire to reduce segregation, and to provide on-site training to increase the likelihood that participants could ultimately obtain competitive employment. The guiding belief of this approach is that if persons with I/DD are able to acquire the skills desired by employers and to demonstrate the ability to complete tasks similar to their co-workers, they will be able to compete in the job market alongside persons without I/DD (Butcher & Wilton, 2008).

While the goals of many employment support programs are well-intentioned, many persons with I/DD report low satisfaction due to social isolation from co-workers and difficulty meeting productivity demands. Furthermore, the transition to competitive employment is rare because agencies responsible for employment supports are reluctant to allow participants to remain in the placements brokered for training purposes. In addition, if persons with I/DD do remain in a position, employers' expectations regarding the quality and quantity of work may be at a level that exceeds the participant's ability (Butcher & Wilton, 2008). For example, Butcher and Wilton (2008) conducted a qualitative analysis of participants' experiences in a pre-employment training program. They found that many employers were willing to provide placements because they wanted to help the community, however they put limits on what participants were allowed to do because employees with I/DD were not able to work at the same pace as regular employees. They also found that participants identified that, while they were in a social environment (i.e., mingling with other people), they were not making social connections that lasted beyond work hours or the length of their placement. Finally, only one of six participants in their study was hired permanently at the job site, with the manager identifying that the budget was the reason for the lack of job openings (Butcher & Wilton, 2008).

Despite the popularity of pre-employment programs as a post-secondary option for youth with I/DD to acquire employment skills, there is varied evidence regarding the efficacy of these programs. For example, Rush and Dale (2002) examined the outcomes of twenty-three supported employment programs for individuals with I/DD in Southwestern Ontario over the course of a year. They found that 58% of participants who were seeking employment during the year were able to secure employment during the period of the study and 20% of participants were participating in other employment support services, likely due to efforts to secure on-going employment. Given that a large number of participants stay in supported employment to sustain their jobs or to continue to find work, these programs do not appear to provide enough support or knowledge for persons with I/DD to continue working with little to no agency support.

A hybrid alternative. Because post-secondary employment and pre-employment supports alone have limitations in addition to their strengths, a program that combines both inclusive job skills training and on-site apprenticeship at potential employment sites is an innovative alternative approach. Owen et al. (2015) examined the social return on investment of Common Ground Co-operative, an organization that provides educational, administrative, and job-coach support for adults with developmental disabilities through a co-operative model. The Foundations Program, embedded within Common Ground Co-operative (detailed description provided in the social enterprise section below), is an eighteen-week career readiness program where youth are engaged in experiential learning that combines in-class experience with direct hands-on training. Students participate in both classroom and co-op placements at one of five enterprises that provide on-site training. A youth who excels at the program may be invited to join the Common Ground Cooperative partnerships as an apprentice if a funded space for another partner is available or if the young person has Passport funding that is provided to them by the Ontario Government (Developmental Services Ontario, 2014). Passport is a program that helps adults with a developmental disability be involved in their communities and live as independently as possible by providing funding for community participation services and supports, activities of daily living and person-directed planning. The program also provides funding for caregiver respite services and supports for primary caregivers of an adult with a developmental disability.

A proxy comparison was made between the Foundations program and a College CICE program with the results indicating that the curriculum from the Foundations program was reasonably comparable to the CICE program. In addition to possibly being elected to remain part of the enterprises upon successful graduation from the Foundations Program, partners also have access to on-going education (e.g., financial literacy) and planned social events (Owen, Readhead, Bishop, Hope, & Campbell, 2015). Increased development and evaluation of programs like CGC may help to provide effective and sustainable models of employment for TAY.

Employment Options for Transitional Aged Youth

When considering what constitutes employment, Bradley et al. (2015) based their definition on the State Employment Leadership Network in the US. While there is variation among the States, they suggested that employment is, "an individual working at a job in a local business, earning the prevailing wage for that position or industry alongside peers that do not have disabilities" (p.5). The Canadian Association for Community Living (CACL) vision of employment equality is that "working-age adults with intellectual disabilities are employed at the same rate as the general population" (Canadian Association for Community Living, 2016). Included in the benchmarks associated with this vision are foci on the need for supports for both persons with I/DD and employers, and the importance of persons with I/DD being free from "financial or other disincentives to seek and maintain employment" (Canadian Association for Community Living, 2016). Interestingly, participants in a case study of Common Ground Co-operative described what they do as work, even though they are not being paid minimum wage. This may be because they are earning a share of revenue of the business for which they are non-share capital partners (Owen, Readhead, Bishop, Hope, & Campbell, 2015; Readhead, 2012). As described in Figure 2, the range of employment options for youth with I/DD includes self-employment, micro-enterprise, social enterprise, supported entrepreneurship and competitive employment.

Self-employment and micro-enterprises. Self-employment and entrepreneurship models are relatively new options for persons with a disability (Maritz & Laferriere, 2016). They may involve the establishment of a small business with decision-making controlled by the person(s) with I/DD. These approaches tend to rely on the availability of start-up funds and need specific planning for business growth. Support can be provided by an agency, a job coach, or a family member (Parmenter, 2011). Natural supports, such as those available in family-based businesses, are commonly used for persons with higher support requirements. This situation provides the opportunity for employment status however it may limit community integration and, at times, provide no wages (Parmenter, 2011). An employment option that does provide wages and social integration is social enterprise.

Social enterprises and supported entrepreneurship. Social enterprises are businesses that combine social objectives with an employment goal. They have legal status and operate by returning a large portion of their profit to the business to expand it and to create employment for persons who would otherwise potentially remain unemployed, such as persons with I/DD (Parmenter, 2011). As discussed by Reddington and Fitzsimons (2013), employment for youth with I/DD through social entrepreneurship is not sought solely for income reasons; this employment option can also potentially be about improving quality of life and social connection to the community.

Supported entrepreneurship can provide an employment option that fosters growth in self-determination, personal skills and independence with appropriate supports. As mentioned previously, one example of supported entrepreneurship is provided by Common Ground Co-operative (CGC) in Toronto that provides administrative supports for five social businesses for which persons with developmental disabilities are non-share capital partners. The partners have given enthusiastic descriptions of their experience of social inclusion, their sense of ownership and empowerment, and their increased autonomy and well-being (Lemon & Lemon, 2003; Owen, Readhead, Bishop, Hope, & Campbell, 2015). In this innovative employment option, the partners support each other, train apprentices and new partners and assist in the hiring of the support workers. The financial supports required for this employment option to be available include start-up funds for the businesses (such as a social economy investment), the costs of administrative and job coach supports (such as government funding), and a cost effective location to operate the businesses. This employment option can be seen as a work environment that extends community connection and social inclusion without the high paced demand of competitive employment.

Competitive employment. Competitive employment involves typical work, regular wages and conventional hours in the mainstream labour force. This type of employment is often the desired outcome of employment supports (described above); attaining this goal depends upon the youth having a job coach and/or co-worker without a disability who can perform a mentorship role or provide natural supports during the training of the necessary work duties.

Family and social networks can be vital supports to the TAY with I/DD finding and maintaining employment. However, the long-term and ongoing dependency on family supports can lead to increased frustration and burnout for those who are tasked with the added responsibility of supporting their loved ones in the competitive employment market. That is, families' lives and their daily time can become consumed with providing supports to ensure that the person with I/DD is able to find employment, is able to have transportation and other personal needs covered during employment and is able to maintain employment status. These long–term supports wear thin over the years as the parents' own needs are commonly neglected (Petner-Arrey, Howell-Moneta, & Lysaght, 2016).

Abbye and Rose (2010) described that the three main reasons that TAY with I/DD are motivated to work are monetary gain, social connection and feeling competent to work. Factors that contribute to successful employment for TAY include: assessing their motivation or desire to work, creating ongoing employment goals, creating a plan that is self-directed, coordinating youth and adult services, and providing on-going guidance.

An example of a competitive employment option is provided by Mark Wafer (Toronto, Ontario) who, since 1995, has opened six successful Tim Horton's locations. One of his first hired employees was a person with I/DD and, at last report, of his 250 employees, 46 are persons who have disabilities (Rushworth, 2014; Wafer, 2016). Wafer described that when he was starting his business and hired his first employee with a disability he realized that "I'm an expert at making coffee, but I'm not an expert at disabilities" so he worked with community partners who identified individuals who might wish to work with him and who helped him with training (Maldonado, 2012). All his employees receive the same wage and the same benefits (Wafer, 2015). This example of competitive employment opens the door to examining what criteria truly define this employment option and whether working full time hours is one of them. In addition, evidence appears to indicate that TAY with I/DD will require on-going support, to some extent, to remain on the job long-term (Parmenter, 2011). For example, Rush and Dale (2002) found that 67% of employed participants in their study were still receiving some form of employment support at the end of the evaluation period.

Transitional aged youth may seek employment options other than conventional work in order to accommodate their personal needs, such as health care or domestic responsibilities. Realistically, the demands of full-time work with a full work-load may not be possible for everyone. For instance in one study, "one parent described how full-time work was not feasible for her son, who lived independently, due to the time required for him to conduct his activities of daily living, like shopping and cleaning his apartment" (Petner-Arrey et al., 2016, p. 793). In other studies, working part-time hours was common and the lack of full time employment did not have an impact on the individuals' sense of satisfaction with their community connection (Blick, Litz, Thornhill, & Goreczny, 2016).

Regardless of which employment option TAY with I/DD choose, positive public perception plays an important role. This perception is shaped by communities being exposed to the work capabilities of persons with I/DD. Work capabilities are valued when TAY with I/DD enter an employment option with effective and necessary supports and with the ongoing development of outcomes, such as work skills; all essential aspects that begin at the secondary educational phase and build through the pathway options described in Figure 2.

Supportive Pathways to Employment

As TAY transition towards employment, the necessary supports (financial, professional, family and social) if implemented effectively, contribute to the development of personal outcomes. Barriers to implementation of supports hinder pathways to employment and can restrict achievement of desired outcomes if they are not mitigated by supports that are appropriate to the individual. Figure 3 describes the potential barriers to achieving their employment goals. These are similar to the barriers that they face during high school (see Figure 1). However, as described above, the range of possible employment models is growing. In order to succeed in any setting, youth need to have job coaches and employers who receive training in how to provide appropriate individualized supports. Appropriate individualized supports and work can help youth to develop work skills to work in settings that fit their interests and needs.

Regardless of trajectory, as illustrated in Table 1 youth need to have financial, professional, personal and social supports as well as early individualized planning and experiences of career

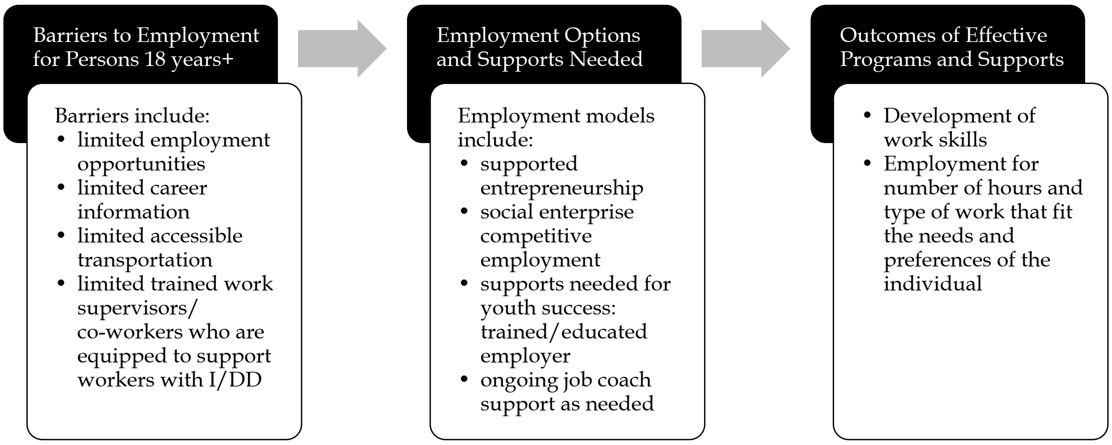

Figure 3. Employment barriers, options and supports for Transitional Aged Youth to achieve successful outcomes for transitional aged youth after high school

choices, such as co-op placements, that include skill assessments and development, during secondary school. It is important that those who provide support and the youth themselves collaborate to develop plans that are meaningful to the individual. Youth may be mentored and helped to develop self-advocacy skills through these processes. Barriers to implementation can hinder achievement of employment goals and desired personal outcomes. Best practices, protocols and written guidelines for professional and family use, that direct a collaborative approach to planning the transition phase, need to be in place and mandated to ensure consistency. In addition, early exploration of community-based opportunities, work experience and career counselling can facilitate youth participation in a transition plan. The IEP must be initiated early, be individualized, follow the student through the high school years and

Table 1. Influences on the Youth Transition Process Towards Employment

Supports	*Implementation of Supports*	*Outcomes*
• Financial supports (government funding for programs and the person with I/DD) • Professional supports (teachers, instructors, professors and support workers) • Family supports • Social supports (friends, neighbours, mentors, community connections)	• Individualized planning • Collaborating • Advocating • Mentoring *Barriers to Implementation* • Lack of supports • Failure to enact elements of the transition plan • Lack of exposure to employment options • Negative community perception	• Educational skills • Work skills • Social skills

be supported collaboratively with consistent guidelines that focus on specific employment strategies. For youth who choose employment, planning should include a specific employment section in the secondary education plan, provided to the student at an early age that includes all employment and skills training program options that may be appropriate to the individuals' needs and interests.

There is a growing focus on best practices in this transition planning process (Grigal et al., 2011) with correlational studies identifying youths' self-determination as a necessary component (Kleinert, Mills, Dueppen & Trailor, 2014) and the need to take into account the employment goals and expectations of both the youth and their family. Expectations of teachers are also a valuable predictor of TAYs' future job outcomes (Grigal, et al., 2011; Holwerda, Brouwer, Boer, Groothoff, & Klink, 2015). A significant number of TAYs, when asked what they planned for their future, stated that they desired to have a paid job (Holwerda, et al., 2015). Thus, planning and continued supports are essential after high school. Post-secondary and job training options are viable pathways to attaining employment. The collaborative support systems and plans that lay out the pathway options from secondary to post-secondary and/or pre-employment training flow from the expectation that inclusive employment is feasible and attainable for those who wish to pursue it.

The purpose of accessing post-secondary employment and/or pre-employment is to improve and/or enhance employment skills and knowledge, community connections and, ultimately, to equip TAY to be ready for employment. With these enhanced skills, the social perception of TAYs' capacity to work will improve (Collin, Lafontaine-Emond, & Pang, 2013). Throughout the pathways model described in this article (see Figure 2), implementation of support that may improve inclusive employment opportunities should include an assessment of the strengths and needs that are unique to each individual (Carter, Brock & Trainor, 2014). Matching these individual needs and strengths, in a "customized" way, with the needs of the employer can improve employment outcomes and change "what it means to be 'qualified' to work competitively in the workforce" (Rogers, Lavin, Trans, Gantenbein & Sharpe, 2008 p.206).

However, barriers and challenges persist. In addition to aspects of an individual's specific disability that may prevent them from being able to accomplish the tasks associated with particular jobs, systemic barriers that hinder pathways to employment include: lack of financial support, lack of professional or family support, implementation of supports not being carried out, lack of informed choices, segregation, negative community perceptions, and lack of personal skills development. There is also a need for training of community work supervisors and co-workers to equip them to support persons with I/DD in the workplace (Burge, Ouellette-Kuntz, & Lysaght, 2007).

In Ontario, some pre-employment programs are offered by transfer payment agencies that are government funded. Access to these and other developmental services involves a process of applying to Developmental Services Ontario (DSO) that includes assessment and determination of approval of eligibility that is based on the range and level of the individual's disability (Ontario Ministry of Community and Social Services, 2013). "The impact is the downtime for those who are transitioning from youth to adult services and others who are awaiting approval for funded services and supports" (Jennifer Hope, personal communication September 26, 2016). Even with PSE or IPSE and pre-employment experience, many youths remain unemployed. However innovative hybrid approaches, and an increasing focus on early and ongoing coordinated planning through the alternative pathways that are available to TAY, offer hope for the future.

Conclusion

Not all TAY are interested in employment. For some, personal needs or preferences may make employment undesirable or unrealistic. There is a growing focus on the importance of examining the nature of authentic engagement and inclusion for persons with I/DD that includes a range of activities that may include but is not limited to employment (Butcher & Wilton, 2008; Hall, 2004; Hall, 2005; Hall, 2010; Hall & Wilton, 2011). However, for

TAY who may wish to explore employment there is a growing range of options for them to consider with the support of coordinated planning beginning early in high school, and with training and ongoing support through the transition. Documents such as the Initial Report of the Ontario Partnership Council on Employment Opportunities for People with Disabilities (2016) highlights the need for government structural support of employment for persons with disabilities on the grounds that "It is an unacceptable failure of human rights for people with disabilities to be so underrepresented in our Ontario labour market" (p. 4). The right to work is well established (United Nations Convention on the Rights for Persons with Disabilities, 2006), but its implementation is dependent on coordinated and individualized planning and effective supports.

Key Messages From This Article

People with disabilities. You have the right to choose what you want to do when you finish high school. You can choose to get job training during high school and after high school at a college or in a business with someone to support you.

Professionals. Individualized, collaborative planning for transition to post-secondary education and employment needs to start early and may include experiential learning opportunities during high school.

Policymakers. There is a need for an increase in high school experiential learning opportunities, specialized post-secondary career development programs and supported work transition programs.

References

Abbye, A., & Rose, J. L. (2010). A preliminary investigation of factors affecting employment in people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, *7*(4), 239–244.

Benz, M. R., Lindstrom, L., & Yovanoff, P. (2000). Improving graduation and employment outcomes of students with disabilities: Predictive factors and student perspectives. *Exceptional Children, 66*, 509–529.

Blick, R. N., Litz, K. S., Thornhill, M. G., & Goreczny, A. J. (2016). Do inclusive work environments matter? Effects of community-integrated employment on quality of life for individuals with intellectual disabilities. *Research in Developmental Disabilities*, *53–54*, 358–366. http://dx.doi.org/10.1016/j.ridd.2016.02015

Boyd, V., Ng, S., Schryer, C. (2015). Deconstructing language practices: discursive constructions of children in Individual Education Plan resource documents. *Disability & Society, 30*(10), 1537–1553. http://dx.doi.org/10.1080/09687599.2015.1113161

Bradley, V., Bershadsky, J., Giordano, S., Hiersteiner, D., Kennedy-Lizotte, R., & Butterworth, J. (2015). Employing people with intellectual and developmental disabilities. In American Association on Intellectual and Developmental Disabilities (Eds.) *Way leads on to way: Paths to employment for people with intellectual disability* (pp. 3–30). Washington: American Association on Intellectual and Developmental Disabilities.

British Columbia Ministry of Children and Family Development. (n.d.). *Transition planning for youth with special needs.* Retrieved from http://www2.gov.bc.ca/assets/gov/family-and-social-supports/support_guide.pdf

Bruce, C. (2011, May). *Inclusive Post-secondary Education for Diverse Learners: Supporting Transition*. Retrieved from https://studentservices.ednet.ns.ca/sites/default/files/IPSE_FinalPDF.pdf

Burge, P., Ouellette-Kuntz, H., & Lysaght, R. (2007). Public views on employment of people with intellectual disabilities. *Journal of Vocational Rehabilitation, 26*, 29–37

Butcher, S., & Wilton, R. (2008). Stuck in transition? Exploring the spaces of employment training for youth with intellectual disability. *Geoforum, 39*, 1079–1092. doi:10.1016/j.geoforum.2007.11.002.

Butler, L. N., Sheppard-Jones, K., Whaley, B., Harrison, B. & Osness, M. (2016). Does participation in higher education make a difference in the life outcomes for students with intellectual disability? *Journal of Vocational Rehabilitation, 44*, 295–298. doi:10.3233/JVR-160804

Canadian Association for Community Living (2016). *Employment equality*. Retrieved from http://www.cacl.ca/area/employment-equality

Canadian Association for Community Living (2011). *Achieving Social and Economic Inclusion: From Segregation to 'Employment First.'* Retrieved from http://www.cacl.ca/sites/default/files/Achieving%20social%20and%20economic%20inclusion_0.pdf

Carter, E. W., Brock, M. E., & Trainor, A. A. (2014). Transition assessment and planning for youth with severe intellectual and developmental disabilities. *The Journal of Special Education, 47*(4), 245–255.

Carter, E. W., Trainor, A. A., Cakiroglu, O., Swedeen, B., & Owens, L. A. (2010). Availability and access to career development activities for transition-age youth with disabilities. *Career Development for Exceptional Individuals, 33*(1), 13–24. doi:10.1177/0885728809344332

Collin, C., Lafontaine-Emond, I., & Pang, M. (2013). *Persons with Disabilities in Canadian Labour Market: An Overlooked Talent Pool.* Retrieved from http://www.lop.parl.gc.ca/content/lop/ResearchPublications/2013-17-e.pdf

Corbett, W. P., Clark, H. B., & Blank, W. (2002). Employment and social outcomes associated with vocational programming for youths with emotional or behavioral disorders. *Behavioral Disorders, 27,* 358–370.

Crawford, C. (2011). *The Employment of People with Intellectual Disabilities in Canada: A Statistical Profile.* Retrieved from https://irisinstitute.files.wordpress.com/2012/01/intellectual-disability-and-employment_iris_cr.pdf

Crawford, C. (2012). *Youth with disabilities in transition from school to work or post-secondary education and training: A review of the literature in the United States and United Kingdom*. Retrieved from https://irisinstitute.files.wordpress.com/2012/01/youth_in_transition_iris_cr.pdf

Dague, B. (2012). Sheltered employment, sheltered lives: Family perspectives of conversion to community-based employment. *Journal of Vocational Rehabilitation*, *37,* 1–11. doi:103233/JVR-2012-0595

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.

DeLuca, C., Godden, L., Hutchinson, N. L., & Versnel, J. (2015). Preparing at risk youth for a changing world: Revisiting a person-in-context model for transition to employment. *Educational Research*, *57*(2), 182–200. http://dx.doiorg/10.1080/00131881.2015.1030854

Developmental Services Ontario (2014). Passport program: Guidelines for adults with a developmental disability and their caregivers. Retrieved from https://www.mcss.gov.on.ca/documents/en/mcss/publications/developmental/passport/Passport_Program_Guidelines-en.pdf

Durham College (n.d.). *Graduate Employment Report: Class of 2014/Fall 2015*. Retrieved from www.durhamcollege.ca/wp-content/uploads/graduate-employment-report-2015.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.

Grigal, M., Hart, D., & Migliore, A. (2011). Comparing the transition planning, postsecondary education, and employment outcomes of students with intellectual and other disabilities. *Career Development for Exceptional Individuals, 34*(1), 4–17. doi:10.1177/0885728811399091

Hall, E. (2004). Social geographies of learning disability: Narratives of exclusion and inclusion. In *Area*, *36*(3), 298–306. http://dx.doi.org/10.1111/ j.0004-0894.2004.00227.x

Hall, E. (2005). The entangled geographies of social exclusion/inclusion for people with learning disabilities. *Health & Place*, *11*(2), 107–115. http://dx.doi.org/10.1016/j.healthplace.2004.10.007

Hall, E. (2010). Spaces of social inclusion and belonging for people with intellectual disabilities. *Journal of Intellectual Disability Research*, *54*, 48–57. http://dx.doi.org/10.1111/j.1365-2788.2009.01237.x

Hall, E., & Wilton, R. (2011). Alternative spaces of "work" and inclusion for disabled people. *Disability & Society*, *26*(7). *https://www.tandfonline.com/doi/abs/10.1080/09687599.2011.618742*

Harrison, A. G., & Holmes, A. (2013). Mild intellectual disability and the post-secondary level: Results of a survey of disability service offices. *Exceptionality Education International*, *23*(1), 22 – 39.

Hart, D. J., Mele-McCarthy, R. H., Pasternack, K. Zimbrich, & Parker D. R. (2004). Community college: A pathway to success for youth with learning, cognitive, and intellectual disabilities in secondary settings. *Education and Training in Developmental Disabilities 39*(1), 54–66

Hart, D., Zimbrichj, K., & Ghiloni, C. (2001*)*. Interagency partnerships and funding: Individual supports for youth with significant disabilities as they move into postsecondary education and employment options. *Journal of Vocational Rehabilitation, 16*, 145–154.

Healthy Child Manitoba (2008). *Bridging to adulthood: A protocol for transition students with exceptional needs from school to community*. Retrieved from https://www.gov.mb.ca/healthychild/publications/protocol_swsn.pdf

Holwerda, A., Brouwer, S., Boer, M. R., Groothoff, J. W., & Klink, J. J. (2015). Expectations from different perspectives on the future work outcome of young adults with intellectual and developmental disabilities. *Journal of Occupational Rehabilitation*, *25*, 96–104. doi:10.1007/s10926-014-9528-3

Kleinert, J. O., Mills, K. R., Dueppen, B. M., & Trailor, A.M. (2014). Self-determined goal selection and planning by students with disabilities across grade bands and disability categories. *Education and Training in Autism and Developmental Disabilities*, *49*(3), 464–477.

Landmark, L., Ju S., & Zhang, D. (2010). Substantiated best practices in transition: Fifteen plus years later. *Career Development for Exceptional Individuals, 33*(3), 165–176. doi:10.1177/0885728810376410

Lemon, C., & Lemon, J. (2003). Community-based cooperative ventures for adults with intellectual disabilities. *The Canadian Geographer, 47*(4), 414–428.

Lysaght, R., Cobigo, V., & Hamilton, K. (2012). Inclusion as a focus of employment-related research in intellectual disability from 2000 to 2010: A scoping review. *Disability and Rehabilitation*, *34* (16), 1339–1350.

Maldonado, M. (2012). *Hiring those with disabilities easier than you think – Tim Hortons franchise owner.* Retrieved from http://accessibilitynewsinternational.com/hiring-those-with-disabilities-easier-than-you-thinktim-hortons-franchise-owner/

Maritz, A. & Laferriere, R. (2016). Entrepreneurship and self-employment for people with disabilities. *Australian Journal of Career Development, 25*(2), 45–54. doi:101177/1038416216658044

McEathron, M.A., Beuhring, T., Maynard, A., & Mavis, A. (2015). Understanding the diversity: A taxonomy for postsecondary education programs and services for students with intellectual and developmental disabilities. *Journal of Postsecondary Education and Disability*, *26*(4), 303–320.

Mock, M. & Love, K. (2012). One state's initiative to increase access to higher education for people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, *9*(4), 289–297.

Ontario Ministry of Community and Social Services (2013). *Policy directives for application entities*. Retrieved from http://www.mcss.gov.on.ca/en/mcss/publications/developmentalServices/policy_application/2_directives.aspx

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/SEAC%2023%20October/06a%20Transition%20Protocol.pdf

Ontario Ministry of Education (2000). *Cooperative education and other forms of experiential learning: Policies and procedures for Ontario secondary schools*. Retrieved from http://www.edu.gov.on.ca/eng/document/curricul/secondary/coop/cooped.pdf

Ontario Ministry of Education (2004). *The Individual Education Plan (IEP): A Resource Guide.* Retrieved from http://www.edu.gov.on.ca/eng/general/elemsec/speced/guide/resource/iepresguid.pdf

Ontario Ministry of Education (2013). *Learning beyond the classroom: Information about school-work opportunities*. Retrieved from http://www.edu.gov.on.ca/eng/general/elemsec/job/passport/SchoolWorkChart.pdf

Owen, F., Readhead, A., Bishop, C., Hope, J., & Campbell, J. (2015). Common Ground Co-operative: Supporting employment options. In J. Quarter, S. Ryan & A. Chan (Eds.), *Social purpose enterprises: Case studies in doing business differently* (pp. 27–51). Toronto: University of Toronto Press.

Owen, F., Li, J., Whittingham, L., Hope, J., Bishop, C., Readhead, A., & Mook, L. (2015). Social return on investment of an innovative employment option for persons with developmental disabilities. *Non-Profit Management & Leadership, 26*(2), 209–220. doi:10.1002/nml.21187

Parmenter, T. R. (2011). *Promoting training and employment opportunities for people with intellectual disabilities: International experience.* Retrieved from http:digitalcommons.ilr.cornell.edu/cgi/viewcontent.cgi/article=1560&context+gladnetcollect.

Partnership Council on Employment Opportunities for People with Disabilities. (2016). *Initial Report*. Retrieved from https://www.ontario.ca/page/partnership-council-employment-opportunities-people-disabilities-initial-report

Petcu, S. D., Chezan, L. C., & Van Horn, M. L. (2015). Employment support services for students with intellectual and developmental disabilities attending postsecondary education programs. *Journal of Postsecondary Education and Disability*, *28*(3), 359–374.

Petner-Arrey, J., Howell-Moneta, A. & Lysaght, R. (2015). Facilitating employment opportunities for adults with intellectual and developmental disability through parents and social networks. *Disability and Rehabilitation, 38*(8), 789–795.

Readhead, A. (2012). *Social economy and developmental disabilities: An employment option that promotes a form of authentic work and fosters social inclusion (*Master's thesis, Brock University, St. Catharines, Canada). Retrieved from https://dr.library.brocku.ca/bitstream/handle/10464/4359/Brock_Readhead_Anne_E_2012.PDF?sequence=1&isAllowed=y

Reddington, T. & Fitzsimons, J. (2013). People with learning disabilities and microenterprise. *Tizard Learning Disability Review*, *18*(3), 124–131. doi:10.1108/TLDR-02-2013-0013

Roebuck, R. & MacLeod, C. J. (2006). *Connections: A guide to transition planning for parents of children with a developmental disability*. Retrieved from http://www.tdsb.on.ca/Portals/0/Elementary/docs/SpecED/SpecED_Connections.pdf

Rogers, C., Lavin, D., Tran, T., Gantenbein, T., & Sharpe, M. (2008). Customized Employment: Changing what it means to be qualified in the workforce for transition-aged youth and young adults. *Journal of Vocational Rehabilitation*, *28*, 191–207.

Rush, B., & Dale, J. M. (2002). Regional application of standardized performance indicators for supported employment programs. *Journal on Development Disabilities, 9*(1), 67–82.

Rushworth, K. (2014). Business benefits drive 'inclusive employment.' *High River Times.* Retrieved from http://www.highrivertimes.com/2014/10/17/business-benefits-drive-inclusive-employment

Saskatchewan Association for Community Living (2012). *The School to Life Transition Handbook.* Retrieved from http://specialneedsproject.ca/resources/links-directory/266-school-to-life-transition-handbook

United Nations Convention on the Rights of Persons with Disabilities (2006). Retrieved from http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf

Wafer, M. (2015). People with disabilities deserve to be paid a legal wage. *The Toronto Star.* Retrieved from https://www.thestar.com/opinion/commentary/2015/03/30/people-with-disabilities-deserve-to-be-paid-a-legal-wage.html

Wafer, M. (2016). Employees with disabilities can have a positive impact on profitability. *The Globe and Mail.* Retrieved from http://www.theglobeandmail.com/report-on-business/rob-commentary/employees-with-disabilities-can-have-a-positive-impact-on-profitability/article28540451/

Wehman, P., Chan, F., Ditchman, N., & Kang, H. (2014). Effect of supported employment on vocational rehabilitation outcomes of transition-aged youth with intellectual and developmental disabilities: A case control study. *Intellectual and Developmental Disabilities*, *52*(4), 196–310. doi:10.1352/1934-9556-52.4.296

Welsh, M. (2015, November 29). Ontario's sheltered workshops to close forever. *The Toronto Star.* Retrieved from http://www.thestar.com/news/canada/2015/11/29/ontarios-sheltered-workshops-to-close-forever.html

Journal on Developmental Disabilities
Le journal sur les handicaps du développement
JoDD
Volume 24, Number 1, 2019

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

Author

Katie McKay

Contact Niagara
for Children's and
Developmental Services,
St. Catharines, ON

Correspondence

katie@contactniagara.org

Keywords

transition planning,
youth engagement,
developmental disability,
service coordination

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

---

[1] The current paper is based on the unpublished master's thesis: McKay, K. (2017). A new approach to transition planning for transitional aged youth with intellectual and developmental disabilities. (Unpublished Master's Thesis). Centre for Applied Disability Studies, Brock University, St. Catharines, ON.

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 planning 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 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?* 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 highlighted 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: A*ge, 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 highlighting 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, Weinkauf (2002) noted a lack of post-secondary school options for youth with disabilities, whereas Griffin, McMillan, and Hodapp (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. 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 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, 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 questions 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.

Acknowledgements

Sincere thanks to Nadine Wallace, Sue Kowalski, and the staff at Contact Niagara for Children's and Developmental Services for their enthusiastic support and guidance throughout this research. I would also like to thank those who participated in this study; without your participation and commitment to improving the lives of those with developmental disabilities, this research would have not been possible.

References

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.

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.

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.

Fereday, J & Muir-Cochrane, E. (2006). Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods, 5*(1), 1–11.

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

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

Laragy, C. (2004). Self-determination within Australian school transition programmes for students with a disability. *Journal of Disability & Society, 19*(5), 519–530.

McKay, K. (2017). A new approach to transition planning for transitional aged youth with intellectual and developmental disabilities (Unpublished Master's thesis). Centre for Applied Disability Studies, Brock University, St. Catharines, ON. Retrieved from https://dr.library.brocku.ca/bitstream/handle/10464/13002/Brock_McKay_Kaitlin_2017.pdf?sequence=3&isAllowed=y

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.

Newman, L., Wagner, M., Knokey, A. M., Marder, C., Nagle, K., Shaver, D. …, & Schwarting, M. (2011). *The post-high school outcomes of young adults with disabilities up to 8 years after high school. A report from the national longitudinal transition study-2 (NLTS2)* (NCSER 2011-3005). Menlo Park, CA: SRI International.

Ontario Ministry of Community and Social Services, Ontario Ministry of Children and Youth Services, & Ontario Ministry of Education (2013a). *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/SEAC%2023%20October/06a%20Transition%20Protocol.pdf

Ontario Ministry of Children and Youth Services, Ontario Ministry of Community and Social Services, Ontario Ministry of Education (2013b). *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 Education (2014). Special Education Update. Retrieved from http://www2.edu.gov.on.ca.../SpecialEd_Update2014.pdf

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.

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

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: Factors that impact employment decisions for individuals with intellectual disability. *Intellectual and Developmental Disabilities, 49*(4), 285–299.

United Nations General Assembly, *Convention on the Rights of Persons with Disabilities: Resolution adopted by the General Assembly*, 24 January 2007, A/RES/61/106. Retrieved from http://www.refworld.org/docid/45f973632.html

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.

Journal on Developmental Disabilities
Le journal sur les handicaps du développement
JoDD
Volume 24, Number 1, 2019

A Better Slice of Life: The Culinary Training Program Creating a Pathway to Employment for Adults With Developmental Disabilities

Author

Jo Anne Nugent

Humber College,
Toronto, ON

Correspondence

JoAnne.Nugent@humber.ca

Keywords

developmental disabilities,
vocational training,
employment,
community college

Abstract

This article provides an overview of an innovative new program offered jointly by Humber College and Christian Horizons. This project, entitled the Culinary Training Program, provides adults with development disabilities with the opportunity to learn the skills and knowledge that will lead to employment in the culinary field. The article traces the history of the program, describes its effectiveness and discusses plans for the future. In particular, the program acts as a pathway to post-secondary education and employment for young adults leaving school board settings.

Creating a Pathway to Employment for Adults With Developmental Disabilities

It is challenging to support adults with developmental disabilities to successfully transition to employment after high school graduation. For many young people in Ontario who do not have developmental disabilities, the community college system acts as a pathway between high school and work. This article will describe an innovative program designed to provide this same pathway for young adults with developmental disabilities.

Since 2013, Humber College and Christian Horizons have jointly offered the Culinary Training Program for adults with developmental disabilities. The specific purpose of the program is to prepare its graduates to obtain employment in the culinary industry. This unique program combines the expertise of a post-secondary institution and a developmental services agency to support these individuals to work in their chosen field.

Community Colleges and Students With Developmental Disabilities

In 1965, the Government of Ontario tabled legislation to create Colleges of Applied Arts & Technology as an alternative to universities (Stoll, 1993). The main purpose of the Colleges of Applied Arts and Technology (referred to as community colleges) was identified as job training to meet the need for skilled labour in Ontario (Drea, 2003).Although they have expanded their mandates, a primary responsibility of community colleges continues to be provision of post-secondary education that will prepare citizens to obtain the job to which they aspire. This includes students with a variety of special needs including learning disabilities, physical disabilities, mental health issues and sensory deficits (Brint, 2003; Scott, 2000).

Studies have indicated that there are two significant advantages for individuals with developmental disabilities who attend college. Firstly, attending college appears to have a broad impact on the adult life of the individual with developmental disabilities since attending post-secondary education increases the likelihood of attaining markers of adulthood (Braun, Alissop, & Lollar, 2006). College attendance increases the individual's access to being involved in all aspects of society. In particular, participating in post-secondary education may support the attainment of adult social roles among young adults with childhood impairment (Braun et al., 2006).

Secondly, attending college increases employment rates. Canadian data from the Participation and Activity Limitation Survey shows that post-secondary education has a strong bearing on employment outcomes for youth with disabilities (Hnatuk, 2016). For example, the Alberta Association for Community Living reported that approximately 70% of individuals with developmental disabilities who participated in inclusive post-secondary education had positive employment outcomes (Hnatuk, 2016). Therefore, community colleges have a vital role to play in the overall quality of life of people with developmental disabilities

The Culinary Training Program

Program history. Christian Horizons is a developmental services agency that supports individuals of all ages with developmental disabilities in Ontario, across Canada and throughout the world. Two recently created priorities of the agency are:

1. "To create and promote education and employment opportunities for people with exceptional needs" (Moore & Nugent [presentation], 2016)
2. "To support individuals and families to recognize post-secondary education and real jobs as viable options" (Moore & Nugent [presentation], 2016)

In 2012, Christian Horizons received an Inclusion and Employment Opportunities Fund grant from the Ontario Ministry of Community and Social Services. With this funding, the agency created the model of the Culinary Training Program.

Christian Horizons approached the Developmental Services Worker Program of the School of Social and Services at Humber College with an invitation for Humber College to partner in this Culinary Training Program. The partnership was formed and expanded to include the School of Hospitality, Recreation and Tourism at Humber College, which administers the culinary courses. The first three courses of the program were each one-week in length. These served as pilot projects, which provided the opportunity to create the structure, fine tune the curriculum, and define organizational roles. In September 2014, the program was expanded to eight months, September to April. Another eight-month course was offered in September 2015 and a new cohort started in September 2016.

In the current model, a one week summer course is offered each year that acts as an intake to the eight month course. This one-week course allows students to experience a brief version of the course and decide if they wish to attend the eight-month course. Humber College produced a film entitled, "A Better Slice of Life," which chronicles the stories of four students in the first eight-month course (Black Cat Advertising Inc., 2015).

Program structure. The structure of the program combines the resources of the agency and the college. Students apply to the program through Developmental Services Ontario, which is the access point to all developmental services in Ontario. The maximum enrolment is 15 participants for each cohort.

The program is offered on a full time basis, five days per week. Day one is employment-related training provided by Christian Horizons staff members on site at Humber College. Students complete Workplace Hazardous Materials Information System (WHMIS), Safe Food Handling, Emergency First Aid and Smart Serve training. The classes for these courses are longer than those that are typically provided in the community, with repetition and hands on practice included. Therefore, the teaching of the materials is adapted to the needs of the students. Adaptations include taking longer to teach the materials, more practice time, and more visual aids. However, the students are still required to pass certification tests at the end of each course. Other content on day one addresses professional behaviour, resume writing, interacting with colleagues, following instructions from supervisors, and interview skills.

Day two is a class at Humber College's culinary laboratory taught by culinary faculty. These instructors developed a curriculum with learning outcomes that incorporate the fundamental skills that students will need to obtain real jobs in the culinary industry. Thus, students learn about commercial kitchen operations, knife skills, safe use of commercial appliances, salad preparation, sandwich making, baking, and cooking of different entrees. Christian Horizons provides two support members who assist the culinary instructor. Students are expected to meet the same behavioural and culinary skills requirements as students without developmental disabilities in Humber's culinary programs. Students receive a pass/fail evaluation at the end of the course.

Days three, four, and five are placement. Students attend field placement at one location for the duration of the program. Placements are in commercial kitchens such as restaurants, hotels, and hospitals. Christian Horizons staff members obtain placements for the students and provide support at the sites. Students are evaluated by the kitchen manager in their assigned site. Upon graduation, Christian Horizons staff members assist the students to obtain employment and provide employment support.

Program Results

The first eight-month course started with fourteen students, all of whom graduated. Thirteen of these graduates are currently working in culinary jobs. The second eight-month course had thirteen students, all of whom graduated. Twelve of these were employed in culinary positions after graduation. There is a continuing demand for the program with 13 graduates in 2016, 14 in 2017, and 11 in 2018.

The four most positive outcomes of the program are:

1. Student retention: The Culinary Program has an extraordinary 100% graduation rate. This can be compared to the 2015-2016 graduation rate of 66.7% for Colleges in Ontario (Government of Ontario, 2016).
2. Graduate employment: The graduates of this Program obtain jobs in the culinary industry. The employment rate of 84% across all four years of this program compares very favourably with the 2015–2017 employment rate of 80%–85% for all Ontario students who graduated from a community college (Ontario Ministry of Training, Colleges and Universities, 2018).
3. Development of professional behaviours: Students are expected to act as professionals at school and at placement. Throughout the eight-month course, maturity and responsibility grows. Students who have previously struggled with distractibility, disruptiveness, following instructions and reliability learn to be culinary professionals.
4. Growth in Self Esteem and Confidence: Being successful in the classroom and at placement has a significant positive impact on each student. Mastering new skills, being able to "do the job" in a professional kitchen, graduating from a college program and obtaining employment appears to contribute to students' sense of accomplishment and pride according to anecdotal comments from family members and the students themselves.

The results of the program are extremely positive and have confirmed the partners' commitment to future plans, as discussed later in this article.

Factors That Contribute to the Effectiveness of the Culinary Training Program

Several aspects of the Culinary Training Program have contributed to its success:

1. The partnership between a community college and a developmental services agency. The program uses the expertise and resources of each organization. It is cost effective

and efficient for organizations to do what they are funded to do and what they do best.

2. The specific vocational focus. There are various options for college programs for students with developmental disabilities. Some programs prioritize social integration and the students attend a variety of academic courses according to their interests. Other programs offer placements in a number of different work settings. The Culinary Training Program was specifically designed for students to obtain culinary jobs. The learning takes place in segregated classes within the broader integrated college environment. However, placement is completely integrated and normalized.
3. The use of professional chefs as instructors. The chefs, who all have worked in the culinary industry as well as being college faculty, know what students need to learn to obtain employment. They also maintain professional expectations and support the students to meet these expectations.
4. The combination of academic learning, culinary laboratories and placement. Students with developmental disabilities have the opportunity to learn information at their own pace, practice skills under the supervision of college chef instructors and then use their skills/knowledge in a real commercial kitchen placement. This maximizes generalization.

What Happens Next? Future Plans for the Culinary Training Program

Christian Horizons and Humber College have established two key priorities for the future of the Program.

Establishing a Permanent Program at Humber for Many Vocations

To this point, the Culinary Training Program has been funded by the grant, which Christian Horizons obtained from the provincial government. This grant ended in May 2017. Therefore, it is crucial to plan for the future, which will include transitioning the program to Humber College.

Humber College is initiating the development of a permanent one-year Employment Certificate for adults with developmental disabilities. While the model of eight months per year, five days per week and combined classroom/laboratory/placement experiences would be retained, students could choose from a range of programs including culinary, landscaping, etc.. Students would pay real fees for the program. Christian Horizons would maintain its involvement by working with students before they enter the program and supporting them on-the-job after graduation.

Working With Younger People With Developmental Disabilities and Their Families

As Humber College launches a permanent Employment Certificate, Christian Horizons will increase its attention on encouraging younger children with developmental disabilities and their families to plan for a future that includes college and employment. Christian Horizons will be meeting with school boards to introduce the model and engage their support in contacting students and families.

In conjunction with Humber College, high school students and their educators will be invited to visit the programs at Humber College. Information evenings will be held for parents and program visits will be arranged for them as well. A two-week summer program at Humber College will be introduced for high school students in which they will become familiar with the College, learn about the programs offered at the college and start to consider future career options.

The Ideal Continuum

Humber College and Christian Horizons have envisioned a continuum across the lifespan, which is described below:

- Parents of very young children with developmental disabilities: Start Registered Educational Savings Plans for these children, introduce responsibilities around the home, and discuss the future.

- Teens with developmental disabilities: Assume increased responsibilities around the home, hold part time jobs, and discuss post-secondary education and jobs at home and at school.
- Older teens: Participate in short term programs at Humber where they will be taught "soft skills" related to employment and they will gain exposure to educational options at the college.
- Graduates from high school: Enrol in the 8-month Employment Certificate at Humber College.
- Graduates from Humber College: Obtain employment in their chosen career.

Thus, the ideal continuum is based on pathways to education and employment.

Conclusions

The Culinary Training Program has the potential to change the provision of post-secondary and employment services for people with developmental disabilities. The model could be used at any community college in partnership with the developmental services agencies in its geographic area. It emphasizes the responsibility that community colleges and the Ministry of Advanced Education and Skills Development have to provide services for citizens with developmental disabilities. It also clarifies potential roles for the developmental services sector with respect to working with younger children and their families to prepare them for college and employment.

The Culinary Training Program answers the question, "How can we support youth with developmental disabilities to successfully transition to adult life?"

Key Messages From This Article

People with disabilities. You have a right to attend community college and take courses that will help you get the job you want.

Professionals. Community colleges and developmental services agencies can work together to provide pathways to post-secondary education and meaningful jobs for people with developmental disabilities.

Policymakers. Employment for adults with developmental disabilities requires policies that mandate cross-sectoral and cross-ministerial cooperation across the life span.

References

Black Cat Advertising Inc. (2015) in collaboration with Humber College School of Social and Community Services and Christian Horizons. *A better slice of life* (video). Retrieved from https://youtu.be/T8qJ7ynI1So

Braun, K. V. N., Alissop, M. Y., & Lollar, D. (2006). A multi-dimensional approach to the transition of children with developmental disabilities into young adulthood: The acquisition of adult social roles. *Disability and Rehabilitation, 28(15*), 915–928.

Brint, S. (2003). Few remaining dreams: Community colleges since 1985. The *ANNALS of the American Academy of Political and Social Science, 586 (March),* 16–37.

Drea, C. (2003). Ontario government policy on accessibility to Colleges of Applied Arts and Technology: 1965–1995. *Dissertation Abstracts International, 64-10A*, 3575.

Government of Ontario, (2016). Key Performance Indicators, Colleges and Other Public Institutions. Retrieved from https://tcu.gov.on.ca/pepg/audiences/colleges/colindicator.html

Hnatuk, T. (2014). Employment of People with Developmental Disabilities in Canada: Six Key Elements for an Inclusive Labour Market. Toronto, CA: Institute for Research on Inclusion and Society. Retrieved from https://www.cfeebc.org/resource/employment-people-developmental-disabilities-canada-six-key-elements-inclusive-labour-market/

Humber College, Key Performance Indicators. Retrieved from http://www.humber.ca/strategicplanning/institutional-analysis/key-performance-indicators-kpi

Moore, I. & Nugent, J. (2016). Culinary Skill Development and Employment. Presented at OADD Annual Conference, May, 2016.

Ontario Ministry of Training, Colleges and Universities (2018). Labour market: Employment profile. Retrieved from https://www.app.tcu.gov.on.ca/eng/labourmarket/employmentprofiles/compare.asp

Scott, M. (2000). *The community college in the 21st century: A systems approach*. Lanham, MD: Cambridge University Press of America.

Stoll, P. W. (1993). *A question of transfer: An historical review of the Ontario colleges' mandate*. Unpublished Master's Thesis, Brock University, St. Catharines, ON.

Journal on Developmental Disabilities
Le journal sur les handicaps du développement
JoDD
Volume 24, Number 1, 2019

System Kids: Transition-Aged Youth From Foster Care to Developmental Services

Authors

Sue Hutton,[1]
Kevin John Head,[2]
Sarah Lyttle,[2]
Jordyn,
Noah Kenneally,[3]
Maja Rehou[4]

[1] ARCH Disability Law Centre, Toronto, ON

[2] Former Foster Kid

[3] OISE/University of Toronto, Toronto, ON

[4] The Bridge: From Prison to Community Toronto, ON

Correspondence

huttons@lao.on.ca

Keywords

transition age youth,
intellectual disability,
human rights,
foster care

Abstract

This paper shines a light on the stories of three young adults labeled with an intellectual disability[1]; all three have transitioned out of foster care and are now receiving developmental services in different settings in Ontario. All three have experienced varying degrees of human rights violations throughout their time in foster care as well as in developmental services. By human rights violations, we mean violations that are not necessarily always under the law, but violations to make their own decisions throughout any given day. This point shall be illuminated through the stories of the three youth who share details of these violations in concrete terms. The three have come from a diversity of backgrounds, representing what it is like to grow up in the system with Fetal Alcohol Spectrum Disorder (FASD), with Autism Spectrum Disorder (ASD), and with mobility disabilities. All three want people to know the truth about what it is like surviving the system with an intellectual disability, not only in foster care, but now, continuing to live "trapped" (as one of the young adults calls it) in the confines of the often rights-restricting world of developmental services. We balance the stories with background on the setting of developmental services and service delivery for transitional aged youth (in this paper we shall say "youth" as our co-authors have chosen) with a literature review and with interviews from developmental services staff in Ontario agency settings. This paper includes the stories of the three young adults providing their truths – painful and honest, in both written form and in graphic form. The graphic data collected provides an accessible visual depiction of the isolation and pain endured in the system.[1]

The transition to adulthood can be an exciting but also challenging time of life for youth. Typically, youth living in a stable household have the support from their family and friends as they work towards careers, post-secondary education and living independently. The transition from adolescence to adulthood for these youth often happens over the course a number of years with the move to independence happening gradually. Youth who grew up in the foster care system, however, do not have the same experience. As Harwick, Lindstrum, and Unruh (2017) point out, "youth who age out of foster care often have an abrupt transition from being supported within a system to being completely on their own" (p. 338). The age at which youth transition out of foster care and are required

---

[1] Please note that we use the term "labeled with an intellectual disability" in order to preserve a "people first" approach to language. In other words, the person comes before the disability, and is much more than their disability.

to be completely independent from support also is substantially different from youth not in care. For example, studies show that in Canada 93% of 18-year-olds and 41% of those aged 20–29 live with their parents (Gough & Fuchs, 2006). Youth in foster care have a completely different experience as care ceases at a much younger age. Youth in Ontario no longer qualify for protective intervention services past the age of 16 (Gough & Fuchs, 2006, p. 2). Once youth reach the "age of majority" (18 years) they are said to have "aged out" of foster care and are on their own emotionally and financially without many of the supports that the general population take for granted (Gough & Fuchs, 2006, p. 2). Youth in foster care in Ontario report "feeling a deep sense of abandonment when they formally age out of the system and anxiety about the impending lack of support after leaving care" (Kovarikova, 2017, p. 6).

Adding disability to the mix only results in compounding the barriers that these foster youth face, including critical issues such as obtaining housing and medical care, and overall emotional well-being.

There have been many studies on youth transitioning out of the foster care system into adulthood. Conversely, little research has been conducted focusing specifically on the experiences and outcomes of youth who have disabilities as they age of the foster care system (Hill & Lightfoot, 2008).The research for youth with disabilities transitioning out of foster care tends to focus on youth with Fetal Alcohol Spectrum Disorder (FASD). However, when it comes to youth labelled with a developmental disability, there has been limited to no research. Hill and Stenhjem (2006) point this out in their research highlighting how Chapin Hall's 2005 longitudinal Midwest Study of youth aging out of foster care neglects to include youth with developmental disabilities, although half of the youth in this study reported receiving special education services. They further highlight how "disabilities are rarely studied in relation to child welfare and are even less frequently considered in the transition from care" (Geenen & Powers, 2006, as cited by Hill & Stenhjem, 2006, p. 2).

This is particularly problematic since 82% of youth in care in Ontario are diagnosed with special needs (Benson et al., 2012, as cited by Kovarikova, 2017). For example, studies of children in care in Manitoba found that "17% of children in care in Manitoba in 2004 had been diagnosed or suspected of having FASD" (Gough & Fuchs, 2006, p. 1). Also, according to the United States Centers for Disease Control and Prevention (2014), Autism Spectrum Disorder (ASD) affects 1 out of 68 children in the US (Havlicek, Bilaver & Beldon, 2016, p. 120) and studies show that the prevalence rates of children and youth with ASD in foster care is "significantly higher than in the general population" (Bilaver & Havlicek, 2013 and Hill, 2012, as cited by Havlicek, Bilaver & Beldon, 2016, p. 120). For these reasons it is important that specific measures are provided to protect these vulnerable groups.

Legislation governing rights for persons with disabilities includes Ontario laws related to accommodations. Specifically, the Ontario Human Rights Code (1990) sets out specific and enforceable legislation for persons with disabilities to receive accommodations related to disability when receiving services. The Accessibility for Ontarians with Disabilities Act (Meilleur, M. & Ontario, 2005) is legislation outlining the requirement that agencies must take certain steps in delivering services to persons with disabilities. The Substitute Decisions Act (1992) and the Health Care Consent Act (1996) both outline legal criteria for determining when a person can make decisions that are fundamental to their well-being. There are law reform efforts underway in Ontario for strong revisions to the current legislation with a push to move toward the Supported Decision-making laws that are in place across Canada in British Columbia, Yukon, Alberta, Saskatchewan, and Manitoba. The concept of Supported Decision-making is one that has received recognition and has been adopted by places around the world such as Sweden, Australia, and Ireland. (Bigby, Whiteside, & Douglas, 2017). It promotes a system of decision-making that provides increased autonomy for persons who need support in making decisions. The Convention on the Rights of Persons with Disabilities (CRPD) is an international law that sets out the rights of people with disabilities (United Nations General Assembly, 2007).

Within the CRPD, Article 12 states that people with disabilities have the right to legal capacity on an equal basis as people without disabilities (United Nations General Assembly, 2007). Legal capacity refers to one's autonomy to make their own decisions without findings of incapacity by a capacity assessor. A capacity assessment is a formal assessment about a person's ability to make their own decisions about property and personal care. Article 12 also states that governments must provide access to supports to help people to exercise their legal capacity. Additionally, Article 12 states that governments must put safeguards in place to prevent abuse of people with disabilities who try to exercise their legal capacity. Let us keep the CRPD in mind when we read the stories of our three youth in the body of the paper

Background

As noted above, it has been well documented that youth leaving foster care experience many challenges that affect their future adjustment and functioning as adults. For example, Courtney (2001, as cited in Osgood, Foster, Flanagan, & Ruth, 2014, p. 43) found that "43% of the males in their sample and 32% of the females had experienced one or more of the following within twelve to eighteen months of leaving foster care: homelessness, incarceration, serious physical victimization, sexual assault, and rape." The Our Voice, Our Turn report published by the Provincial Advocate for Children and Youth (as cited in Kovarikova, 2017) also highlights that youth outcomes after aging out of care include "low academic achievement; unemployment or underemployment," as well as "early parenthood; poor physical and mental health; and loneliness" (Kovarikova, 2017, p. 4).

Research also tells us that foster youth with developmental disabilities aging out of care, including those with ASD, have "heightened risks and vulnerability" (Osgood, Foster & Courtney, 2010, as cited in Havlicek, Bilaver & Beldon, 2016, p. 119) and experience a wide range of difficulties similar to their non-disabled peers such as: drug and alcohol abuse, high rates of teenage pregnancy, homelessness, criminal justice involvement, living in poverty, and chronic medical problems (Hill & Stenhjem, 2006). It is also important to note, as Osgood et al. (2014) point out, that "problems in any one of these domains can make success in another less likely" (p. 33).

In this paper, we want to improve our understanding of how developmental services can better support youth who have come from foster care, by shining a spotlight on the stories directly from the youth, as well as by looking at what research says. Our paper's main focus is hearing their stories, which are told in their own words, and supported by images that were developed using processes of collaborative graphic research.

Methodology

At the heart of this paper are the narratives and graphics of youth labeled with an intellectual/developmental disability. The stories provided by the youth co-authors were transcribed by Maja Rehou and Sue Hutton. Stories were transcribed with editing in order to remove pauses and hesitations. The youth co-authors reviewed all transcriptions for accuracy and approval. Headings in the subsections of the stories are based on content directly from the youth. We contextualize these stories and images by intertwining them with background information. This background information consists of a literature review and one-on-one interviews with staff serving these youth. We interviewed seven staff members from across Ontario over the course of five months. The interviews consisted of open-ended questions. Themes and recommendations that emerged from these interviews are woven through the body of this paper. Our goal is to add to the knowledge regarding transition aged youth receiving developmental services in Ontario.

Based on past success using arts-based methods in conjunction with personal narratives of institutional experiences (Hutton, Park, Levine, Johnson & Bramesfield, 2017), this article employs a similar approach. The narratives of young people who have recently transitioned from foster care and who also access developmental services are juxtaposed with collaboratively generated images that communicate their feelings about and experiences of foster care.

Using art-based research and collaborative knowledge production techniques is becoming more common, particularly in the social sciences (Leavy, 2015). More and more, creative visual methods are considered to be accessible, expressive, and reflective practices that engage participants themselves in knowledge production, a process known as enabling methodologies (Gauntlett & Holzwarth, 2006). Enabling methods counter power imbalances in research, and particularly power dynamics that exist between adult researchers and youth participants, by engaging participants directly in the processes of knowledge production, (Barrère, 2003; O'Kane, 2008). Enabling methods invite young people into the research in a different way, moving the focus away from research ON or ABOUT youth to research WITH youth (Christensen & James, 2008). Arts-based methods also offer an approach to meaning-making that communicates emotionally-charged material by circumventing words or attempting to answer questions that lack straightforward answers (Springgay, Irwin & Kind, 2005).

The images featured in this article were generated during sessions (both one-on-one and group) with the youth, using collaborative, arts-based graphic elicitation techniques. The transition-aged youth were engaged in graphic research processes to assist in making their experiences in foster care visible and understandable. The youth were provided with an option of drawing their own image, or having one of the co-researchers assist with drawing it using a collaborative co-creation process. In this process, the youth provided the direction as to what image from their story they wanted to have in the paper. They directed the co-researcher to sketch it out and changes would be made as the youth chose. One of the youth is an artist, and chose to have the co-researcher draw part of the drawing, and she then took over and completed it. Time was taken to ensure that the image depicted the scene they chose to convey from their foster care experience.

Although the youth are co-authors on this paper, due to the trauma of their stories in foster care, plain language written consent was obtained and the option to withdraw from the process at any time was underlined and reinforced regularly.

The youth had relationships with the co-authors through previous advocacy work in developmental services and a trust was previously established. Ongoing phone calls and communication took place to ensure support was there for the youth during the telling of these stories. Every effort was made to ensure the process of creating the paper was as accessible as possible.

Our Stories Entwined With Background Literature and Interviews With Staff

Seven developmental services staff were interviewed to explore their perspectives on providing services to transition aged youth in Ontario. All staff interviewees agreed that youth labeled with a developmental disability aging out of foster care were not given enough opportunities to acquire the skills needed for independence. They also agreed that these youth face long developmental services waitlists to get access to adult services and programs that support their transition into adulthood, including access to extremely limited affordable housing. All these waitlists and lack of available supportive programming and lack of access to housing can lead to these youth going into crisis as they face the experience of very little support in life.

Staff interviewed agreed that transition aged youth are provided limited experiences doing things for themselves in foster care. These things include basic daily living skills such as cooking, shopping for food and clothing, and banking. Staff reported that youth were so well protected while in care that they did not have the opportunity to take risks and learn from their mistakes while they still had support. As one developmental services agency staff interviewee stated, "youth need opportunities to build capacity and resiliency while still in care." From an agency/sector perspective staff felt it was complicated supporting and providing service for transition aged youth because, as Crown Wards, they are over protected and frustrated by being told what to do for so long. Staff interviewed reported that when youth transition out they often want to take risks and "do and try everything" because they had no freedom or opportunity to make choices while in care.

Staff felt that youth not having enough opportunity to make choices in their services is an issue of infringing on their right to make choices. Youth are not provided with opportunities to really choose who to live with and spend time with because of system constraints and waitlists, funding, services and appropriate housing.

Staff interviewed also felt these youth are like typical teenagers who like to push boundaries, but they never had a chance to do so in foster care. Youth want to do things that other youth are doing, such as have friends, hang out with them, and make choices to fit in. At times, these choices are related to risky activities such as drugs and stealing. Staff reported that there is a risk of them then becoming involved in the criminal justice system as a result. It was also a staff perspective that these youth crave more social acceptance because they were socially isolated as a result of being in foster care or in school special education programs. As a result, they are very vulnerable to being taken advantage of.

We will see some of the perspectives of staff echoed in Sarah's story below.

Take a Walk in My Shoes

Sarah's story: We Are All System Kids

By Sarah Lyttle

*Figure 1***.** Image co-created by Sarah Lyttle and Graphic researcher Noah Kenneally. The image shows a drawing of Sarah walking down a path in the dark, stepping out of one shoe, leaving it for the viewer to step into.

Change is a process, not an event. It doesn't happen all at once. 18 and all of a sudden I'm out in the world. The system never helped me prepare for the transition. I grew up as a system kid, and I'll always be a system kid. We all are.

A number, not a person. *I'm not Sarah Lyttle in the foster care system. I'm child profile 14541. That's how I'm known in the system. I'm a number. I'm not an actual person. I'm a number that's it. It's very discouraging… like it's not just fair.*

I have three huge binders that are my case files from the Toronto Children's Aid Society. These files start from 1992. I was born in 1991. So literally a year after I was born this case was opened and there are a lot of not so nice things in there that are written about me or things they had done are not right, not ok whatsoever. I read a lot of this and they withheld it from me when it actually first came in. They withheld it from me for almost about a year. They didn't want me to see it at all because they were afraid what it was going to do to me. But really honestly just with the things I've read, I couldn't understand why they held it from me just because of things they said about me or my family or just experiences and stuff.

I know the system, I don't know family. *Yes, I was moved 18 different times …and it's not just foster homes it's also group homes as well too. It's extremely discouraging. Mmm because you will move into a home sometimes and some of the foster parents… I think they mean well but they will sit there and be like "ohh we're going to be a family, it's going to be fantastic, you're going to be here for a long period of time" and then all of a sudden I have a worker showing up at my school taking me to a new home. Umm it's not the funnest thing at all whatsoever. I eventually learned to cut off everyone that I was living with in the home. I didn't want to talk to them, you're not my friends. I have nothing to say to you, I really don't. Umm it's really unfortunate because some people I should have really given the chance to but I just couldn't do it because 18 different placements… it's really not fun. Knowing what it's like to have a family? No. I know the system. I don't know family. I don't know anything at all about family at all whatsoever. It's really not a fun experience…discouraging…yep.*

We shall pause from Sarah's narrative to discuss the research.

Instability in care: What the Research Says

Just as Sarah talks about being plucked by the system from a "home," and instantaneously placed in another in a different part of Ontario, the research confirms her story. Lack of continuity caused by multiple placements in care is a key factor highlighted in the literature when it comes to why transitioning to adulthood is so problematic for youth with disabilities in care. For example, Gough and Fuchs (2006), in their report, state, "youths in care with FASD experienced from one to 20 residential placements during their time in care" (p. 3) and a study conducted by Harwick, Lindstrum and Unruh (2017) found that the youth they interviewed

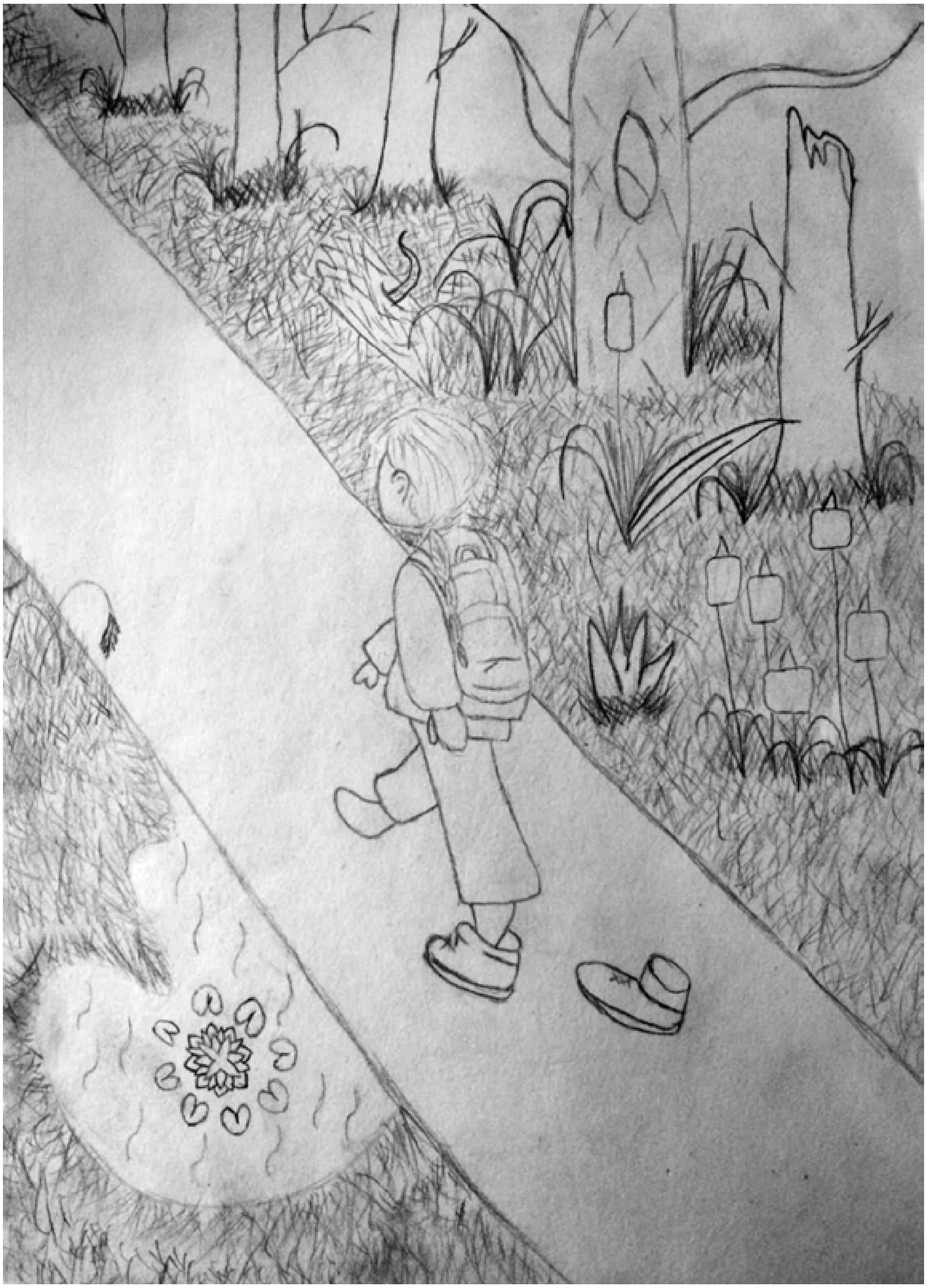

Figure 1. *Image co-created by Sarah Lyttle and Graphic researcher Noah Kenneally. The image shows a drawing of Sarah walking down a path in the dark, stepping out of one shoe, leaving it for the viewer to step into.*

experienced between four to 15 placements while in care. Kirk and Day (as cited in Kovarikova, 2017, p. 11) reported that foster youth may move up to three times per year on average." This "placement impermanency" is what appears to "affect the development of meaningful relationships" (Kovarikova, 2017, p. 33).

Instability not only occurred in living arrangements, it also occurred with staff supporting youth. For example, research by Gough and Fuchs (2006) found that youth had a number of child welfare workers while they were in care ranging from two to 15 workers per youth, with an average of 5.7. This lack of stability in care workers and other social connections due to being in foster care also leads to a lack of supportive relationships, especially at a critical time when youth need adult mentors to help guide them through major life decisions such as career planning and post-secondary education. Not having an adult mentor also makes it difficult for youth with disabilities to navigate through adult disability services and funding sources. Developmental services are also notorious for high staff turnover. When these youth enter into developmental services, they often find themselves having the same experience of instability in staffing as they did when in foster care. Developmental services workers are among the lowest paid in Ontario, and after pressure from unions, steps are being taken by the Ministry of Community and Social Services to increase wages to help with staff retention (OPSEU, 2014).

Since schools often facilitate transition planning efforts, Gough and Fuchs (2006) highlight how transition planning is also interrupted by placement instability because of the subsequent transitions to different schools. Research by Kovarikova (2017) revealed that "every time a youth move[s], they lose four to six months of academic progress and then struggle to make up the loss over time" (p. 9) "due to the disruption and logistical coordination between academic and child protection institutions" (p. 11).

This instability also has a negative impact on the mental health of these youth who are not only dealing with the trauma caused by going through many transitions while in care. Compounding that is the fact that the "sexual and physical victimization" they often experience while in care "puts them at a particular disadvantage" (Osgood et al, 2014, p. 35) with regards to mental health. Research is consistent in finding that former foster youth experience mental health problems during the transition to adulthood (Osgood et al, 2014, p. 36). Studies show youth with developmental disabilities also have a high rate of co-occurring disabilities. For example, 88% of youth with FASD have co-occurring disabilities, which includes 46% of youth diagnosed with FASD also having a mental health disability (Gough & Fuchs, 2006, p. 1).

Consistent with the lack of rights that foster children have to make their own decisions, Sarah's story describes how she sees her rights being violated in multiple ways. Being denied the basic right to be involved in decision-making is something all three stories share – from their time in foster care to their time in adult services.

We will now resume Sarah's narrative.

Where are decision-making rights?: Office of the Public Guardian and Trustee. *I was not very involved at all in my plan of care in foster care. The Provincial Advocate for Children and Youth office says if you are 12 or over, you have the right to help make your plan of care. They never involved me in my plan of care in the system.*

Then when I was transitioning out of care, I got assigned a Public Guardian and Trustee with Toronto and it has been not the greatest experience at all whatsoever. They were supposed to transition more funding for me when I moved independently and my money has been decreasing since I've been here. Like you can't get a hold of them half the time, like at all whatsoever, which is not very fun because if I want to go and do something personally and I needed some funding I can't get a hold of them so I have to cancel my plans half the time.

Where are health care rights?: Depo Provera. *I was put on Depo Provera against my will. They just put me on it. That was the worst needle in the world. That's all I can say about that. I started taking this when I was 14 years old. They told me it would be good for me to take. Obviously because I started it as a teen. But I did not realize nor was I told the side effects of Depo Provera could actually do. I stopped taking Depo Provera when I moved here into the* *city. I did not know that I had a choice not to take it. I thought I had to take it because that is what I was told up until I moved here.*

Finally transitioning to developmental services. *I had to meet with multiple agencies to see what the options were. It was a lot of pressure. First thing was the DSO [Developmental Services Ontario] then I got contact with an agency. Literally I met them and they were like we can do all this work and in 9 months we will meet again. Awesome cool. Then 9 months again same story. I literally said no thank you and I left. I have nothing to say to you either. After that I met a program. I didn't like them whatsoever. It was when I met with another agency, and they actually had a solid plan. This is what it looks like. This is what a budget looks like. This is how we help and support you. We will show you a couple of places. We have a couple places available. They actually came with a plan. I didn't have to say much to them. He asked how they could help me be supported in the community and how they can help me with day to day living. I was taken aback because that was the first time anyone asked me that type of question.*

My 21st birthday consisted of me moving into my first place. I didn't really have a choice. I had to go at 21. I went to a bachelor apartment. That was probably one of the worst experiences that I had. It felt like four walls closing in. There was not a lot of support. I struggled a lot with you know just dealing with day to day things. Just because of the fact that I was not fully, properly supported to do the transitioning part of it. So it was very hard for me. It became very stressful with no supports in the bachelor. Because of my anxiety I went back to foster care. I had nowhere else to go.

I had to move back into the foster care system and stay in a foster house for another two years, which while trying to get into a program, I actually struggled with addiction for those two years. I kind of became a little bit of an alcoholic and even when I came down here I was still drinking…drinking a lot of alcohol. Some people were really shocked at the amount I would drink. They were like my liver…your poor liver but I'm on the healing track now. Actually my last drink was in January. I haven't drank since then. It's hard when it comes to addiction.

I have FASD. I'm quite well aware about how my disability affects me on a day to day basis. I know sometimes my communication… it's motor skills and memory loss too. When I'm over stimulated I get very forgetful.

Sarah Has a Support Worker Whom She Refers to as Her "External Brain" Sometimes

It's important to have a staff who is consistent with me. My staff now is. She's like tomorrow. Can we do it tomorrow? Yes let's do it. That's what I need. Not someone who will call back in 9 months. My cat Donatello has been with me through all my changes. He's consistent.

Sarah clearly states the need for consistency in people around her. The research echoes her sentiment.

Lack of supportive relationships or connections with caring adults. In the literature reviewed, youth indicated the need to have at least one supportive adult relationship as they make the transition to adulthood (Office of the Provincial Advocate for Children and Youth, 2014). Instability and lack of continuity in care, as well as the social isolation that youth experience due to having a disability (e.g., being placed in special education classes) leads youth to have an inability to form core relationships.

Gough and Fuchs (2006) suggest the importance of ensuring youth in care have attachment to at least one significant adult who is able to act as a mentor (p. 2). Hill and Stenhjem state: "the consistent presence of a single caring adult has been shown to have a significant positive impact on a young person's growth and development" (2006, p. 3). However, as Havlick, Bilaver and Beldon (2016) point out, relationship building needs to be persistent, with consistent communication and information sharing, if it is to be successful (p. 119).

Also, the staff we interviewed noted that the lack of healthy attachment patterns formed, due to the abuse and neglect the youth experienced with biological family before going into care, is also a factor that can diminish Transition-Age Youth's (TAY) capacity for acquiring supportive relationships.

Staff interviewed pointed out how a large percentage of these youth live in congregate care. Since congregate care facilities are generally staffed by relatively young shift workers who tend not to stay in their jobs very long, youth in congregate care may find it difficult to form the kind of lasting relationships with responsible adults that will help them move towards independence. They also suggested another way to ensure these youth form social attachments is through fewer placements and more stability while in care. Staff reported transitioning to adulthood can be a huge re-socialization process.

As Sarah's story continues below we see the impact instability and poor-attachment patterns have had on her life:

I was in foster care, I had been going to the same access centre to see my biological mom and dad for years. It's kind of like a school. Literally like an elementary school. I went there for years actually. When I graduated from Grade 8, the two people standing beside me in my photo I had been living with them for five years. They are literally my forever mom and dad. They are my mom and dad. No one else is going to be my mom and dad. My own parents are not my mom and dad. They are very supportive people. I moved in with them when I was 10 and still even to this day I still have contact with them. I'm still talking to them. Going out for dinners every now and again. They're a huge part of my life, like massively. Then I graduated from Grade 12. I'm actually the first in my family who has graduated from Grade 12.

Some people were with me there through thick and thin. I struggled with drugs as a teen. There was an amazing lady who was the director of a foster care home. She once knocked down a drug house with 12 cops because that's where I had been hiding out. And this lady. I really put this lady through hell for three years. I had 43 missing persons reports while living in her house because I struggled. I didn't want to be at her house. I didn't like her at the time but you know I feel bad right now to this day that I put that lady through that. But she stuck with me for three years. She put up with that.

And my dad. I'm going to have to say that I don't have a love/hate relationship towards him but what I will have to give him out of everything that's ever happened is that he's always been there. Dead as a dog he'll show up to my visits. At my graduations he's there. Anything really important he's there. Grade 12 grad. When my dad heard about some of the things that were happening to me he was like whoa… He wanted to do something but he had no rights because I was a Crown Ward. He did not have the legal right to do anything. I was basically government. Sometimes you're born into a family that can't help themselves. It's very unfortunate even with a large family. I don't even know half of them. They had nothing to do with my father just because of what happened to me and my family.

I don't really talk about my mom too much because she was not a very huge support in my life. She stopped seeing me at the age of 10 and then when I was 16 I had got a phone call basically that she had passed away. I had no feelings towards that. Later on in my case files, I found the reason that she had stopped seeing me was kinda not nice. She got upset because I was calling my foster parents mom and dad. So she felt I was replacing her and stopped seeing me just because of that, which unfortunately happens sometimes.

Art helped through the changes. *Art helped me through changes. While struggling in my teen years, I found art was one of my massive escapes. So I would draw a lot just to escape reality and when a lot was going on around me.*

And now I'm heavy into gaming. I love gaming. I play this one game called Minecraft and I have been creating a Lord of the Rings. I'm absolutely obsessed with Lord of the Rings. I love Lord of the Rings.

What do I feel like I need from staff? *Stability is so important. It's really hard when you have workers, foster parents, staff, one-to-one workers from different agencies. When you have so many people talking about the same thing, you're totally hearing different messages from everybody. That's really hard. I have seen people become numb with the information. Even me, myself who has been told all these different things from all these different people, it's like in one ear and out the other. I didn't want to listen to it. It was too over stimulating sometimes. Even with the transitioning, you become numb. It's like when I was at school and they told me to pack my bags. When I asked why they said I'm going to another school. I said "oh ok." To me it was just another day.*

They should consider changing how they do things because I may have had friends at that point. I've lost a ridiculous amount of friends because of transitioning and that's not cool because it basically impacts my communication with other people in the world. I have only one friend that I kept in contact with from elementary school. But the amount of times that I moved I could talk to her but I couldn't maintain a friendship. So you're always constantly *making new friends and meeting new people and stuff. It kinda sucks. It really does.*

You eventually…some people… I don't really want any friends. I'm at that point now that I'm living here in the city. I don't want to make any friends because I still live in that brain mentality, I'm going to move. I'm going to be going somewhere else. So it's a struggle, it really is.

Despite all that she has gone through, Sarah's story is one of deep strength and resilience.

I have a poster on my wall. Pretty much defines me. I get to look at every day. This definitely defines who I am. 'Don't let anyone hold you back. Take risks. Spread love. This life is your message to the world. Let it be extraordinary'. [End of Sarah's Story]

It Was a Sad Story: By Kevin John-Head

The beginning of foster care. *I moved out from my mom's apartment to a group home. It was a different type of home. It was a house. It was in Scarborough.*

It was different living there. It was hard living with different types of people because I was there and my friend was there. My friend grabbed my arm and pinched me very hard. It's very serious.

There were two group homes I went to… for six years and then I moved to foster care. I'm not sure how old I was. There was a staff office there. I would go swimming for exercise when I was a kid. Staff were good to me.

I went to a special school. It's a special place where special people go there.

Figure 2. *It was a Sad Story. Image co-created by Kevin-John Head with graphic researcher Noah Kenneally. This image shows Kevin lying in his bed in his room. The bedroom door is locked with two locks and bars across the door from the outside.*

I was scared at the group home. *When I left that foster care I went to the group home. I was scared because I had never been there before. Kids had a problem in this group home. You would get serious consequence. People would tell me to go upstairs and say "good night Kevin." It was very serious. The staff had an alarm on the door of my bedroom. The alarm would go off when I went to the washroom. Staff gave me time out in the kitchen. I came home from school and I would get consequence. Staff told me I can't go out and I can't watch TV. I don't know what the consequence was for. I had to stay in my room for seven hours at bedtime. When I came home from school staff would give me my meds and I would have supper. After supper I would have to do some chores in the house. I would wash dishes. I would do some mop in the kitchen, living room and dining room.*

Staff weren't nice there. *They would yell at me – "Kevin can you go upstairs to your room or you would get grounded for two weeks." No TV, can't go outside and do things, do nothing, just stay in your room, that's it. I could play with the toys in my room. I had a roommate and he would be in the room too because he was grounded.*

After the group home (for four years) I went to another group home for four years. I was still a teenager. The second one was a better group home than the first group home. It had hard wood floors. There was a brand new kitchen, brand new basement, brand new couch it was beautiful there. Staff treated me very well at that group home. After that group home I went to another group home. I was in this other group home for three years before I moved to where I live now. At the third group home the food was locked up. The fridge had a lock too. Staff would say "Kevin come here – sit down or you will go upstairs. Kevin do you understand me? You're going to go upstairs or you will have a serious consequence."

I was scared. All the kids were scared. I did not know what was going to happen to me. Staff should protect me, protect Kevin. It's very important to me, so important.

It's not just me. It's everybody. It should not happen to anyone. *That breaks your heart right? It will not happen ever again. It's like a terrible roller coaster ride. Up and down.*

The transition from foster care. *Group home staff told me I was moving to a new place a year before I moved. I was 22 when I moved to where I live now. At the group home they taught me how to cook like chicken, rice and vegetable – my favourite food.*

What do youth leaving care need? *I needed support. I needed to learn. I wanted to learn basketball and track and field. I used to do Special Olympics when I was in the group home. Teach staff how we talk– to understand us. Staff never understood me. I should have been taught more in school like how to read and write.*

What it's like today. *I like where I am now in independent living, because they support me with things like my budget. I go out now and have fun. I go to rights groups, self-advocates groups and People First. I'm a treasurer. I won elections. I'm so excited. I'm part of relationship working group***.** *I have a busy life. I have a whole life to go. I want to be a better person. I want to be open.*

Congratulations to me, Kevin John-Head. I'm going to be a successful person. [End of Kevin's Story]

Transition aged youth need trauma/mental health support. Through Kevin's story we see the physical and emotional trauma that he experienced while in care. Staff interviewed expressed how youth who have gone through this type of trauma need emotional/psychological support. However, there are waitlists for this type of support, or youth refuse this service. Their trauma history needs to be addressed regardless of what we feel their capacity is. One staff interviewee stated how we also need to provide trauma support to caregivers/foster parents if the child is a victim of trauma because of the impact of vicarious trauma from the child they are supporting. According to studies reviewed by Osgood et al. (2014), "former foster youth suffer from more mental health problems than the general population" (p. 34). These mental health problems can negatively affect other outcome domains and are less likely to be treated once they leave care (Osgood et al. 2014, p. 43).

Mental health issues can be exacerbated if these youth also do not have skills and abilities because of disability or special education. Therefore, as Hill and Stenhjem (2006) suggest, youth would benefit from individual/group counselling and service coordination (p. 1). As Hill and Stenhjem (2006) also suggest, having a required transitional independent living plan supports youth to develop critical competencies; obtain education, career counselling, physical/mental health care, housing, develop relationships with caring adults, access community resources, public benefits/services and acquire daily living skills (Pokempner & Rosado, 2003, as cited by Hill & Stenhjem, 2006, p. 1) because "'aging out' without a permanent family and/or adequate preparation for adulthood is a crisis. It is a personal injury to each and every youth in care and a public emergency for our national child welfare system" (Frey, Greenblatt, & Brown, 2005 as cited in Hill & Steinjem, 2006).

The Need for Multi-Sector Collaboration Between Ministries

A strong recurring theme repeated throughout the interviews was the need for a systemic-collaborative relationship between agencies before and throughout the transition process so staff have access to the appropriate expertise when it comes to supporting these youth. One staff interviewed highlighted this when he said, "there needs to be a better communication system between sectors."

Currently, as staff interviewed mentioned, all systems work independently. Collaboration needs to be at the Ministerial level (i.e., Ministry of Community and Social Services and Ministry of Corrections) but at the sector and agency level as well. For example, one staff interviewee suggested that Children's Services work closely with developmental service sector agencies while the youth are still in care so that staff can get advice from developmental service staff as to where to get the best supports for these individuals when they start to transition out of care. One staff interviewed said if support is not put in place before these youth transition out of care they will, "fall through the cracks."

The importance of interagency/sector collaboration was also mentioned in the literature. As Frey, Greenblatt and Brown (2005, as cited by Hill & Stenhjem, 2006) point out "coordination of transition planning among key agencies and systems is imperative" (p. 3). Stroul and Friedman (1986) agree that "interagency collaborations" are needed because they "bring together and engage critical stakeholders in a coordinated and integrated effort" (as cited by Havlick, Bilaver & Beldon, 2016, p. 119). Research also shows this lack of collaboration results in no "single point of access for information about services (Havlicek, Bilaver & Beldon, 2016, p. 126)." Poor coordination between child welfare and adult service systems or "silos" makes transition to adult services/systems "confusing" for both service providers, as well as foster youth (Havlicek, Bilaver & Beldon, 2016, p. 126). ***Earlier and longer transition planning.*** Staff interviewed not only agreed that there needs to be more collaboration between sectors, but they also felt there needs to be more time (i.e., one year) in the planning process, so there is time to put the supports in place before the person is actually transitioning out of foster care. Currently, according to staff interviewed, transitional planning/support from child to youth is only approximately one month. Child and youth sectors need to come together in the transitional planning process. The system needs to prepare youth/foster parents about the shift in the system (i.e., getting into DS services, ODSP) that will happen after they turn 18, and it should be started when they are 16 years old. The need for better cross sector collaboration and earlier on will lead to better transition planning. The consequence of having poor transition planning is exemplified in the anonymous youth's story below:

Trapped: By Anonymous

I would like to have no name associated with my story. I don't feel safe where I am living now, and don't want them to find out I am saying this. The drawing I created – Trapped – that's what it feels like. It felt like that when I was in foster care, and it still feels like that today. I feel like I'm trapped – in jail.

To start with, it's [developmental services] not a pretty picture for people coming from foster care. It's sad now. Because I don't to this day know what developmental services is. I don't even know why I was put here to begin with. I don't even know what my problem is. What does this mean for my future – whether I even have a future, or whether I need to go find a future somewhere else. I'm still young. I don't even know if I belong here. It's sad. Nobody tells you anything.

Figure 3. Trapped. Image co-created by anonymous and researcher Sue Hutton. This image shows a figure slouched in poorly fitted pyjamas in a manual wheelchair with no foot rests. They are seated within a jail cell, with no windows.

I also want to say to whoever is still in the foster care system today; you need as many people as you can on your side to fight for you. I only had CAS [Children's Aid Society] and my foster family. My foster family didn't have much say, because my biological family still had legal rights. I wasn't a crown ward. I was placed under something called a special needs agreement.

Little me in foster care. *Just imagine – little me being carried down 12 flights of stairs to visit my family member. It was bad. Children's Aid didn't protect me. On the visits they were drinking and on all kinds of medication. They even hit me with a converter. Apparently they hit me because I was crying – because I didn't know what was going on. And they were sleepover visits. My family member was addicted to heroin. CAS didn't keep me safe from* *harm's way. This is why I want NO contact now. They're not family to me. They are just biologically related to me.*

This is why the kids have behaviours. They get punished for something they didn't do. I would get grounded when I was communicating my frustration. I would hit and bite and get angry. Of course I did. I was just communicating.

At 18, I was still being made to go visit my family member with the addictions. I was supposedly transitioning into this adult world. The social workers thought it was best for me to grieve – to figure out who I am as a person. To be honest, I wish I was adopted. No one should ever have to live through that turmoil.

Children's Aid did nothing to protect me. *Then I was being abused in the second foster home. I never got a wheelchair accessible shower in foster care. My second foster home I moved into when I was 13 had stairs. Imagine being told in six months you'll have everything accessible. Nope! I had to get sponge baths. I was allowed to have a shower once a week at the goddamned swimming pool. I was only allowed to have a motorized wheelchair at school. They made me stay in a manual chair in the home. Because the home wasn't accessible. A motorized chair wouldn't fit through the doors.*

I fell on the floor and I had bruises. The foster family refused to pick me up. I was being told to transfer from a bed to a chair with no brakes. It was four times I was moved between different foster parents. I was getting beat up by a kid hitting me and punching me. From age 13–18, why didn't anybody do anything!? The Children's Aid did nothing to protect me. I feel bad for the little kids

The school tried to complain. *I felt safe at the school. They listened to me. I would have slept there if I could. They knew everything that was going on in foster care. Somebody made a call at school to the advocacy office about everything that was going on. They [the advocacy office] came in. They talked to me. The director from the home says to me…call them back and tell them everything is okay. They wanted me to do that. I felt I would get in trouble if I didn't. I was forced to call the advocacy office back and tell them everything was okay.*

Deep inside I didn't have anybody to tell me whether that was the right thing or the wrong thing to protect me. So my protection doesn't matter to them. They would say I'm making it all up. All the stories I told them about what was happening. They still say that today. Still nobody is listening.

Still fearful today. *Even today I have fears. I still live in an organization where everything has to be locked up. Today, they say that this is my house. Wrong. It's like a group home status. Everything is locked up. The thing I don't like is they say it's my home. All medication, all case binders, money, even tickets to a show have to be locked up in safe keeping. I get my bus pass every month and I don't even bother to give it to them because they would lock it up. There is no explanation why they lock it up. They get mad if I ask. I have no privacy. Nothing is confidential. Not even the manager's office is confidential. No privacy.*

I know it's hard when people take your legal rights away. That worries me every day of my life. They don't tell me what I'm signing. I'm like any other human being on this planet, but because I live in an organization my privacy and rights have to be violated.

I don't know who hires these people. I feel very alone and very trapped. I want people to take a moment and think about how to really just listen to us. I was never heard. And I'm still not heard.

Leaving foster care into developmental services. *After 18, I had my own decision-making rights. Nobody told me I was leaving foster care. The social worker just told me she was going to close my file. I was told I was no longer their concern.*

I didn't even know what to think at that point. I was stuck. Another big agency came in. They apparently help people find housing. I remember the worker not being honest. I was 20 when I finally left foster care.

I wanted to move closer to my first foster parents – who I call my mom and dad. Nobody was listening to me.

Nobody sends complaints to the complaints department because they are scared of what is going to happen. I've wanted to complain but I have been too afraid to send it. The Ministry needs to be more aware of not only foster homes but also in developmental services group homes. Trust me. It's not a pretty picture. The Ministry should show up on a surprise visit to these places more often. They should show up in the foster care but also in the developmental services.

There is no transition. It's just, "Bye – Enjoy your life – Good luck!" Even when I moved here, they were so afraid that me and my roommate were going to get ourselves into trouble. They had a staff following us around 24/7. There was no breathing room whatsoever. We could never pick different programs we wanted to do because there was only one staff. It was scary when I first moved there. I couldn't even see the apartment. Normally you should be able to see the place to see if you like it. They didn't even let me look at the place to see if I liked it. The place is plain white. I don't get to choose what my own place looks like. The staff buy the furniture out of our budget. They make the choices. Now it's gotten worse. No choices. Sometimes staff meet at my apartment and tell me to leave so they can talk to each other while I'm not there.

What I want staff to know today. *I want developmental services staff today to know these things: Get a chance to know the person you are working with. Go for a coffee or go for lunch. To get to really know the person and what they need. There is never a time where me and my staff will go for a walk on a nice day and sit down. Here's what you should know about me and here's what I should know about you.*

They should be asking questions like, "What can I do to make your life easier?" They are here to support us to live our lives. But they overstep. They are trying to act like my mother instead of a staff. I'm always doing something. I'm at home and a staff says, "I think it's time for you to get a part-time job," "you're pacing a lot." I said maybe next summer. They say what they think we need instead of asking us.

I would suggest a booklet for staff on how the person is feeling. When they know foster kids are moving out on their own, spend a couple days and comfort them. Just let them know that you are a good person. Just let them know that somebody else would be there for you. Because I never had that. Just maybe having a photo album, getting pictures together of the last living arrangement and put it in a photo album. I call it living arrangement because that's what it is. It's not a home. Especially when kids are moved all over the goddamned city. A home is something you feel safe in. You come home and you have your teddy bear on your bed. A home is asking what you want for dinner. The sad thing is when a child is feeling upset the staff don't even hug them. You're in this field because you want to help a child, right? [End of Anonymous's Story]

Conclusion

The painful stories of the three youth are clear first-hand statements on how the system has failed youth transitioning out of foster care and into developmental services. As we can see in their stories, backed up with the research, not only did the foster care system leave scars on the youth, but the current developmental services system also has a long way to go to improve services and meet the needs of these "system kids."

Staff we interviewed for this research highlighted that we need more options for people in crisis, such as having more treatments available. For example, there is a need for the creation of more safe beds, more intensive support for short periods of time, so that people can be diverted from the criminal justice system.

More crisis planning is needed, as are protective factors built into developmental services. For example, an option is to build crisis support capacity within group homes so that in the event that something happens suddenly, they will be able to handle it.

Staff stated that if these youth are not well supported then they can potentially end up in the criminal justice system, which costs society as well as these individuals' well-being. As one interviewee stated, "jail is used like foster care for adults as we try to get support as we have no other options because there are large waitlists or no service at all for this cohort." Staff reported that the criminal justice sector is often the last resort. If there was more support for caregivers, and better transition support conducted earlier, then that would significantly reduce the number of these individuals who are ending up in jail. This is only one of the critical issues that needs to be addressed in improving service delivery for these youth.

The face of developmental services is changing before our eyes, with youth transitioning out of foster care, asking for a different kind of service than the sector has known how to deliver. The developmental services sector has major adaptations to make as we learn about the needs of the new population we are serving so that we do not continue to re-victimize these youth. As the three storytellers have outlined in their narratives, there are unique needs that come with having grown up in foster care. Deinstitutionalization is, thankfully, behind us; however, youth leaving foster care bring a whole new world of advocacy and critical human rights work that is calling to be done. Youth like the three telling their stories in this paper are voices unto themselves. They are asking for their rights to be respected, and for their stories to be honoured. They are asking to be listened to.

As one staff interviewed stated: "Agencies… the sector is not equipped to service the needs of these TAY." The changes that are needed are needed now, and need to be implemented quickly. We hope these stories serve to remind us of the importance of listening, of changing how we are delivering service and most importantly, of bringing well deserved respect to these youth who have already proved their resilience over and over, and deserve better.

Key Messages From This Article

People with disabilities. Transition aged youth labelled with intellectual disabilities who have grown up in foster care deserve to be treated with respect. The respect needs to be there in foster care, and also in developmental services.

Professionals. Transition aged youth labelled with intellectual disabilities who have grown up in foster care need stability and kindness to thrive.

Policymakers. Policy to ensure that transition aged youth are given the supports they need to have success in life when leaving foster care and entering developmental service is very important.

References

Barrère, A. (2003). *Travailler à l'école. Que font les élèves et les enseignants du secondaire?* Rennes: Presses Universitaires de Rennes.

Bigby, C., Whiteside, M., Douglas, J. (2017) Providing support for decision making to adults with intellectual disability: Perspectives of family members and workers in disability support services, *Journal of Intellectual & Developmental Disability, Doi:*10.3109/13668250.2017.1378873

Christensen, P., & James, A. (Eds.). (2008). *Research with children: Perspectives and practices* (2nd ed.). New York, NY: Routledge.

Gauntlett, D., Holzwarth., P. (2006) Creative and visual methods for exploring identities, *Visual Studies, 21:1,* 82–91.

Gough, P. & Fuchs, D. (2008). *Transitions out-of-care: Youth with FASD in Manitoba.* Centres of Excellence for Children's Well-being. Retrieved from https://cwrp.ca/publications/transitions-out-care-youth-fasd-manitoba

Harwick, R. M., Lindstrum, L. & Unruh, D. (2017). In their own words: Overcoming barriers during the transition to adulthood for youth with disabilities who experienced foster care. *Children and Youth Services Review, 73*, 338–346.

Havlicek, J., Bilaver, L., & Beldon, M. (2016). Barriers and facilitators of the transition to adulthood for foster youth with autism spectrum disorder: Perspectives of service providers in Illinois. *Children and Youth Services Review, 60*, 119–128.

Health Care Consent Act (1996). SO 1996, c 2, Sch A, Retrieved from https://www.ontario.ca/laws/statute/96h02

Hill, K., & Lightfoot, E. (2008). *The Transition of Youth with Disabilities from the Child Welfare System.* Centre for Advanced Studies in Child Welfare. Retrieved from https://cascw.umn.edu/wp-content/uploads/2013/12/TransitionYouthSubSum.pdf.

Hill, K., & Stenhjem, P. (2006). *Youth with disabilities aging out of foster care: Issues and support strategies.* University of Minnesota. Retrieved from http://ici.umn.edu/products/impact/191/default.html.

Hutton, S., Park, P., Levine, M., Johnson, S., & Bramesfield, K. (2017). Self-advocacy from the ashes of the institution. *Canadian Journal on Disability Studies, 6*(3), 30–59.

Kovarikova, J. (2017). *Exploring youth outcomes after aging-out of care.* Provincial Advocate for Children and Youth. Retrieved from https://www.provincialadvocate.on.ca/reports/advocacy-reports/report-exploring-youth-outcomes.pdf

Leavy, P. (2015). *Method meets art: Arts-based research practice* (2nd ed.). New York: Guilford.

Meilleur, M., & Ontario. (2006). *Accessibility for Ontarians with Disabilities Act, 2005 (AODA): 2006 annual report*. Toronto: Ministry of Community and Social Services. Retrieved from http://www.ontla.on.ca/library/repository/ser/272468/2006.pdf

Office of the Provincial Advocate for Children and Youth (2014). Submission to the Ministry of Children and Youth Services on the Review of the *Child and Family Services Act*. Retrieved from https://www.provincialadvocate.on.ca/reports/advocacy-reports/english-reports/OPACY%20CFSA%20Review.pdf

O'Kane, C. (2008). The development of participatory techniques; facilitating children's views about decisions which affect them. In P. Christensen & A. James (Eds.), *Research with children: Perspectives and practices* (2nd ed.), (125–155). New York, NY: Routledge.

Ontario Human Rights Code (1990). RSO 1990, c H.19, Retrieved from http://canlii.ca/t/52v2w.

Osgood, D. W., Foster, E. M., Flanagan, C., & Ruth, G. R. (2014). *On your own without a net: The transition to adulthood for vulnerable populations.* Chicago: University of Chicago Press.

Springgay, S., Irwin, R. L., & Kind, S. W. (2005). Artography as living inquiry through art and text, *Qualitative Inquiry, 11*(6), 897–912.

Substitute Decisions Act (1992). S.O. 1992, c. 30. Retrieved from https://www.ontario.ca/laws?search=&search=substitute+decisions+act+&type=&op=

United Nations General Assembly (2007). *Convention on the Rights of Persons with Disabilities: Resolution Adopted by the General Assembly*. Retrieved from http://www.refworld.org/docid/45f973632.html

Journal on Developmental Disabilities
Le journal sur les handicaps du développement
JoDD
Volume 24, Number 1, 2019

"Well Where's he Supposed to Live?" – Experiences of Adoptive Parents of Emerging Adult Children With FASD in Ontario

Authors

Jenna Pepper,[1]
Shelley Watson,[2]
Kelly D. Coons-Harding[3]

[1] Carleton Univeristy, Ottawa, ON

[2] Laurentian University, Sudbury, ON

[3] CanFASD: Canada FASD Research Network, Vancouver, BC

Correspondence

JPepper@cheo.on.ca

Keywords

fetal alcohol spectrum disorder,
emergent adulthood,
adaptation,
families

Abstract[1]

The purpose of this study was to gain a better understanding of the experiences of adoptive parents of adult adoptees with Fetal Alcohol Spectrum Disorder (FASD), and to examine their needs as they are adapting to their children's transition into adulthood. Twenty parents from Ontario completed the Questionnaire on Resources and Stress – Friedrich's Version (QRS-F), as well as a semi structured interview focused on parents' lived experiences. Using Interpretative Phenomenological Analysis (IPA), three major themes were identified from the interviews: the transition of the child into adult housing, children's inabilities to manage finances, and difficulties associated with individual characteristics. Each theme is discussed in detail. The QRS-F was analyzed using descriptive statistics and results indicate that parents were, on average, experiencing moderate levels of stress. The findings suggest that those parents required additional resources such as adult housing to facilitate adaptation and minimize perceived parental stress. Understanding adoptive parents' needs is crucial for providing the appropriate supports to avoid family crisis.

Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term that refers to the range of effects caused by prenatal exposure to alcohol (Cook et al., 2016). Currently the most commonly cited estimate of the prevalence of individuals with FASD in Canada is 9.1 per 1000 live births, or approximately 1% of the population (Canada FASD Research Network, 2015). Because of the lifelong challenges associated with the disability, the annual cost of individuals with FASD in Canada has been estimated to be approximately 7.6 billion dollars (Thanh & Jonsson, 2009). A recent study examining the cost of children (aged 0–18) in care with FASD estimated the total cost in Ontario to be between $15,929,201 and $54,545,446 and the total cost in Canada to be between $57,917,032 and $198,321,958 (Popova, Lange, Burd, & Rehm, 2014). Individuals with FASD in care often make use of formal services throughout their lifespan, and many are unable to achieve self-sufficiency by the age of 18 (James Williams, Dubovsky, & Merritt, 2011).

Individuals within the child care system (e.g., foster care, child welfare system) are particularly at risk of an FASD

---

[1] This article is based on: Pepper, J. M. (2016). *Families raising children with FASD and autism in Ontario* (Master's thesis, Laurentian University, Sudbury, Canada). Retrieved from https://zone.biblio.laurentian.ca/bitstream/10219/2576/1/Jenna%20Pepper%20Final%20Thesis.pdf

diagnosis (Popova et al., 2014). Between 2013 and 2014, there were 977 finalized adoptions in Ontario (Ontario Association of Children's Aid Societies, n.d.). In 2014, there were an estimated 18,564 children in care in Ontario and, of those children, there were an estimated 612 to 2,096 individuals with FASD (Popova et al., 2014). Those adoptees are at risk for primary and secondary challenges.

Primary impacts are caused by underlying brain or central nervous system irregularities and include symptoms such as cognitive impairments, negative changes in adaptive functioning, memory deficits, and language comprehension (Malbin, Boulding, & Brooks, 2010; Streissguth & Kanter, 1997). Primary impacts can cause individuals with FASD to be predisposed to secondary risks, which tend to occur later in life (Streissguth et al., 2004). These secondary impacts include trouble with the law, alcohol/drug use problems, inappropriate sexual behaviour, dependent living, and problems with employment (Clark, Minnes, Lutke, & Ouellette-Kuntz, 2008; Streissguth et al., 2004). These secondary challenges, such as school drop out, criminality, and homelessness, are more likely to occur for any individual who is not provided with sufficient support, compassion, and understanding.

Individuals with FASD often contend with primary and secondary challenges across their lifespan, but there are surprisingly few longitudinal studies including adults with FASD (Connor & Streissguth, 1996; Connor, Sampson, Streissguth, Bookstein, & Barr, 2006; Streissguth, 2007;Streissguth et al., 2004). Primary impacts are especially problematic for adult individuals with FASD because skills such as problem solving, abstract reasoning, and functioning memory are required in any given workplace and are necessary for managing personal appointments or finances. Deficits in these areas mean that individuals with FASD may require lifelong intervention for these factors (Chudley et al., 2005; Connor et al., 2006; Connor & Streissguth, 1996; Streissguth & Kanter, 1997) and may thus never become truly self-sufficient.

Due to the lifelong challenges encountered by individuals with FASD, parents may be assisting their children with the aforementioned tasks, when children of typical development are able to complete them independently. Research shows that the majority of adults with FASD reside in their parents' household, with up to 80% living in the home of their primary caregiver (Clark et al., 2008; Streissguth & Kanter, 1997). Studies show that being raised in, or living for an extended period of time, in a stable home environment can act as one factor that reduces the risk of secondary impacts (Streissguth et al., 2004; Streissguth & Kanter, 1997). Living with a caregiver has also been found to have the maximum impact on improving the inclusion of adults with FASD into the larger community (Clark et al., 2008).

Living within the home of a caregiver as an adult is typical of a life stage called emergent adulthood, that includes individuals who are 18 to 25 years old (Arnett, 2000; Bynner, 2005). Young adults in this phase of life have a tendency to exhibit a pattern of moving in and out of their parents' home, and do not view that movement pattern as a negative reflection upon their adult status (Arnett, 2000). Emerging adults vary with regards to residential living arrangements and often have diverse experiences. For example, emerging adults may take on some responsibilities of adult living (e.g., live in their own apartment, cohabitate with a romantic partner, live away from home to attend university or college), while still maintaining a connection to others (e.g., having their parents pay their rent). Individuals in the emergent adulthood period enjoy a prolonged period of exploration, and often postpone typically adult transitions, such as marriage and having children, until their late twenties, leaving the teenage years and early twenties as a period for exploring various possible life domains. Emerging adults also typically believe there are three characteristics an individual needs to demonstrate before they can be considered a normative adult: the ability to accept responsibility, to make independent decisions, and to become financially independent (Arnett, 1997, 2000). Emerging adulthood is best described as a stage of change, where individuals are forming their identities as adults (Arnett, 2000).

The transition from emergent adulthood to adulthood for individuals with disabilities is a time of increased uncertainties and challenges (Arnett, 2000; Kim & Turnbull, 2004). There is a shift in parents' goals for their children, from a focus on education to an emphasis on employment, independent living, and social relationships (Henninger & Taylor, 2014). There is also a transfer from children's services into adult services. Parents of children with FASD face unique challenges procuring adult supports because of their children's capacity to over-represent their abilities (e.g., decision making) in comparison to other individuals with disabilities (Chudley, Kilgour, Cranston, & Edwards, 2007). Consequently, individuals with FAD may not qualify for developmental disability services or funding.

A child's transition into adulthood can also result in a change in the family's core functions with regards to the required economic support and nurturance (Patterson, 2002). A change in core family functioning is considered a crisis within family adaptation literature, and can result in significant perceived parental stress (Patterson, 1988; Watson, Coons, & Hayes, 2013). Families of adult children with FASD have spoken to challenges such as illegal behaviours, substance use, and mental health challenges (Watson, Hayes, Coons, & Radford-Paz, 2013).

To the authors' knowledge, there is no existing published research regarding the experiences of parents concerning the adulthood of their adult children with FASD. Research shows that the majority of adult individuals with FASD are residing within their parents' home, but very little is known about the needs of parents at this stage of their children's lives. Adulthood poses new and unique requirements from childhood, such as the transition into adult services. Parents who lack required adult supports fear negative outcomes for their children's futures and perceive this to be a source of stress, indicating they are struggling to adapt to the adult stage of their children's lives (James Williams et al., 2011; Michaud & Temple, 2013; Watson, Coons, et al., 2013; Watson, Hayes, et al., 2013). The purpose of the present study was to identify the experiences of adoptive parents of adult children with FASD, and to examine their needs as they are adapting to their children's transition into adulthood.

Methods

The current study employed a mixed methods research design and is part of a larger project regarding families of children with developmental disabilities (Coons, Watson, Schinke, & Yantzi, 2016; Pepper, 2016; Watson, Coons, et al., 2013; Watson, Hayes, et al., 2013). Semistructured interviews were conducted and the Questionnaire on Resources and Stress – Friedrich's Version (QRS-F) was administered (Friedrich, Greenberg, & Crnic, 1983).

Mixed Methods Research

Mixed method research designs involve the collection and integration of qualitative and quantitative data in a single research study (Creswell, 2014; Teddlie & Tashakkori, 2009). The rationale for mixed methods is that the combination of qualitative and quantitative data can provide a more valid and in-depth analysis of parents' experiences than each type of data can achieve when analyzed alone (Creswell, 2014; Guest, MacQueen, & Namey, 2012; Teddlie & Tashakkori, 2009). Data were analyzed using a convergent parallel design, whereby each type of data was analyzed separately, and then were compared and contrasted with one another (Creswell, 2014). The interviews were analyzed and the descriptive statistics for the QRS-F were calculated separately, followed by an integration of the results.

Qualitative Interviews

Semistructured interviews were conducted with adoptive parents of adult children with FASD, following a basic interpretive approach (Merriam, 2002), an inductive strategy used in an effort to understand how participants make meaning of a given situation. The interviews consisted of 22 open-ended questions, and prompts were used if deemed necessary. Example questions included "When you think about the future, what do you see?" and "In what ways have you changed and in what ways do you see yourself differently as a result of your child having FASD?" Participants were asked prompting questions when required. For example, "Can you please run me through your morning routine?" was a prompt for the question, "Please describe a typical day in your home." No close-ended questions were asked to prevent leading the participants in their answers. The interviews were conducted by the lead researcher of the present study, in addition to three other researchers who were part of the larger family project. Interviews were conducted at a time and place convenient for participants (e.g., coffee shops or family homes). Parents were interviewed separately or together, based on their preference. Follow-up questions were asked via email or telephone if questions arose during the qualitative analysis.

All interviews were audio recorded and transcribed verbatim. Researchers reviewed the transcripts several times, whilst making notes in the margins. Using Interpretative Phenomenological Analysis (IPA; Smith, Flowers, & Larkin, 2009), the transcripts were reviewed again multiple times in order to transform the notes into specific themes, or codes, which were clearly defined (Smith et al., 2009). Searching for repetition in answers is considered one of the most common methods for defining themes (Guest. MacQueen, & Namey, 2012; Ryan & Bernard, 2003). Afterwards, a search was conducted across the emergent themes to then cluster them into groups, thereby further reducing the data and providing them with additional meaning (Smith et al., 2009). The cluster of themes were then given descriptive labels derived from quotations from the interviews to promote theme validity (Guest et al., 2012).

In addition to employing direct quotes to demonstrate themes, attempts were made to make the analytic process as transparent and valid as possible. An audit trail was maintained, including the development of the definition of themes, the exclusionary theme criteria, and quotes associated with each theme. Member checking was also conducted wherein participants were given the opportunity to provide feedback on the validity of the themes via email. Finally, interrater reliability was established through the discussion of findings with other researchers of the larger project.

Questionnaire

The QRS-F was provided to participants for completion either in person or via Canada Post (Friedrich et al., 1983). The QRS-F measures aspects of perceived stress as experienced by families with a child with a disability. The QRS-F has been used with parents of children with a variety of developmental disabilities, including parents of adult children (e.g., Ben-Zur, Duvdevany, & Lury, 2005; Honey, Hastings, & McConachie, 2005). Previous research has demonstrated internal consistency and reliability, with a reliability coefficient of 0.95 (Honey et al., 2005; Vijesh & Sukumaran, 2007). The QRS-F contains 52 items assessing four areas of stress related to: parent and family problems, parental pessimism about their child's future, child characteristics, and the physical incapacity of the child. The answers are provided in a true or false format. Higher scores indicate higher levels of perceived stress and lower scores vice versa. A score ranging from 0–17 indicates a mild level of perceived parental stress, a score of 18–34 indicates a moderate level, and a score of 35–52 indicates a severe level of stress (Ben-Zur et al., 2005; Friedrich et al., 1983). An example item is, "The family does as many things together now as we ever did."

Due to the exploratory nature and small sample size of the present study described below, descriptive statistics, such as percentages, were calculated. The questionnaire data were analyzed separately from the interviews after the IPA was completed to minimize any researcher bias during interview analysis. The quantitative data are presented in an embedded format within the qualitative data as its function is to provide additional theme evidence (Creswell, 2014). For example, a theme is triangulated with a corresponding questionnaire item as further support.

Participants

Twenty parents participated in the study, representing 12 adoptive families. In order to participate, parents had to have at least one adopted child with FASD, who had reached the legal age of adulthood (i.e., 18 years) and the adoption of the child had to occur before adulthood. Adult adoptees ranged in age from 19 to 37, with a mean age of 27.35. Adoptive parents were recruited through FASD organizations located across Ontario, Canada. Emails were sent to 28 agencies, who then asked participants to contact the lead researcher if they wished to participate in the study. Respondent driven sampling was also used, in which the researchers contacted known individuals for assistance in accessing families interested in participating in the study (Salganik & Heckathorn, 2004). Parents ranged in age from 52 to 73, with a mean age of 61.19. The data were gathered as part of a larger family project, but for the purpose of this study, only the data pertaining to the parents of adopted children in the young adult age were examined. (See Table 1 for a summary of additional participant demographics.)

Table 1. Participant Demographics

Parent Characteristic	*n*	%
Gender		
Male	5	35
Female	15	75
Current Marital Status		
Married	16	80
Divorced	2	10
Single	2	10
Family Type		
Adoptive Mother	15	75
Adoptive Father	4	20
Step Father	1	5
Number of Children with FASD		
1	17	85
2	3	15

Results

All parents identified stressors that acted as barriers to planning for the future for both the child and their parents. The transition of a child into adulthood can create a crisis within the family system and there are only limited resources available to provide support (e.g., housing) in Ontario. Through the use of IPA, three major themes emerged from the interviews (Smith et al., 2009). These themes included the transition of the child into adult housing, children's inabilities to manage finances, and difficulties associated with individual characteristics (e.g., risky behaviours). Each of the themes is presented in detail, with integrated quantitative and qualitative supporting evidence. The questionnaire data were confirmatory of each theme. Pseudonyms are used to protect the identity of participants.

Parents reported on the QRS-F that they were, on average, experiencing moderate levels of total perceived stress (*M* = 24.6, *SD* = 9.5). Parents' total stress scores ranged from 10 (mild) to 36 (severe). Unfortunately, only 12 parents' scores were calculated as eight of the questionnaires were missing responses for several items. The questionnaires identified that parents were experiencing stress, and the interviews provided insight as to why or why not parents felt they were stressed. The following themes are examples of issues associated with parents' elevated levels of perceived stress.

Housing and Transition Into Adult Housing

All parents reported a strong desire to acquire or maintain a stable living environment for their child. Two subthemes emerged. Parents expressed that the problem of a lack in appropriate housing services is compounded by their children's unwillingness to change their living situation or daily routines. The adult children maintained a heavy reliance upon their parents and were unwilling to make modifications.

"Cause he's gonna stay here, he's not leaving": Difficulty managing change. Parents discussed a propensity for their children to believe that their home life will remain the same, and that their parents will always be there to support them. Change of any kind was reported by parents to be perceived as a great source of anxiety for their children. Melissa, who has a 37-year-old son with FASD, discussed her son's lifelong aversion to change: "Even when he was a kid, a change of clothes, a change of driving route in the car, any change has been really difficult for him." This distaste for change can be problematic for adult children who desire independence, but are too fearful to leave the home. Gabrielle, mother of an adopted daughter thought to have FASD, explained that, "It was like she couldn't let go of me. But she didn't want to be home and abide by the rules." The struggle of adult children to maintain an independent lifestyle and make their own rules whilst living dependently was reported to be a source of frustration for everyone involved. Sharon, a mother of two boys with FASD, described her 19-year-old son's capacity to follow household rules: "It's like he's always a child but he doesn't want to be a child. It's like we're stuck." However, not all children with FASD remained in the home permanently.

In the event that the adult children had the capacity to make the foray into a life independent from their parents, they rarely remained there permanently. The adult children often returned to the home as a sort of safety net. Parents reported a pattern of child movement in and out of the home and/or frequently changing housing situations. They described their child's living situation as a "revolving door." Adoptive parents Bailey and Trevor described their adult son's attempts to leave the home: "The stress was unbelievable. No, he didn't wanna come home. As far as he was concerned he was doing fine. And then he was back. And then he went out. And then he was back."

Parents reported that the indecisive nature of their children's lives was a great source of anxiety and stress for them. All parents reported having "no idea" what their children's futures will hold. Beverly and Drew commented that they will "always be worried" about their son. A sense of apprehension about the future was also reflected in results from the QRS-F, where 100% of respondents responded *true* to the item, "I often worry about what will happen to ____ when I no longer can take care of him/her." Parents reported attempting to assuage their worry by assisting their child in the search for housing and/or other services.

Parents' efforts to assist with their child's transition out of the home (e.g., providing an alternative living situation or enforcing follow-through for a job) were often thwarted by their children, as parents no longer held legal power over them. Parents lose legal guardianship when their child turns 18, which is a fact that many adult children took advantage of for the improvement of their personal freedom. For example, parents lost their ability to enforce rules. The children were reported to be aware of their newfound rights as adults, and were resistant to upholding household rules or chores. For example, Stacey and Ivan described a typical interaction with their son regarding rules to be followed in the home: "He always tells us he's legal now, he can do whatever he wants." Although tension between growing children and their parents is a normative experience, it became clear to parents that their children needed to move on to their own homes. Parents reported not knowing where to send their children to live, even if their adult child was willing to move.

"He's too good for this, but not bad enough for that… He shouldn't be living there": Lack of appropriate housing services. Parents discussed how the lack of appropriate housing left their adult children with few residence choices available to them. Sharon, an adoptive mother, asked, "Is it better that your kid's in jail or out on the street?" Parents expressed a need for more support for their child than standard subsidized housing. Joseph discussed his daughter's disappointing use of government funded housing, stating that it "gave her cheap rent" but that "it doesn't give her support."

Parents referred to the requirement of a structured living environment that can foster independence, while simultaneously ensuring that their children are supported (i.e., direct supervision). Emerging adults with FASD required someone to say, "these are the things you are going to do today." Parents reported that their children required special help with specific responsibilities, such as taking medication, personal hygiene, maintaining an appropriate diet, and reminders to complete tasks (e.g., go to work). Ivan described what he felt would be the perfect living experience for his children:

> A built-in community housing project or whatever that totally understands the problem, lets the kid be independent as an adult, gives them some rules and responsibilities, but yet is there saying "uh-uh, shower day is today," or "you're not going out the door till you've brushed your teeth."

Six families (50%) reported that they were able to procure housing outside the home for their children, paid for, at least in part, through the Ontario Disability Support Program (ODSP). Five families reported having children living in apartments, and one in residence; however, their children did not achieve full independence in their new environments and often looked to home for additional support. For example, Stephanie and Chad reported having their adopted son live at their home on the weekends. Parents described helping individuals who lived outside the home with finances, as well as finding and/or maintaining their jobs (see subsequent sections). Furthermore, parents stated that housing of any kind can be exceedingly expensive, and those who did not qualify for social services (e.g., ODSP) required extra financial support.

Managing Money/Finances

Parents described a heavy cost associated with procuring services (e.g., housing) for their children. The high cost can be mitigated through Ontario financial assistance programs like ODSP, but only if the adult children manage to qualify. In the event that their emerging adult children did attain financial assistance, parents reported that their children were often not able to effectively manage those resources, as they struggled with budgeting and financial planning. Additionally parents recounted how acceptance of financial aid, although monetarily helpful, can reduce their children's motivation to adhere to a structured lifestyle (e.g., obtain and maintain meaningful employment).

"There was always a reason why she wasn't eligible": Difficulty accessing adult services. It can be difficult for adult children to meet the qualifying criteria for funding programs, such as ODSP, because the features of their FASD may not present as severe enough for program acceptance. Often children with FASD were considered to have IQs that were too high to qualify for developmental disability services. This experience is supported in the literature, as Streissguth (1992) reported that only 16% of her sample of 473 individuals with FASD had a low enough IQ to be diagnosed with an intellectual disability. There is a great variability in IQ scores for individuals with FASD and no one specific pattern of deficits exists; individuals with FASD often have average to above average IQs (Jacobson & Jacobson, 2002; Kodituwakku, 2009; Streissguth, Barr, Kogan, & Bookstein, 1997). Stefanie recalls being turned down for a funding opportunity because her son "was one [IQ] point above" the cut off for the qualifying level of IQ. Ivan encountered the same issue when applying for services and described why his son is "not dumb enough" because "his IQ's too high so you can't [access services]." The aforementioned children all had a formal diagnosis on the FASD continuum, and it can be even more difficult for those who do not have a formal diagnosis.

IQ criteria notwithstanding, a formal diagnosis of FASD is also often required to obtain funding. It can be particularly difficult for adult children to receive a professionally recognized diagnosis of FASD because of issues such as missing biological family information (i.e., to confirm prenatal exposure to alcohol), which places them at a further disadvantage for services. Chad described his experience with one doctor who said his son, "doesn't look FAS and unless you can get a history we can't [diagnose]." Jocelyn also noted the difficulty of attaining a diagnosis for older individuals stating that "these older ones are just hanging around without any formal diagnosis, it's hard for them to get help." Jocelyn further discussed how services, like ODSP, are becoming increasingly reliant upon diagnosis for service qualification. Upon an eventual professionally recognized diagnosis, Chad almost immediately received a "pension" for his son; however, even after the qualification of services was granted, parents reported that it was a lengthy process to actually acquire the services. Julie described her experience with the availability of services for adults with disabilities in Ontario, stating that "services kind of dry up for children in that 16 and above. Certainly 18 and above."

Parents also reported that the few existing services available, such as respite care, were overburdened with too many individuals looking for help, resulting in extensive waiting lists. Mandy recalled being told that her desired housing service was chronically full. She explained that "we're on the list but we're not making our way up the list." The few available services were also expensive. Julie recounted how fortunate she was to have a good income and noted that the supports she was able to find were "not available to people without lots of money." In addition to parents' struggles with financial strain, their adult children experienced difficulties with procuring and managing their finances independently.

"If you gave the kid $100, it would be gone": Adult child difficulty procuring and managing finances. Parents of adult children who had obtained financial aid like ODSP referred to it as "a double-edged sword" because any income adult children made while working was deducted from their automatic income. It was more cost effective for their children to subsist on ODSP alone than to work through initiatives like Ontario Works. Stacey discussed how ODSP created a "catch-22" for her twenty-two-year-old adopted son:

> If he does get a part time job, that's partially deducted from his ODSP, which is reasonable but what's the incentive of him getting up and going out to do anything? On the other hand, if he wasn't getting ODSP, we have to be financially responsible for him. Whether or not he'd actually go out and look for work, we don't know.

Parents also reported that not only are their children not motivated to work for additional money, but they also have a propensity to spend any money they have access too. Emerging adults had difficulty planning ahead and sticking to a budget. Parents described their children's notions about budgeting, and how those strategies were hastily abandoned when they were granted access to money. For example, Kaylee described how her son always had "wonderful plans" for the use of his money but that "the first thing he and his roommate do is go out and buy beer." An inclination for excessive expenditure is problematic for children who are limited financially, and who were considered by parents Beverly and Drew to be classified as the "working poor." All parents agreed that their children needed additional aid managing finances at least one point in their lives.

In times of financial need, parents reported stepping in to financially assist their children. Parents reported that although they had enough funds to support their own necessities, they worried on behalf of their children. According to the QRS-F, 80% of participants reported that they almost always had an adequate amount of money to support their family. Parents also reported that although their immediate needs were met, the additional financial burden of supporting their child has, at least at one point in time, caused them to forgo "extra activities." Fifty two percent of parents reported that "other members of the family have had to go without things because of ____."

Parents reported attempting to intercede to help their children with financial tasks such as putting money away to save, paying the bills, or keeping track of bank accounts. For example, Stephanie described her process of ensuring her son's rent is paid and "letting so much money in his account to use." She did not believe he would ever pay rent on his own. Parental financial intervention can be difficult if the child resists, as parents do not have legal control over their adult children (see subtheme *Difficulty Managing Change*). Parents also described the tendency of their children to give money to others amongst a host of other risky behaviours that are barriers to the maintenance of a normative adult life. The individual behaviours and characteristics of emerging adults with FASD varied; however, there were two patterns of behaviours that emerged from the interviews: risky behaviours and employment instability.

Individual Characteristics

Parents described several behavioural tendencies exhibited by their children that made it difficult to obtain or maintain employment, further contributing to their financial need. Children with FASD were reported to be easily taken advantage of by others, to have a predisposition for alcohol and drug use, and to have had involvement with the criminal justice system. The aforementioned adult child behaviours, in addition to features inherent to FASD (e.g., difficulty sustaining attention), further promote job instability.

"The level of risks they take are huge": Risky behaviours. Parents described how their children were easily led astray by antisocial individuals. Specifically, they were described as prone to giving away their money or to following others in engaging in criminal activity. Parents described their children as potentially being the perfect gang members or how they could easily get into trouble with the law because of their compliant behaviours, particularly when money was involved. Trevor described his son's relationships with others: "It never clued in to him that the only time he really had friends, close friends, was when he had a pocket full of money." Beverly and Drew reported that their son has "always been influenced by other people to a greater extent than we felt was healthy." John also described his son as "mixing with the wrong crowds."

Furthermore, parents reported that their children's desires to fit in and follow others were chronic. Emily, an adoptive mother, described her daughter "getting hurt over and over again and [she] just doesn't get it." The propensity to be easily led by others can lead to engagement in criminal activity. For example, Peter described his son's behaviours while living on the street: "He will go and put himself in extreme[ly] dependent situations, very exploitive situations. When he's living on the street with…people who exploit him for selling drugs."

In addition to the risk of criminal activity, parents also reported alcohol use, running away, a risk of self-harm, and psychological disorders. Stefanie described one instance in which the police were searching for her missing son: "He would have a knife and rope with him and you never knew whether his intention was to outwit them or do harm to himself." Several parents also explained how their children struggled with comorbid mental health disorders. Emily described her daughter's diagnoses as "starting to look like alphabet soup" because of the high number of formal diagnoses her daughter had received. Her daughter was diagnosed with a list of psychological disorders, including borderline personality disorder, which required additional mental health support.

In order to deal with their children's risky behaviours and mental health disorders, some parents were successful in finding support services. Daphnie described having success with a residential program designed to address addiction, mental health issues, and self-harm behaviours stating that "it's the first time in five or six years that she's stable." Several parents reported that their children were attending, or had been attending, rehabilitation facilities for alcohol abuse. The ability of the adult children to cope with the aforementioned addiction and mental health issues have implications for their futures. Risky behaviours, including behaviours unrelated to mental health and addiction, not only resulted in jail time, but also made it difficult for emerging adults to maintain employment, a milestone essential for the transition to adulthood.

"She seems to be able to find jobs. She has trouble holding on to them": Difficulty maintaining employment. The majority of parents reported a pattern of sporadic child employment. The children often had multiple jobs in one year. Jocelyn recounted how her daughter had 18 jobs between the age of 18 and 24. Parents described how their children were always enthusiastic about a newly acquired work position, but soon discovered that they were "in over their heads." Gabrielle described the emergent work cycle: "They're so anxious to please and so anxious they have this new job, they're going to do so well. But with every passing day the expectations are more and more and then they realize they can't do it."

The children were then typically "let go" from their respective jobs due to absences, miscommunications, a lack of focus, and/or a lack of skill. Parents reported that their children viewed their jobs as temporary, but did not have the skills to do anything else. Lacking the appropriate skill set was very disheartening for the emerging adult child with FASD. Daphnie described her daughter's intense disappointment in her shortcomings at her job, and how she thinks "she can't do it [be]cause she's too stupid."

Parents discussed how their children's primary challenges, and in particular memory deficits, were responsible for their children's mistakes on the job. According to the QRS-F, 76% of parents responded that their child "can't pay attention for very long." There were reports of adult children forgetting shifts because of their difficulty sustaining attention and difficulties with memory. Jocelyn explained that "there are other factors in FASD, behavioural factors, which render a lot of people affected unable to keep their work." To compensate for their children's deficits, parents often had to personally drive or ensure that their child got to work to confirm a greater likelihood of job success.

Although parents exerted considerable effort to ensure their children maintained their employment, they described a need for their children to have a job to do outside of the home to promote general self-esteem and to provide them with something to be proud of. Even small jobs for an hour or two were said to be helpful. Results from the QRS-F showed that 60% of parents thought that their child with FASD "has too much time on his/her hands." A structured work position was requested by parents to occupy some of that time and to give them a purpose in life.

However, even when their adult children with FASD addressed interest in obtaining employment, many parents emphasized that employers were not willing to train or supervise them, and noted that employers often told parents that dealing with their children at work was more like "babysitting than employment." As Stacey described:

> We've had one person after he was fired who just said to me "I'm not gonna babysit someone." So there has to be some way that you can actually find work for these people and find out who are the employers who will do that.

Parents also expressed their wish for someone who could help their child locate a job, even if it was just a part-time job, to help them understand what working life is like.

In summary, parents were experiencing three major areas that were acting as barriers to their children transitioning to a normative adult life (e.g., independent, financially stable). Parents described a lack of housing for their children as adults and discussed their children's resistance to the changes required to move into adulthood (e.g., moving or finding a job). Additionally, parents described the problem of too few and often overburdened adult services, as well as their children's financial strain. Finally, parents reported their child's risky behaviour, which in part led to difficulties maintaining employment, caused further financial strain.

Discussion

This mixed methods study integrated interview and questionnaire evidence focusing on issues facing adoptive parents and their children's transition into adulthood. To the authors' knowledge, this is the first study regarding the experiences of parents concerning their grown adoptive children who have FASD. The demands on adoptive parents are extensive in the areas of adult living, financial management, and challenging behaviour.

It appears that the adopted adult children with FASD were encountering demands consistent with those encountered by the general adult FASD population (e.g., birth families). For example, the majority of parents reported that their children were living within the family's home for at least one period of time during adulthood (i.e., dependent living), which is consistent with studies citing that 69 to 80% of individuals with FASD continue to live within their parents' home (Clark et al., 2008; Streissguth & Kanter, 1997). The tendency for adult children to remain in the home as a result of their inability to transition into adulthood is also consistent with the literature on emergent adulthood (Arnett, 2000). Research on emerging adulthood in normative populations indicates that although independent living is associated with adulthood, continued co-residence with parents during emerging adulthood slows down the process by which an individual moves towards becoming a self-sufficient and independent person (Kins & Beyers, 2010), a requirement for adulthood (Arnett, 2000). However, because of the primary and secondary challenges associated with FASD, individuals with FASD appear to not be able to progress past the emerging adulthood stage or become fully self-sufficient, and instead require support to be interdependent, as opposed to fully independent, in society. They are thus unable to fully transition to adulthood, as it is normatively conceived.

Additionally, parents reported a pattern of job instability, which is also consistent with previous research pertaining to adults with FASD, citing that 80% of individuals with FASD have problems with employment (Clark et al., 2008; Streissguth et al., 2004). For participants in the present study, jobs were often lost due to poor choices (e.g., not attending work on time). Parents indicated how a lack of job stability acted as a barrier to their children's financial independence. Parents also reported that job loss was often due to poor decision making. These issues reflect the literature on secondary impacts in individuals with FASD in general, and are not necessarily specific to individuals who have been adopted (Bertrand, 2009; Michaud & Temple, 2013).

It appears that children with FASD were also unable to move out of the emergent adulthood life stage into adulthood. The children were struggling with financial independence, as well as making independent and responsible decisions, all of which are essential to adulthood (Arnett, 2000). Furthermore, they were continuing their pattern of sporadically living within their parents' homes, or never leaving the home at all, well past the age of 25 (i.e., the end of emergent adulthood). Fifty percent of participants' children were over the age of 25, but they still exhibited behaviours consistent with emergent adulthood. Parents reported attempting to step in and assist their children with their transition into adulthood, which was described as a source of perceived parental stress.

Parents described the transition into adulthood as a process of new, and sometimes overwhelming, demands. To ensure a successful transition, there are resources that need to be bolstered, such as semi-independent housing and access to adult services. Parents hoped that there would be resources in place to help their children live in a safe, supported housing environment. Adults with FASD require tremendous support to be part of their community; however, most have few supports other than family members or friends (Clark et al., 2008). Not surprisingly, adults with FASD who have a history of addictions, sexually inappropriate behaviour, and confinement in prison or a psychiatric hospital often have difficulty with community integration (Clark et al., 2008). With appropriate supports throughout the lifespan, and during the transition to adulthood, individuals with FASD may be able to avoid the development of these adverse life outcomes, including dependent living arrangements.

The area of greatest concern for parents was the lack of resources pertaining to living arrangements. Research indicates that maintaining one place of residence for more than an average of 2.8 years can act as a protective factor against secondary risks, including incarceration (Streissguth et al., 2004). Providing adult children with structured and stable living environments outside the home, where they can remain semi-independent, would remove them from environments where they could be victimized or get in trouble with the law. Providing semi-independent housing would also relieve parents of the strain of worrying about the safety of their children, and the stressors related to their children constantly moving into and out of their home.

Another area of parental concern was qualification for assistance like ODSP. There are support services available to adults with developmental disabilities, including FASD, in Ontario. Services like Ontario Works help individuals who are in financial need acquire a working position (Ontario Ministry of Community and Social Services, 2012). Additionally, individuals may apply to ODSP for financial assistance for basic needs, and to apply for medical benefits (Ontario Ministry of Community and Social Services, 2015). However, to gain access to ODSP, an applicant must first qualify as an individual with a disability and, as noted above, many individuals with FASD in this study struggled to quality for such programs because of elevated IQs or a lack of a formal FASD diagnosis. Application can be more difficult for those who have an "invisible" disability that does not have a physical identifier, such as FASD. Individuals who do not exhibit facial features considered characteristic of FASD may therefore appear as if they are simply making bad decisions, rather than being affected in some way by their disability (i.e., there is a discrepancy between their capabilities and environmental demands), making it even more difficult to qualify for services (Chudley et al., 2005; Michaud & Temple, 2013). Other than formal services, such as ODSP, individuals with FASD rely on informal supports like their parents (Clark et al., 2008), thus preventing a full transition to adulthood.

Because of the difficulties associated with qualifying for services, parents reported feeling stressed about their children's ability to manage their personal finances independently. Parents worried about their children's source of income, and what they would do with the money once they had it. One method to improve their children's financial status is to streamline the application process and to create guidelines for qualifications specific to FASD. Creating an application process that is more easily navigated would help adult children gain access to financial funding, taking the burden off of parents. Parents reported that their children's disabilities are not viewed as "severe enough" to warrant service access, regardless of their difficulties holding employment. One parent called for the education of service providers on the characteristics of adults with FASD to further avoid confusion about service qualification. Parents also discussed a need for someone to manage the money of those children who did qualify for services, in order to conserve the money they received.

According to the QRS-F, parents were experiencing moderate levels of perceived stress, and were generally lacking in the access to and utilization of resources. These findings were supported and developed further in the interviews. The moderate discrepancy between parents' demands and resources suggests they are adjusting to their children's transition into adulthood, but clearly parents require additional aid to facilitate the transition to adulthood and consequently lower their stress levels.

Considerations and Future Directions

The use of mixed methods is a strength of this study. The use of interviews and questionnaires helped to capture what families were experiencing when attempting to adapt to their child's transition into adulthood. Mixed methods research ensures higher trustworthiness of the data than either the questionnaires or interviews would provide alone. Member checking was particularly helpful as participants were given the opportunity to respond to the findings, and inform the researchers of any missing information, opposing viewpoints, or unique differences in each family's constructed meanings. Participant feedback was positive and confirmed the themes. Interrater reliability was also established through standardized interview training and discussion of themes with other researchers involved in the larger project. These methods strengthen the credibility of the themes presented here.

Although the methods were rigorous, there were also several limitations to the study. First, there was the heavy reliance on FASD services for participant recruitment (i.e., through FASD support groups). Individuals who do not make use of support services may or may not be at different stages in terms of family adaptation or the transition to adulthood. Accessing parents of children with FASD who are not using online or in-person groups would have eliminated some potential participant biases. However, the observation that not all parent participants had adapted to the transition to adulthood of their children with FASD, even when accessing formal supports, lends credibility to the findings and may point to challenges that are generalizable to other families raising children with FASD who may or may not be accessing formal assistance.

The second limitation was the lack of information on the QRS-F for eight participants. All participants completed the questionnaires, but for eight of them there was at least one item missing, rendering the researchers unable to calculate those participants' total scores. Although there were total scores for more than half of the participants, it may be that the missing participants would have yielded different results. Participants may have forgotten to answer, or they may have chosen not to answer the missing items. Some questions may have been left blank because they were inapplicable (e.g., questions regarding vacation). However, it was possible for researchers to examine individual items on the QRS-F, as all participants completed most of the questions. Examining individual items on the QRS-F was useful as they pertained to, and supported, the interview themes.

This study also provides direction for future research. Further research examining the experiences of adult adoptees themselves would be beneficial in order to address what supports they feel they need to move into adulthood. The interviews in this study were conducted with parents, and they may be unaware of their children's activities outside of their home. Including both parents' and their children's viewpoints would also allow for further data triangulation, providing a more complete picture of each family's experiences (Guest et al., 2012). The adult children could give a more subjective account of their struggle with personal issues, such as mental health, risky behaviours, and their difficulties with change, allowing for specific information about the supports individuals with FASD require.

Furthermore, future research should also be extended to birth families of children with FASD, whose experience of the adult transition may be different. In adulthood, there are no adoption-specific resources and therefore birth families are likely encountering similar needs as adoptive parents and their children. However, birth families may differ from adoptive families in that birth parents may have FASD or mental health issues themselves and therefore require even more supports than adoptive parents who do not have FASD (Denys, Rasmussen, & Henneveld, 2011). It is possible that birth parents who have FASD may themselves be struggling to adapt to adulthood. In that case, both the birth parents and their adult children would be in need of adult services.

Conclusion

This study has shown that there are particular challenges for parents who wish to assist their children as they grow older and transition from emergent adulthood into full-fledged adulthood. In the interviews, parents requested adequate and appropriate housing, in addition to work initiatives for their adult children with FASD. Providing parents with those services will help balance the demands and capabilities related to their child's transition into adulthood. Parents can act as protective factors for their children's secondary challenges and require appropriate support to continue helping their adult children move forward from adolescence to adulthood.

Key Messages From This Article

People with disabilities. You deserve the tools you need to help you start your life and live as an adult.

Professionals. Assisting parents with finding resources (e.g., housing) for their children with FASD would help manage the demands they face as their children transition into adulthood.

Policymakers. Resources such as housing and work initiatives are essential for the transition into normative adulthood for children with FASD.

References

Arnett, J. J. (1997). Young people's conceptions of the transition to adulthood. *Youth & Society, 29*(1), 3–23. doi:10.1177/0044118X97029001001

Arnett, J. (2000). Emerging adulthood. A theory of development from the late teens through the twenties. *The American Psychologist*, *55*(5), 469–480. Retrieved from http://doi.org/10.1037/0003-066X.55.5.469

Ben-Zur, H., Duvdevany, I., & Lury, L. (2005). Associations of social support and hardiness with mental health among mothers of adult children with intellectual disability. *Journal of Intellectual Disability Research*, *49*(1), 54–62. Retrieved from http://doi.org/10.1111/j.1365-2788.2005.00662.x

Bertrand, J. (2009). Interventions for children with fetal alcohol spectrum disorders (FASDs): Overview of findings for five innovative research projects. *Research in Developmental Disabilities*, *30*(5), 986–1006. Retrieved from http://doi.org/10.1016/j.ridd.2009.02.003

Bynner, J. (2005). Rethinking the youth phase of the life-course: The case for emerging adulthood? *Journal of Youth Studies*, *8*(4), 367–384. Retrieved from http://doi.org/10.1080/13676260500431628

Canada FASD Research Network. (2015). Prevalence. Retrieved from http://www.canfasd.ca/research-teams/prevalence/

Chudley, A., Conry, J., Cook, J. L., Loock, C., Rosales, T., & LeBlanc, N. (2005). Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. *Canadian Medical Association Journal*, *172*(5 Suppl), S1–S21. Retrieved from http://doi.org/10.1503/cmaj.1040302

Chudley, A., Kilgour, A., Cranston, M., & Edwards, M. (2007). Challenges of diagnosis in fetal alcohol syndrome and fetal alcohol spectrum disorder in the adult. *American Journal of Medical Genetics. Part C, Seminars in Medical Genetics*, *145C*(1), 261–272. Retrieved from http://doi.org/10.1002/ajmg.c

Clark, E., Minnes, P., Lutke, J., & Ouellette-Kuntz, H. (2008). Caregiver perceptions of the community integration of adults with foetal alcohol spectrum disorder in British Columbia. *Journal of Applied Research in Intellectual Disabilities*, *21*(5), 446–456. Retrieved from http://doi.org/10.1111/j.1468-3148.2007.00414.x

Connor, P., Sampson, P., Streissguth, A., Bookstein, F., & Barr, H. (2006). Effects of prenatal alcohol exposure on fine motor coordination and balance: A study of two adult samples. *Neuropsychologia*, *44*(5), 744–751. Retrieved from http://doi.org/10.1016/j.neuropsychologia.2005.07.016

Connor, P., & Streissguth, A. (1996). Effects of prenatal exposure to alcohol across the life span. *Alcohol Health & Research World*, *20*(3), 170. Retrieved from http://doi.org/Article

Cook, J. L., Green, C. R., Lilley, C. M., Anderson, S. M., Baldwin, M. E., Chudley, A. E., … Canada Fetal Alcohol Spectrum Disorder Research Network (2016). Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan. *Canadian Medical Association Journal*, *188*(3), 191–197. doi:10.1503/cmaj.141593

Coons, K. D.,Watson, S. L., Schinke, R. J., & Yantzi, N. M. (2016). Adaptation in Families Raising Children with Fetal Alcohol Spectrum Disorder. Part I: What Has Helped. *Journal of Intellectual & Developmental Disability*, *41*(2), 150–165. Retrieved from http://doi.org/10.3109/13668250.2016.1156659

Creswell, J. (2014). *Research design* (4th ed.). Thousand Oaks, CA: Sage Publications Inc.

Denys, K., Rasmussen, C., & Henneveld, D. (2011). The effectiveness of a community-based intervention for parents with FASD. *Community Mental Health Journal*, *47*(2), 209–219. Retrieved from http://doi.org/10.1007/s10597-009-9273-9

Friedrich, W., Greenberg, M., & Crnic, K. (1983). A short form of the questionnaire on resources and stress. *American Journal of Mental Deficiency*, *88*, 41–8.

Guest, G., MacQueen, K., & Namey, E. (2012). *Applied thematic analysis*. Thousand Oaks, CA: Sage Publications Inc.

Henninger, N. a, & Taylor, J. L. (2014). Family perspectives on a successful transition to adulthood for individuals with disabilities. *Intellectual and Developmental Disabilities*, *52*(2), 98–111. Retrieved from http://doi.org/10.1352/1934-9556-52.2.98

Honey, E., Hastings, R. P., & McConachie, H. (2005). Use of the questionnaire on resources and stress (QRS-F) with parents of young children with autism. *Autism: The International Journal of Research and Practice*, *9*(3), 246–255. Retrieved from http://doi.org/10.1177/1362361305053256

Jacobson, J. L., & Jacobson, S. W. (2002). Effects of prenatal alcohol exposure on child development. *Alcohol Research and Health*, *26*(4), 282–286.

James Williams, S., Dubovsky, D., & Merritt, J. (2011). Legal and psychological implications of nondisclosure in the adoption of a child with fetal alcohol spectrum disorder. *Journal of Psychiatry and Law*, *39*(1), 193–215. Retrieved from http://doi.org/910378054

Kim, K.-H., & Turnbull, A. (2004). Transition to adulthood for students with severe intellectual disabilities: Shifting toward person-family interdependent planning. *Research and Practice for Persons with Severe Disabilities (RPSD)*, *29*(1), 53–57.

Kins, E., & Beyers, W. (2010). Failure to launch, failure to achieve criteria for adulthood? *Journal of Adolescent Research*, *25*(5), 743–777.

Kodituwakku, P. W., & Kodituwakku, E. L. (2011). From research to practice: An integrative framework for the development of interventions for children with fetal alcohol spectrum disorders. *Neuropsychology Review, 21*, 204–223.

Malbin, D., Boulding, D., & Brooks, S. (2010). Trying differently: Rethinking juvenile justice using a neuro-behavioral model. *ABA Criminal Justice Section: Juvenile Justice Committee Newsletter*, *5*, 1–14.

Merriam, S. (2002). *Qualitative research in practice: examples for discussion and analysis*. San Francisco, CA: John Wiley & Sons Inc.

Michaud, D., & Temple, V. (2013). The complexities of caring for individuals with fetal alcohol spectrum disorder: The perspective of mothers. *Journal on Developmental Disabilities*, *19*(3), 94–101.

Ontario Association of Children's Aid Societies. (n.d.). Adoption. Retrieved from http://www.oacas.org/childwelfare/adopt.htm

Ontario Ministry of Community and Social Services. (2012). Ontario works: Who can receive Ontario works. Retrieved from http://www.mcss.gov.on.ca/en/mcss/programs/social/ow/eligibility.aspx

Ontario Ministry of Community and Social Services. (2015). Ontario disability and support program. Retrieved from http://www.mcss.gov.on.ca/en/mcss/programs/social/odsp/

Patterson, J. (1988). Families experiencing stress: I. the Family Adjustment and Adaptation Response Model: II. applying the FAAR model to health-related issues for intervention and research. *Family Systems Medicine*, *6*(2), 202–237. Retrieved from http://doi.org/http://dx.doi.org.librweb.laurentian.ca/10.1037/h0089739

Patterson, J. (2002). Understanding family resilience. *Journal of Clinical Psychology*, *58*(3), 233–246. Retrieved from http://doi.org/10.1002/jclp.10026

Pepper, J. M. (2016). *Families raising children with FASD and autism in Ontario* (Master's thesis, Laurentian University, Sudbury, Canada). Retrieved from https://zone.biblio.laurentian.ca/bitstream/10219/2576/1/Jenna%20Pepper%20Final%20Thesis.pdf

Popova, S., Lange, S., Burd, L., & Rehm, J. (2014). Canadian children and youth in care: The cost of fetal alcohol spectrum disorder. *Child & Youth Care Forum*, *43*(1), 83–96. Retrieved from http://doi.org/10.1007/s10566-013-9226-x

Ryan, G., & Bernard, H. (2003). Techniques to identify themes. *Field Methods*, *15*, 85–109. Retrieved from http://doi.org/10.1177/1525822X02239569

Salganik, M. J., & Heckathorn, D. D. (2004). Sampling and estimation in hidden populations using respondent-driven sampling. *Sociological Methodology*, *34*(1), 193–240. Retrieved from http://doi.org/10.1111/j.0081-1750.2004.00152.x

Smith, J., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method, and research*. Thousand Oaks, CA: Sage Publications Inc.

Streissguth, A. P. (1992). Fetal alcohol syndrome: Early and long-term consequences. *National Institute on Drug Abuse Research Monograph, 119*, 126–130.

Streissguth, A. (2007). Offspring effects of prenatal alcohol exposure from birth to 25 years: The Seattle prospective longitudinal study. *Journal of Clinical Psychology in Medical Settings*, *14*(2), 81–101. Retrieved from http://doi.org/10.1007/s10880-007-9067-6

Streissguth, A., Barr, H., Kogan, J., & Bookstein, F. (1997). Primary and secondary disabilities in fetal alcohol syndrome. In A. Streissguth & J. Kanter (Eds.), *The challenge of fetal alcohol syndrome: Overcoming secondary disabilities* (pp. 25–39). Seattle, WA: University of Washington Press.

Streissguth, A., Bookstein, F., Barr, H., Sampson, P., O'Malley, K., & Young, J. (2004). Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Journal of Developmental and Behavioral Pediatrics: JDBP*, *25*(4), 228–38. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/15308923

Streissguth, A., & Kanter, J. (Eds.). (1997). *The challenge of fetal alcohol syndrome: Overcoming secondary disabilities*. Seattle, WA: University of Washington Press.

Teddlie, C., & Tashakkori, A. (2009). *Foundations of mixed methods research: Integrating quantitative and qualitative approaches in the social and behavioral sciences*. Thousand Oaks, CA: Sage.

Thanh, N., & Jonsson, E. (2009). Costs of fetal alcohol spectrum disorder in Alberta, Canada. *Canadian Journal of Clinical Pharmacology*, *16*(1), 80–90.

Vijesh, P. V, & Sukumaran, P. S. (2007). Stress Among Mothers of Children With Cerebral Palsy Attending Special Schools. *Asia Pacific Disability Rehabilitation Journal*, *18*(1), 76–92.

Watson, S., Coons, K., & Hayes, S. (2013). Autism spectrum disorder and fetal alcohol spectrum disorder. Part I: a comparison of parenting stress. *Journal of Intellectual & Developmental Disability*, *38*(2), 95–104. Retrieved from http://doi.org/10.3109/13668250.2013.788136

Watson, S., Hayes, S., Coons, K., & Radford-Paz, E. (2013). Autism spectrum disorder and fetal alcohol spectrum disorder. Part II: a qualitative comparison of parenting stress. *Journal of Intellectual & Developmental Disability*, *38*(2), 105–13. Retrieved from http://doi.org/10.3109/13668250.2013.788137

Journal on Developmental Disabilities
Le journal sur les handicaps du développement
JoDD
Volume 24, Number 1, 2019

State-of-the-Art Review of Transition Planning Tools for Youth With Fetal Alcohol Spectrum Disorder in Canada

Authors

Kelly D. Coons-Harding,[1,2]
Anna Azulai,[1,3]
Audrey McFarlane[1]

[1] Canada FASD Research Network, Vancouver, BC

[2] Department of Psychology, Laurentian University, Sudbury, ON

[3] School of Social Work, Faculty of Health and Community Studies, MacEwan University, Edmonton, AB

Correspondence

kelly.harding@canfasd.ca

Keywords

fetal alcohol spectrum disorder,
transition planning,
transition of care,
family needs,
state-of-the-art review

Abstract

While the nature of the formal transition to adulthood has changed over the past decade, it continues to be premised on the notion of achieving independence. Individuals with Fetal Alcohol Spectrum Disorder (FASD), however, may never reach full independence in their adult years, instead more so achieving interdependence. Consequently, their transition into adulthood may be particularly challenging because of the expectation of increased responsibilities and autonomy in many areas of life. While there is considerable interest in the area of transitional aged youth and youth leaving care, there is much less research addressing the needs of those with developmental disabilities, particularly FASD, leaving care and transitioning to adult services. It is not clear what services currently exist in Canada for transitional aged youth with FASD. Furthermore, it is also unknown to what extent existing programs enable youth with FASD to successfully transition into adulthood. Using a state-of-the-art review method, the purpose of this project was to review the literature on transition planning processes for youth with FASD from across Canada to determine the strengths and challenges of these existing transition planning tools, and to provide recommendations for the future for youth with FASD and their families.

Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term that refers to the range of physical, mental, behavioural, adaptive, and cognitive effects associated with prenatal exposure to alcohol (Cook et al., 2015; Pei, Tremblay, McNeil, Poole, & McFarlane, 2017; Warren et al., 2004). Previously, the full spectrum of alcohol-related developmental disorders included Fetal Alcohol Syndrome (FAS) with confirmed prenatal exposure, FAS without confirmed prenatal exposure, Partial FAS, Alcohol-Related Neurodevelopmental Disorder (ARND), and Alcohol-Related Birth Defects (ARBD; Warren et al., 2004). However, as the Canadian guidelines for FASD diagnosis were updated in 2015, FASD is now a diagnostic term that refers to an assortment of presentations and impairments resulting from prenatal alcohol exposure, including potential diagnoses of FASD with or without sentinel facial features and the inclusion of an at-risk category (Cook et al., 2015). Current studies suggest that up to 4% of individuals in Canada are affected by FASD (May et al., 2014; Thanh, Jonsson, Salmon, & Sebastianski, 2014). Consequently, an estimated 1,406,069 people in Canada and 171,000 residents of Alberta are impacted by FASD.

FASD is a serious social and health problem for the child welfare, health, and education systems, both in North America and worldwide (Fuchs, Burnside, Marchenski, & Mudry, 2010). As FASD are a spectrum of lifelong conditions that do not disappear with maturity (DeJoseph, 2011), individuals affected by FASD may require substantial supports across their lifespan (Milne, Moorhouse, Shikaze, & Cross-Ministry Members, 2011). Because individuals with FASD require an extensive use of formal services throughout their life course, as well as ongoing support from parents and caregivers (e.g., Pepper, Watson, & Coons-Harding, 2019; Watson, Hayes, Radford-Paz, & Coons, 2013), many individuals may be unable to achieve self-sufficiency by the age of 18 (James Williams, Dubovsky, & Merritt, 2011; Pepper et al., 2019). While the formal transition to adulthood has changed over the past decade, including the introduction of a new developmental stage referred to as emerging adulthood (Arnett, 1997, 2000), individuals with FASD may never reach full independence in their adult years.

Due to the documented inconsistency between developmental abilities of youth with FASD and their chronological age, navigating adolescent years can be particularly difficult for this group of young people (DeJoseph, 2011). According to DeJoseph (2011), unaddressed psychological, behavioural, and social problems of these individuals in adolescence could progress into more serious challenges in adulthood. However, it is well documented that adolescents with FASD struggle to access services as adults because of personal complicated histories, a range of intellectual and other disabilities, a variety of family and living situations, and varied availability of supports (Fuchs et al., 2005; 2010; Milne et al., 2011). Additionally, the adolescent period may be particularly challenging for individuals with FASD given the high rates of a variety of adverse outcomes, including mental health problems, difficulties with academic achievement, trouble with the law, inappropriate sexual behaviours, and alcohol or drug use (Clark, Minnes, Lutke, & Ouellette-Kuntz, 2008; Streissguth et al., 2004). Consequently, the transition into adulthood may be challenging for individuals with FASD because of the expectation of increased responsibilities and independence in many areas of life.

Despite awareness of the secondary risk factors associated with an FASD diagnosis, there is limited longitudinal research including adults with FASD (e.g., Connor, Sampson, Streissguth, Bookstein, & Barr, 2006; Streissguth et al., 2004). Furthermore, while there is considerable interest in the area of transitional aged youth and youth leaving care, there is much less research addressing the needs of those with developmental disabilities, particularly FASD, leaving care and transitioning to adult services (Burnside & Fuchs, 2013; Fuchs et al., 2010). It is not clear what services currently exist in Canada for transitional aged youth with FASD. Furthermore, it is also unknown to what extent existing programs may enable youth with FASD to successfully transition into adulthood.

The Government of Alberta has declared its commitment to work towards the prevention of FASD, as well as to support those affected by the FASD in the province by enhancing age-appropriate provincial service delivery system, supporting transition through life changes, and ensuring consistency in access and navigation to vital programs and supports, including transition planning (Alberta Government, 2016; Alberta Human Services, 2016). Alberta Human Services (2016) defines transition as a passage from one stage or place to another. Transition planning, therefore, is a process of preparing for the move from one phase of life to another, including youth with FASD approaching age 18 making the transition to adulthood (Alberta Human Services, 2016). This roadmap is developed together with the youth, their family, guardians, or caregivers (Alberta Government, 2016). Transition planning is designed to assist youth and families during the transition to adulthood by providing information, service referrals, and planning for the future.

The transition plan should address several critical areas. The transition plan should: reflect the youth's vision and goals for the future; focus on the proactive shift from child to adult services; identify and build upon the youth's strengths and natural support systems; promote the youth's greatest level of independence possible and their inclusion within their community; promote self-determination; identify and address the youth's and their family's individual needs during the transition period; and prepare for necessary services and supports to be in place when the youth turns 18 (Alberta Government, 2016; Carter, Brock, & Trainor, 2012; Hagner, Kurtz, May, & Cloutier, 2014; Stewart et al., 2014; Trainor, Morningstar, & Murray, 2016; Wehman et al., 2015). Although the complexities involved in the interactions between individuals and their environments during the transition to adulthood appear to be similar for different disability types (e.g., Stewart et al., 2014), the aforementioned unique and highly individualized needs of youth with FASD warrant particular attention during the transition planning process. This means there is no clear, single pathway to adult services available for these individuals; rather, in keeping with the increasing emphasis on person-directed planning, an individualized transition plan to determine what the possible pathways and directions are for youth with FASD is warranted (Alberta Government, 2016).

Although there are many written documents about transition planning and how to conduct these across different provinces in Canada (see, for example, Bunch, Finnegan, & Pearpoint, 2009; McLeod, 1999; Roebuck, Coultes-MacLeod, & First Leadership Limited, 2007; The Delta Transition Sub Committee, 2013), anecdotal knowledge indicates that very few youth with FASD have such a plan in place; moreover, research with parents and caregivers of individuals with FASD demonstrates that they often have considerable fears and concerns for their child's future (Gardner, 2000; Morrissette, 2001; Mukherjee, Wray, Commers, Hollins, & Curfs, 2013; Olson, Oti, Gelo, & Beck, 2009; Pepper et al., 2019; Salmon, 2008; Sanders & Buck, 2010; Watson et al., 2013). Parents and caregivers often accept the reality that their children will be reliant on some form of support throughout their lives, and that their roles as caregiver does not end when their children turn 18 (Olson et al., 2009; Sanders & Buck, 2010). It remains unclear which transition planning tools or processes are the most beneficial, and whether there are any barriers to the uptake of the transition planning process by youth with FASD and their families and caregivers. To that end, the purpose of this project was to review the literature on transition planning processes for youth with FASD from across Canada. Additionally, the purpose of this project was to identify and gather existing transition planning tools and written evaluations on these tools for youth with FASD, both to determine the strengths and challenges of these existing transition planning tools and to provide recommendations for the future for youth with FASD and their families as they navigate the transition process.

Methodology

This review was conducted using a state-of-the-art review method (Grant & Booth, 2009), which aims for a comprehensive search of literature to describe the current state of knowledge about a particular phenomenon. Compared to a traditional literature review, state-of-the-art reviews address more current matters compared to combined retrospective and contemporary accounts of existing bodies of knowledge (Grant & Booth, 2009; Higgins & Green, 2011). According to Grant and Booth (2009), the state-of-the-art literature review considers mainly the most current research and information on a given issue and may offer new perspectives or point out priorities for future research (i.e., transitional aged youth with FASD). In state-of-the art reviews, researchers do not conduct formal quality assessment of sources. Rather, the content is synthesized and reviewed, compared, and presented as a narrative. State-of-the-art reviews offer considerable value for individuals new to a certain area, and provide the reader with a "feel" for both the quantity and main characteristics of a particular field (Grant & Booth, 2009).

In this study, we reviewed peer-reviewed publications and grey literature sources on the transition planning process today for youth with FASD in Canada, as well as the available transition planning tools and any evaluations of these tools. Any recent literature that was relevant was included in this review. No specific inclusion or exclusion criteria were applied, as the purpose of this review was to assess the breadth of existing information on specific transition planning resources for youth with FASD in Canada. This information was critically analyzed and discussed to address similarities and differences between transition planning processes, barriers to transition planning, and unmet needs, with a view to offering recommendations for future practice. Relevant transition planning tools and resources are presented below. The information and practical suggestions from these resources were compared and contrasted with one another and analyzed to formulate specific recommendations for transition planning for youth with FASD.

Results and Discussion

The review of the current literature indicated that several Canadian provinces, particularly Alberta, Manitoba, Ontario, and British Columbia, have transition planning tools and resources that are helpful when considering the transitional needs of individuals with FASD and their families. Some provinces, such as Alberta and Ontario, have developed transition planning tools targeted specifically to youth with FASD. Other Canadian provinces, such as Manitoba and British Columbia, have general transition planning tools for youth with developmental disabilities, while others do not offer specific tools, but rather provide outlines or guides that map the transition process in local areas. In some jurisdictions, different agencies offer a combination of tools and guiding process outlines. These instruments and guides are organized by province and are briefly described below. For additional information, please refer to the Appendix in which the instruments and guides are summarized, expanding upon a comprehensive list of the transition planning instruments for youth with developmental disabilities offered by Roebuck et al. (2007).

Brief Description of the Transition Planning Tools, Guides, and Processes in Canadian Jurisdictions

Alberta

Integrated Transition Planning for Youth with Disabilities. This is a guide, developed by the Family Support for Children with Disabilities (FSCD) program by the Alberta Human Services ([AHS], 2016; Alberta Government, 2016). This guide is not specific to the youth with FASD but to the youth with developmental disabilities. The FSCD program is designed to assist youth and families during the transition to adulthood by providing information (e.g., how to take action for their youth prior to the age of 18, ensuring that youth and their families are aware of the adult supports and services available), appropriate service referrals, and formal planning (e.g., what supports and services will be necessary; determining individual goals for the future; thinking about what might change after a youth with FASD is legally able to make their own decisions; AHS, 2016). This guide is an AHS coordinated access to programs and services conducted through the joint forces of FSCD, Persons with Developmental Disabilities, Assured Income for the Severely Handicapped, Office of the Public Guardian and Trustee, Alberta Health Services, and Alberta Works, committed to helping youth with disabilities and their families with planning for the future. All youth ages 16 to 17 who access the FSCD program, which provides services for children with disabilities up to 18 years of age, are supported by a transition planning team that includes Human Service staff and community partners who work collaboratively to create the Transition to Adulthood Plan (AHS, 2016).

Strategies Not Solutions. This is an educational resource for parents and caregivers of children with FASD, created by The Child and Youth Working Group and the Edmonton Area Fetal Alcohol Network (EFAN; The Child and Youth Working Group, 2007). This resource has a section called *Transition from Childhood to Adulthood* that provides a step-by-step outline of important tasks for caregivers to undertake to support youth with FASD in the transition, such as identifying members of the transition team and setting clear objectives, developing a history of any illnesses of the individual with FASD, maintaining a history of all treatments, including medical, addiction, and mental health interventions, and making sure all formal assessments are completed and current.

Transition to Adulthood: Transition Planning Tip Sheet. This is a simple, informal resource created by the EFAN (2016) that provides a brief outline of 12 specific tasks for parents or caregivers to support the transition of youth with FASD to adulthood. Some of the tasks on this tip sheet include applying for assured income and helping to fill out paperwork and collect necessary documentation, helping the individual with FASD find a job that suits their body clock, and assisting the transitional aged youth in setting a schedule for preparing for work each day (e.g., time to wake up, time to be at the bus stop or be ready for transportation).

Youth with FASD Transitioning Initiative Toolkit. The purpose of this toolkit, created by Lakeland Centre for FASD (Badry, Wight

Felske, Rutman, Mwandala, & McFarlane, 2009) and funded by Alberta Employment, is to offer direction for youth with FASD transitioning to adulthood. This toolkit was developed for young people in stable living situations, who have a reliable support person to assist them in their transition to adulthood and beyond.

Manitoba

Bridging to Adulthood: A Protocol for Transitioning Students with Exceptional Needs from School to Community. This resource provides guidelines and support materials for transition planning and implementation of youth with special needs in Manitoba (Government of Manitoba, 2008). This resource outlines the interactive roles and responsibilities of transition planning partners and their timeline. These interactive roles include involvement on behalf of many different sources, including the individual with FASD, their parents and caregivers, substitute decision makers, teachers and school staff, and community workers from designated programs or agencies. According to the protocol, transition planning should begin when the youth with FASD enters high school, with particular emphases on certain planning processes from ages 14 to 16, ages 16 to 17, and ages 17 to 18.

Ontario

Complex Care Transition Resource Guide: Help Them Grow... So, They Are Good 2 Go! This resource is a transition timeline, developed by the Neurology/Neurosurgery programs together with the Good 2 Go Transition Program at The Hospital for Sick Children in Ontario (Good to Go Transition Program, 2013; Sick Kids, 2014). This program is not specific to FASD, but aimed at children with complex healthcare needs. The key idea behind the Good 2 Go program is that transition planning begins at the time of diagnosis, usually early in child development or, sometimes, during adolescence. The program provides parents of youth with complex healthcare needs with tasks and ideas for the youth to develop independence in different areas of life, such as social and family life, school environment, and medical aspects of care. This guide is organized as a developmental timeline with tasks in two main blocks: (1) for parents; and (2) for teens and youth ages 12 and up. All tasks are also divided into 5 main domains: general, social, self-care, education, and medical.

A Guide to Transition Planning for Parents of Children with Developmental Disability. This five-step guide to transition planning of children with developmental disabilities was developed by the Surrey Place Centre, Ministry of Community and Social Services of Toronto and York Regions, and York Support Services Network (Roebuck et al., 2007). The steps include creating a vision for the future and developing a family profile; building a transition team of two to eight members; setting short- and long-term goals; developing an action plan that includes skills and behaviours that the youth need to follow through (e.g., life skills, communication skills and engagement in social interactions, and emotional well-being); and updating the plan on a regular basis by a transition coordinator.

Health Watch Table: Fetal Alcohol Spectrum Disorder. This resource, developed by the Surrey Place Centre Developmental Disabilities Primary Care Initiative (Tao, Temple, Casson, & Kirkpatrick, 2013), provides a number of recommendations to address common issues experienced by adults with FASD. The recommendations include: psychosocial assessment in late adolescence or early adulthood to ensure the FASD diagnosis; cognitive functioning assessment; evaluation of adaptive daily living skills; physical health screening; monitoring for mental health and behavioural conditions; evaluation of sleeping patterns due to common sleep disturbance in people with FASD; and sensory assessment (Tao et al., 2013).

Ministry of Community and Social Services (MCSS), Ministry of Children and Youth Services (MCYS), and Ministry of Education (EDU) Integrated Transition Planning for Young People with Developmental Disabilities. This implementation guide provides an overview of the updated tri-ministry protocol being developed in Ontario on integrated transition planning to support young adults with developmental disabilities (MCSS, MCYS, & EDU, 2013). A transition planning framework was first introduced by the MCYS and MCSS in 2011 to improve the transition planning support available to individuals with disabilities and their families who are preparing to transition to adulthood. Through the integrated transition planning process, young adults with developmental disabilities should have a single, integrated transition plan that informs educational planning and changeovers from secondary school and child-centred services to adult services, considering the individual's future work goals, additional education, and community living. This guide comprehensively outlines the roles and responsibilities of each provincial ministry, children's service providers, schools, and developmental services organizations to facilitate a single, smooth transition experience for young adults with developmental disabilities.

British Columbia

Information for Families: Youth in Transition. This resource was developed by Community Living British Columbia (CLBC), a public-sector organization that delivers services for BC citizens to support adults with special needs and their families (CLBC, 2010). The guide presents as an information sheet available for downloading on the CLBC website, which describes CLBC's role in assisting youth and their families. CLBC suggests that the transition process should begin at the age of 16 and contain three main steps: demonstrating eligibility for CLBC services at the age of 16; learning about the CLBC supports, processes, and services after the age of 17; and developing a transition plan for adult life at the age of 19.

The Cross-Ministry Transition Planning Protocol for Youth with Special Needs. This protocol describes how youth, their families, and the relevant government organizations work together. These organizations include: Ministry of Children and Family Development (MCFD), Ministry of Education, Ministry of Health, Ministry of Social Development, Ministry of Advanced Education, Ministry of Justice, CLBC, Public Guardian and Trustee, BC Housing, Bridges to the Future, Caring for First Nations Children Society, Family Support Institute, and PLEA Community Services (British Columbia, 2012).

The goal of this cross-ministry initiative is to improve access to resources and ensure the coordinated transition process for youth with FASD and their families. The protocol outlines various components of a transition planning process and identifies the roles and tasks for transition planning team members (Fuller, Danzer, & Kulusic, 2012). The transition protocol suggests the guiding principles of the transition planning process and outlines necessary services (e.g., multi-disciplinary FASD assessment and diagnosis, MCFD and Ministry of SD programs and services, CLBC personalized supports initiative). Furthermore, the transition protocol identifies the roles and tasks timeline for transition planning team members (a document that outlines the roles of the youth, family, and staff from schools, youth and adult services, in which the starting age of transition planning is indicated as 14–15). This resource was stated as adapted from the aforementioned resource from the Government of Manitoba (*Bridging to Adulthood: A Protocol for Transitioning Students with Exceptional Needs from School to Community*; Government of Manitoba, 2008).

Your Future Now: A Transition Planning and Resource Guide for Youth with Special Needs and Their Families Who Live in Delta. This collaborative initiative was developed by Delta Community Living Society, Delta School District, CLBC, Government of British Columbia, and REACH Child and Youth Development Society (The Delta Transition Sub Committee, 2013). In this guide, the youth is considered a key player and decision-maker, underscoring their autonomy. This guide also provides samples of transition plans and a transition planning workbook, template, and resource guide. The guide further offers six steps to successful transition to adulthood: (1) building the transition planning team; (2) gathering necessary information for the plan, including specific goals, strengths, needs, and family history; (3) developing the transition plan, including the needed services and support, medical, functional, residential, financial, educational, legal, spiritual, and social needs; (4) identifying specific tasks and putting them in action; (5) designating the transition coordinator and updating the transition plan as needed; and (6) holding an exit meeting.

Common Factors for the Successful Transition to Adulthood

Analysis of the literature sources on available transition planning tools in Canada showed that, although there are some variations, most of the aforementioned transition planning tools and guides share common characteristics, suggested as pivotal for the successful outcomes in the transition to adulthood. These characteristics include: (1) transition planning should be conducted; (2) transition planning should start early; (3) a transition plan timeline should be created and followed; (4) there should be a designated transition plan coordinator; (5) the voices of the youth with FASD need to be included in the transition planning process; and (6) the transition planning process requires a multi-dimensional perspective. These six common factors are summarized in the table below.

This emerging framework of principles is consistent with the observations of Roebuck et al. (2007), who conducted a review of transition tools for youth with disabilities and concluded that to be successful, transition planning should be grounded in best practices, defined as “programs, initiatives, or activities which are considered leading edge and can serve as exceptional models for others to follow” (p. 6). The authors suggest that these practices are rooted in person-centred or youth-centred care within the strength-based approach to engagement of the youth in planning the transition, consistent with their abilities. Parents, family members, and significant others (i.e., friends, teachers, social workers, employers, trustees, etc.) are all important partners. For a successful transition, it is pivotal to identify the transition coordinator, whose role is to link together various transition activities, maintain the transition file that contains assessments, the transition

Table 1. Common Factors for the Successful Transition to Adulthood

Key Characteristics	*Description and Recommendations*
It should be done	An agreement that planning is necessary to support youth with FASD in their transition to adulthood.
An early start	Specific age recommendations vary from pre-teen to high-school years.
The timeline	A specific step-by-step and time-sensitive task plan should be developed.
A designated transition plan coordinator	This can be a parent, caregiver, guardian, or a staff member in the social service agency, whom the youth and their parents feel comfortable with. Transition care coordination is responsible for initiating the process, facilitating the team building, ensuring collaborative effort in developing the task plan, monitoring the task plan implementation, linking all stakeholders and resources together, and ensuring that the plan addresses the individual unique needs of the youth.
The voice of the youth	Young people with FASD need to be included in the planning of their transitions into adulthood and participating in the decision-making. The goals should reflect the wishes and dreams of the youth in both short-term and long-term plans, and should be realistic and attainable.
A multi-dimensional approach to the focus areas that require broad, ongoing collaboration with multiple stakeholders	The transition plan should address a number of crucial focus areas, including: stable income support, employment, or life skills and job training; medical and mental health services; creating a simple and structured work and life environment; housing and residential supports; assistance in financial management and supervision; community engagement opportunities and positive social life; stable and supportive caregivers to assist in advocacy and implementation of the transition plan; and mechanisms to respond to crisis (e.g., legal, financial, social, health, and mental health).

plan, and related materials, as well as to monitor the progress of the transition plan in action.

Roebuck et al. (2007) also identify an early start as another critical factor for a successful transition. In fact, Roebuck et al. recommend beginning casual conversations with youth about their transition to adulthood during their preteen years around the age of 9, and developing a formal plan at age 14. They also suggest that the transition planning process should be well managed, with the bulk of responsibility left to parents, caregivers, and guardians who need to take charge of the process. Given the challenges that exist for youth with FASD transitioning to adulthood, early, person-centred planning is critical in having both the youth with FASD and their caregivers prepared for the transition process, and for the planning and navigation of formal services in adulthood. Furthermore, because of the complexity of the transition planning process, an early start is essential in order to coordinate support across multiple organizations and to provide sufficient time for these organizations to coordinate care and support in a meaningful way. In short, transition planning is conceptualized as a collaborative partnership between the youth, their parents, and these other various important stakeholders.

Variations Among the Tools and Guides

Transition planning guides do not appear identical. In some jurisdictions, specialized guides for youth with FASD are lacking, and transition planning is conceptualized, in general, for youth with developmental disabilities or special needs. Some guides are designed to be used by youth, others by parents and caregivers, and still others by agencies and policymakers. Furthermore, despite the recommendation to start early, there is no unified understanding on how early in childhood development the transition planning to adulthood should begin. Other disagreements emerge around who is responsible for the transition planning initiation and monitoring; while there is a general agreement regarding the need for coordinating efforts of the teamwork, some protocols designate parents or guardians as the coordinating role, while others refer to social workers and social service agents for this purpose, and still others imply that the youth themselves may be capable. Despite the lack of consensus about who the main role should belong to, it is clear that the main point person (e.g., parent, social service agent, youth worker, etc.) needs to be someone whom both the individual with FASD and their parents or caregivers trust and feel comfortable with. Youth with FASD need to be included in their own planning for adulthood and should collaborate with the coordinator and other transition team members to engage in decision-making processes for their own future.

The most noteworthy, though subtle, difference between the transition planning tools was regarding their discussion about youth-centredness within the transition planning process. While some tools bear an empowering message of promoting youth leadership in decision-making in every aspect of the transition planning process, others reserve the use of the youth's role as a consultant or merely an interviewee. Similarly, the degree of youth self-determination in the process varies from guide to guide. For example, guides for youth with developmental disabilities, that are not necessarily specific to FASD, promote self-determination in career paths and academic aspirations for the youth, while guides developed specifically for youth with FASD endorse focusing on life skills, job training, and supervised work experience rather than academics. Given the variability in the neurocognitive profiles and behavioural deficits present in individuals with FASD, youth involvement in their transition planning process may differ depending on each unique individual with FASD. However, individuals with FASD should be consulted and included, at least in some capacity, in their own transition planning process. Focusing on the strengths of each individual with FASD is important in determining realistic and attainable short- and long-term goals for their future success.

Finally, areas of focus vary among the transition plans. Some plans center mostly on physical health and environmental well-being, while others endorse social and emotional needs. Still other plans and research on transitions for youth with disabilities attempt to embrace a more holistic perspective that endorses strength-based and collaborative approaches, as well as integrated planning (Stewart et al., 2014). Integrated planning, manifested, for instance, in multi-ministry initiatives, as well as in other collaborative, cross-agency endeavours has been evident in some tools but not others. Importantly, the multi-dimensionality of the transition planning process for youth with FASD as well as systemic readiness and organizational capacity for integrated planning necessitate both some level of independent functioning of the youth and the available continuity of their care. These expectations indicate potential challenges for the successful transition of youth whose lives do not satisfy the aforementioned conditions, as many youth with FASD may not be capable of functioning fully independently or may not have support personnel who can assist in ensuring that the transition to adulthood is a successful one. In fact, some protocols and guides specifically state that a transition process of this type is suitable only for stable youth with consistent caregivers. Therefore, it is important to note that while specific recommendations for youth with FASD are warranted, they may not be applicable or feasible for all youth with FASD. Despite the clear need for formal, consistent recommendations for transitional aged youth with FASD, it is unclear to what extent any of the existing tools and resources presented here are currently being implemented in the transition planning process.

Evaluation of Transition Planning Tools in Canada: What Does the Research Evidence Say?

Park (2014) performed a qualitative, exploratory study on transition follow-up system development for youth with disabilities from the stakeholders' perspectives (i.e., youth with disabilities, parents, teachers, administrators, principles, adult service providers, and government representatives). Park (2014) conducted focus group and in-depth interviews with these stakeholders on their perspectives about the transition follow-up system (TFS) for youth with disabilities in Manitoba. Results of that study suggested that there was a need for to minimize the time required to successfully complete the transition activities for schools and adult services programs, as well as to increase the capacity (e.g., funding, and human resources) of the government, schools, and adult programs/agencies to establish and maintain the TFS.

Fuchs, Burnside, Marchenski, and Mudry (2008) evaluated the process of transition planning for youth with FASD in child welfare care in Manitoba and concluded that the transition process was, generally, well-developed, arguing that the uptake of transition process guidelines and protocol would result in effective transitions for youth with FASD to adult services. However, Fuchs et al. (2008) were unable to support this claim in their study of children in care. According to Fuchs et al. (2008), it was not clear that any guidelines for the transition process of youth with FASD were being used, or that any such plans were actually being developed, suggesting a lack of sufficient data about the youth with FASD leaving the child welfare system. They stated that "the transition to adulthood for youth exiting the child welfare system is challenging, particularly for those with disability" (Fuchs et al., 2008, p. v). Some of the challenges included increased risk for homelessness, poverty, incarceration, and limited success in education, employment, stable income, and mental health well-being (Fuchs et al., 2008).

Fuchs et al. (2008) also reported that placement breakdowns for youth in care happen most often in the adolescent years, after a history of high caseworker turnover and when only a minority of children have comprehensive plans for the transition out of care. These particular barriers need to be addressed by providing training and support for foster parents or creating alternate resources for placement, as well as offering an extension of care or raising the age at which youth must leave care to give additional time for transition planning. Fuchs et al. (2008) recommend conducting a qualitative study gathering information from youth leaving care as the richest source of information on the issues that youth face, and the gaps in services that impact their transition to adulthood. Also, Fuchs et al. (2008) argued that services are inconsistently available across Manitoba. However, it would also be important to note to what extent services are available across Canada, and how these services may be differently distributed or applied provincially or regionally (e.g., urban, rural, and remote settings) across the nation. Given the variability in the tools and resources reviewed in this paper, including resources from Alberta, Manitoba, Ontario, and British Columbia, it is likely that there are differences nationally based on levels of awareness of FASD, the identification of

FASD as a priority within these regions, and the acknowledgment of the need for specific transition planning for individuals with developmental disabilities generally, and for individuals with FASD specifically.

According to Burnside and Fuchs (2013), there is a scarcity of research including the voices of youth with FASD as they leave care. In their qualitative study, Burnside and Fuchs (2013) described the lived experiences of youth with FASD in Manitoba who were in the transition process from the child welfare system to adulthood. Based on the youth experiences, the authors outlined the supports and services required by youth with FASD transitioning out of care, from both the child welfare system and from services for adults with FASD. They reported the perceived lack of supportive services and limited trust levels in the transition planning process (Burnside & Fuchs, 2013). This is consistent with another study by Mukherjee et al. (2013), who found that many of the families of children with FASD reported difficulties in getting appropriate and sufficient support from professionals, including doctors, social workers, and educators. This lack of support led to greater perceived difficulties and the impression that they had nowhere to turn to obtain answers about how to best support their children. These results are also in line with recent research in Ontario, Canada, highlighting that parents and caregivers of individuals with FASD often feel unsupported from health care professionals and educators (Coons, Watson, Schinke, & Yantzi, 2016; Coons, Watson, Yantzi, & Schinke, 2018). However, it is also important to note that there may be differences in the transition process for youth with FASD transitioning from the child welfare system (Burnside & Fuchs, 2013) compared to youth who are not in care. It is possible that there are additional barriers transitioning from the child welfare system that are not present for other individuals with FASD, such as limited family support or a lack of consistent and trusted caregiver to coordinate the youth transition process, though more research is needed in this area. Transition team members should be cognizant of the life circumstances of each youth with FASD and should carefully consider these individual determinants of health as they formulate their transition plans.

Additionally, in her exploratory research with participants from Ontario, Salahadin (2016) examined perspectives of caregivers of children aged 10 and older with FASD on support needs when they transition into adulthood. Participants responded to two questions: “What do caregivers need to help young adults live as independently as possible?” and “What services would help young adults live as independently as possible?” Experiences of participants overlapped with findings in existing research (Mukherjee et al., 2013; Salmon, 2008; Sanders & Buck, 2010; Watson et al., 2013). An important area of concern was the limited availability of helping professionals despite a critical need for them, underscoring the importance of designated case managers in the transition planning process (Salahadin, 2016).

Salahadin (2016) also reported an interesting finding of a need of the caregivers to support their children in accessing college programs directed towards individuals with learning disabilities. This finding adds evidence to the earlier mentioned discourse around goal setting for youth with FASD in transition planning, specifically in this instance on whether to include or discourage academics in the plan. Research in Ontario comparing parents of individuals with FASD to parents of individuals with Autism Spectrum Disorder highlighted that parents raising individuals with FASD are concerned about their child’s ability to be fully included in the community, including in a post-secondary educational setting (Watson et al., 2013). While parents of children with Autism Spectrum Disorder believed that their children would be able to attend post-secondary education and be successful with the appropriate accommodations, parents of children with FASD were much more pessimistic and perceived post-secondary education to be beyond their realistic expectations of their children’s abilities. It is possible that if parents and caregivers do not perceive their children with FASD as being able to complete these types of programs or educational pathways, these perceptions may have a significant impact on the focus of the transition planning process, particularly if the parent or caregiver is the transition coordinator. These perceptions also speak to the need for transition plans to be individualized for each person with FASD, focusing on their unique strengths and weaknesses.

Lastly, Clow (2012), in his recommendations report on children and youth services in Prince Edward Island, Canada, wrote about the necessity of innovative approaches to service delivery for youth, claiming that "it is not for the children and youth to adapt to the way in which services are delivered. It is for programs and services to adapt to the needs of the children and youth" (p. 1). He advised that the provincial government should develop a working framework for cross-departmental professional development that would promote a common vision and philosophy on service delivery for children and youth across Canada. Further discussion is warranted in this regard, given that service delivery is within the purview of each individual province and a more specific strategy is needed to facilitate a set of consistent transition planning recommendations nation-wide.

Conclusion

This state-of-the-art review showed marked commonality among the transition planning tools and guides across Canada in outlining factors crucial for the successful transition to adulthood of youth with FASD. There is an agreement on a number of important factors including: the necessity of the transition process; an early start to and structured timeline of tasks for this process; collaborative teamwork of multiple stakeholders that are important in the youth's life; the presence of available caregivers; the stable condition and the relative independence of the youth; the incorporation of the youth in the decision-making process; and the critical role of the transition care coordinator as the link between various aspects of this complex and multi-faceted process. These factors, moreover, are embedded in shared values of person-centred care, continuity of care, strength-based approaches, and pro-active planning. However, these values, although mentioned, were not equally manifested across the tools.

In fact, the transition process guides notably vary in the extent to which recommendations regarding person-centred care and self-determination of youth with FASD are included. Additionally, the tools place a different emphasis on various aspects of the youth's life (e.g., biological, psychosocial), and have very limited agreement on who bears the responsibility for the transition planning process. Furthermore, the underpinning assumption of the stability (e.g., not in crisis) of the youth, the availability of caregivers, and an uninterrupted continuity of care poses a serious question about whether these protocols are applicable to youth in the child welfare system, who may experience breakdowns, and therefore may be at a higher risk for life complications during the transition to adulthood compared to youth with FASD who have supportive and stable environments. It is likely that it is increasingly more difficult to engage in the transition planning process with youth who are currently in crisis.

There is a scarcity of evaluative studies on the implementation of the transition planning process for youth with FASD in Canada. Review of the limited available studies suggests the existence of multiple barriers to the successful transition to adulthood of youth with FASD, including fragmentation and challenges navigating the complex system, inadequate availability of services and other resources, insufficient continuity of care, shortcomings in and a lack of trust in the system – from both the youth and caregivers' perspectives – and unsatisfactory stakeholder training. Some of the recommendations in these studies suggest the need for the collection of reliable information and data to enhance the success of the transition process, simplification of the process to decrease the time it requires for staff and families, individualization of the transition plan outcomes within the structural processes, and increasing funding and other resources to support consistent and effective transition planning. More broadly, the effectiveness of the transition planning implementation in various provinces across Canada remains unclear, particularly among Indigenous youth, children in foster care, and youth in correctional facilities.

Future research is needed to evaluate the extent to which transition planning tools are used to assist the youth with FASD in their transition to adulthood in Alberta and Canada generally. Comparing the transitional outcomes between youth who participate in the transition planning process compared to those who do not would also be an important area of investigation. Finally, there is a need for an exploratory study of the lived experiences of youth with FASD during their transition to adulthood, as well as the perspectives of youth and their families on the needs, barriers, and efficacious strategies for the successful transition to adulthood.

Key Messages From This Article

Persons with disabilities. You deserve to be supported in your transition from adolescence to adulthood. Your voice should be included in the process.

Professionals. There are several tools available to assist you with creating a transition plan. There is a scarcity of research evaluating the implementation of these plans, but there is agreement that all plans should be person-centred and strength-based.

Policymakers. There is a need for consistent recommendations for the transition to adulthood, given that current resources vary in the extent to which recommendations for youth with FASD are included and the extent to which the voices of individuals with FASD are heard.

Acknowledgments

The authors would like to acknowledge Transition to Adulthood Planning for Children with FASD, funded and managed by PolicyWise for Children & Families. It is with thanks that we also acknowledge the many individuals and organizations who have contributed their wisdom, experience, and perspectives to this project.

References

Alberta Government. (2016). *Transition planning brochure. Transition planning: Supporting youth with disabilities in transitioning to adulthood.* Retrieved from http://www.humanservices.alberta.ca/documents/transition-planning-brochure.pdf

Alberta Human Services (2016). *Integrated transition planning.* Retrieved from http://www.humanservices.alberta.ca/disability-services/15864.html

Arnett, J. J. (1997). Young people's conceptions of the transition to adulthood. *Youth & Society, 29*(1), 3–23. doi:10.1177/0044118X97029001001

Arnett, J. J. (2000). Emerging adulthood. A theory of development from the late teens through the twenties. *The American Psychologist*, *55*(5), 469–480. doi:10.1037/0003-066X.55.5.469

Badry, D., Wight Felske, A., Rutman, D., Mwandala, T., & McFarlane, A. (2009). *Youth with FASD Transitioning Initiative Toolkit*. Cold Lake, Alberta: Lakeland Centre for FASD.

British Columbia. (2012). *XI. Appendix C – Roles and tasks for transition planning team members.* Retrieved from www.mcf.gov.bc.ca/spec_needs/adulthood.htm.

Bunch, G., Finnegan, K., & Pearpoint, J. (2009). *Planning for real life after school: Ways for families and teachers to plan for students experiencing significant challenges*. Toronto, Ontario: Inclusion Press. Retrieved from http://www.inclusion.com/books/planningforlife.pdf

Burd, L., Fast, D. K., Conry, J., & Williams, A. (2010). Fetal alcohol spectrum disorder as a marker for increased risk of involvement with correctional systems. *Journal of Psychiatry and Law, 38*(4), 559–584. doi:10.1177/009318531003800408

Burnside, L., & Fuchs, D. (2013). Bound by the clock: The experiences of youth with FASD transitioning to adulthood from child welfare care. *First Peoples Child and Family Review, 8*(1), 40–61. Retrieved from http://journals.sfu.ca/fpcfr/index.php/FPCFR/article/view/200/28

Carter, E. W., Brock, M. E., & Trainor, A. A. (2012). Transition assessment and planning for youth with severe intellectual and developmental disabilities. *The Journal of Special Education, 47*(4), 245–255. doi:10.1177/0022466912456241

The Child and Youth Working Group (2007). *FASD: Strategies not solutions*. Edmonton, Alberta: The Edmonton and Area Fetal Alcohol Network. Retrieved from http://www.humanservices.alberta.ca/disability-services/16025.html

Clark, E., Lutke, J., Minnes, P., & Ouellette-Kuntz, H. (2004). Secondary disabilities among adults with fetal alcohol spectrum disorder in British Columbia. *Fetal Alcohol Research, 2*(e13), 1–12. Retrieved from http://www.motherisk.org/JFAS_documents/Secondary_Disabilities_Adults.pdf

Clow, J. (2012). *Child and youth services in Prince Edward Island: Recommendations report.* Charlottetown, Prince Edward Island: Child and Youth Services in Prince Edward Island.

Community Living British Columbia (2010). *Information for families: Youth in transition*. Retrieved from http://www.communitylivingbc.ca/individuals-families/support-for-adults/youth-in-transition/

Connor, P. D., Sampson, P. D., Streissguth, A. P., Bookstein, F. L., & Barr, H. M. (2006). Effects of prenatal alcohol exposure on fine motor coordination and balance: A study of two adult samples. *Neuropsychologia, 44*(5), 744–751.

Cook, J. L., Green, C. R., Lilley, C. M., Anderson, S. M., Baldwin, M. E., Chudley, A. E., … Canada FASD Research Network. (2015). Fetal alcohol spectrum disorder: A guideline for diagnosis across the lifespan. *Canadian Medical Association Journal*, 1–7. doi:10.1503/cmaj.141593

Coons, K. D., Watson, S. L., Schinke, R., & Yantzi, N. (2016) Adaptation in families raising children with fetal alcohol spectrum disorder part I: What has helped. *Journal of Intellectual and Developmental Disability, 41*(2), 150–165. doi: 10.3109/13668250.2016.1156659

Coons, K. D., Watson, S. L., Yantzi, N., & Schinke, R. (2018). Adaptation in families raising children with fetal alcohol spectrum disorder part II: What would help. *Journal of Intellectual and Developmental Disability, 43*(2), 137–151. doi:10.3109/13668250.2016.1267718

DeJoseph, M. (2011). Chapter 6: Improving outcomes for adolescents and adults with Fetal Alcohol Spectrum Disorders. In S. A. Adubato and D. E. Cohen (Eds.), *Prenatal alcohol use and Fetal Alcohol Spectrum Disorders: Diagnosis, assessment and new directions in research and multimodal treatment* (pp. 127–148). New Jersey: Bentham Books. doi:10.2174/978160805031 41110101

The Delta Transition Sub Committee. (2013). *Your future now: A transition planning and resource guide for youth with special needs and their families who live in Delta.* Victoria, British Columbia: Ministry of Children and Family Development.

Edmonton and Area Fetal Alcohol Network Society [EFAN]. (2016). *Transition to Adulthood – February 2016 Tip Sheet*. Retrieved from https://edmontonfetalalcoholnetwork.org/2016/02/08/transition-to-adulthood/

Fuchs, D., Burnside, L., Marchenski, S., & Mudry, A. (2005). Children with disabilities receiving services from child welfare agencies in Manitoba. Winnipeg, Manitoba: Centre of Excellence for Child Welfare. Retrieved from http://www.cecw-cepb.ca/DocsEng/DisabilitiesManitobaFinal.pdf

Fuchs, D., Burnside, L., Marchenski, S., & Mudry, A. (2008). *Transition out-of-care: Issues for youth with FASD.* Winnipeg, Manitoba: Centre of Excellence for Child Welfare and Public Health Agency of Canada.

Fuchs, D., Burnside, L., Marchenski, S., & Mudry, A. (2010). Children with FASD and related disabilities receiving services from child welfare agencies in Manitoba. *International Journal of Mental Health and Addiction, 8*(2), 232–244. doi:10.1007/s11469-009-9258-5

Fuller, A., Danzer, O., Kulusic, T. (2012). *Lessons learned in supporting youth with FASD into adulthood.* 5th National Biannual Conference of Adolescents and Adults with FASD, April 18–21. Vancouver, British Columbia, Canada. Retrieved from http://www.interprofessional.ubc.ca/AdultsWithFASD/documents/B4_Fuller.pdf

Gardner, J. (2000). Living with a child with fetal alcohol syndrome. *The American Journal of Maternal/Child Nursing, 25*(5), 252–257. doi:10.1097/00005721-200009000-00007

Good to Go Transition Program (2013). *Complex care transition resource guide*. Toronto, Ontario: The Hospital for Sick Children. Retrieved from http://www.sickkids.ca/pdfs/Good2Go%20Transition%20Program/45804-CCRWebsiteOctober.pdf

Government of Manitoba (2008). *Bridging to adulthood: A protocol for transitioning students with exceptional needs from school to community.* Winnipeg, Manitoba: Healthy Child Manitoba.

Grant, M.J., & Booth, A. A. (2009). A typology of reviews: An analysis of 14 review types and associated methodologies. *Health Information and Libraries Journal, 26*(2), 91–108. doi:10.1111/j.1471-1842.2009.00848.x

Hagner, D., Kurtz, A., May, J., & Cloutier, H. (2014). Person-centered planning for transition-aged youth with autism spectrum disorder. *Journal of Rehabilitation, 80*(1), 4–10. Retrieved from https://ccids.umaine.edu/wp-content/uploads/sites/26/2016/03/Hagner_Kurtz_May_Cloutier_PCP_with_ASD_c-clause.pdf

Higgins, J. P. T., & Green, S. (2011). *Cochrane handbook for systematic reviews of interventions*, version 5.1.0. Available from http://handbook-5-1.cochrane.org/

James Williams, S., Dubovsky, D., &, & Merritt, J. (2011). Legal and psychological implications of nondisclosure in the adoption of a child with Fetal Alcohol Spectrum. *Journal of Psychiatry and Law, 39*(1), 193–215. doi:910378054

May, P. A., Baete, A., Russo, J., Elliott, A. J., Blankenship, J., Kalberg, W. O., … Hoyme, H. E. (2014). Prevalence and characteristics of fetal alcohol spectrum disorders. *Pediatrics, 134*(5), 855–866. doi:10.1542/peds.2013-3319

McLeod, R. (1999). *School to life transition handbook: Five steps to successful planning.* Regina, Saskatchewan: Saskatchewan Association for Community Living. Retrieved from http://www.rytmus.org/shared/clanky/767/Rita%20McLeod%20manu%C3%A1l.pdf

Milne, D., Moorhouse, T., Shikaze, K., & Cross-Ministry Members. (2011). A cross-ministry approach to FASD across the lifespan in Alberta. In E. P. Riley, S. Clarren, J. Weinberg, & E. Jonsson (Eds.), *Fetal Alcohol Spectrum Disorder: Management and policy perspectives of FASD* (pp. 353–369). Hoboken, New Jersey: Wiley-Blackwell.

Ministry of Community and Social Services, Ministry of Children and Youth Services, & Ministry of Education. (2013). *MCSS/MCYS/EDU Integrated transition planning for young people with developmental disabilities 2013-2014: Tri-ministry implementation guide.* Available from http://www.edugains.ca/resourcesSpecEd/SystemLeader/InstGuid/ImplementationGuide.pdf

Morrissette, P. J. (2001). Fetal alcohol syndrome: Parental experiences and the role of family counselors. *The Qualitative Report, 6*(2). Retrieved from http://nsuworks.nova.edu/cgi/viewcontent.cgi?article=2000&context=tqr

Mukherjee, R., Wray, E., Commers, M., Hollins, S., & Curfs, L. (2013). The impact of raising a child with FASD upon carers: Findings from a mixed methodology study in the UK. *Adoption & Fostering, 37*(1), 43–56. doi:10.1177/0308575913477331

Olson, H. C., Oti, R., Gelo, J., & Beck, S. (2009). "Family matters:" Fetal alcohol spectrum disorders and the family. *Developmental Disabilities Research Reviews, 15*, 235–249. doi:10.1002/ddrr.65

Park, Y. (2014). Transition follow-up system development for youth with disabilities: Stakeholders' perspectives. *Exceptionality Education Institutional, 24*, 31–36. Retrieved from http://ir.lib.uwo.ca/eei/vol24/iss2/3

Pei, J., Tremblay, M., McNeil, A., Poole, N., & McFarlane, A. (2017). Neuropsychological aspects of prevention and intervention for FASD in Canada. *Journal of Pediatric Neuropsychology, 3*(1), 25–37. doi:10.1007/s40817-016-0020-1

Pepper, J. M., Watson, S. L., & Coons-Harding, K. D. (2019). "Well where's he supposed to live?": Experiences of adoptive parents of emerging adult children with fetal alcohol spectrum disorder in Ontario. *Journal on Developmental Disabilities*, *24*(1), 66–80.

Roebuck, R., Coultes-MacLeod, J., & First Leadership Limited (2007). *Connections: A guide to transition planning for parents of children with developmental disability.* Toronto & York Regions, Ontario: Ministry of Community and Social Services. Retrieved from http://www.surreyplace.on.ca/resources-publications/transition-planning-for-parents-2/

Salahadin, A. (2016). *An exploration of service needs for adults who live with fetal alcohol spectrum disorder* (Master's Thesis). The University of Western Ontario, London, ON, Canada.

Salmon, J. (2008). Fetal alcohol spectrum disorder: New Zealand birth mothers' experiences. *Canadian Journal of Clinical Pharmacology, 15*(2), e191-e213. Retrieved from http://www.jptcp.com/articles/fetal-alcohol-spectrum-disorder-new-zealand-birth-mothers-experiences.pdf

Sanders, J. L., & Buck, G. (2010). A long journey: Biological and non-biological parents' experiences raising children with FASD. *Journal of Population Therapeutics and Clinical Pharmacology, 17*(2), e308–e322. Retrieved from http://www.jptcp.com/articles/a-long-journey-biological-and-nonbiological-parents-experiences-raising-children-with-fasd.pdf

Sick Kids (2014). *Good 2 Go transition program: Help them grow… so, they are Good 2 Go! Neurology/Neurosurgery programs.* Toronto, Ontario: Hospital for Sick Kids. Retrieved from http://www.sickkids.ca/Good2Go/For-Youth-and-Families/Transition-Tools/Help-Them-Grow-so-They're-Good-2-Go-Timelines/Index.html

Stewart, D., Law, M., Young, N. L., Forhan, M., Healy, H., Burke-Gaffney, J, & Freeman, M. (2014). Complexities during transitions to adulthood for youth with disabilities: Person-environment interactions. *Disability and Rehabilitation, 36*(23), 1998–2004. doi:10.3109/09638288.2014.885994

Streissguth, A., Bookstein, F., Barr, H., Sampson, P., O'Malley, K., & Young, J. (2004). Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Journal of Developmental and Behavioral Pediatrics, 25*(4), 228–38. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/15308923

Tao, L., Temple, V., Casson, I., & Kirkpatrick, S. M. L. (2013). *Health watch table – fetal alcohol spectrum disorder.* Toronto, Ontario: Surrey Place Centre. Retrieved from http://www.surreyplace.on.ca/Documents/HWT_FASD_2013_Nov_2013.pdf

Thanh, N. X., Jonsson, E., Salmon, A., & Sebastianski, M. (2014). Incidence and prevalence of fetal alcohol spectrum disorder by sex and age group in Alberta, Canada. *Journal of Population Therapeutics and Clinical Pharmacology, 21*(3), e395–404.

Trainor, A. A., Morningstar, M. E., & Murray, A. (2016). Characteristics of transition planning and services for students with high-incidence disabilities. *Learning Disability Quarterly, 39*(2), 113–124. doi:10.1177/0731948715607348

Warren, K., Floyd, L., Calhoun, F., Stone, D., Bertrand, J., Streissguth, A., … Little, A. (2004). *Consensus statement on FASD.* Washington, DC: National Organization on Fetal Alcohol Syndrome.

Watson, S., Hayes, S., Radford-Paz, E., & Coons, K. (2013). "I'm hoping, I'm hoping…": Thoughts about the future from families of children with autism or FASD. *Journal on Developmental Disabilities, 19*(3), 76–93. Retrieved from http://www.oadd.org/docs/41014_JoDD_19-3_FASD_76-93_Watson_et_al.pdf

Wehman, P., Sima, A. P., Ketchum, J., West, M. D., Chan, F., & Luecking, R. (2015). Predictors of successful transition from school to employment for youth with disabilities. *Journal of Occupational Rehabilitation, 25*(2), 323–334. doi:10.1007/s10926-014-9541-6

Appendix 1: Identified Tools and Resources

A List of the Transition Planning Tools, Guides, and Process Outlines in Canada by Province

ALBERTA

Agency	Persons with Developmental Disabilities Central Alberta Community Board
Tool or Guide	*A Parents' Guide to Transitional Planning*
Specific to FASD or Developmental Disability (DD)	DD
Availability	Website: www.pdd.org/Central/resources/transplanning.shtml

Agency	Family Support for Children with Disabilities (FSCD) of the Alberta Human Services
Tool or Guide	*Integrated Transition Planning for Youth with Disabilities*
Specific to FASD or Developmental Disability (DD)	DD
Availability	Program is open to all FSCD clients; information and contact information of the FSCD worker is available on the Alberta Human Services website (AHS, 2016) and a downloadable information brochure at the same website (Alberta Government, 2016).

Agency	Edmonton Area Fetal Alcohol Network (EFAN): The Child and Youth Working Group
Tool or Guide	*Strategies Not Solutions (section: Transition from Childhood to Adulthood*
Specific to FASD or Developmental Disability (DD)	FASD
Availability	Website (The Child and Youth Working Group, 2007).

Agency	Edmonton Area Fetal Alcohol Network (EFAN)
Tool or Guide	*Transition to Adulthood: Transition Planning Tip Sheet*
Specific to FASD or Developmental Disability (DD)	FASD
Availability	Website: Edmonton and Area Fetal Alcohol Network Society [EFAN], 2016

Agency	Lakeland Centre for FASD
Tool or Guide	*Youth with FASD Transitioning Initiative Toolkit*
Specific to FASD or Developmental Disability (DD)	FASD
Availability	Report: Badry, Wight Felske, Rutman, Mwandala, & MacFarlane (2009)

Appendix 1: Identified Tools and Resources

A List of the Transition Planning Tools, Guides, and Process Outlines in Canada by Province (continued)

MANITOBA

Agency	Government of Manitoba (2008).
Tool or Guide	*Bridging to adulthood: A protocol for transitioning students with exceptional needs from school to community*
Specific to FASD or Developmental Disability (DD)	DD and other special needs
Availability	Report and downloadable resource Government of Manitoba (2008)

ONTARIO

Agency	The Good 2 Go Transition program, the Hospital for Sick Children
Tool or Guide	*Complex Care Transition Resource Guide: Help Them Grow… So, They Are Good 2 Go!*
Specific to FASD or Developmental Disability (DD)	DD
Availability	Downloadable brochure (Good to Go Transition Program, 2013; Sick Kids, 2014)
Agency	The Surrey Place Centre, Ministry of Community and Social Services of Toronto and York Regions, and York Support Services Network
Tool or Guide	*A Guide to Transition Planning for Parents of Children with Developmental Disability*
Specific to FASD or Developmental Disability (DD)	DD
Availability	Roebuck, Coutles-MacLeod, & First Leadership Limited, 2007
Agency	The Surrey Place Centre, Developmental Disabilities Primary Care Initiative
Tool or Guide	*Health Watch Table: Fetal Alcohol Spectrum Disorder*
Specific to FASD or Developmental Disability (DD)	FASD
Availability	Report (Tao, Temple, Casson, & Kirkpatrick, 2013) Website: http://www.surreyplace.on.ca/resources-publications/primary-care/

Appendix 1: Identified Tools and Resources

A List of the Transition Planning Tools, Guides, and Process Outlines in Canada by Province (continued)

Agency	Ministry of Community and Social Services (MCSS), Ministry of Children and Youth Services (MCYS), and Ministry of Education (EDU)
Tool or Guide	*MCSS/MCYS/EDU Integrated Planning for Young People with Developmental Disabilities 2013–2014* Tri-Ministry Implementation Guide
Specific to FASD or Developmental Disability (DD)	DD
Availability	Downloadable implementation guide http://www.edugains.ca/resourcesSpecEd/SystemLeader/InstGuid/ImplementationGuide.pdf (MCSS, MCYS, & EDU, 2013)

BRITISH COLUMBIA

Agency	Community Living British Columbia (CLBC)
Tool or Guide	*Information for Families: Youth in Transition*
Specific to FASD or Developmental Disability (DD)	DD
Availability	Downloadable brochure (Community Living British Columbia, 2010)

Agency	Government of British Columbia
Tool or Guide	*The Cross-Ministry Transition Planning Protocol for Youth with Special Needs*
Specific to FASD or Developmental Disability (DD)	FASD
Availability	(British Columbia, 2012) (Fuller, Danzer, & Kulusic, 2012)

Agency	BC Ministry of Children and Family Development, Delta Community Living Society, Delta School District, CLBC, and REACH Child and Youth Development Society
Tool or Guide	*Your Future Now: A Transition Planning & Resource Guide for Youth with Special Needs and Their Families*
Specific to FASD or Developmental Disability (DD)	DD
Availability	Government website and downloadable brochure www.mcf.gov.bc.ca/spec_needs/pdf/your_future_now.pdf www.mcf.gov.bc.ca/spec_needs/pdf/support_guide.pdf (The Delta Transition Sub Committee, 2013)