

Transitional Aged Youth: Navigating Planning Across Systems

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 lim-

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ited 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 plan-

ning 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.

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