

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

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,

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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, Coultres-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

<i>Key Characteristics</i>	<i>Description and Recommendations</i>
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 pre-teen 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.

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Appendix 1: Identified Tools and Resources

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

ALBERTA

<i>Agency</i>	Persons with Developmental Disabilities Central Alberta Community Board
<i>Tool or Guide</i>	<i>A Parents' Guide to Transitional Planning</i>
<i>Specific to FASD or Developmental Disability (DD)</i>	DD
<i>Availability</i>	Website: www.pdd.org/Central/resources/transplanning.shtml
<i>Agency</i>	Family Support for Children with Disabilities (FSCD) of the Alberta Human Services
<i>Tool or Guide</i>	<i>Integrated Transition Planning for Youth with Disabilities</i>
<i>Specific to FASD or Developmental Disability (DD)</i>	DD
<i>Availability</i>	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).
<i>Agency</i>	Edmonton Area Fetal Alcohol Network (EFAN): The Child and Youth Working Group
<i>Tool or Guide</i>	<i>Strategies Not Solutions (section: Transition from Childhood to Adulthood)</i>
<i>Specific to FASD or Developmental Disability (DD)</i>	FASD
<i>Availability</i>	Website (The Child and Youth Working Group, 2007).
<i>Agency</i>	Edmonton Area Fetal Alcohol Network (EFAN)
<i>Tool or Guide</i>	<i>Transition to Adulthood: Transition Planning Tip Sheet</i>
<i>Specific to FASD or Developmental Disability (DD)</i>	FASD
<i>Availability</i>	Website: Edmonton and Area Fetal Alcohol Network Society [EFAN], 2016
<i>Agency</i>	Lakeland Centre for FASD
<i>Tool or Guide</i>	<i>Youth with FASD Transitioning Initiative Toolkit</i>
<i>Specific to FASD or Developmental Disability (DD)</i>	FASD
<i>Availability</i>	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

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

ONTARIO

<i>Agency</i>	The Good 2 Go Transition program, the Hospital for Sick Children
<i>Tool or Guide</i>	<i>Complex Care Transition Resource Guide: Help Them Grow... So, They Are Good 2 Go!</i>

<i>Specific to FASD or Developmental Disability (DD)</i>	DD
<i>Availability</i>	Downloadable brochure (Good to Go Transition Program, 2013; Sick Kids, 2014)

<i>Agency</i>	The Surrey Place Centre, Ministry of Community and Social Services of Toronto and York Regions, and York Support Services Network
<i>Tool or Guide</i>	<i>A Guide to Transition Planning for Parents of Children with Developmental Disability</i>
<i>Specific to FASD or Developmental Disability (DD)</i>	DD
<i>Availability</i>	Roebuck, Coutles-MacLeod, & First Leadership Limited, 2007

<i>Agency</i>	The Surrey Place Centre, Developmental Disabilities Primary Care Initiative
<i>Tool or Guide</i>	<i>Health Watch Table: Fetal Alcohol Spectrum Disorder</i>
<i>Specific to FASD or Developmental Disability (DD)</i>	FASD
<i>Availability</i>	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)

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

BRITISH COLUMBIA

<i>Agency</i>	Community Living British Columbia (CLBC)
<i>Tool or Guide</i>	<i>Information for Families: Youth in Transition</i>
<i>Specific to FASD or Developmental Disability (DD)</i>	DD
<i>Availability</i>	Downloadable brochure (Community Living British Columbia, 2010)
<i>Agency</i>	Government of British Columbia
<i>Tool or Guide</i>	<i>The Cross-Ministry Transition Planning Protocol for Youth with Special Needs</i>
<i>Specific to FASD or Developmental Disability (DD)</i>	FASD
<i>Availability</i>	(British Columbia, 2012) (Fuller, Danzer, & Kulusic, 2012)
<i>Agency</i>	BC Ministry of Children and Family Development, Delta Community Living Society, Delta School District, CLBC, and REACH Child and Youth Development Society
<i>Tool or Guide</i>	<i>Your Future Now: A Transition Planning & Resource Guide for Youth with Special Needs and Their Families</i>
<i>Specific to FASD or Developmental Disability (DD)</i>	DD
<i>Availability</i>	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)