Transitioning to Adulthood as a Young Person with an Intellectual Disability: Two Case Studies of Mothers' Perceptions

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This article presents the findings from two case studies, which examine the mother's perspectives of the process of transitioning from high school to adulthood for their children with Intellectual Disabilities (ID). Making the transition from high school to adult life is a challenging process for youth with ID, and is complicated by policies, fragmented systems, and uncoordinated services. We use case study analysis, supported by an Enhanced Critical Incident Technique (ECIT) framework, to collect and analyze our data, in an effort to understand the particular experiences of two mothers. Through these interviews we determined that factors such as communication and interagency cooperation had huge impacts on the two mothers, suggesting that additional supports are necessary to allow for a smooth transition for students with ID.

Cet article présente les résultats de deux études de cas portant sur les perspectives de mères quant au processus de transition de l'école secondaire vers l'âge adulte que vivent leurs enfants ayant une déficience intellectuelle. La transition de l'école secondaire vers l'âge adulte constitue une étape difficile pour les jeunes personnes ayant une déficience intellectuelle, et le processus est rendu plus compliqué par des politiques, des systèmes fragmentés et des services mal coordonnés. La collecte et l'analyse de nos données ont été effectuées selon une analyse d'étude de cas appuyée par un cadre d'analyse d'incidents critiques (ECIT—Enhanced Critical Incident Technique), de sorte à comprendre les expériences particulières de deux mères. Par l'entreprise d'entrevues, nous avons déterminé que des facteurs tels la communication et la coopération interservices avaient un énorme impact sur les deux mères. Nos résultats portent à croire qu'il faudrait davantage de supports pour permettre aux élèves ayant une déficience intellectuelle de vivre une transition harmonieuse.

Research suggests that transitioning to adulthood is more challenging for youth with an Intellectual Disability (ID) than for their typically developing peers. Many factors contribute to the differences including personal limitations (e.g., physical, sensory, cognitive, communicative, and mental health) and environmental barriers (e.g., access to employment and adult services) which present significant difficulties for youth and their families (Stewart et al., 2010). In addition, bureaucratic policies, systems, and services are complicated, fragmented, and uncoordinated, making it difficult to navigate the transition process successfully (Wehmeyer,

Morningstar, & Husted, 1999; Wiart et al., 2010).Ultimately, these challenges limit the opportunities for youth with ID to fully participate in adult life including independent living (Huang & Blum, 2010), meaningful engagement in employment and/or volunteer opportunities (Grigal, Hart, & Migloire, 2011), and social relationships (Forte, Jahoda, & Dagnan, 2011). In order to increase successful transitions for youth with ID, it is critical to broaden our understanding of the process of transition from high school to life after graduation and to investigate the factors that contribute to positive and negative outcomes. Specifically, examining mothers' perceptions of the transition process is important for finding practical ways to augment the probability of success, especially given that family involvement continues after students graduate from high school.

An Intellectual Disability (ID) is a neurodevelopmental disorder defined by deficits in general mental abilities including reasoning, problem solving, and abstract thinking, as well as impairment in everyday adaptive functioning which involves daily living skills, communication, and social skills (American Psychiatric Association [APA], 2013). The severity of ID ranges from mild to profound, a distinction that is based on the level of adaptive functioning deficits in conceptual, social, and practical domains.

Given that youth with ID learn at a slower rate than their peers without ID, some considerations and decisions about future living arrangements, education, employment, finances, and community involvement need to be made in preparation for the transition to adulthood. The term *transition planning* is used to describe the process of setting goals, identifying opportunities or experiences, and connecting to resources during the high school years in a way that helps students and their families prepare to meet their academic and functional achievement goals, taking into consideration the students' strengths, needs, and preferences (Individuals with Disabilities Education Improvement Act [IDEA], 2004).

Transition from High School: Best Practices

The transition between school and adulthood is a critical period for individuals with ID because it involves adapting to new roles and adjusting to significant changes in life (Davies & Beamish, 2009; Osgood, Foster, & Courtney, 2010; Young, Dagnan, & Jahoda, 2016). Functional academics (which are related to daily functioning), adaptive skills, motor development, communication, navigating the community, and safety are important areas of focus for transition planning necessary to prepare youth for adult demands (Turnbull, Turnbull, Shank, Smith, & Leal, 2001). These needs require strategies and supports aimed at ensuring individuals with ID achieve desired outcomes related to independent living, employment, and social relationships as well as to establish a satisfying and a successful adult life.

A number of best practices are recommended by researchers and professionals in the field of transition to help improve outcomes for youth with ID. For example, best practices suggest that transition preparation to post high school life should include observable measurable goals related to specific post-secondary outcomes which are determined in collaboration with students and their families and are monitored regularly (Test et al., 2009). These include work experience opportunities, employment preparation, life skills instruction, and consumer purchasing instruction (Alberta Children and Youth Initiative [ACYI], 2006; Landmark, Ju, & Zhang, 2010; Prince, Katsiyannis, & Farmer, 2013; Test et al., 2009). Throughout this process, all stakeholders including parents, teachers, community service providers, as well as the students, provide a valuable perspective. Each stakeholder contributes suggestions for ongoing

support strategies; aide in decision-making regarding appropriate living arrangements, accessible education, employment and/or volunteer opportunities; and assist with securing ongoing financial and legal support. A systematic literature review found continued support for nine areas identified as predictors of post-school success for students with disabilities, which are career awareness, exit exam/high school diploma status, inclusion in general education, paid employment/work experience, parent involvement, self-care/independent living skills, social skills, vocational education, and work study (Mazzotti et al., 2016). Papay and Bambara (2014) analyzed longitudinal data about transitioning from high school to determine whether the use of best practices such as youth involvement, family involvement, transition planning, work experiences, life skills instruction, inclusion in general education, interagency involvement were predictive of post high school outcomes for youth with ID. The study suggests that the use of best practices significantly predict employment, postsecondary education, and enjoyment of life (Papay & Bambara, 2014). Haber and colleagues (2016) conducted a meta-analysis examining which in-school predictors (e.g., student-focused planning, interagency development) work for which population (e.g., type of disability; geographic area) and in which outcome areas (e.g., education, employment). Results of their study indicated that most of the identified practices had significant, although small, positive relationships with outcomes. They also found that some strategies increased employment outcomes while other strategies increased education outcomes. Additionally, results of this study suggest a robust impact of strategies related to multi-stakeholder collaboration (Haber, 2016).

Families are particularly important in supporting individuals with ID in transitioning from high school to adulthood. For example, approximately 60%-70% of adults with ID in the United States and Canada live with family members (Huang & Blum, 2010), highlighting the ongoing role of the family in supporting their young adult children. Family involvement in the transition process is frequently identified as a best practice as it is related to better outcomes including increased chance of attending postsecondary school and higher reported rates of enjoying life (Mazzotti et al., 2016; Papay & Bambara, 2014; Test et al., 2009).

Best practices for supporting youth with disabilities to prepare for the transition from high school are derived from a variety of sources including systematic literature reviews (Mazzotti et al., 2016; Test et al., 2009), longitudinal studies (Papay & Bambara, 2014), and meta-analyses (Haber et al., 2016). While further experimental and quasi-experimental investigation is recommended (Test et al., 2009), research to date has consistently supported similar best practices to assist students with disabilities in the process of transitioning out of high school and into the adult world.

Transition from High School to Adulthood: Current Practices

Although there is a well-established body of research outlining a set of best practices that result in effective transition to adulthood, this knowledge has not translated into the consistent application of these practices which has resulted in continued poor outcomes for youth with ID (Grigal et al., 2011; Osgood et al., 2010). For example, despite legislation mandating transition planning, research suggests that in the United States as few as 10% of transition plans were actually written down (Williams-Diehm & Lynch, 2007). Transition plans that were written included goals related to employment, independent living, and recreation that used vague or non-specific language, such as get a job, rather than specific language, such as demonstrate job-readiness skills including punctuality and hygiene; Williams-Diehm & Lynch, 2007). There is no

equivalent legislative imperative for transition planning in Canada; as a result we found no equivalent literature from the Canadian context.

Unfortunately, the lack of consistent transition planning practices disproportionately impact students with ID. For example, when comparing students with other disabilities such as emotional disturbance, behavioural disorders, autism, or learning disabilities to students with ID, students with ID were less likely to attend a post-secondary school and less likely to be competitively employed than students with other disabilities (Grigal et al., 2011). Additionally, studies from the United States, United Kingdom, and Australia, demonstrate that individuals with ID often struggle to maintain employment and tend to hold jobs for shorter periods of time which results in lower annual income (Landmark et al., 2010). In contrast, when individuals with ID are involved in the process of writing their transition plan, they are more likely to secure and maintain competitive employment due to higher levels of self-determination (Foley et al., 2013; Landmark et al, 2010).

Unfortunately, in practice, the transition process is often complex and constrained by stakeholders operating in a fragmented and disconnected fashion (Chambers, Hughes, & Carter, 2004; Davies & Beamish, 2009; Hetherington et al., 2010; Kohler & Field, 2003). Research indicates that stakeholders, including school staff, community workers, and parents, often lack knowledge about the transition process and resources available including how to access those services (Stewart et al., 2010). Due to these barriers, individuals with ID often experience gaps in service when they reach adulthood. If reconnected with supports, many individuals experience challenges with the nature of adult-based services that are not tailored to the appropriate developmental level for young adults (Osgood et al., 2010).

Individuals with ID often have social experiences that differ from their typically developing peers when they transition into adulthood. Studies indicate that individuals with ID have less opportunity to interact with other people at work compared to individuals without a disability (Mank, Cioffi, & Yovanoff, 1998). Following school completion, many individuals with ID reside with family members or in residential group home facilities as opposed to more independent living arrangements as a result of both their level of support needs and a lack of transition goals related to independent living (Murray, 2007). These individuals also tend to experience more social isolation, segregation, and have little community-based participation. Those individuals who do have high social involvement tend to have high levels of caregiver or group home support in arranging social activities (Murray, 2007). For the limited number of individuals with ID who participate in some form of post-secondary education, programming tends to be segregated from the general university classroom and campus recreational activities (Neubert, Moon, & Grigal, 2002).

In some jurisdictions, specific policy and legislation promotes transition planning in an attempt to achieve more positive outcomes. For example, in the United States, the *Individuals with Disabilities Education Improvement Act of 2004* (P.L. 108-446) mandates that the student be actively involved in developing the transition plan. It also mandates that measurable transition goals are embedded in the Individualized Education Plan (IEP; referred to as the Individualized Program Plan or IPP in Alberta), appropriate transition assessments, coordinated activities, involvement from outside agencies, and transfer of rights when the child reaches the age of majority (Prince, Katsiyannis, & Farmer, 2013; Turnbull, 2005; Turnbull, Huerta, & Stowe, 2004). In the Canadian context, federal legislation is lacking regarding transition planning requirements, as the provinces have jurisdiction over education, with the exception of First Nation reserve schools. Provincial education guidelines in Alberta (ACYI,

2006; ACYI, 2007; Alberta's Commission on Learning, 2003; Alberta Learning, 2004), however, provide recommendations related to transition planning. The provincial recommendations suggest that transition planning should: involve collaboration among stakeholders with increasing student participation as they near transition; begin well in advance of the actual transition; be dynamic and ongoing, meaning that it is not a static document but one that is revisited and updated regularly; and include a written record of the plan. As there are no legislative mandates with accountability requirements these recommendations are aspirational rather than prescriptive, meaning that there are no consequences for not following these guidelines.

Further, despite best practice recommendations for multi-stakeholder planning, research indicates that parents often feel isolated in the planning process and experience school and community agencies that provide minimal input throughout their child's transition from high school (Hetherington et al., 2010; Wehmeyer et al., 1999). Parents also indicated being overwhelmed and under-informed about the process of transitioning, often seeking out information from support groups without help from school personnel (Martinez, Conroy, & Cerreto, 2012). Since the scope of care needs are greater and connections to resources outside of the family home are limited, the parents of young people with ID have exceptional caregiving responsibilities that are more complex, extensive, and ongoing than typical caregiving responsibilities (Blacher, Kraemer, & Howell, 2010). Traditionally, mothers take on the primary duties of parenting and family management (Craig, 2006; Craig & Mullan, 2011) and, therefore, are often the main sources of support across the lifetime for their children with ID.

Individuals with ID are at risk for poor outcomes when transitioning to adulthood unless adequate supports are put in place (Foley et al., 2013). Despite the noted importance of parental involvement in both the experience of transition as well as the outcome of the transition, we found no Canadian studies that focused on mothers' experiences in supporting the transition from high school of young people with ID. Therefore, the purpose of the current study was to investigate mothers' experiences in supporting their children with ID through the transition from high school to adulthood within the Alberta context. This study is informed by Enhanced Critical Incident Technique (ECIT), as a way to identify factors that supported and interfered with the transition process as well as what would have made the process more effective from the perspective of two mothers' of youth with ID.

Method

Case Study Design

To investigate factors that contributed to mothers' perception of the process of supporting their child's transition from high school to adult life, we used exploratory case studies. We used case study to describe the phenomenon of mothers supporting their child in moving from high school to adulthood, addressing the contextual complexity of the real-life events (Yin, 2009) through the specific instances of their experience as examples of the class of maternal experiences in supporting their children through the process of transitioning into adulthood which is the bounded system for this case (Merriam, 1998). This case study research helps to voice the unique perspectives of these mothers, whose involvement continues after students graduate, helping us to better understand the impact of current transition practices on individuals with disabilities and their families (Brantlinger, Jimenez, Klinger, Pugach, & Richardson, 2005). In

each case, we attempt to understand the particular experiences of the mothers who have lived through this phenomena (Stake, 1995). ECIT framed the process of data collection and analysis (Butterfield, Borgen, Amundson, & Maglio, 2005; Butterfield, Borgan, Maglio, & Amundson, 2009; Flanagan, 1954); ECIT focuses on understanding the factors that facilitated or hindered the process of navigating a specific situation through semi-structured interviews—in this instance, supporting a child in the process of transitioning from high school to adulthood.

Participants

The mothers of two students with ID who transitioned from high school within one year of the interview took part in one-on-one interviews. After receiving clearance from the Conjoint Faculties Research Ethics Board (CFREB) of the University of Calgary, participants were recruited from a local transition fair. We think it is important to note that although the study was open to parents generally, only mothers chose to participate. We also obtained descriptive information to provide context for their experiences due to the broad range of functioning observed across individuals diagnosed with ID. Only descriptive information necessary to assist the readers' understanding of these mothers' experiences in supporting their individually unique child is provided. Both mothers reported that their children received special education services during high school. Although the services each student received varied in terms of focus and intensity, generally they consisted of individualized supports, modifications to general curriculum outcomes, and one-on-one or small group instruction. Both mothers described programming as primarily segregated from the mainstream classroom with the majority of their child's time spent in resource or special education rooms. Both youth qualified for a local program aimed at supporting individuals with developmental disabilities that generally requires low intellectual functioning as well as significant adaptive functioning impairment for program eligibility. Each case study brought a unique perspective to our research, highlighting the perceived complexity of the process of supporting a child with ID in transition from high school to adult life. Their perspective as mothers who have lived through the process of supporting their children in transitioning from high school is important in understanding their individual experiences of this process, providing an emic or insider's perspective to this experience (Merriam, 2009).

    Case Study: Sandie. Sandie (pseudonym) has a son who was diagnosed with a mild ID and lives in a rural setting who described herself as a married, stay-at-home mother who attended post-secondary school for one year. She noted that she was very involved in her son's elementary and high school education. Her son attended a small, rural school with individualized programming. Sandie described her son's educational environment as having minimal integration into the mainstream classroom. At the time of the interview, her son was attending a postsecondary education program focusing on employment preparation. He was living independently in the postsecondary residence with regular check-ins and support from his parents.

    Case Study: Laura. Laura (pseudonym), has a daughter with a severe ID and lives in an urban setting. She is divorced and co-parents with her daughter's father; she has a post-secondary degree and works full time. Laura described her daughter's high school as highly supportive with small class sizes and a high assistant-to-student ratio. Laura's daughter currently lives in a supported group home.

Data Collection

Our main source of data came from the interviews we conducted individually with each of the two participants. The interview questions for this case study research were informed by ECIT (Butterfield et al., 2005; Butterfield et al., 2009; Flanagan, 1954) as the interview questions in this technique investigate what supported and hindered participants during a process. Both Laura and Sandie provided demographic information, described incidents that supported or hindered them while supporting their child's transition, as well as wish list items including experiences or resources that were absent but would have been helpful during transition. The interviewer asked clarifying questions to increase depth and clarification of answers the participants provided. The interviews were audiotaped and transcribed verbatim to preserve the accuracy of the information collected.

Data Analysis

Data was analyzed using the steps of the ECIT including selecting the frame of reference (i.e., experiences of supporting a child with ID in transitioning out of high school), forming the categories and determining the appropriate level of specificity and generality to report (Butterfield et al., 2005; Flanagan, 1954). The first and second authors independently read through the interview transcripts highlighting critical incidents, which include supporting factors, hindering factors, or wish list items, identified by the participants. Incidents were identified as a factor if they either helped or hindered them in effectively supporting their child in transitioning from high school and were identified as a wish list item if they indicated that it would have been helpful if it existed. Then, under each area (supporting, hindering, wish list), the first two authors independently grouped participant statements into categories or themes in a table using an inductive process by considering critical incidents (both supporting and hindering factors) and wish list items that were similar in nature across the two case studies. They compared categories for consensus and combined categories with overlapping content, referring back to the purpose of the data collected. Additionally, the first and second authors referred directly to the transcripts to ensure that the final categories aligned with the participants' wording (Butterfield et al., 2005; Butterfield et al., 2009; Flanagan, 1954).

Results

Supports

Table 1 displays the mothers' perceptions of the factors that supported a successful transition. Selected participant quotes are included to highlight common themes between the case studies which included parental advocacy, institutional supports, serendipity, as well as placement fit and continuity of care.

   Parental advocacy. Advocacy is defined in disability research as the act of speaking and acting on behalf of another person to help address their preferences, strengths, and needs (Wolfensberger, 1977). Strong parental advocacy born out of parental responsibility was perceived to facilitate success during transition, and quotes that were grouped under this heading exemplified attempts by these mothers to influence the supports and services that their children received. Both of the mothers reported active involvement in their child's transition

Table 1

Parents' Perceptions of Supports for a Successful Transition

Theme	Example
Parental advocacy	"So I started making the calls myself because I wanted to see what was going on" (Laura).
	"So I started looking online as much as I could in regards to, ok, what is out there for [son] academically after high school?" (Sandie).
Institutional supports	"The nice thing about [daughter] being at school is the teacher would email me every day and tell me how she was doing" (Laura).
	"So, I guess they [school staff] did have to play a part in that—they did have to fill out paperwork for post-secondary, so I guess they did do that" (Sandie).
	"We were fortunate to get good advice [from an agency social worker] to get started early" (Laura).
	"That [peer group for youth with special needs] was very supportive!" (Sandie).
Serendipity	"Well, as luck would have it, a spot came up right away" (Laura).
	"That was just by chance that she happened to know of a place that I didn't even know about" (Laura).
Placement fit & continuity of care	"Which I really liked the way they [service provider] did that, they didn't just fill a spot. They wanted to make sure she was a good fit with the roommate" (Laura).
	"I said, 'Would you hire the worker that's working with her now' and they said, 'Absolutely. We want someone who knows her. ' So that was great that they did that and the funding just came into place" (Laura).

process and described seeking out information by researching online and making phone calls to service providers. They also expressed feeling as though they needed to be strong advocates in order to ensure that their children would get adequate support after finishing high school. For example, Laura said, "I think, unfortunately, with these guys, they can't speak for themselves, and they can't communicate, so they need somebody to step up and say, 'No, you can't do that' or 'This is what she's doing." The steadfastness of Laura's advocacy was emphasized when she said that supporting her daughter was, "something that I would just do for her. Like it just comes naturally, I guess. If I'm mad about something or if something isn't right, I try and make it right."

Likewise, Sandie reported feeling fortunate that she was able to be highly engaged in her son's transition process: "I'm lucky because I have had more time because I am a stay-at-home mom now, and so, from that perspective, I probably had more involvement with [her son] and his education." She went on to note that "we definitely had to push, from our perspective, to get [her son] the things we felt he needed going forward." Sandie also perceived her advocacy to have a positive impact on staff at her son's school by increasing their knowledge of the transition process for students with special needs. For example, she described working closely with a specialized teacher throughout the transition process offering ongoing information to the teacher about what her son required in preparation for transition out of high school:

And I think we have made good change going forward. The people that we dealt with at the high school, especially the specialized teacher, we kind of changed her life as well, in bringing issues to her that perhaps she didn't see in grade 9 to when he [son] graduated, so that is a comfort. (Sandie, interview)

Sandie's description of her process of seeking out services and information for her son, provided his teacher with new information about services and what he needed in order to be prepared for transition, and she believed that this would inform the way the teacher supported students in the future.

These mothers spoke clearly about being committed caregivers who had their children's best interests in mind. They also emphasized how their continued activities were required to influence decision-making and the provision of supports for their children throughout the transition process; for this reason, strong parental advocacy appears to be play an important role in successful transition.

Institutional supports. The mothers perceived school-based supports as well as support from agencies and local professionals to be important during their child's transition. Laura reported feeling comforted that her daughter was in a safe high school environment where there was daily communication with school staff. It was also helpful that Laura's daughter was in the same place for four years with a low student to teacher ratio. Furthermore, she said that there were regular meetings at school to discuss potential group home placements her daughter after graduation. Referring to external supports, Laura said, "I think when [my daughter] was 16 [a social worker] said, 'You have to get the process started early. Don't wait until she is 18." Receiving advice to complete paperwork early from a person who understood the adult services system was a pivotal moment in the transition process as, "we could have been in the dark and we could have been one of those ones that said, 'Ok, school's over now, now what?'"

Sandie had a less positive experience working with her son's school and had difficulty identifying school-based supports that facilitated transition. Upon further inquiry, she reported that school staff supported the transition process by following through on recommendations that she brought to their attention and by completing necessary paperwork. However, Sandie felt that a community-based peer group for youth with special needs was beneficial for her son, as it provided him with an opportunity to interact with his peers:

[My son] saw a psychologist in grade 9/grade 10 and so through the psychologist we were able to find a group … for kids with special needs, or basically any social issues, whether it's Asperger's or whatever your disability might be, so that was really beneficial. Um, it was wonderful! That was very supportive. Finally he was able to be with people who are like him … it gave him an outlet to talk about what he was doing in his life because [he] doesn't have any friends, and so those were his friends and, you know, they were just accepting, right? (Sandie, interview)

Both of these mothers found that when institutions, such as schools or other community agencies engaged in activities related to transitions by completing paperwork or supporting social skill development, they felt supported in preparing their children for the transition to adulthood. These school-based and other professional supports proved to be important during these mothers' experience with their child's transition out of high school.

Serendipity. Both mothers recalled chance events, those that they did not actively seek out and were not part of specific agency interactions, during the transition process that positively

impacted their experiences. For example, Laura reported that, "it was just by chance that [an acquaintance] happened to know of a place [offering support services that was not on the official list] that I didn't even know about." Laura felt that unexpectedly meeting someone who had useful information was an experience that facilitated her daughter's transition. Furthermore, she expressed perceiving good fortune to play a role in successful transition by saying, "because I think we really lucked out. I don't know how it works with other people, but I think we really lucked out in getting her a really good place with somebody that we really like." A similar theme emerged from the interview with Sandie, as she reported that there happened to be another family in her neighborhood who had recently supported their child with special needs through the transition to adulthood, so she was able to ask questions about how they dealt with issues such as guardianship.

Chance or fortuitous access to informal supports facilitated successful transition for both mothers in this study. They highlighted that these events occurred by chance as opposed to by their intentional actions, ultimately helping them in the transition process and potentially improving outcomes for their child.

Placement fit and continuity of care. Laura also felt that appropriate placement fit and continuity of care were important during her daughter's transition from high school to adult services. She appreciated that a service provider took time to ensure that her daughter was a good fit for a potential residential program before making decisions about the placement noting that "they wanted to make sure she was a good fit with the roommate." The service provider also agreed to hire a staff member who had already been working with her daughter to provide continuity of care. These were significant events for Laura during transition because her daughter was already going through a great deal of change at the time and was comforted by working with a familiar person in her new placement.

This client-centered transition planning supported placement fit and continuity of care for Laura's daughter as she transitioned from high school to a supportive placement within the adult services system. However, the same theme did not emerge from the interview with Sandie, perhaps because the process of transitioning from high school to post-secondary education is different from the transition to more supportive adult services. Sandie's experiences will be taken up in the next section when we elaborate in more detail the hindrances of each mother's experiences.

Hindrances

Table 2 outlines the themes that the mothers identified which hindered the transition process out of high school for their children with an ID. Common themes emerged from the parent interviews, indicating that the mothers involved in this study perceived similar barriers to success when supporting their children through transition. Selected participant quotes are included to highlight common themes between the case studies which included burden of parental advocacy, poor communication and follow up' limited transition planning and programming' poor placement fit, paperwork stress, and system strain.

Burden of parental advocacy. Both mothers reported facing numerous challenges in their attempts to advocate on behalf of their children. The transition planning process was reportedly difficult and anxiety provoking for both parents. Laura said,

> There seemed to be a lot of on the phone, asking, I just remember taking that list [of potential resources]; I think it was the end of April and school was going to end at the end of May. I remember taking that list and just calling them all and emailing them all and just going through, panicking.

Sandie also reported having to "push" to make things happen for her son and noted that the majority of the responsibility for transition planning fell back on her: "It was kind of left up to us, like 98% of it, to try to find those things [supports] and bring them to school so that we could work on a plan going forward."

Table 2

Parents' Perceptions of Hindrances to a Successful Transition

Theme	Example
Burden of parental advocacy	"I was told, 'You can't make the referral yourself. The PDD worker is going to make the referral" (Laura).
	"So we definitely had to push, from our perspective, to get [son] the things we felt he needed going forward" (Sandie).
Poor communication & follow-up	"The PDD worker was supposed to get back to us…but I didn't hear back from her and it wasn't happening fast enough for me and we were getting very anxious that school was ending and there was nothing for her" (Laura).
	"I think there is a disconnect between head office and our community because they are not here every day, and so we do not get support every day. In a bigger center…you will have more resources in your school that are available" (Sandie).
Limited transition planning & programming	"Um, well it's not clear on the funding, I'm still not clear on the funding of how it works" (Laura).
	"Okay how do we go about this? Where do we go to get him to apply for PDD? Where do we go to apply for AISH? Where do we go for all of that stuff?" (Sandie).
	"The school was quite insular, which makes a very safe place, but it didn't really prepare her for after school or what's going to happen outside of school" (Laura).
Poor placement fit	"She didn't like it …. and so it didn't really fit and she was just really unhappy. And so I was unhappy" (Laura).
	"We had to kind of push to get … things at the school because we didn't feel that his learning should be limited to practicing laundry, we wanted him to get educated, he was still in high school, right?" (Sandie).
Paperwork stress	"I guess things that would hinder, I guess just basically stress in just trying—paperwork and stress. Paperwork causes stress and just trying to figure out everything on your own" (Sandie).
System strain	"I think PDD workers are very over-worked" (Laura).
	"The turnover is great. We went through so many caseworkers and they're so overloaded … they've got so many things on their plate" (Laura).

Note. AISH = Assured Income for Severely Handicapped; PDD = Persons with Developmental Disabilities

Laura also experienced barriers in the transition planning process due to limits on the authority that she had to make decisions or take action regarding her daughter's care. For example, she was told, "You can't make the referral yourself; the PDD [Persons with Developmental Disabilities] worker is going to make the referral" when seeking out potential placement options for her daughter after graduation. Laura had to wait for someone else to take action regarding her daughter's care, leaving her feeling "uncertain" and "worried" about the future.

Both mothers' expressed that their continued efforts to influence decision-making and the provision of supports for their children throughout the transition process resulted in a burden that impacted them personally and left them feeling strain and stress due to the level of work required. There was also a level of uncertainty of how to successfully navigate the process and limits to what they could accomplish through their advocacy that added additional distress.

Poor communication and follow-up. Issues with poor communication and lack of follow-up were reported as hindrances to successful transition. Laura felt that decisions about transition were not communicated to her quickly enough and that service providers did not work together to effectively support her daughter: "the PDD worker was supposed to make the contact and then let us know where she would be going. But I didn't hear back from her." Laura was especially concerned because "It was so different from what she was doing at school [compared to] the day program, and if there was more communication between the day programs and the school, I think it would have helped." Sandie also identified a disconnect between services and suggested that perhaps school personnel were not equipped to support her son through the transition process as they did not have access to relevant information noting that "I think that if they would have had more information to come to the table with, as opposed to us bringing stuff to the table, could have been helpful."

The challenges that service providers and school systems have communicating effectively with each other as well as the limited amount of information that school personnel have about transition were reported to impede the transition process for these mothers and their children.

Limited transition planning and programming. Both mothers perceived their children's transition to adulthood to be hindered by unclear transition planning processes and inappropriate transition programming in school. Information about funding for services, including placement and specialized support, was specifically described by parents as unclear. Laura said,

> We never see the costs. We have no idea how much it costs, but when there is funding cutbacks—for example last year when the government was saying … there was a big to-do about the cutbacks. Well, we were kind of thinking in the dark saying, "How is that going to affect her [my daughter]?

Sandie also expressed difficulty trying to access information about services for her son, including where to go to apply for PDD and Assured Income for the Severely Handicapped (AISH). She reported, "I guess there was no one really that came to us and said, 'What can we do to help?' You are basically left to do it on your own." Despite taking an active role in planning for their children's futures, both parents reported feeling uncertain about the transition process.

In terms of transition programming in school, Laura reported that she would have liked her daughter to be involved in activities that prepared her for adulthood; however, a work experience program in high school ended the same year that her daughter was enrolled:

> When we first went to [high school], they had an employment option where they would take the kids out into the community and they would do small jobs. They ended that the year that [my daughter] started and I think that would have been really helpful because school, it was very insular where she was. They didn't go out a lot. If that last year, they could have modeled what she would be doing in the year after that might have been helpful for her. (Laura, interview)

Furthermore, Laura reported that the school hindered her daughter's transition to adult life "because everything was done for her" at school, rather than addressing goals related to independent living skills that would have prepared her for life after graduation.

Sandie also reported a lack of transition programming in school, particularly when comparing her son's programming to that of other students his age. There was no transition plan related to his post-secondary goals that would have prepared him for what would be expected of him. She said,

> I don't know if it's the same everywhere. I think when it comes to kids with special needs they wash their hands of them. They are not important, is kind of how you feel, because I mean they are secluding them in another room, you know, okay now kids are planning for their post-secondary but our counsellor at our school really wasn't involved in our process. (Sandie, interview)

Both mothers felt that their child's school provided limited transition planning and preparation for adult goals. While both of these students have ID, they and their families had very different post-secondary goals. Despite having different goals, both mothers felt that the schools their children attended did not address their goals effectively through their transition planning.

Poor placement fit. Poor placement fit also hindered successful transition according to both mothers. Laura expressed that her daughter did not enjoy living in the first group home that she was placed in: "She didn't like it … It was mostly men who were the caregivers, and she was with two quite older roommates … so it didn't really fit, and she was just really unhappy. And so I was unhappy." The transition to this placement was difficult because there was not a good match between what the group home offered and the types of things that Laura and her daughter wanted.

Sandie discussed the additional challenges that she perceived living in a rural setting posed for placement fit. She said,

> We definitely didn't want [him] … to stay within a small rural community because his opportunities would definitely be less than there would be going forward in a bigger centre for him. So … we had to kind of push to get specialists to come out to support him academically and to try to get things at school because we didn't feel that his learning should be limited to practicing laundry; we wanted him to be educated. He was still in high school, right? And so to get those people to come out and help was a bit of a struggle because you know that costs money, right? (Sandie, interview)

Sandie reported that she faced obstacles when trying to access support for her son because there were few other students with special needs in the local school system. There was also a perceived disconnect between rural community schools and larger school boards, and information about transition for students with special needs was not available at the rural school that Sandie's son attended. Overall, Sandie perceived her son's high school placement to be a poor fit for his particular needs.

For both mothers, various aspects of their child's placement throughout the transition process lacked goodness of fit. When the placement fit did not align with their individual child's needs, the transition process was hindered.

Paperwork stress. Sandie perceived that an overwhelming amount of paperwork caused her stress and hindered the transition process. Sandie described how she felt frustrated by this process and chose not to reapply for services that she had accessed previously because she would have been required to redo all of the paperwork. "We basically had to do it all on our own because we didn't want to have to fill out any more paperwork than we needed to (laughs) because at this point your drowning it" (Sandie, interview). While Laura noted completing paperwork, the stress of paperwork was more in waiting for someone else to follow up on the paperwork as she attempted to find a placement for her daughter, noting that "I started making the calls myself because I wanted to see what was going on, and they would say, 'You need to be referred' or 'Yes, we have the referral." For these mothers both the amount of paperwork required throughout the transition process as well as the sometimes lengthy wait times in response to such paperwork added stress and impeded the transition experience.

System strain. Laura expressed that over-worked and under-resourced agency systems hindered her daughter's transition to adult life. She reported,

> "I know PDD tries to do that [walk people through the transition process] but they're so—the turnover is great. We went through so many caseworkers, and they're so overloaded. They just don't, they've got so many things on their plate." (Laura, interview)

Sandie noted specific strain in the school her son attended noting that "schools are going through lots of transition in regards to special education. The government seems to keep changing the rules on that." Additionally she noted that "there is a disconnect between head office and our community because they are not here every day, and so we do not get support every day" (Sandie, interview)

Laura's and Sandie's perspectives on the strain placed on the established social systems necessary for successful transition, including both the provincial social services and services provided through the education system, highlights their importance in the process and emphasizes that parents and youth transitioning to adulthood do not always have adequate support from these systems. For these mothers' a high degree of turnover in staffing, frequent changes in policy and procedure, and a disconnection between various levels of the systems hinder the transition process.

Wish List

The items that parents identified on their wish list were closely related to both the supports and the hindrances they experienced. Table 3 displays parents' perceptions of the resources they believe would have supported the transition process for their child with an ID. Selected participant quotes are included to highlight common themes between the case studies which included better communication; training and resources; as well as planful transitions.

Better communication. Both Sandie and Laura indicated that better communication about what to expect in the process and where they should go to find information would have eased the transition process. Specifically, Sandie indicated that she wished that government agencies and schools communicated more effectively so that school personnel could provide

Table 3

Parents' Wish List of Supports for a Successful Transition

Theme	Example
Better Communication	"It would be nice as you're kind of gearing up for this that they could have a package of information to present to parents, as opposed to parents feeling like we're having to do it all on our own" (Sandie).
	"More communication and more time to—there doesn't seem to be the process—I was unclear on what the process was" (Laura).
Training & Resources	"Or even have a seminar, a workshop. I would have gone to seminars. I would have gone to workshops. I would have signed up for a 12-week course on it. Just anything. I just need information. I don't know how to do this … I would have paid for a consultant" (Laura).
	"It was kind of left with the special education lady, and I didn't feel that she was getting supported enough either; she was trying to find some information for us, and we're bringing her most of that information, and I don't think the schools have the package, you know what I mean?" (Sandie).
Planful Transitions	"If that last year they could have modeled what she would be doing in the year after, that might have been helpful for her" (Laura).

more support to students and families. She noted that "it would be nice as you're gearing up for this that they could have a package of information to present to parents." A sentiment that Laura agreed with when she indicated she would have liked "more communication and more time to— there doesn't seem to be the process—I wasn't clear on what the process was."

Both mothers reported a desire for clearer and more detailed communication about the transition process. Without this communication they were left feeling unclear on the process causing them to assume an active and tiring role in seeking information and clarity. As such, enhanced communication about what to expect in anticipation of their child's transition to adulthood, information about this process, and details on where to find additional transition-related information was identified by these mothers as being helpful for future parents.

Training and resources. Both mothers expressed a desire for resources and/or training opportunities to help them better understand what they needed to do to support their children in transitioning between school-age services to adult services so that they could take the necessary steps to ensure a smooth move from high school to post-secondary goals for their children. To that end, Laura said "I would have gone to seminars. I would have gone to workshops. I would have signed up for a 12-week course on it. Just anything. I needed information. I don't know how to do this." She was eager for support including information packages clearly outlining what to do and how to do it or someone available to hire as a consultant. Further, Sandie suggested that school personnel need additional training and resources because she found them to be underprepared and unable to help her understand the process even though the school, especially during Individual Program Planning (IPP) meetings, is a logical place to support students and families in the transition process. She noted that it would make the most sense that support information "would come from the school because, obviously, you're meeting with the special education teacher anyways" (Sandie, interview).

Although Sandie's son went on to post-secondary school while Laura's daughter went on to a community group home, they both expressed a strong desire for resources and opportunities for

parent training regarding how to navigate the process.

Planful transitions. Although both mothers identified the need for planful transitions, only Laura specified what those transitions might look like. Laura spoke about two components to planful transitions that she wished had occurred throughout the transition process: preparation for demands of adult placement and preparation for the move. First, Laura indicated that her daughter's high school experiences did not prepare her for the demands she would need to meet after transitioning out of high school. For example, her high school programming did not prepare her to take public transportation, ensure she received correct change after a purchase, or communicate effectively with new people. She stated that, "if in that last year they could have modelled what she would be doing in the year after, that might have been helpful for her." Second, Laura noted that familiarizing her daughter to a new place gradually would increase her comfort with the transition.

For Laura advanced planning with an emphasis on specific learning opportunities designed to adequately prepare her child for the demands that she would later face in adulthood was desired. These aspects call for a planful transition that includes goals tailored to the needs and desires of the individual youth and family, the provision of opportunities and experiences to help the youth attain these goals, and a proactive connection with resources necessary for preparing the youth for what their future entails. While Sandie mentioned the lack of planful transitions in the hindrances section, she did not specifically mention planful transitions when discussing wish list items.

Discussion

While the mothers who participated in this study had differing situations, including living in rural/urban settings and supporting a child with mild/severe disabilities, they reported similar supports, hindrances, and wish list items. Parental advocacy, institutional supports, serendipity, as well as placement of fit and continuity of care emerged from the interviews as facilitators of successful transition. On the other hand, the burden of parental advocacy, poor communication and follow-up, limited transition planning, poor placement fit, paperwork stress, and system strain emerged as hindrances. Additionally, better communication, access to training and resources, as well as planful transitions were identified by the mothers in this study as supports they wished they had during the transition process.

Both mothers noted several areas of supports for a successful transition that aligned with best practices in transition planning. Most notably, both mothers indicated that they believed their active involvement in the process of supporting their children in the process of transitioning from high school was beneficial to the process. They also noted some areas that implicated other areas of best practice including involvement of agency personnel in locating support groups and supportive living placements as well as school staff involved in completing paperwork and communicating with the family. Research regarding best practices in supporting youth with disabilities in transitioning from high school to adulthood support the importance of involving parents and other agencies throughout this process (Haber et al., 2016; Mazzotti et al., 2016; Papay & Bambara, 2014; Test et al., 2009).

Overall, the findings of our study are consistent with results from previous research related to the hindrances and wish list items we identified (Stewart et al., 2010). In particular, both of the mothers indicated that school staff, community workers, and parents of children with ID often lacked important knowledge about the transition process and were unaware of how to

access appropriate services (Martinez et al., 2012), this included insufficient communication both with and between the school and agencies (Hetherington et al., 2010). Despite actively connecting to community agencies and discussing the upcoming transition with their children's school teams, these mothers felt lost and were in need of significantly more support throughout the process, indicating the limits of what they could accomplish through advocacy. Relatedly, both Laura and Sandie felt that the level of advocacy required of them was a burden, largely because they felt that they had to shoulder the process of navigating the transition from school with limited support from school systems and other agencies. When these mothers did access community support, they noted doing so without the help of school personnel, similar to the findings of other research (Martinez et al., 2012). In addition, both of the mothers desired a more planful process with a clear and guided approach to completing all of the steps necessary to prepare for their child's transition with better synergy between all levels of bureaucracy, a finding supported by previous research (Hetherington et al., 2010; Martinez et al., 2012; Wehmeyer et al., 1999).

It was notable that while the mothers involved in this study had many resources that should have supported their transition experiences including post-secondary education, socioeconomic status, English speaking, and significant time investment in their children, they reported many barriers to a positive and effective transition. The experience of these mothers suggest that families who do not have these kinds of resources, for example, parents who have special needs themselves, limited social support, financial difficulty, language or cultural diversity, may have even greater difficulty navigating their child's transition from high school to adult life. Laura and Sandie were able to seek out resources through the internet, case workers, and connections with people in their social circles. A mother, for example, who is new to Canada with limited English or who has functional limitations due to a mental health diagnosis may have difficulty accessing information effectively on the internet, accurately completing the extensive paperwork, and actively pursuing information from school personnel and case workers. Additionally, people in these families' social circles may be less likely to be able to provide the information and support that Laura and Sandie received. Consequently, some mothers' may be likely to experience even greater challenges in this fragmented process.

These mothers' experiences highlight the importance of considering the unique needs of youth and their families rather than instituting broad policies that are uniformly implemented. The two mothers in this study had different goals for their children, based on their levels of functioning and family values. For example, Sandie was unhappy with activities focusing on daily living skills because her son was preparing for postsecondary school, whereas Laura wished that her daughter had more training focusing on increasing independence in daily living skills. This finding is supported by research suggesting that all stakeholders need to be involved in transition planning and that transition planning should cover a wide range of goals guided by the needs and desires of individual students and their families rather than simply adopting a singular stance regarding transition planning and support that is applied universally (Hetherington et al., 2010; Landmark et al., 2010; Test et al., 2009).

Test, Bartholomew, and Bethune (2015) provided a summary of evidence-based practice related to transition that is written for high school administrators that includes suggestions for implementing supports related to better outcomes. These predictors follow the evidence-based transition planning information provided earlier such as student, parental, and agency involvement, transition programming, and work experiences. A cross-ministry working group (ACYI, 2007) created a detailed document outlining a protocol for transition planning for youth

who have disabilities. This document is closely aligned with the best practice literature; consequently, it would be beneficial for the ministry to promote this as a model of transition planning and to provide supports for school districts to ensure that they have the training and resources to implement this transition protocol. It would also be beneficial to provide information to parents so that they know what transition planning should entail so that they can advocate more effectively for their children. As Wiart and colleagues (2010 highlighted, there are significant differences in the philosophies and values of the provincial ministries involved in supporting students with disabilities in Alberta, including education and health. Consequently, it is imperative that these ministries collaborate to clarify pathways between these systems for parents and youth.

Test and colleagues (2015) highlight important information for high school administrators to consider in supporting students with disabilities as they transition from high school to adulthood that are relevant to the findings of this study. For example, general education and specialist teachers both need to have an understanding of best practices in transition planning and monitoring student transition goals (reference). School psychologists, who have specialized training in data-based decision making including assessment, intervention, and progress monitoring (Canadian Psychological Association, 2007; Williams, 2010) can be a resource in supporting transition planning through professional development and collaboration with teachers and families as they create and monitor goals (Kellems, Springer, Wilkins, & Anderson, 2016). Relatedly, it would be beneficial for school administrators to review current transition planning practices within their school districts in order to determine areas which require additional resources to meet the needs of this vulnerable population.

Recommendations for transition planning that have been outlined in provincial education guidelines for more than a decade, including Alberta's Commission on Learning (2003) and Alberta Learning (2004) continue to be aspirational in nature. Even with knowledge of best practices, the systems intended to facilitate transition continue to be disjointed, and efforts between parents, schools, and community agencies continue to be uncoordinated (Hetherington et al., 2010). These systemic problems are widespread, as there is evidence that students with ID in Canada, the United States, and abroad experience similar challenges in the transition from high school to adult life (Foley et al, 2013; Stewart et al., 2010). In the Canadian context, both provincial legislation and local policy to help mandate a more planful and systematic transition for students with ID and other special needs are lacking. The findings of this study suggest that putting in place mandatory, rather than recommended, provincial and local guidelines may help parents more effectively advocate for the transition needs of their children although regulations alone are not sufficient to ensure strong transition planning. Furthermore, clarifying transition planning processes and streamlining practices may help to bridge the existing gap between what should be happening and what is actually happening during transition.

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