

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

Abstract¹

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

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

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

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

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

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

Due to the lifelong challenges encountered by individuals with FASD, parents may be assisting their children with the aforementioned tasks, when children of typ-

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

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

The transition from emergent adulthood to adulthood for individuals with disabilities is a time of increased uncertainties and challenges (Arnett, 2000; Kim & Turnbull, 2004). There is a shift in parents' goals for their children, from a focus on education to an emphasis on employ-

ment, independent living, and social relationships (Henninger & Taylor, 2014). There is also a transfer from children's services into adult services. Parents of children with FASD face unique challenges procuring adult supports because of their children's capacity to over-represent their abilities (e.g., decision making) in comparison to other individuals with disabilities (Chudley, Kilgour, Cranston, & Edwards, 2007). Consequently, individuals with FAD may not qualify for developmental disability services or funding.

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

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

Methods

The current study employed a mixed methods research design and is part of a larger project regarding families of children with

developmental disabilities (Coons, Watson, Schinke, & Yantzi, 2016; Pepper, 2016; Watson, Coons, et al., 2013; Watson, Hayes, et al., 2013). Semistructured interviews were conducted and the Questionnaire on Resources and Stress – Friedrich's Version (QRS-F) was administered (Friedrich, Greenberg, & Crnic, 1983).

Mixed Methods Research

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

Qualitative Interviews

Semistructured interviews were conducted with adoptive parents of adult children with FASD, following a basic interpretive approach (Merriam, 2002), an inductive strategy used in an effort to understand how participants make meaning of a given situation. The interviews consisted of 22 open-ended questions, and prompts were used if deemed necessary. Example questions included "When you think about the future, what do you see?" and "In what ways have you changed and in what ways do you see yourself differently as a result of your child having FASD?" Participants were asked prompting questions when required. For example, "Can you please run me through your morning routine?" was a prompt for the question, "Please describe a typical day in your home." No close-ended questions were asked to prevent leading the participants in their answers. The interviews were conducted by the lead researcher of the present study, in addition to three other researchers who were

part of the larger family project. Interviews were conducted at a time and place convenient for participants (e.g., coffee shops or family homes). Parents were interviewed separately or together, based on their preference. Follow-up questions were asked via email or telephone if questions arose during the qualitative analysis.

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

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

Questionnaire

The QRS-F was provided to participants for completion either in person or via Canada Post (Friedrich et al., 1983). The QRS-F measures aspects of perceived stress as experienced by families with a child with a disability. The QRS-F has been used with parents of children with a variety of developmental disabilities, including parents of adult children (e.g., Ben-Zur, Duvdevany, & Lury, 2005; Honey, Hastings,

& McConachie, 2005). Previous research has demonstrated internal consistency and reliability, with a reliability coefficient of 0.95 (Honey et al., 2005; Vijesh & Sukumaran, 2007). The QRS-F contains 52 items assessing four areas of stress related to: parent and family problems, parental pessimism about their child's future, child characteristics, and the physical incapacity of the child. The answers are provided in a true or false format. Higher scores indicate higher levels of perceived stress and lower scores vice versa. A score ranging from 0–17 indicates a mild level of perceived parental stress, a score of 18–34 indicates a moderate level, and a score of 35–52 indicates a severe level of stress (Ben-Zur et al., 2005; Friedrich et al., 1983). An example item is, "The family does as many things together now as we ever did."

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

Participants

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

ger family project, but for the purpose of this study, only the data pertaining to the parents of adopted children in the young adult age were examined. (See Table 1 for a summary of additional participant demographics.)

Table 1. Participant Demographics

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

Results

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

Parents reported on the QRS-F that they were, on average, experiencing moderate levels of total perceived stress ($M = 24.6$, $SD = 9.5$).

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

Housing and Transition Into Adult Housing

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

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

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

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

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

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

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

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

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

Managing Money/Finances

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

"There was always a reason why she wasn't eligible": Difficulty accessing adult services.

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

IQ criteria notwithstanding, a formal diagnosis of FASD is also often required to obtain funding. It can be particularly difficult for adult children to receive a professionally recognized diagnosis of FASD because of issues

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

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

"If you gave the kid \$100, it would be gone": Adult child difficulty procuring and managing finances.

Parents of adult children who had obtained financial aid like ODSP referred to it as "a double-edged sword" because any income adult children made while working was deducted from their automatic income. It was more cost effective for their children to subsist on ODSP alone than to work through initiatives like Ontario Works. Stacey discussed how ODSP created a "catch-22" for her twenty-two-year-old adopted son:

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

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

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

Parents reported attempting to intercede to help their children with financial tasks such as putting money away to save, paying the bills, or keeping track of bank accounts. For example, Stephanie described her process of ensuring her son's rent is paid and "letting so much money in his account to use." She did not believe he would ever pay rent on his own. Parental financial intervention can be diffi-

cult if the child resists, as parents do not have legal control over their adult children (see sub-theme *Difficulty Managing Change*). Parents also described the tendency of their children to give money to others amongst a host of other risky behaviours that are barriers to the maintenance of a normative adult life. The individual behaviours and characteristics of emerging adults with FASD varied; however, there were two patterns of behaviours that emerged from the interviews: risky behaviours and employment instability.

Individual Characteristics

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

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

Furthermore, parents reported that their children's desires to fit in and follow others were chronic. Emily, an adoptive mother, described her daughter "getting hurt over and over again and [she] just doesn't get it." The propensity to be easily led by others can lead to engagement in

criminal activity. For example, Peter described his son's behaviours while living on the street: "He will go and put himself in extreme[ly] dependent situations, very exploitive situations. When he's living on the street with...people who exploit him for selling drugs."

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

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

"She seems to be able to find jobs. She has trouble holding on to them": Difficulty maintaining employment. The majority of parents reported a pattern of sporadic child employment. The children often had multiple jobs in one year. Jocelyn recounted how her daughter had 18 jobs between the age of 18 and 24. Parents described how their children were always enthusiastic about a newly acquired

work position, but soon discovered that they were "in over their heads." Gabrielle described the emergent work cycle: "They're so anxious to please and so anxious they have this new job, they're going to do so well. But with every passing day the expectations are more and more and then they realize they can't do it."

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

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

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

However, even when their adult children with FASD addressed interest in obtaining employment, many parents emphasized that employ-

ers were not willing to train or supervise them, and noted that employers often told parents that dealing with their children at work was more like “babysitting than employment.” As Stacey described:

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

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

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

Discussion

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

It appears that the adopted adult children with FASD were encountering demands consistent with those encountered by the general adult FASD population (e.g., birth families). For example, the majority of parents reported that their children were living within the family’s home for at least one period of time during adulthood (i.e., dependent living), which is con-

sistent with studies citing that 69 to 80% of individuals with FASD continue to live within their parents’ home (Clark et al., 2008; Streissguth & Kanter, 1997). The tendency for adult children to remain in the home as a result of their inability to transition into adulthood is also consistent with the literature on emergent adulthood (Arnett, 2000). Research on emerging adulthood in normative populations indicates that although independent living is associated with adulthood, continued co-residence with parents during emerging adulthood slows down the process by which an individual moves towards becoming a self-sufficient and independent person (Kins & Beyers, 2010), a requirement for adulthood (Arnett, 2000). However, because of the primary and secondary challenges associated with FASD, individuals with FASD appear to not be able to progress past the emerging adulthood stage or become fully self-sufficient, and instead require support to be interdependent, as opposed to fully independent, in society. They are thus unable to fully transition to adulthood, as it is normatively conceived.

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

It appears that children with FASD were also unable to move out of the emergent adulthood life stage into adulthood. The children were struggling with financial independence, as well as making independent and responsible decisions, all of which are essential to adulthood (Arnett, 2000). Furthermore, they were continuing their pattern of sporadically living within their parents’ homes, or never leaving the home at all, well past the age of 25 (i.e., the end of emergent adulthood). Fifty percent of partici-

parents' children were over the age of 25, but they still exhibited behaviours consistent with emergent adulthood. Parents reported attempting to step in and assist their children with their transition into adulthood, which was described as a source of perceived parental stress.

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

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

Another area of parental concern was qualification for assistance like ODSP. There are support services available to adults with developmental disabilities, including FASD, in Ontario. Services like Ontario Works help individuals who are in financial need acquire a working position (Ontario Ministry of Community and

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

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

According to the QRS-F, parents were experiencing moderate levels of perceived stress, and were generally lacking in the access to and utilization of resources. These findings were

supported and developed further in the interviews. The moderate discrepancy between parents' demands and resources suggests they are adjusting to their children's transition into adulthood, but clearly parents require additional aid to facilitate the transition to adulthood and consequently lower their stress levels.

Considerations and Future Directions

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

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

The second limitation was the lack of information on the QRS-F for eight participants. All participants completed the questionnaires, but

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

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

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

Conclusion

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

Key Messages From This Article

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

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

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

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