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Expectations of Youth With a Fetal Alcohol Spectrum Disorder in Adulthood: Caregiver Perspectives

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Abstract

There are limited data about adults who have fetal alcohol spectrum disorders (FASD). Caregivers of youth with FASD (N = 16) participated in telephone interviews that included the open-ended question, "What kind of adult life do you think they will have?" A total of 57 unique responses were made to the question. These responses were grouped together independently by participants. Grouping data were analyzed using multidimensional scaling and cluster analysis. It is noteworthy that as well as highlighting concerns, participants also highlighted youths' assets and hope for them as adults. Caregivers' concerns about the future needs of their youth mirrors the literature on needs and expectations of adults with FASD. This consistency reinforces the lack of research attention to adults' needs from caregiver perspectives. Participants also revealed deep concerns about their youth's futures. Despite being committed to caregiving, caregivers indicated that they will not be able to do it well enough or long enough to keep their adult children from having serious problems.

Fetal alcohol spectrum disorders (FASD) are a significant cause of compromised child and youth development (Bell et al., 2016). Canadian estimates of FASD range from 0.26 to 26.9% (Ospina & Dennett, 2013; Pei, Tremblay, McNeil, Poole & McFarlane, 2017). The most frequently used Canadian estimate is 9.1 per 1,000 births (Health Canada, 2006). Effects of prenatal exposure to alcohol range in type and severity but manifest as lifelong challenges. Modifications to living and learning environments increase the opportunities for optimal growth and functioning, but underlying conditions do not disappear.

There is limited knowledge about the issues faced by adults with FASD (Chudley, Kilgour, Cranston, & Edwards, 2007). Few diagnostic and intervention protocols or programs exist for them (Temple, Ives, & Lindsay, 2015). Yet with growing awareness, early identification and diagnostic services, the effects of prenatal exposure are more frequently identified. With this visibility it is increasingly important to meet the needs of youth as they mature into adults with FASD (Popova, Lange, Burd, & Rehm, 2015). The purpose of the present study is to identify anticipated service needs for adults with FASD from the perspectives of caregivers on youth.

Literature Review

Fetal alcohol spectrum disorder can be diagnosed in adults based on both medical and neurodevelopmental assessment (Cook et al., 2016). The medical assessment includes social and health history with a physical exam. In addition, confirmation of prenatal alcohol exposure is necessary unless all three facial features (distinctive shape and size of palpebral fissure, philtrum and upper lip) are present. A neurodevelopmental assessment indicating severe impairment in three domains is required. These domains include motor skills, neuroanatomy/physiology, cognition, language, achievement, memory, attention, executive functioning (impulse control and hyperactivity), emotion regulation, social skills and communication (Committee on Substance Abuse, & Committee on Children with Disabilities, 2000; Kodituwakku, 2007; Rangmar, Sandberg, Aronson, & Fahlke, 2015; Streissguth et al., 1991). Given the persistence of neurological deficits as well as behavioural and social challenges, youth often require ongoing support (Barr, et al., 2006). Developmental changes in early adulthood as well as the service gaps for adults with FASD and the emotional experience of planning for the child's future as an adult are described in the following three sections.

Developmental Changes

Transition-aged youth with FASD do not mature mentally, emotionally or socially at the same pace as they do physically (DeJoseph, 2011). As their bodies grow, others' expectations increase putting them in situations for which they are not prepared (Denys, Rasmussen, & Henneveld, 2011). Underlying challenges persist but manifest differently as differences from typically developing peers become more apparent (Brownell et al. 2013; Jirikowic, Gelo, & Astley, 2010). For example, communication problems are reflected in socio-behavioural challenges (Kelly, Day, & Streissguth, 2000; Kully-Martens et al., 2012) and acting "younger" than one's age (Åse et al., 2012; Kully-Martens et al., 2012;). Unsafe situations with "older" peers raise chances of perpetrating or being a victim of crime (Denys et al., 2011). Difficulties with impulse control may increase risk of problematic substance use or self-harm (O'Malley & Huggins, 2005). Finally, challenges associated with inattention or cause and effect reasoning are associated with learning and behavioural problems at school (Millians, 2015) as well as in a job (Kalberg et al., 2006).

In a large retrospective study of adults with FASD it was noted that 1 in 5 was raised by a biological parent and half had been confined within a justice or health care setting (Streissguth, et al., 2004). Substance abuse and depression were the most frequent mental health needs identified (Famy, Streissguth, & Unis, 1998; Chudley et al., 2007). Relative to adults without FASD, they were more likely to have been unemployed and in receipt of disability benefits.

Service Needs

Adults with alcohol-related disabilities require moderate to high levels of support (Clark, Lutke, Minnes, & Ouellette-Kuntz, 2004). As an adult, it is difficult to obtain a diagnosis. Barriers include the relative lack of diagnostic expertise, navigating the health system to find assistance, as well as doing paperwork and getting to appointments (Denys et al., 2011). Importantly, it is challenging to obtain information from a parent about prenatal alcohol exposure (Chudley et al., 2007). A comprehensive multidisciplinary assessment and diagnosis also identify the specific needs of each individual as well as services that are matched to meet those needs. The diagnosis is necessary to access services.

Most FASD programs are not equipped or funded to deliver services to adults (Petrenko Tahir, Mahoney, & Chin, 2014a). Adults with FASD who receive services often do so through generalist disability, health and justice systems. Professionals working with adults in these systems are less often FASD-sensitive (Petrenko et al., 2014b). Without specialized preparation many are legitimately uncomfortable working with FASD (Caley et al., 2008). As a result, adults rarely receive targeted intervention or support (Paley & O'Connor, 2009; Spohr & Steinhausen, 2008). Those without networks to help with general decision-making, residential support and direct assistance, such as obtaining medical and social services (Streissguth, Barr, Kogan, & Bookstein, 1996) will become isolated (Clark, Minnes, Lutke, & Ouellette-Kuntz, 2008).

Reliance on Caregivers

Plans for children when they became adults are important to caregivers. Many caregivers worry a great deal about what their adult lives may be like (Clark et al., 2008; Michaud & Temple, 2013; Watson, Hayes, Coons, & Radford-Paz, 2013). The process of determining what the youth could or would do, as well as what they are unable to do, as aging adults is very stressful (Jirikowic, Olson, & Astley, 2012; Paley, O'Connor, Frankel, & Marquardt, 2006). Many caregivers decide to remain on as service coordinators and advocates as well as sources of residential and personal support (Clark et al., 2008). Among those caregivers the prospect of open-ended and high levels of involvement and responsibility is substantial (Michaud & Temple, 2013; Mukherjee, Wray, Commers, Hollins, & Curfs, 2013).

Method

Concept mapping is an approach to the quantitative analysis of qualitative data. The main benefit of concept mapping compared to other qualitative approaches is that multiple participants organize the data and together determine the thematic structure. Concept mapping has been used in program development (Trochim & Kane, 2005), theory development (Rosas, 2005) and program evaluation (Markham, Mintzes, & Jones, 1994). It has also been used with different stakeholders in social work such as students (Chun & Poole, 2009), practitioners (Osmond & Darlington, 2005) and clients (Brown, 2007). In the present study, five steps for developing a concept map were followed including: (a) determination of the focal question and population from which sample was drawn, (b) collection of participants' responses to the focal question, (c) provision of all participants' responses to participants for grouping into concepts, (d) statistical analysis of participants' grouping of responses, and (e) construction of the concept map.

Focal Question and Sample

The study was conducted in partnership with a local clinic and community network of professionals and caregivers to children and youth with a FASD. The question was focused on service planning needs for youth and adults with FASD. Email advertisements were sent through the network with the request to share with any individuals who might be interested in participating. Interested individuals were asked to contact a member of the research team by telephone.

This study was focused on outcomes caregivers anticipated for their youth as adults with FASD. For this reason, individuals who had cared for a youth over the age of 10 years who had a diagnosis of FASD or was suspected to be affected, were invited to participate. Potential caregiver participants with a youth who was suspected of having FASD were screened prior to inclusion using the Neurodevelopmental Screening Tool (NST; Nash, Koren, & Rovet, 2009; Nash, et al., 2006). This instrument, based on preliminary findings in support of a behavioural phenotype for FASD, was used to score responses to several questions about a child's behaviour (https://ken.childrenshealthcarecanada.ca/xwiki/bin/download/FASDScreeningToolkit/A+Novel+Screening+Test+for+the+Behavioral+Phenotype+of+FASD/TheNeurobehaviouralScreeningToolRevised.pdf).

Participants' Responses to the Focal Question

When interested individuals contacted a member of the research team by telephone, each was provided an overview of the study and information about what their involvement would include. Following receipt of verbal consent, in accordance with the institutionally-approved research protocol, an interview was administered by telephone. The interview included several demographic questions. If a participant cared for a youth who was suspected of having FASD, the NST was administered. The interview also included several open-ended questions, of which the following was the focal question for the present study: "What kind of adult life do you think they will have?" Following the interview, the responses were scored using the NST and responses from participants below a minimum cutoff score were excluded from the analysis. Scores below the cutoff suggested that the child did not fit the behavioural phenotype. Data from participants who had not cared for at least one child who fit the phenotype were excluded.

In total, 16 participants had cared for a youth with a suspected or confirmed FASD who was over the age of 10 years. Together, participants cared for 24 youth. Seven youth were aged 10–14, 11 youth were 15–19, and 5 were 20 years or older at the time of interview. Participants included aunts, birth parents, grandparents, foster and adoptive parents. One male participated. Their average family incomes were evenly split between less and more than $50,000.

Grouping of All Responses Returned to Participants Into Concepts

Responses recorded by hand during the telephone interviews were assembled into a master list. The list of responses was independently reviewed by three researchers to identify any that were unclear or redundant (i.e., appeared more than once). The researchers' combined ratings for each response were reviewed and any that was identified by two reviewers as either unclear or redundant was discussed. Responses that were judged to be redundant were removed and any that were unclear were edited for clarity.

The final list of responses was printed for interested participants to group together. Each response was printed on a separate card. A complete set of cards was sent to each participant. Participants were asked to look at all responses and group them together in whatever way made sense to them. A member of the research team mailed out the package, confirmed receipt by telephone, followed up with a call to answer any questions and schedule a call to obtain the groupings over the telephone at a mutually agreeable time. A total of 15 participants returned their groupings.

Statistical Analysis of Grouping

The sorting data were analyzed by the Concept System Global MAX software (Concept Systems, 2019). Multidimensional scaling used the groupings provided by participants to organize responses spatially on an x-y axis with distances between the points reflecting the frequencies with which each was grouped together by participants with every other response (Kruscal & Wish, 1978). Responses close to each other on the map indicated that the participants had placed those particular responses into the same group often, while responses further apart indicated that participants had rarely placed those two responses together in the same group.

Cluster analysis was applied to the multidimensional scaling data to determine the underlying thematic structure. The analysis began with each response as its own concept. Each step of the analysis included the combining of two concepts until the point where all responses were within a single concept (Anderberg, 1973; Everitt, 1980). Bridging indices were generated for each response based on the frequency with which each was grouped together by participants with only those in the vicinity on the map, or with others in different regions of the map. A low bridging index (i.e., 0.25 or less) indicated that the response was grouped together only with those nearby on the map while a high bridging index (i.e., 0.75 or greater) indicated that the response was grouped together with other responses in areas of the map at greater distances. More detail on these procedures can be found at https://socialresearchmethods.net/mapping/mapping.htm.

Construction of the Concept Map

The final decision about the number of concepts and labels for each was made by two of the researchers. The determination about concepts utilized both qualitative and quantitative data. Responses were reviewed for similarities within and differences between concepts. Map solutions with concepts that had the greatest within concept homogeneity and between concept heterogeneity were favoured. Bridging index data was used to assist with the determination of the best number of concepts favouring maps with concepts reflecting lower average bridging indices. Concept maps of 12, 10, 6, 5, 4, and 3 were reviewed before determining that the four-concept solution fit the data best. Individual bridging indices were used to identify responses that were the most central to the content of each concept. These responses within each concept were used to guide the decision about appropriate labels. Labels provided by participants for their own groupings also informed the labels applied by the researchers.

Results

The resulting concept map (see Figure 1) was constructed based on the responses generated and grouped together by participants. There were 57 unique responses for the analysis (see Table 1). Responses were grouped together by 15 participants. A validity index, called the stress value, was calculated for the map. The value was 0.29 which was within an acceptable range (Rosas & Kane, 2012). The four concepts included: (a) have a purpose, (b) serious problems, (c) continuous challenges, and (d) always need support. Participants described positive qualities of their youth, as well as expectations for ongoing challenges their youth will face as adults such as housing issues, and finally, the need for ongoing support throughout their lives.

Have a Purpose

Responses in this concept centered on the youths' positive qualities and hopeful outlook for them as adults in several ways. In some cases, caregivers made plans for their future, such as "we have set up some resources for her" as well as made a commitment to remaining involved, so that "parents will help him be mentored." Participants were hopeful that their adult children will "find a purpose" and "find a career." With the recognition that "he is a hard worker," it was felt to be "possible he will get a job," perhaps "working part time" and in some cases, there is a "need to create a job." For some, their hopes included education. A goal could be to "get her high school diploma" or continue with the "occupational therapist is helping her to go to college." Participants were "hoping he will be financially independent" through employment or by "be on Disability Support

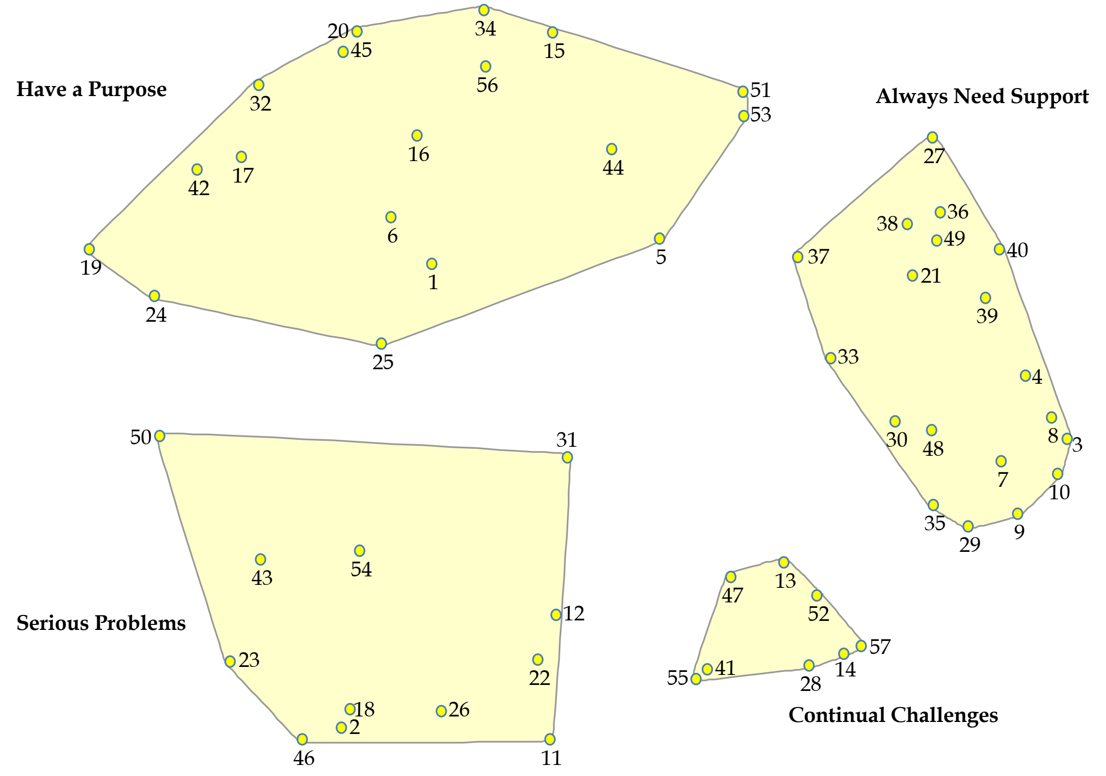

Figure 1. *Concept map of participants' responses. Numbers identify responses listed in Table 1. Distance between numbered responses indicate frequency with which participants placed them together in the same grouping. Nearby = more often grouped together. Far Apart = less often grouped together.*

Table 1. Participants' Responses Organized by Concept

Concept		*Response*	*Bridging Index*
Have a Purpose			**0.36**
	44.	Parents will help him be mentored	0.19
	15.	Find a career	0.19
	53.	We have set up some resources for her	0.2
	16.	Find a purpose	0.2
	5.	Be on disability support program	0.2
	1.	Need to create a job	0.25
	51.	Take a special needs cooking class	0.27
	56.	Working part time	0.27
	20.	He is a hard worker	0.31
	32.	Lives in a house independently	0.34
	45.	Possible he will get a job	0.35
	25.	Hoping they will find happiness	0.37
	17.	Get her high school diploma	0.38
	34.	Loyal, so if he finds the right person, he can have a good partner	0.4
	6.	Being able to maintain structure and routine	0.4
	42.	Occupational therapist is helping her to go to college	0.51
	24.	Hoping he will be financially independent	0.67
	19.	Have some friendships	1
Serious Problems			**0.34**
	12.	Do as much as you can to prepare but don't know what will happen	0.13
	31.	Live with us for most of his life	0.16
	11.	Discouraging because work so hard to raise them	0.18
	2.	Afraid he is going to end up in jail	0.19
	22.	Hope she will not drink and do drugs	0.2
	46.	Pregnant, uneducated, and in abusive relationship	0.22
	26.	If we can't manage him, he will need to leave	0.24
	18.	Getting into conflict with the law	0.32
	54.	Will live with mother whole life	0.45
	23.	Hope will not get kicked out of the house	0.47
	43.	Only supervision strong enough is parental	0.68
	50.	Stay in high school until she is 21	0.78

Legend

- Concept is a descriptive label given by researchers based on responses contained within given categories.
- Responses are words provided by participants in response to the focal question.
- Bridging index is a number between 0.00–1.00 indicating the degree to which a response was grouped together by participants with others near to it in a given category on the concept map (less than 0.25 = often grouped with others nearby; greater than 0.75 = often grouped with responses in other regions of the map).
- Concept average (bolded number) is the mean of all individual bridging indexes within each of the concepts.

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Table 1. Participants' Responses Organized by Concept (continued)

Concept	*Response*	*Bridging Index*
Continual Challenges		**0.07**
14.	Fear that there will be a hard road	0.02
57.	Worry about lack of impulse control	0.04
13.	Don't know if he will be able to support himself	0.05
28.	It's a worry	0.05
52.	They will struggle	0.08
41.	Not very hopeful right now	0.09
47.	Safety will be a concern	0.09
55.	Won't have a normal life	0.11
Always Need Support		**0.07**
33.	Lowered expectations	0
38.	Needs help with money	0
21.	He is going to be closely supervised	0.04
36.	Need someone to help him financially	0.04
48.	She will never be able to handle own money	0.04
30.	Likely never earn his own living	0.04
35.	Maturity is not there	0.05
3.	Always need help with living tasks	0.06
39.	Needs personal hygiene reminders	0.07
4.	Always need someone to help with decisions	0.07
29.	Lack of boundaries	0.07
10.	Disability doesn't mature with them	0.07
9.	Cognitively can't have what she wants	0.08
7.	Can't be responsible for himself	0.08
37.	Need to be safe in the house	0.08
49.	Someone to cue him to help him regulate	0.1
40.	Needs someone to help with transportation	0.11
8.	Can't do typical jobs	0.14
27.	Involve as many people as possible to help him	0.22

Legend

- Concept is a descriptive label given by researchers based on responses contained within given categories.
- Responses are words provided by participants in response to the focal question.
- Bridging index is a number between 0.00–1.00 indicating the degree to which a response was grouped together by participants with others near to it in a given category on the concept map (less than 0.25 = often grouped with others nearby; greater than 0.75 = often grouped with responses in other regions of the map).
- Concept average (bolded number) is the mean of all individual bridging indexes within each of the concepts.

Program." Life skills included cooking for self after "take a special needs cooking class," as well as "being able to maintain structure and routine" in order to "lives in a house independently." Participants hoped that they would "have some friendships" and noted that a positive quality was being "loyal, so if he finds the right person, he can have a good partner." They were "hoping they will find happiness."

Continual Challenges

Participants were concerned about ongoing struggles for their youth as adults and that in general, they were "not very hopeful right now." They "fear that there will be a hard road" ahead for them and "don't know if he will be able to support himself." "It's a worry" for participants that "they will struggle" and "won't have a normal life." There was also "worry about lack of impulse control" and knowledge that their "safety will be a concern."

Serious Problems

In this concept, responses focused on difficulties participants anticipated for their youth as adults. They were aware that they would "do as much as you can to prepare but don't know what will happen." While it was anticipated that they "live with us for most of his life" because the "only supervision strong enough is parental" they knew that "if we can't manage him, he will need to leave." Sometimes, reunification with another parent was expected "will live with mother whole life," but that was also qualified with the response: "hope will not get kicked out of the house." Participants felt that it was "discouraging because work so hard to raise them" and they could not imagine a way they could prevent more potential problems from occurring. They wanted them to "stay in high school until she is 21." For that to happen, they also "hope she will not drink and do drugs" and their biggest fear that she could be "pregnant, uneducated, and in abusive relationship." Participants were concerned about their adult children "getting into conflict with the law" and "afraid he is going to end up in jail."

Always Need Support

Responses in this concept focused on the types of supports necessary for their youth throughout their lifetimes and to "involve as many people as possible to help him." They also had accepted that their futures have been largely predetermined by their disabilities in that the "disability doesn't mature with them" and that he will need "someone to cue him to help him regulate" because he "can't be responsible for himself." Because the "maturity is not there" and a "lack of boundaries" caregivers need "lowered expectations" and to help their youth recognize themselves that "cognitively can't have what she wants." As adults, they will "always need help with living tasks," consistently "needs personal hygiene reminders" and "needs someone to help with transportation." They suggested that they will "likely never earn his own living" because "can't do typical jobs" and "need someone to help him financially" because "she will never be able to handle own money." It will be important that "he is going to be closely supervised" because he will "always need someone to help with decisions" and "need to be safe in the house."

Discussion

Responses provided by participants in the four concepts were compared to the literature. Similarities and differences were found. Issues identified by participants that have been reported in the literature lent support to the concepts and constructs studied. Issues identified by participants that had not been reported in the literature suggested areas potentially worthy of exploration.

Have a Purpose

Connections between education and employment opportunities and how they were related to being included in one's community were identified by participants. There is literature about the benefits of such opportunities and their association with feeling connected to others and prevention of social isolation (Spohr & Steinhausen, 2008). The need for assistance in these areas was similarly identified by both participants and within existing literature (Clark et al., 2008; Streissguth et al., 1996).

However, we found no literature on the positive characteristics of youth and how these could extend into adulthood concerning their personal contentment or the relevance to them of having or being a good partner in an intimate relationship.

Continual Challenges

There has been considerable research on the pervasive and persistent challenges associated with neurological problems among youth with FASD (Streissguth et al., 1991) that are expected to continue throughout adulthood (Rangmar, Sandberg, Aronson, & Fahlke, 2015). These are consistent with participants' expectations for their youth into adulthood. There has been attention to the needs of caregivers of children and youth who are affected. However, neither the caregiving responsibilities – nature, extent, and impact – have been explored, nor the emotional toll of immediate, unanticipated and significant problems that caregivers face have been identified, as participants have done in the present study, within the literature. Additionally, there has been little attention to how the caregiving challenges vary according to the role and responsibilities of the caregiver in the lives of their youth as adults.

Serious Problems

There is a great deal of literature on the nature and extent of secondary disabilities (e.g., Barr et al., 2006). Such problems may include disrupted education, substance abuse and trouble with the law (Rangmar et al., 2015). Participants also mentioned that despite their best efforts to provide care for their youth, they worried about the development of secondary disabilities for them as adults who could be without such care should they be unable to continue to care for them. In the literature, consistent parenting and residence are known to have strong preventive effects against secondary disabilities (Streissguth et al., 1996).

Always Need Support

Responses in this concept overlapped considerably with the existing literature. Several references to the need for long-term caregiving support have been made (DeJoseph, 2011), given life skills and problem-solving challenges (Denys et al., 2011) affecting interpersonal relationships and residential stability (Åse et al., 2012; Kelly et al., 2000; Kully-Martens et al., 2012; Manji, Pei, Loomes, & Rasmussen, 2009). There is divergence between participants' views and what has been reported in the literature concerning on the absence of any support for the family to take on these responsibilities with their youth and view it as a lifetime commitment. There is some literature on the experiences of youth aging out of care and hoping to continue to rely on their foster parents (Burnside & Fuchs, 2013). However, caregivers in the present study reported that lifelong care would be necessary and if they were unable to provide it, they worried about who it would be provided by and how.

Conclusion

Despite all of the problem focus in the current literature, participants did highlight positive characteristics of their youth and the contributions they would make as adults. Caregivers noted that in the presence of necessary supports and services they could, as adults, live productive and full lives. However, the hopefulness evident within some responses was overshadowed by the realities of social barriers as well as absence of FASD-designated services for adults. The lack of social and professional support for adults who experience FASD-related impairments was evident in the literature and noted by participants.

Participants in the present study held a view about the futures of their youth as adults that placed ongoing caregiver support as necessary but insufficient. While they were cognizant of the need for support of the youth into adulthood, they did not envision a future within which they were enough of an influence to prevent negative outcomes. Indeed, they envisioned a future with continual challenges and insecurity about their own abilities as well as a lack of resources to provide the kind of support they expected would be needed.

Interestingly, participants did not identify any specific resources, other than provincial disabilities funding, to assist their youth as adults. This absence reflects a general absence of services that exist for adults with FASD. Additionally, the references to professionals who are knowledgeable about FASD, presumably with adults as well, that were prevalent in the literature were not identified by participants in the present study. The absence of professionals or agencies having a role in the lives of their youth as adults can be contrasted with their awareness of the potential for them to go to become involved in illegal activities and the justice system.

Implications

Participants' identification of strengths and optimism for their youth aging into adulthood was countered by a great deal of concern about their welfare. The impairments they know the youth have were expected to be increasingly exacerbated and frustrated as they grew older. Caregivers' concerns centered on the needs of their adult children potentially becoming more than what they could effectively support themselves. This combined with the lack of social inclusion, service access and knowledgeable professionals for adults in the community left them very worried. It is suggested that dedicated transitional support and services would be of great help for youth who have an FASD diagnosis to assist with planning for adulthood. Such planning should include housing and income support as well as education and employment. Arrangements for health care would also be necessary.

Key Messages From This Article

People with disabilities. You have a lot of positive qualities. You can do many things that other people do. You also need other people to help you sometimes.

Professionals. The challenges that accompany fetal alcohol spectrum disorder require environmental accommodation and lifelong support.

Policymakers. Fetal alcohol spectrum disorders should be formally recognized and targeted in services for adults with disabilities.

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