ADULTS WITH FETAL ALCOHOL SPECTRUM DISORDER: FACTORS ASSOCIATED WITH POSITIVE OUTCOMES AND CONTACT WITH THE CRIMINAL JUSTICE SYSTEM

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ABSTRACT

Background

Adults with FASD are at increased risk for contact with the criminal justice system (CJS). To date, there has been limited research devoted to development of supports for adults with FASD and it is unclear what supports are required to improve outcomes and reduce CJS contact.

Objectives

To examine the services and supports experienced by a small group of adults with FASD living in both rural and urban locations in Ontario, and their contact with the CJS.

Methods

A sample of 14 individuals with FASD and 11 support persons participated in the study. Semi-structured interviews were conducted and coded according to key themes which were qualitatively analysed using quotations that supported each key theme. A reliability analysis was conducted for the interview coding.

Results

Early diagnosis and lower substance use were found to be factors associated with reduced contact with the CJS. Participants reported on: knowledge of their diagnosis and caregiver training and education about FASD; interdependence; routine, structure, and supervision; evidence of a strength-based approach; effective communication; and collaborative services. Few participants had received training and education around FASD and further research is needed to determine the training required for more successful interventions and outcomes.

Conclusion

As has been found previously, early diagnosis of FASD is associated with more positive outcomes including reduced amount of contact with the CJS. It is likely that early diagnosis leads to the receipt of more supports throughout childhood and contributes to a better understanding of FASD by family and caregivers.

Key Words: *Fetal alcohol spectrum disorder, adults, criminal justice system, early diagnosis, intervention and support*

Fetal Alcohol Spectrum Disorder (FASD) refers to a group of diagnoses associated with prenatal exposure to alcohol, including Fetal Alcohol Syndrome, Partial Fetal Alcohol Syndrome, and Alcohol Related Neuro-Developmental Disorder.[1] Symptoms of FASD can include restricted growth, diminished neurological functioning, characteristic facial features, and behavioural challenges.[1,2,3] The developing brain is particularly vulnerable to alcohol and prenatal exposure can lead to a variety of adverse effects on cognition, memory, attention, emotional/behavioural control, social skills, academic abilities, and daily living skills.[4,5] Individuals affected by FASD frequently require lifelong assistance and support.[6,7]

There have been numerous papers and studies published about FASD and its subsequent effects on children and youth.[5] There is, however, more limited information about the effects and impacts of FASD on the lives of adults.[8] The longitudinal research available to date finds that a significant number of adults with FASD face difficult life circumstances.[6,7,9] In the absence of appropriate identification and lifelong support there is a stronger chance that individuals will experience secondary or associated disabilities such as those related to vocational problems, mental health problems, social/emotional relationship problems, and legal difficulties.[9]

In addition to having limited research on the life experiences and quality of life for adults with FASD, there is minimal information regarding the effectiveness of interventions that are currently in use. A recent review[10] of the intervention literature on FASD published after 1997 found only 11 studies which measured intervention effectiveness for adults. This lack of adult-focused research is likely related to the higher number of researchers that are focused and funded to explore children's issues coupled with the limited number of resources and programs currently available that target adults with FASD.[8,11]

Although researchers have yet to consider the full range of challenges faced by adults who live with FASD, one of the more prominent long term outcomes that caregivers and individuals face is the higher-than-average risk of contact with the criminal justice system (CJS).[9,12,13] Difficulties associated with FASD include deficits in social and daily living skills, abstract reasoning, and executive functioning that can lead to problems in adapting to societal norms and potentiate conflicts with the law.[14] It has recently been acknowledged by the Canadian courts that an accused person with FASD who becomes involved with the CJS may have difficulties understanding police-based arrest procedures, court etiquette and related processes.[15] These conduct and process-based difficulties can exacerbate and extend their interactions with the justice system.[16] Equally important, some studies report a high rate of recidivism for individuals who have FASD.[9,12,17] Researchers have recommended that correctional systems would benefit from improved protocols for the recognition and identification of affected individuals because adults with FASD are often more vulnerable to coercion or misunderstandings by police officers and corrections officials and thereby encounter prolonged or repeated contact with the CJS.[9,14,18] As far back as 1998, researchers recommended that the Canadian CJS establish specialized units to deal with the potentially high percentage of inmates who had FASD, whether diagnosed or undiagnosed.[19] As well, several studies conducted in Canada which estimated the economic impact associated with FASD across the lifespan have noted that a lack of services and supports for adults can lead to higher costs when one includes the expense of contact with the CJS, intensive case management, mental health assessment and care, and housing.[20,21]

An Ontario advocacy group known as FASD-Ontario Network of Expertise (ONE) recently offered a position paper that outlined best practices for services and supports aimed at individuals with FASD and called these recommendations "effective practices".[22] These effective practices were collected through a survey of caregivers in the Ontario region and supported with a review of existing literature for both children and adults with FASD. Some of the recommended effective practices included the following: getting an early diagnosis, preferably in the primary school years; training and education about FASD for family and support workers; using a strength-based approach to service and care; accessing collaborative community supports; accepting life-long interdependence for the individual with FASD rather than independence; the introduction of structure, routine and supervision; and the use of specially adapted communication strategies. Many of these effective practices reflect findings from well-regarded longitudinal studies[9] and practices promoted by FASD educators.[23]

Using the previously described effective practices[22] as a guide, this study aimed to examine the services and supports experienced by a small group of adults with FASD who live in both rural and urban locations in Ontario. Individuals with FASD and their key support persons were interviewed to gain their perspectives about whether these supports and services were in place within their lives and communities and if they were believed to be effective. The study also investigated any reported contact with the CJS and how these effective practices might be related to justice system involvement from the perspective of the individuals and their key supports.

METHOD

Participants

This study was reviewed and approved by the Research Ethics Board of an Ontario provincial government transfer payment agency that supports individuals with developmental disabilities. The study involved 14 participants (7 female and 7 male) with a diagnosis of FASD (aged 18 to 41 years) and 11 of their so-named "key support persons" (8 female and 3 male). Key support persons were identified by the participant with FASD and were defined as the person most knowledgeable about and involved with them in their community. Key support persons included 3 paid support workers, 1 friend, and 7 family members. Eight participants with FASD resided in the Grey Bruce region of Southwestern Ontario and 6 resided in the greater Toronto area. Table 1 presents demographic information regarding individuals with FASD including age at the time of the interview, schooling, functional level, age of FASD diagnosis, support services used, and type of agency referring the individual to the study.

TABLE 1 Demographic Information for Participants with FASD

Category	**Number (Percentage) n=14**
Sex	
Female	7 (50)
Male	7 (50)
Age at Interview	
18-23	3 (21.5)
24-30	8 (57)
31+	3 (21.5)
Age at Diagnosis	
0-8	3 (21.5)
9-18	6 (43)
19+	5 (35.5)
Functional Level	
Average	4 (28)
Borderline	4 (28)
Intellectual Disability	6 (43)
Schooling	
Completed Highschool	5 (35.5)
Partial Highschool	5 (35.5)
Unknown	4 (29)
FASD diagnosis	
FAS	2 (14)
pFAS	2 (14)
ARND	3 (22)
FASD (specific diagnosis unavailable)	7 (50)
Referring Agency	
Community Living Agency	8 (57)
Clinical Services for Developmental Disability	6 (43)
Support Services Used	
Community Living	11 (78)
Clinical Services for Developmental Disability	6 (43)
Community Mental Health	3 (22)
Children's Aid	2 (14)
Probation services	2 (14)
Public Health	1 (7)
None	0

Procedures

Flyers describing the study were sent out to the staff of local community agencies and community partners. Agency staff and community partners were asked to review their client records and approach individuals identified in their records as having a diagnosis of FASD. Staff and community partners were further asked to read the study flyer with individuals and if they were interested, to support them in contacting one of the study's primary investigators. It was hoped that a relatively equal number of participants could be included from both Grey Bruce and Toronto, however more participants with FASD expressed interest from the Grey Bruce area. For this reason, all those who expressed interest from Toronto were included in the study while participants from Grey Bruce were selected by drawing names.

Each participant with FASD was interviewed by a research assistant in a safe, warm, supportive, face-to-face environment. Participants with FASD were asked to give permission for the researchers to contact and interview their key support person in order to be accepted into the study. Key support person interviews were completed either in person or on the telephone depending on the participant's preference. Although all 14 individuals gave permission for the researchers to contact a key support person, 2 key supports declined to be interviewed and one could not be contacted. Participants with FASD were given an honourarium of $25 to acknowledge their time and were offered a transportation stipend (or token) to assist getting to and from the interview. Each participant with FASD and their key support person completed a separate semi-structured interview which lasted approximately 1 hour. Questions for participants with FASD and their key support person followed an identical format but were worded slightly differently to accommodate the interviewee. For example, rather than "At what age did this person receive a diagnosis?" the participant with FASD would be asked, "When did you receive your diagnosis?" All interviews were tape-recorded on a digital audio device and transcribed. Interview questions are presented in *Appendix 1*.

Analyses

Each transcribed interview was read by the researchers in order that they become familiar with the unique content and issues shared by the participant with FASD and their key support. Information from the interviews was then reviewed and coded for the following: age at diagnosis; evidence of training and/or education regarding FASD for the individual and their key support; adoption of a strength-based approach by care providers and the individual themselves; collaborative services within the described circle of care; impressions about the effectiveness of communication between the individual with FASD and their care providers; evidence of structure, routine, and supervision in the life of the individual with FASD; and, opinions about the need for life-long interdependence for the individual with FASD. Participants with FASD and their key support persons were also asked about CJS involvement by the participant with FASD at any time in the past. Finally, information regarding lifestyle factors such as drug and alcohol use, prescribed medications, availability of a dentist and/or physicians, exercise activities, and future plans for the participant with FASD was gathered.

For most categories the researchers coded the presence or absence of each factor and gathered specific quotes from the transcripts to support these observations. The researchers each reviewed 4 of the 25 transcripts in order to arrive at consensus about coding definitions. The 4 transcripts that were coded jointly included 2 participants with FASD and their key supports. After establishing consensus, transcripts were divided among the investigators and coded in sets. Each set consisted of a participant with FASD and their key support. An Excel spread sheet was used to record the codes for each effective practice and to collate relevant quotations from both participants with FASD and their key supports. Simple frequencies and percentages were calculated using the coding from each category along with the presence or absence of any CJS involvement. Results for CJS involvement are presented in Table 2.

After the coding was completed, transcripts were reviewed a second time so that themes and recurrent issues could be grouped by topic. These themes are discussed below and highlighted with relevant quotes from participants and key supports. A summary of participant responses to selected interview questions from each category is given in Table 3.

TABLE 2 Participants With Criminal Justice System Involvement and Without for Each Area of Study

	Criminal Justice Involvement n=8 # (%)	**No Criminal Justice Involvement n=6 # (%)**
Reported alcohol/street drug use	7 (87%)	2 (33%)
Reported structure in daily life	4 (50%)	6 (100%)
Reported supervision in daily life	5 (62%)	6 (100%)
Reported routines in daily life	3 (37%)	6 (100%)
Identified personal strengths	8 (100%)	6 (100%)
Reported collaborative services	5 (62%)	4 (66%)
Reported receiving education or training regarding FASD	2 (25%)	3 (50%)
Reported having effective communication with supports	8 (100%)	6 (100%)

TABLE 3 Example Responses for Each Category of Questions

Category of Question	Example Responses	Number (percentage)
Evidence of understanding about FASD How has the diagnosis of FASD impacted you?	..I would have been able to explain that I don't have an internal clock .. (I) have problems doing math which has greatly interfered with my life. …It makes a big difference to know it… all my life I thought I had LD (learning disability) and didn't know the alcohol affected me	6 (43) individuals had awareness about their FASD
Evidence of Training or Education about FASD Did supports receive training about FASD?	…his teachers knew but there was no evidence that it made a difference… ..we told teachers so they would not think she was misbehaving… the most important thing to tell teachers is it might seem as though she is not trying to learn.. …I've done several seminars over the years... ..only the workshops through CAS..	7 (50) individuals had family, teachers, or support workers with training and education about FASD
Evidence of a Strengths-Based Approach Can you identify something positive about yourself?	…I fix machinery, engines, farm work.. do repairs on my own truck… ..give the shirt off my back kind of guy. …I'm good at anything but school.. good at cleaning....I have a good heart …I'm good at babysitting, taking care of children, making things, cooking, cleaning	14 (100) could identify one or more personal strengths

Category of Question	Example Responses	Number (percentage)
Evidence of a Strengths-Based Approach (Key Supports only) Can the key supports identify something positive about the adult with FASD?	.. aware of her strengths and she has opportunities to use them within the context of her week. ….he helps with the dog-related chores, …he likes being with friends (it) helps him see he is a good person	11 (100) could identify one or more strengths about the adult with FASD (N=11 key support interviews)
Collaborative Services Who is on the support team? How often do you have case conferences?	…rarely...we would have a meeting once a year.. …we are just getting into that… it's complicated because he doesn't just fit in one stream… ...every 4 to 5 months with family... …everything is ad hoc (but) I keep in contact with the people around her... ..me and my husband, her community living worker, public health nurse... …Never. There is no help in this area...	10 (71%) of individuals or key supports spoke of collaboration or case conferences (N=11 key support interviews)
Life-long Interdependence Where do you live? Who helps you with problems?	The wiser side of me says it's better to ask for help. I don't want to end up in jail... She (support worker) takes care of all my finances so I go to her for money and to pay bills...I may not like it (getting help) but I'll take it.	13 (93) individuals spoke of the need for help or depending on others
Reported having effective communication with support systems Is there evidence that someone really "gets" them?	..You have to be very calm and deal with one thing at a time. ..Make an agenda and every time he does one thing then he crosses one thing off - step by step. I learned this from his grade 8 teacher.	8 (73) key supports reported understanding and altering their communication strategies to accommodate FASD (N=11 key support interviews)

	.. be very calm; you have to at the top of your game; you cannot be a mess yourself… …caring.. it is so important to be caring. ..he is an intelligent adult; he can accept guidance and expects to be treated with respect.	
Reported structure, supervision and routines in daily life Is there evidence of structure, supervision and routine in the individual's daily life?	..my mom gives me reminders….they set up a calendar and use cell phones to text reminders. … I get ready the night before and do a physical run through to make sure I have my keys and wallet ...I put up signs and check my list… if it is a new place and location, then I have to have someone walk with me.	13 (93) individuals or key supports spoke about using structure, supervision or routine

Interrater Reliability

A sample of 6 transcripts were randomly selected from a total of 25, and were used to calculate reliability of transcript coding. The reliability coder was a student assistant who was naive to both the participants and procedures of the study and was provided with an Excel spreadsheet containing coding instructions and definitions used by the primary investigators for each category of effective practice. The reliability coder's responses were compared to the primary coding and percentages of agreements were derived across categories. Overall, a 75% level of reliability was found between the student assistant and researcher's coding's, indicating an acceptable level of agreement.

RESULTS

Criminal Justice System (CJS) Involvement

Table 2 presents results for selected effective practice categories that have been broken down for participants with and without CJS involvement. Results are presented as simple frequencies based on researchers' codings. Overall, 8 of 14 (57%) participants reported some kind of CJS involvement. The types of charges varied and included theft of property, impaired driving, failure to appear in court as ordered, break and enter, and assault. Participants with CJS involvement were more likely to consume street drugs/alcohol, less likely to have key supports trained about FASD, and reported somewhat less overall structure, routine, and supervision in their lives. The two groups were equally likely to identify their own personal strengths and to report effective communication in their lives. As noted above, those with CJS involvement tended to receive their diagnosis of FASD later in life. The mean age of diagnosis for those with CJS involvement was 20 years versus 16.75 years for those without.

Diagnosis

The age at which participants were diagnosed with FASD ranged from 6 to 39 years. Three of the 14 received a diagnosis before the age of 8; another 6 between 11 and 18; and the final 5 after 21 years of age. Generally, as age of diagnosis went up, the percentage of individuals with CJS involvement increased. Individuals diagnosed before the age of 8 had 0% CJS involvement; between 11 and 18 it was 67%; after 21 years of age 80%.

Education, Training, and Understanding of FASD

When asked about prior training or education about FASD, family members were the most likely to report they had received training or education. Of the 7 family members interviewed, 4 (57%) stated they had attended workshops or read information materials about FASD. Individuals with FASD themselves often had some knowledge or understanding of FASD, but only 5 (36%) had received formal education or training. When asked what they know specifically about FASD, participants frequently discussed its causes or the challenges and frustrations they face because of their disorder. In some cases, participants with FASD could also articulate a sense of relief at receiving a diagnosis:

"I know it's a term that they use for mothers that drank during their pregnancy. Now I know because I'm 40 that the brain damage is permanent and I know it can't be fixed. It interferes with my daily life and keeps me from doing a lot of regular things."

"I know I have to work extra hard…I find it challenging…it's frustrating."

"For a very long time before I properly understood what this was, I just thought of myself as a freak…and I always blamed myself and would tell myself I'm an idiot…Eventually I learned that it was not my fault to an extent…I was predisposed to do these things."

Using a Strength-Based Approach

All of the 14 adults with FASD (100%) could self-identify personal strengths such as being artistic, helpful, or kind-hearted. As well as personal attributes, participants with FASD reported activities that they were good at and these were most often hands-on, visual, or physical tasks such as looking after children, sports, or mechanical skills.

"I'm pretty good with kids and animals."

"I have a knack for putting things together…I'm very good at hands-on…tasks that require you to figure out what you are doing..."

I like helping other people. I am the giving-my-shirt-off-my-back kind of guy"

"I'm a good mom and have a good heart"

"Sports….snowboarding, baseball, I like any kind of sport."

Some key support persons also reported changing the way they provided supports to their adults with FASD based on these strengths. All eleven (100%) key support persons were able to identify a strength about the participant with FASD:

"We just keep focused on the positive and give her lots of feedback on the things she does well"

"..He's pretty sympathetic with lots of situations, and a lot of the time I try to explain from a moral point of view".

Collaborative Services

Ten of 14 (71%) participants with FASD were reported by themselves or their key support to have collaboration or interaction between support providers in their circle of care. Collaboration was represented as meetings between family and community support workers--and less often referred to formal case conferences. Although there was frequent collaboration it sometimes became the "job" of a family member to coordinate these services and key support persons commented on the difficulties of managing multiple services and service providers:

"We see them all separately…it's the time (it takes) to make everything work…and the paperwork! Oh my gosh the on-going paperwork…..she has umpteen workers at ODSP. A huge thing is doctor's appointments. Wherever she goes I try to find people who understand. We try to put things into place where she needs extra help. But its hit and miss."

Lifelong Interdependence

Research has suggested that rather than independence during adulthood, individuals with FASD would benefit from living interdependently.[22] This involves having and accepting support to make decisions on a daily basis and understanding the need for assistance in a broad range of areas over time. Most of the participants with FASD acknowledged their need for support (93%). However, it was often the case that they were not willing to accept or were ambivalent about that support, despite acknowledging the need.

"If you asked me when I was younger, say 22, I would say I don't want your help. But now I need it. I want to get out by myself. I don't want to be restrained…I don't want people to be involved in my life…."

"I appreciate they help me but I wish I didn't need help….my goals are being independent and someday being able to have a family"

".… I did best when I had someone on me all the time telling me what to do."

Key support persons also spoke of the need for support and interdependence:

"…she has a solid family system in place; they have been strategic for her to be supported so that there is that inter-dependence.. She has no contact with the CJS. ".

"…He still has an interdependent life with support from family while living with the girl friend. He has other supports involved as well".

Effective Communication

All participants with FASD (100%) reported they had someone to talk to who understands them well and who made them feel comfortable.

"People understand me when they know me well. They give no judgement and they give advice."

"They're patient and know how to go through things."

Most key support persons (73%) felt that their communication with the individuals with FASD was effective. Some key support persons reported that they changed their communication style to accommodate the participant with FASD and were aware of the need to modify their communication.

"Avoiding power struggles is important"

"We need to use supportive language, not directive."

Structure, Supervision and Routine

Although originally placed into a category all together, it became apparent during the review of the transcripts that structure, supervision and routine did not always occur simultaneously in an individual's life; in fact, these 3 variables frequently fluctuated over time and place. For example, a participant might live with a caregiver for some period of time and have strong supervision and support, but then decide to move into a friend's home where there is little to none. Or, a participant might have a part-time job where there is available structure and support but have no other routine-based activities planned outside of work. Overall, it was apparent that structure, supervision, and routine were variable for participants with FASD throughout their lives. This variability made it difficult to code, quantify, and interpret results across this domain. Despite these difficulties, it was clear based on comments from both participants with FASD and key supports, that these factors were very important for optimal functioning. Overall, 13 of 14 (93%) reported having one of more of either structure, routine or supervision in their lives.

"… I put signs up. I have a check lists. But if it is a new place and it is a new location, then in that case I have to have someone with me to walk me there and point out where the place is. There are certain rules in my life that I set and I just don't break. …I always make sure that I get home by 5 pm.."

"…I don't really have a schedule. If I have to work, I have to work. If not I just sit around the house"

"…It was hard to get a routine down because I didn't know how to do it."

"*I try to decide what I do each day… I have a schedule - one week - I use a one month calendar too. I write down what my week is going to be - it usually stays the same; I have an iPod and an alarm to help me".*

"…You have to be very calm and only deal with one thing at a time. Make an agenda and every time I do

one thing I cross one thing off - step by step. You have to be at the top of your game - you cannot be a mess yourself to deal with him".

"…they use 3 self-schedules. They have a computer calendar. There are 4 paid staff monitoring and a new girlfriend and her family too; but still too much free time in his week. He plays a lot of video games".

DISCUSSION

This study described the lives and community-based support practices reported by a small sample of individuals with FASD and their key support persons who live in rural and urban locations in Ontario. Participants with FASD and their key support persons were interviewed and asked a series of questions about the age the individual received a diagnosis of FASD, their community supports and services, communication styles, areas of strength, understanding of interdependence, training and education about FASD as well as any past contact with the CJS.

As has been previously reported[24], the current study suggests that an early diagnosis of FASD is associated with more positive adult outcomes. In this group of individuals with FASD, early diagnosis may have supported a reduced amount of contact with the CJS. It is likely that early diagnosis leads to the receipt of more supports throughout childhood and a better understanding of people with FASD by family, caregivers and teachers. The results presented here provide additional support for the claim that early diagnosis is an important initial step when providing services for individuals with FASD.

Another participant factor closely associated with CJS involvement in this study is drug/alcohol use. Seven of 8 or 87% of the individuals with CJS involvement reported consuming drugs/alcohol, often frequently, while only a third (2 of 6) of those without CJS contact used drugs/alcohol. As well, when discussing the circumstances of their CJS contact, alcohol and drug use was mentioned in several cases. The association of substance use and CJS contact points to an area of intervention that might be important in preventing future CJS involvement—that being, developmentally appropriate substance use/abuse treatment for adults with FASD.

A relatively low number (50%) of family members and participants with FASD (36%) reported receiving education or training about the disorder. Because this is a small and non-representative sample it is impossible to tell if education or training levels are similarly low in other groups. However, given the potential benefits of early education for helping individuals and their families/care providers access and implement effective strategies and gain a better understanding of needs, it may be important to consider further research in this area. For example, what types of education, training and employment supports are most helpful to adults with FASD? If the individual was diagnosed as a child, were they informed of what the diagnosis means and the potential lifelong impacts? As an adult, are they now capable of understanding more about FASD? What information do families, service providers and communities need to support adults compared to supporting children?

Although structure, routine, and supervision are often cited as important factors for success when supporting individuals with FASD[22,23] defining exactly what each means is challenging. While reviewing and coding transcripts it became apparent to the researchers that many different situations existed and co-existed across timelines and contexts. Not only was the simple presence of routine, structure, and supervision important but also the quality and quantity of each across an individual's day. Supervision levels varied between individuals from 24 hours a day to less than once per week. Because providing supervision, structure and routine can be costly from a service provider perspective, further research in the area of understanding the type, quantity and quality of each that is needed in FASD would be beneficial.

Another important area for future research is how to develop more appropriate vocational placement opportunties for adults with FASD. During the interviews, individuals with FASD shared their frustrations and insights along with anecdotes about a typical day in their lives and some of their preferred lifestyle choices. Despite their challenges, these adults easily shared personal strengths that seemed to point to an under-explored and perhaps unrealized potential for meaningful vocational activities. Many individuals reported enjoying simple, repetitive tasks associated with daily living; several commented on their preference for being out at night time rather than during the day; others commented that wearing tight clothing or heavy clothing felt calming. These comments point to the possible benefit of exploring certain categories of work such as night shifts, manufacturing and packing jobs, or jobs that necessitate wearing heavy or tight-fitting uniforms such as mining/forestry. Although these are only a few limited observations, they suggest a need for further research into sensory issues and activity/lifestyle preferences that might provide a better understanding about the support needs of individuals with FASD and contribute to more appropriate placements in day programs and vocational actitivities.

Limitations

An important limitation of this research is the small sample of individuals included. The impressions and issues discussed by this group may be similar to those of other groups or they may be specific to the places and contexts studied here. As well, all the information presented here was gathered by either self-report or caregiver report. No independent collaboration of facts from other sources was sought. This means results should be understood as representing the views and perceptions of the individuals themselves with all of the inherent weaknesses of self-reported measures and studies.

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APPENDIX 1

Semi-Structured Interview Guide

(questions were adapted depending on whether the study respondent was a participant with FASD or a Key Support Person)

Early Diagnosis of FASD

- At what age did this person receive a diagnosis?
- Where did they get their diagnosis?
- Did caregivers and professionals know about the diagnosis? Did this knowledge make a difference to the caregiver approach?

Training and Education in FASD

- Have you had training/education on FASD?
- Are there other staff in the agency/family members that have training on FASD?
- What are your key learning's that assist you to support someone with FASD?
- Has it made a difference? If so how?
- What do you think is the most important thing to tell other people involved with your client /family member about FASD?
- How does your agency provide information to new staff about FASD? How does your agency support staff and caregivers to use the information they have on FASD?

Strength-Based Approach

- What does this person do well?
- What do they like to do?
- What are their best qualities?
- What do you like about (working with) adults with FASD?
- How do other people describe this person?
- How do you use this person's strengths in providing support to them?

Collaborative Services

- How often do you have case conference/team meetings?
- Who attends the meetings?
- Are there key people who help this person who do not attend? Is anyone missing?
- If no team meetings how do you communicate with each other?

Lifelong Interdependent Supports

- What type of residence does this person live in?
- How long has the person lived here? Who does he/she live with? What do you think are the good things about this arrangement? What would you really like to see for this person?
- Does this person have long standing relationships? If so who and how are they involved now?
- Can you share some of the person's history of living situations and relationships?

Structure, Routine and Supervision

- Who helps the individual plan what they are doing each day and how do you do that?
- How many people are involved in providing support to this person?
- Is the person's week similar every week?
- Are there unpaid people that are a part of the support system?
- How many activities is the person involved in?
- How much free time do they have in their week?
- How does this person manage time by themselves and what do they do?
- What kinds of tools do you use to support this person? (Social Stories, sequence charts, written, calendars or pictorial schedules)

Effective Communication

- What approach or style of communication works best for this person?
- If you were teaching someone else how to support this person what would be important for you to know to be sure the support person understood you?
- Have you changed in your approach to communication style in order to be successful in supporting this person?

Lifestyle

Does the individual living with FASD :

- participate in sports, exercise, walks?
- take medications? Do the medications help?
- drink alcohol?
- take non-prescription drugs?
- have a family doctor? Psychiatrist ? Dentist? Do they see them regularly?

Criminal Justice Involvement

Has the individual living with FASD :

- ever had criminal charges? How were the charges resolved?
- ever been in jail or in custody? How long?
- ever used emergency services during any arrests?
- ever gone to court? When? Ever received court support? Was mental health diversion offered or discussed?
- ever entered drug or alcohol treatment programs? Anger management programs?

REFERENCES

1. Chudley A, Conry J, Cook J, Loock C, Rosales T, LeBlanc N. Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. CMAJ 2005;172:S1-21.
2. Hoyme HE, May PA, Kalberg MA, et al. A practical clinical approach to diagnosis of Fetal alcohol spectrum disorder: Clarification of the 1996 Institute of Medicine criteria. Pediatrics 2005;115:39 47.
3. May PA. A multi-level comprehensive approach to the prevention of fetal alcohol syndrome (FAS) and other alcohol related birth defects (ARBD). International Journal of Addiction 1995;30:549–602.
4. Coles C, Lynch ME, Kable JA, Johnson KC, Goldstein FC. Verbal and nonverbal memory in adults prenatally exposed to alcohol. Alcohol Clinical and Experimental Research 2012;34:897-906.
5. Kodituwakku PW. Defining the behavioral phenotype in children with fetal alcohol spectrum disorders: A review. Neuroscience and Biobehavioral Reviews 2007;31:192–201.
6. Streissguth A, Aase J, Clarren S, Randels S, LeDue R, Smith D. Fetal alcohol syndrome and in adolescents and adults. Journal of the American Medical Association 1991;265:961-7.
7. Sphor HL, Willms J, Steinhausen HC. Fetal alcohol spectrum disorders in young adulthood. Journal of Pediatrics 2007;150:175-179.
8. Chudley A, Kilgour A, Cranston M, Edwards M. Challenges of diagnosis in Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorder in the adult. American Journal of Medical Genetics 2007;145C:261–272.
9. Streissguth A, Bookstein F, Barr H, et al. Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. Developmental and Behavioral Pediatrics 2004;25:228-237.
10. Wheeler JA, Kenney KA, Temple VK. Fetal alcohol spectrum disorder: An exploratory investigation of services and interventions for adults. Journal on Developmental Disabilities 2013;19:64-77.
11. Naumann D, Reynolds J, Smith H. An environmental scan of programs available to residents of eastern Ontario affected by fetal alcohol spectrum disorder. Journal on Developmental Disabilities 2013;19:30-47.
12. Fast D, Conry J. Fetal alcohol spectrum disorders and the criminal justice system. Developmental Disability Research and Reviews 2009;15:250-7.
13. MacPherson & Chudley, AE. FASD in a Correctional Population: Preliminary Results from an Incidence Study. Ottawa, ON: Correctional Services Canada, 2007. Accessed on: August 24, 2015 http://events.onlinebroadcasting.com/fas/090707/ppts/correctional.ppt
14. Brintnell ES, Bailey PG, Sawhney A, Kreftin L. Understanding FASD: Disability and social supports for adult offender. In: Riley EP, Clarren S, Weinberg J & Jonsson E, eds. Fetal Alcohol Spectrum Disorders-Management and Policy Perspectives of FASD. Toronto, ON: Wiley, 2011.
15. Institute of Health Economics. Consensus Statement on Legal Issues of Fetal Alcohol Spectrum Disorders. Edmonton, Alberta: Institute of Health Economics, 2013.
16. Cox L, Clarimont D, Cox S. Knowledge and attitudes of criminal justice professionals in relation to fetal alcohol spectrum disorder. Canadian Journal of Clinical Pharmacology 2008;15:e306-e313.
17. Mitten HR. Barriers to Implementing Holistic, Community-Based Treatments for Offenders with Fetal Alcohol Conditions. Saskatoon, S.K: University of Saskatchewan Department of Law, 2003.
18. Moore T, Green M. Fetal alcohol spectrum disorder (FASD): A need for closer examination by the criminal justice system. Criminal Reports 2004(4);19:99-108.
19. Boland F, Burrill R, Duwyn M, Karp J. Fetal Alcohol Syndrome: Implications for Correctional Service. Ottawa, ON: Correctional Services Canada, 1998.
20. Thanh NX, Jonsson E. Cost of FASD in Alberta, Canada. Canadian Journal of Clinical Pharmacology 2009;16:e80-e90.
21. Popova S, Stade B, Bekmuradov D, Lange S, Rehm J. What do we know about the economic impact of fetal alcohol spectrum disorder? A systematic literature review. Alcohol and Alcoholism 2011;46:490-7.
22. Hall N, Cunningham M, Jones S. Advancing effective service provider practices in fetal alcohol spectrum disorder. Fetal Alcohol Spectrum Disorders-Ontario Network of Expertise. (2010). Accessed on: August 31, 2015 http://www.fasdontario.ca/cms/wp-content/uploads/2014/01/Toward-a-Provincial-

Strategy-Advancing-Effective-Service-Provider-Practices-2010.pdf

23. Malbin D. Fetal alcohol syndrome and fetal alcohol effects: Trying differently rather than harder. (2002). Accessed on: August 30, 2015 http://www.fascets.org/Bibliography.html