

Needs of Persons with FASD: A Descriptive Case Study

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Abstract

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term used to describe persons who were affected by their mother's consumption of alcohol while in the womb. The extent and appearance of developmental characteristics and cognitive deficits for a person with FASD are influenced by several factors: the frequency, timing and amount of alcohol consumed, the age and nutritional status of the mother, the level of intelligence and educational attainment of the parents and the age of the child over time (causing changes in the expression of some characteristics). The Diagnostic and Statistical Manual of Mental Disorders (currently DSM-IV, with the DSM-V around the corner) does not list FASD as a clinical disorder, which affects the abilities and attitudes of physicians regarding the investigation into, diagnosis, and treatment of alcohol-related disorders. This may contribute to the harmful social perception that controlled alcohol intake may not be severely damaging to a fetus. For the purpose of this study an adult with FASD and his wife, given the pseudonyms of Matthew and Nadine respectively, were interviewed to learn of his condition of FASD. Their responses to the interview questions identified key areas of concern and need that are largely not being met. The results indicate that while there are some differences in perception between the two, there is consistent information suggesting that this population of special needs is largely over-looked and under-served in northeaster Ontario, Canada.

Keywords: FAS, FASD, maternal alcohol consumption, characteristics, critical issues, needs, supports

Pediatricians Kevin Jones and David Smith first coined the term 'fetal alcohol syndrome' in 1973. Since that time, there has been an increase in awareness and research into the prevalence and causes of birth defects resulting from alcohol exposure in the womb. In 2004, the National Organization on Fetal Alcohol Syndrome (NOFAS) introduced the term Fetal Alcohol Spectrum Disorder (FASD) to encompass the various diagnostic categories for the range of effects and possible lifelong implications alcohol poses on an unborn child.

Prevalence Rates

FASD is an umbrella term used to describe the range of irregular characteristics associated with the maternal consumption of alcohol during pregnancy. It is the leading cause of cognitive impairment worldwide with references to infant malformation dating back to early Greek and Roman mythology (Banakar, Kudlur, & George, 2009). India reports a rate of nearly 2 per 1000 births. In the United States, May, Gossage, Kalberg, Robinson, Buckley, Manning, & Hoyme (2009) reported that the prevalence rate of FASD in typical, mixed-racial, and mixed socio-economic populations is 2 to 7 per 1000 and that among younger children from 2 to 5% in the United States and some western European countries. According to Health Canada (2003), 9 in every 1000 Canadian-born infants is born with FASD and the direct costs associated with FASD over a lifetime is estimated at \$1.5 million per person. Over 125,000 newborns each year are exposed to heavy or binge drinking (NOFAS).

Characteristics of FASD

Included within the spectrum are Fetal Alcohol Syndrome (FAS) and partial FAS (pFAS), Alcohol-Related Birth Defects (ARBD) and Alcohol-Related Neurodevelopmental Disorder (ARND). While some conditions of FASD (such as FAS) involve an obvious triad of facial dysmorphism, retardation of growth and neurocognitive deficits of the central nervous system, other disorders or specific cases (ARND) are hidden for not having the physical characteristics typically associated with the disorder. Furthermore, the extent and appearance of developmental characteristics and cognitive deficits are influenced by several factors: the frequency, timing and amount of alcohol consumed, the age and nutritional status of the mother, the level of intelligence and educational attainment of the parents and the age of the child over time, causing changes in the expression of some characteristics.

These variables produce a broad range of individual differences (unique strengths and weaknesses) in the expression of FASD, which makes finding the appropriate treatments or interventions challenging, as they must be both individualistic and complex in nature. Common behavioural and cognitive deficits include slow information processing, impulsivity, attention and memory deficits, and decreased performance in tasks involving language and visual perception (Kodituwakku, 2007). On average the intelligence scores of children with prenatal alcohol exposure fall two standard deviations below the mean. Approximately 50% of children with FASD are intellectually impaired but IQ scores ranging from severely intellectually impaired to high average intellectual ability exist in this population (Streissguth, Barr, Kogan, & Bookstein, 1996). Because of this wide variability in intellectual ability and the known deficits in higher order cognitive functioning found with persons with FASD (Connor, 2000; Kodituwakku, May, Clericuzio, & Weers, 2001; Mattson & Riley, 1999; Mattson & Riley, 1998; Wilford, Richardson, Leech, & Day, 2004) an individual learning profile of each child is essential to their school experience. As might be expected, these characteristics result in a high proportion of those with FASD encountering academic troubles (May, 2009).

It was found by Kodituwakku et al. in a study in 2001 that children who possess average intelligence and who have been prenatally exposed to alcohol demonstrate marked difficulty in complex working memory, planning ability, cognitive flexibility, selective inhibition, and concept formation and reasoning. Additionally executive functioning deficits were correlated with behavioural issues, leading to a lifetime of legal and addiction troubles (Fast, Conry, & Loock 1999).

In a collective case study involving adolescents and young adults Duquette, Stodel, Fullarton, and Haggland (2006), investigated the perspectives of students with FASD. The study revealed that those with FASD experienced learning difficulties, behavioural problems, or both. They cited problems with hyperactivity, failing to consider the consequences of their actions, over-stimulation in social situations, unresponsive to social cues, lack of reciprocal friendships, over-reacting emotionally, task incompleteness, lack of initiative, poor judgment in issues of trust, and attention-seeking. Paradoxically, they described themselves as academically and socially successful. This they attributed to the strong support of, and advocacy by, their adoptive parent. The researchers concluded that individuals with FASD are deficit in their adaptive functioning, particularly in the areas of communication, daily living, and socialization skills, as measured by the Vineland Adaptive Behaviour Scales.

In an earlier study, Duquette and Stodel (2005) explored the perspectives of adolescents and young adults with FASD and their parents. The findings were consistent regarding learning and behavior problems. In addition, they found that caring teachers and appropriate educational programs were vital to school success. Parents stressed the need for a consistent and structured home environment, the importance of a diagnosis, and the necessity of advocacy for their child.

Secondary Disabilities

Streissguth and O'Malley (1997; 1991) reported that without a diagnosis, a child is at risk of developing "secondary disabilities" that may be debilitating. In a study of over 400 persons with FASD, they found depression, suicidal ideation and attempts, attention deficit problems, panic attacks, and auditory and visual hallucinations prevalent mental health concerns. These increased with age and were linked to the primary disability of central nervous system (CNS) damage due to maternal consumption of alcohol (Streissguth, et al., 1996).

In a study of secondary disabilities in 415 adolescents and adults with FASD, Streissguth et al. (1996) discovered that 60% of the individuals had a disrupted school experience of suspension, expulsion, or drop-out. As well, Gorman (1995) interviewed individuals with FASD between the ages of 15 and 20 years regarding their perceptions of school and learned the majority had disrupted school experiences. The most frequent learning problems reported for all ages were inattention and incomplete schoolwork. Behaviourally, the most cited problems were difficulty in social relations and being disruptive in class.

Identification and Programming

Children are at an optimal stage of life for an accurate diagnosis of FASD by the time they are 6-7 years of age. Because the early identification of FASD makes early intervention possible, it is important to observe developmental milestones and encourage communication between the community, school, and the family.

Current popular options for intervention, limited in scope, include vocational training (Duquette et al., 2006), teacher-specific FASD instruction and training (Kalberg & Buckley, 2007), awareness programs and education for youth at-risk of drinking and engaging in sexual intercourse (Banakar, et al., 2009; Connolly-Ahern, 2008) and the provision of an external brain.

The External Brain

As mentioned, the secondary characteristics of FASD can cause individuals to have poor memory, lack of impulse control, poor judgment, and difficulty understanding cause and effect relationships. This creates a situation where persons with FASD need help from others to make decisions and understand consequences. They also need help with schedules and routines, and the completion of tasks. People with FASD need a person whom they can trust to help them function: an external brain. The external brain guides, assists, and supervises the individual to help them make good decisions and meet their potential.

Critical Issues

Despite these findings and recent advances in policy and scientific involvement, perceptions of FASD remain conflicted and funding and critical services are consistently withheld from this community of persons with special needs. Worse yet, studies have demonstrated that physicians are *still* giving mixed advice to pregnant mothers regarding abstaining from alcohol while pregnant (Connolly-Ahern, 2008). The Diagnostic and Statistical Manual of Mental Disorders (currently DSM-IV, with the DSM-V around the corner) does not list FASD as a clinical disorder, which affects the abilities and attitudes of physicians regarding the investigation into, diagnosis and treatment of alcohol-related disorders. This may contribute to the harmful social perception that controlled alcohol intake may not be severely damaging to a fetus.

Purpose of the Study

The purpose of this study was to provide evidence of need for community and educational resources, funding for FASD, and recommendations for successful services. The study focused on perceptions of FASD by persons affected and their significant other or caregivers in a community in northeastern Ontario, Canada. Research questions included:

- What are the perceptions of persons with FASD of their characteristics that contribute to their unique needs?
- What are the perceptions of other stakeholders of the characteristics of this population that contribute to their unique needs?
- What are the services needed by persons with FASD and their families?
- What are the services currently available to persons with FASD?

With ethical permission from Nipissing University, data was collected from a variety of stakeholders in a northeastern Ontario community (adults with FASD, significant other, caregivers, mental health practitioners) in order to develop an understanding of their needs and how they are currently being met. This article shares the findings from the interviews with persons with FASD and their significant other or caregiver.

Method

Participants

An advocate for FASD who is well known within this community recruited participants for the study. Individual phone calls and meetings were undertaken to explain the purpose of the study, the role and rights of participants, and to gain informed consent to participate should they agree to do so. There were 4 persons who agreed to participate: one who has the condition of FASD and his partner, and two mothers who adopted children with FASD. This case study describes the life of one man with FASD and his partner.

Materials and Procedures

All participants requested that the interviews be undertaken in their home. The interview protocols can be found in Appendices A and B. Each interview took approximately 60 minutes. At the beginning of each interview the purpose of the study, the role and rights of the participant, and the informed consent were reviewed and confirmed.

Participants were informed of their right to refusal at any point during the interview and their right to review the transcript to approve or deny all or part of the content. The participants also were advised that they could ask for a recess at any point during the hour interview. The researcher followed an interview protocol as mentioned, but allowed for digressions and clarifications on the part of the participant. At the closing of the interview the participant was asked if there were further comments or discussion that he or she wished to undertake. Interviews were recorded with the use of a Smart Pen and transcribed using Livescribe software. Once the transcripts were ready the participants were asked to review and either approve or deny the use of their information. Some material was removed at the request of one interviewee. Participants authorized authenticity, privacy maintained by the use of pseudonyms, and the use of their interview data for the purpose of this study.

Findings of the Study

Matthew and Nadine

The participant in the study who lives with FASD, we shall refer to as Matthew, has a twin brother Myles. Matthew explained that they were adopted about the time they were 3 years old. His adopted mother was an advocate for the boys as they went through school. His school career consisted of failing Kindergarten and being placed in special education programs. School was difficult for Matthew as he was unable to concentrate, especially with the distractions of a classroom. Letter and number reversals and omissions were part of his processing difficulty so that even he was not able to read what he had written. Matthew was a serious person, even as a child, so that he would not speak or laugh. People questioned whether he was cognitively challenged. Getting the strap in school numerous times did not help him to understand why he was being punished. He was not misbehaving on purpose and he could not understand what he had done wrong. Matthew recalled being called stupid and working hard, later as a young adult taking on college courses and a variety of jobs to prove that he was not stupid.

When asked about this, his wife, Nadine said, “He’s a very smart man. He doesn’t give himself half the credit he should. I know he doesn’t think that he can do well at things that he does very well. He needs that boost of encouragement a lot.”

Despite the difficulties he has faced throughout his life, neither Matthew nor his brother, have an official diagnosis of FASD. In the past testing had not been an option as the nearest testing center was about 4 hours away. Recently one has opened in a city 1 ½ hours away but he has not undertaken the assessment. Matthew feels he has a good understanding of FASD as a result of meeting an advocate for FASD who shared information about his condition. Nadine, contends that it is very difficult to get a diagnosis in northern Ontario. “You just don’t hear about it in this community.” She and Matthew watched a video together that talked about FASD. Her reaction was, “Wow! That’s my husband!”

Alcohol remains a constant and persistent problem for Matthew. “I’ve got to try to get out of it because, like I said, it’s expensive and, to me, it’s like drinking diet coke. The only difference between diet coke and my beer is I start wobbling after the fourth one. But you know, it doesn’t feel any different – it’s just so natural.” When he had his first drink of alcohol he said it was, “Where have you been all my life? His twin had been involved with alcohol and weed from the age of 14 but Matthew had stayed the straight and narrow course until age 28. With a marriage break-up he broke down and began using alcohol and drugs. During those dark days he lost his driver’s licence and sustained assault charges as his behavior spiraled out of control. “My brother and I have wicked tempers.”

Nadine found that after Matthew quit drinking, he seemed happy but now that he is back on the booze she finds little things in life upset him. “He comes down too hard on himself and he wants to just turn to the addictions so bad and so fast that he doesn’t sit there and think about the goals at the end. It’s almost like they don’t matter.”

Matthew had worked at a hospital for a while and used to talk to the counselors there about his problem with alcohol and weed. “And it helped a lot. It was nice because I was working there – I found they took a different outlook. It wasn’t like you’re just some old drunk that comes off the road. They’d give you a little more help”.

Matthew searched for his birth parents in his quest for understanding why he felt the way he did, why he was having problems, and why he was adopted. The reunion with his mother was disappointing. He learned of problem drinking and physical abuse.

The birth parents had lost 3 children due to inappropriate child rearing, drinking, drugs, and assaults. Matthew felt that “it would have helped me a lot in life if I would have known about my mother’s consumption of alcohol during pregnancy. How much different maybe our lives would have been if we’d been told this.” Matthew met other siblings at this time and he “knew for a fact” that they too were affected by FASD. The whole thing was emotional and hard to understand. The entire family was made up of alcoholics. “My grandfather killed my grandmother and then shot himself. Alcohol and abuse were rampant as well as FASD probably. My parents had 2 older girls who had to clean up each other’s blood from the beatings from our father. Mother gave us up because she feared he would beat the boys even worse. My mother probably had FASD too.”

Matthew explained that the Children’s Aid Society (CAS) told his adoptive parents that he and his twin brother had behavioural issues and they were warned of possible criminal activity in their future. Matthew also claimed that testing was done at a later date but that his parents refused to divulge the results and he has been unable to locate the information. “Without any of the information from those assessments I fought for 11 years to get on ODSP (Ontario Disability Support Program) but was unsuccessful. My brother was given it upon his discharge from jail without even asking for it.”

Matthew described how he would be motivated and driven to do something and then suddenly would become sick or simply could not continue. From that he was labeled as lazy. On the verge of a breakdown due to refusals for ODSP and lack of finances he called his old school and found someone who agreed to help him. She provided Matthew with the information on file regarding his academics and behavior. Based on that information the ODSP finally approved his claim.

I’m doing well compared to some people who are in jail and they are told they’re stupid. They’re not stupid but they don’t know why they feel the way they do. Without my adoptive parents I would not have made it as far as I did. I would sit at the table with my homework and cry because I couldn’t figure it out. I can’t read. It’s like you’re always fighting this blockage. The more I get upset, the more you just can’t do what you need to be doing. I’d like to have a normal person’s brain just for even 5 minutes to see how it feels.

Nadine added that Matthew has to take everything on all at once, and then he just spins.

When asked what he felt might have helped him to be more successful in school Matthew considered a tutor or someone at school with more patience might have been helpful. “Some teachers wouldn’t talk, some really cared, and some of them just really didn’t understand. To talk about anything like that back then- it was just an excuse-people would think you were just making it up. And still to this day, some people do think that.”

Nadine finds when he’s done something wrong, he’ll do it again and at the time think it is okay to do it, knowing full well that it is not okay to do what he just finished doing. “It isn’t until after it’s over that it’s like ‘I shouldn’t have done that’ or ‘I shouldn’t have said that.’ There are times when he just doesn’t realize the same consequences will happen down the road.”

On the topic of money and managing money, Matthew said,

I’ve been evicted out of almost every house because when you got your money it’s like, well let’s go get some beer and let’s get some weed and get our cigarettes and order pizza, and worry about tomorrow when she comes. You’re being kicked out of your home, you owe \$10,000, you’ve got a little baby. Everybody figures, “Oh well, Matthew’s just putting it on – he’s too lazy.” And it’s only been about 3 years, or maybe 2 years, that I’ve stopped doing that. This year is the first year ever that our hydro, gas, rent and phone would be paid on a monthly basis. It’s the first year in my life.

Matthew described becoming frustrated with a lack of understanding by other people of his condition. “It was way too long to try to tell somebody that you’re not lazy. It gets to the point where you get tired of fighting. You just can’t keep explaining to somebody who doesn’t want to listen. Nobody seems to understand what this is all about.” Nadine offered, “They don’t want to, in my opinion. Which makes it hard because I always have somebody saying, “Well why doesn’t Matthew want to do this?” or “Why isn’t Matthew getting a job?” or “Why aren’t you doing this?” or “Why aren’t you going here?” It’s hard because they don’t understand. So they just figure you are just being lazy and antisocial. He has one friend Kevin who accepts Matthew the way he is even if he does not fully understand.”

When asked about his relationship with his parents Matthew explained that his father thinks it is laziness. “If he and I try to talk, we’ll talk for a little bit but we almost don’t... we’re just kind of sitting there... if you say something, is it just going to be sneered at?” Nadine said that neither of their families would talk about fetal alcohol. And I think that’s the hardest part. I think it would be easier if they would at least listen and watch the video on FASD.”

Matthew offered that he believes his wife is the only person who really understands him. “Even my grandmother – she’s going to be 80 on Friday. She’ll call once a month and, ‘Did you get a job?’ And I’ll say no, I’m not working. ‘Well why not? People go out there and they have kids and they put them in day care and they go to work at 7 in the morning and they come home, and you guys aren’t the only ones; you act like you’re the only ones that have a hard time.’”

Matthew says he gets discouraged and depressed. Why can’t I have that? Is it because I am lazy? You always doubt yourself and you’re always saying well, maybe I should try harder. And then you try really hard and you end up failing. My Dad gets all excited because I get a job, and then when I can’t hold it he’ll be all, ‘Why has he lost his job again?’ without trying to understand it. I’ve tried to commit suicide twice. My brother’s tried it twice. Because you just get to the point where you just don’t feel like anybody.

The side effects of anti-depressants take a toll. “When I first wake up, I feel like I’m in a fog and I need to be left alone and it takes a bit for me to get going. And it’s very hard on family because they’re like, “What the hell?” But it’s not my fault.

Keeping a job remains a persistent problem. I don’t do it on purpose, but I’ve lost probably 20 jobs. Even in the military, I planned on staying there for 25 years. And one day, it was just “I can’t do this, I don’t want to do this. And they were just staring at me. I just don’t have the energy to do it, and I just walked away. I wish I could change to be able to work on a regular basis like everybody else. And be able to control my money.” Nadine can remember the days when she would come home from work and he was drunk. The bills weren’t paid and the rent wasn’t paid. She had to become his “external brain” in order to pull their lives together. “Matthew responds well to it because he likes to talk things over with me. For example, before spending money he will check it out with me. But when it comes to booze and weed he loses it.”

Losing interest seems to be a thread throughout Matthew’s story. He started fixing computers and donating them to families in need. “I donated probably 40 or 50. And I was going to take an online computer course, and thought maybe if I could get my certificate, maybe we could move from here get a really good computer job. I was all hyped to do that, and now I don’t even feel like doing it”.

His wife added,

It doesn’t matter what he does – he’ll be right into something and he’ll put 100% of his time into whatever it is at the time that he is interested in doing, and then all of a sudden out of nowhere he’ll say, ‘I don’t want to do this anymore.’ And you just kind of go, ‘What?! What do you mean you don’t want to do it anymore?’ It’s, ‘I don’t want to do this anymore. I changed my mind. I’m too tired. I don’t want to be bothered.’ And he walks away and you’re standing there going, ‘I don’t get it. Did I miss something?’

Matthew goes on further to explain, “There are times where I’m just useless. There are nights where I’ll sit up until 4 in the morning because I’m scared of the dark. And then I’ll have to sleep half the day to get caught up. Both my brother and I are scared of the dark.”

Nadine added that if there’s too much noise, “it’s almost like his brain starts thinking something totally different and he gets off on to some weird track where he’s not even near doing what he was planning to do before all the noise started.”

His wife feels that if Matthew could get rid of his substance abuse, that would be life changing. “I said he’s a very smart caring man, he’s a wonderful father, loves his kids to death. He’d give you the shirt off his back. It’s just the substance abuse that really brings him down another level.” Then she added, “You can always tell when he is off the booze because he’s got more life about him. He wants to do things, where right now, if he could hide in the basement and wish the world away, he would. The only time he wants to go out is if it’s in his benefit. He doesn’t want people to come see him, he doesn’t want to go see anybody; he just wants to hibernate.”

Matthew suggested that the biggest challenge to getting help with FASD is that when people are drinking they do not want help, will not seek it, and will not accept it. The next problem is that if a person wants help in this community there is none available. When asked what he would do if he had the opportunity he said, "I'd probably try to advocate for fetal alcohol and see if I can figure out how I can start feeling better and maybe be able to hold a job down, and use that advocacy to maybe prop myself up."

Discussion

From this study we have learned that the realities of a life with the condition of FASD are seemingly grim. There are few or no supports for these people as even the medical community has largely overlooked them. A lack of diagnostic guidelines in the Diagnostic and Statistical Manuals of the American Psychological Association creates a situation where the diagnosis is unrecognized and misunderstood. An absence of community supports follows where people and their families are left to their own devices to deal with the fall-out in school, social service, and judicial systems.

The stigma attached to a diagnosis prevents many mothers from divulging the information regarding alcohol consumption during pregnancy, deemed necessary for a diagnosis to be made. This same stigma that silences voices prevents them from gaining the knowledge that the consumption of alcohol during gestation has the potential to wreck havoc on their unborn child.

Public awareness is one key to changing lives of unborn children. Public awareness campaigns, women-centered supports for making healthy choices during child-bearing years, school-aged programs to educate children and youth on the perils of alcohol on an unborn child, supports to families, and education for the health and judicial systems to build knowledge and understanding are essential components of effective community supports for people and their families living with FASD. Gaining government awareness through advocacy and education of the costs to society may prompt many of these measures to be employed. Let us continue to uncloak Fetal Alcohol Spectrum Disorder in order to make it happen.

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Appendix A



NOTE TO RESEARCHER: Questions for adults suspected of having FASD or having a diagnosis of FAS, partial FAS, alcohol-related neurodevelopmental disorders or any other disorder under the umbrella of Fetal Alcohol Spectrum Disorders (FASD).

***probe for understanding**

Have you been diagnosed with FASD?.

- If yes, what were you told about FASD and how it would affect you?
- If no, what were you told about your condition and how it would affect you?

How well do you feel you understand FASD?

Where did you spend most of your childhood?

- a) With biological mother and father
- b) With biological single parent
(Mother _____ or Father_____)
- c) With other parent or a step-parent
- d) With adoptive parent
- e) With a grandparent
- f) In foster homes
- g) Other

Did you ever go looking for your roots? (This could be your biological family or the culture of your biological family)

- If yes, did it help you feel better or did it make things worse?
- Explain why it made you feel that way
-

What was the last grade you completed in school?

Did you receive extra help in school?

- If yes, what was the extra help you received?
- If no, do you think it would have helped?

What do you think would have been the most help to you in school?

Did you ever fail a subject or a grade?

- If yes, why do you think you failed?

Are you currently working?

What kinds of jobs are you qualified for?

Do you have enough money for rent and food each month?

Do you have difficulty getting and/or keeping a job?

- Please explain.

How easy is it for you to manage your money?

What is your favourite interest or hobby?

What was the time in your life that was most difficult for you?

- What person or group of people helped you the most when you were at your lowest?
- What did they do to help?

What was the worst “help” you ever received? For example, when someone tried to help you but it made things worse.

Looking back, now that you are an adult, can you think of one thing that you needed that you didn’t get and you think might have really helped?

- What was it that kept you from getting the help you needed?

Have you been able to ask people for the help you need?

- As a child?
- As an adult?

What substances have you used in your life and what age were you when you began using them?

- Tobacco? What age? _____
- Alcohol? What age? _____
- Prescription drugs? What age? _____
- Street Drugs? What, and at what age? _____

- Can you tell me more about that?

Do you have addiction problems today?

- If yes, please explain.

Have you previously had addiction problems?

- Are you seeing an addiction counselor or have you been through a treatment centre for your addictions?
 - How did they treat you?
 - Were you on time for your appointments?
 - Did anyone remind you about your appointments?
- Have you ever quit going to a counsellor?
 - Did you start again? Why? Or why not?
- Can you tell me more about that?

Have you ever been in trouble with the law?

Are you currently in trouble with the law?

If you could change one small thing about your life today, what would you change?

What can your community do to help you get what you need (or want)? What can you do?

On an average day, what do you feel the most?

- Anger _____
- Depression _____
- Physical aches and pains _____
- Fatigue _____
- Worry _____
- Hunger _____
- Loneliness _____
- Sadness _____
- Happiness _____
- Fear _____
- Success _____
- Friendship _____
- Love _____

On an average day, what are you doing when you are happiest?

Tell me about yourself:

- Are you in a relationship?
- How long have you been in this relationship? _____ years, _____ months

- c) How well do you and your partner get along? Please explain.
- d) Do you think your partner likes you as much as you like them?
- e) How well do you get along with other people?
- f) What is the best relationship you have ever had?
 - i. IF DATING: How is the relationship you are in the same as that best relationship?
(Probe for repeating mistakes in relationships)
- g) Do you feel that other people understand you?
- h) What is a close friend like?
- i) How many close friends do you have?
 - i. What kinds of jobs do they have?
- j) Do you like to get involved in other peoples' problems?

If you could take one small step towards improving your life today, what would it be?

Appendix B



NOTE TO RESEARCHER: Questions for caregivers and/or significant others of adults suspected of having FASD or having a diagnosis of FAS, partial FAS, alcohol-related neurodevelopmental disorders or any other disorder under the umbrella of Fetal Alcohol Spectrum Disorders (FASD).

Has your _____ (son, daughter, friend, partner, etc.) been diagnosed with FASD? What have been the challenges or barriers to diagnosis?

- What have you been told about FASD and how it might affect your _____ (son, daughter, friend, partner, etc.)?
- What have you been told about FASD and how it might affect your relationship with _____?

How well do you feel you understand FASD?

What was _____'s placement like in school?

Did _____ receive extra help in school?

- If yes, what was the extra help s/he received?
- If no, what do you think would have helped?

Did _____ ever fail a subject or a grade?

- If yes, why do you think s/he failed?

Caregivers

What are _____ strengths? What is s/he good at?

What are _____ needs? What does s/he find difficult?

How well did _____ respond to consequences provided for inappropriate behaviour?

Have you heard of the concept of the External Brain? If no, *explain it to them* and ask the question. If yes, go straight to the question:

Do you think _____ would respond well to the construct of an external brain? Why or why not? In what ways would this be helpful? What are the barriers?

Did _____ get along well with her/his peers? Did s/he have friends in school? Did s/he participate in school activities?

What kinds of jobs is _____ qualified for?

Does _____ have difficulty getting and/or keeping a job?

- Please explain.

Does _____ have enough money for rent and food each month?

How easy is it for her/him to manage money?

What was the time in your life that was most difficult for you with respect to _____?

- What person or group of people helped you the most when you were at your lowest?
- What did they do to help?

What was the worst "help" you ever received? For example, when someone tried to help you but it made things worse.

Looking back, can you think of one thing that _____ needed but didn't get and you think might have really helped?

- What was it that kept her/him from getting the needed help?

Has _____ been able to ask people for the help s/he needs?

- As a child?
- As an adult?

What substances has _____ used in her/his life and what age was s/he when s/he began using them?

- a) Tobacco? What age? _____
 - b) Alcohol? What age? _____
 - c) Prescription drugs? What age? _____
 - d) Street Drugs? What, and at what age? _____
- Can you tell me more about that?

Does s/he have addiction problems today?

- If yes, please explain.

Has s/he previously had addiction problems?

- Is s/he seeing an addiction counselor or has s/he been through a treatment centre for addictions?
 - How was the addiction treated?
 - Was s/he on time for appointments?
 - Did you have to remind her/him about appointments?
 -
- Has s/he ever quit going to a counselor?
 - Did s/he start again? Why or why not?
- Can you tell me more about that?

Has _____ ever been in trouble with the law?

Please explain.

If you could change one small thing about your life today, what would you change?

What can your community do to help _____ get what s/he needs (or wants? What can your _____ (son, daughter, friend, partner, etc.) do?

Tell me about _____'s relationships:

- a) Is s/he in a relationship?
- b) How long have they been in this relationship?
- c) How well do they get along with their partner? Please explain.
- d) How well does _____ get along with other people?
- e) What is the best relationship or friendship _____ has ever had?
- f) Do you feel that other people understand your _____ (son, daughter, friend, partner, etc.)?

If you could recommend one thing that would help to improve _____'s life today, what would it be?