

**Evaluation of the Fetal Alcohol Spectrum Disorder Pilot Diagnosis  
and Support Project: Caregivers and Social Workers' Perspectives**

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## Section I – Executive Summary

While Vancouver Island Health Authority (VIHA) – Queen Alexandra Centre and the University of Victoria (UVIC) have collaborated on a number of proposals with a variety of funders, the FASD Community Circle in Victoria has been the first organization to provide funding to undertake an interdisciplinary assessment of children with suspected Fetal Alcohol Spectrum Disorder (FASD). The initiative is a limited pilot project, intended to inform future planning and funding.

The overall goal of the FASD Pilot Diagnosis and Support Project was to provide timely diagnosis, assessment and planning for children and youth affected by FASD and their caregivers.

The Pilot Project was unique in a number of ways and included: a multidisciplinary approach, specific training for the team, accountability within the structure of VIHA, clearly articulated selection criteria for participants, intake procedures, and diagnosis/assessment before, during, and after the clinic day.

Fifteen children were assessed between September 2004 and May 2005: eleven boys and four girls, aged 7 years to 15 years. Only one family of two children involved the birth mother (who has a care agreement with MCFD). The remainder of the families fostered the children with MCFD acting as legal guardian. The composition of the group was influenced by the admission criteria, specifically having to be referred from MCFD clients and on the UVIC neuropsychology waitlist.

The aim of the formative evaluation carried out by our research team was to evaluate the process of the diagnosis and assessment, from the perspective of the caregivers and social workers. We sought to identify the services provided and the caregivers' level of satisfaction with these services, their concerns and needs as caregivers, and to evaluate the support they

received while participating in the project. Social workers provided further feedback on the diagnostic and assessment process as it pertained to their relationships with caregivers. The ultimate purpose of the evaluation is to provide recommendations, based on caregiver and social worker input, for future diagnostic services and support for families of children suspected of FASD.

The design included two components: interviews with caregivers and a discussion group with social workers involved with the children diagnosed with FASD. Research interviewers received the names and contact information of participants from Carol Hale, social worker on the assessment and diagnostic team. Participants were contacted and interview times arranged. Eight caregivers out of the possible eleven agreed to be interviewed. Interviews were audio taped and the two research interviewers took field notes immediately after each of the interviews. The interviews were transcribed verbatim and participant's answers to each question were tabled using direct quotes.

The second component of the evaluation included a Social Worker's discussion group, organized by Lynn Stretch. The meeting took place at the MCFD office on 1195 Esquimalt Road, Victoria. All seven social workers who worked with children in the Pilot Project attended. The group lasted 60 minutes. Immediately after the discussion group, the researchers listened to the tape and took field notes. The tape was then transcribed verbatim.

Caregivers reported some important changes for their children as a result of the diagnosis and assessment process. The children themselves gained clarity about FASD and the ability to speak about having FASD. One child was able to drop the label of being "a mental case" and another had come to understand the need to be vigilant in his own behaviour in reference to the use of alcohol. Another younger participant had become an active member of his own caregiving team because he now understood why he acted in certain ways and what needed to be done by

himself and others to deal with his behaviours. Caregivers also spoke of how the day was long but one child was proud of his ability to complete the process. Sitting through the de-briefing process was not as productive for one child as his caregiver had hoped it would be and another child had problems with having his facial photo taken and his perception that the team thought something was wrong with his face.

For the caregivers, change happened due to the clarity they gained about FASD and their child's behaviours, the validation they obtained about their own perceptions and abilities to work with their child, and an appreciation for the thoroughness of the entire process. The personal contact and support of Carol Hale and Janet Christie were seen as having a large impact on caregivers, as was the willingness of professionals such as Dr. Down and Dr. Kerns to go into the schools and present information regarding the child's FASD diagnosis. Educating the school system was viewed as an important need by most caregivers. One caregiver spoke of the absolute need for the diagnosis and assessment to lead to concrete services for the child.

The social workers echoed the caregivers concern about the school system and the need for schools to better understand FASD. They saw the diagnostic and assessment process as educative and offering validation for caregivers, making them better prepared to care for their child/children.

The biggest challenge for social workers in the process was the time needed to search MCFD files to verify maternal drinking during pregnancy. The social workers saw their ongoing role as one of advocacy and the diagnosis allowed them to advocate for various services for the child and the caregivers.

The following recommendations are the result of our evaluative research into the FASD Pilot Diagnosis and Support Project:

- Prepare caregivers thoroughly for the diagnosis/assessment process before it begins.

- Continue the educational component of the diagnosis/assessment process.
- Shorten or break-up the diagnosis/assessment process for young people.
- Streamline the number of forms for caregivers to fill out.
- Focus on creative ways for professionals to get information about FASD across to young people.
- Continue the personal outreach aspects of the project.
- Place an emphasis on professionals' willingness to go into the family's world with their knowledge of the child (i.e. into schools and community settings).
- Continue to adapt to meet the specialized needs of the children being diagnosed.
- Create a way to handle facial photographs with adolescents who may be particularly sensitive to this aspect of the process.
- Encourage caregivers and support workers to open the dialogue about FASD with the children involved.
- Give caregivers concrete validation of their child's FASD diagnosis which will serve to validate the child's rights and needs in the eyes of the community.
- Provide caregivers with concrete information about supports and resources available to them after the diagnosis/assessment process is complete.
- Provide social workers with a school version of the diagnosis that contains no third party information.
- Time the release of the diagnostic report for optimum use in schools, for example, when I.E.P.'s are being written and when resources are being allocated.
- Write reports with insight into what type of wording schools require in order to provide various services.

- Continue and expand the outreach of the diagnostic team members, Dr. Down and Dr. Kerns, into the schools.
- Clarify the role of all members of the diagnostic team for all involved in the process.
- Develop a special debriefing model for adolescents.
- Develop a model of debriefing for birth parents that will emphasize sensitivity and specific ways in which the birth parent can understand the information provided.
- Ensure that there is adequate time to carry out the valuable educational component of the diagnosis/assessment process.
- Develop presentations and educational tools for school and parent groups.
- Give more credence to collateral reports of maternal drinking and allow the criteria for inclusion in the diagnosis/assessment process to be predicated on strong a suspicion of maternal drinking based upon observed lifestyle.

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## Section II – Background Information on Project

### A. Origin of the Project

While Vancouver Island Health Authority (VIHA) – Queen Alexandra Centre and the University of Victoria (UVIC) have collaborated on a number of proposals with a variety of funders, the FASD Community Circle in Victoria has been the first organization to provide funding to undertake an interdisciplinary assessment of children with suspected Fetal Alcohol Spectrum Disorder (FASD). The initiative is a limited pilot project, intended to inform future planning and funding. The funding was provided on a one time basis and is now concluded as of June 2005.

The contract between the VIHA, UVIC and the FASD Community Circle was signed in the summer of 2004. Five team members were recruited and subsequently attended training at the University of Seattle in early September 2004. The team included an occupational therapist, a social worker, a developmental paediatrician, a speech language pathologist, and a neuropsychologist. A family support worker was added to the team after the pilot project began through support from the FASD Community Circle. The contract goals included:

1. To provide a comprehensive assessment and diagnosis for 15 children suspected of having FASD and discussion of the results and recommendations with the legal guardians of the child.
2. To provide the experience and information to evaluate the effect of the process of diagnosis and assessment of children suspected of having FASD.
3. To provide referrals as appropriate to FASD intervention

## B. Goal of the Project

The University of Victoria (UVIC), and Vancouver Island Health Authority (VIHA) - Queen Alexandra Centre collaborated with the FASD Community Circle of Victoria to conduct a pilot initiative to provide an interdisciplinary assessment for fifteen children for the assessment and diagnosis of Fetal Alcohol Spectrum Disorder. The overall goal of the FASD Pilot Diagnosis and Support Project was to provide timely diagnosis, assessment and planning for children and youth affected by FASD and their caregivers.

## C. Characteristics of the Project

The Pilot Project was unique in a number of ways and included: a multidisciplinary approach, specific training for the team, accountability within the structure of VIHA, clearly articulated selection criteria for participants, intake procedures, and diagnosis and assessment before, during, and after the clinic day.

The multidisciplinary team approach is important to this pilot study. A team approach to assessment and intervention is necessary for understanding the complex problems presented by a child suspected of FASD (Clarren, Olson, Clarren, & Astley, 2000).

All five members of the diagnostic team attended a two-day training program conducted by the FAS Diagnostic and Prevention Network at the University of Washington, Seattle. The program is designed for interdisciplinary teams preparing to provide diagnostic services in their own community. The basis of the training is the application of the FASD 4 digit diagnostic code. The training experience provided each team member with the guidance of a peer, and the experience of a day at the diagnostic clinic. At the conclusion of this course, participants were expected to:

- Know the full spectrum of outcomes associated with prenatal alcohol exposure called Fetal Alcohol Spectrum Disorder (FASD).
- Recognize the importance of an interdisciplinary approach to FAS screening, diagnosis and prevention.

In addition to the above training, the team attended a 2-day program in January 2005, at the Asante Centre in Maple Ridge, BC. This program has been developed to support teams using the Canadian Guidelines for FASD assessment and diagnosis.

Accountability, within VIHA, for the Pilot Project was in the domain of Early Intervention Services at Queen Alexandra under the direction of Phyllis Straathoff. The day to day operations and support of the program was handled by Audrey Gibson – program coordinator. Dr. Kim Kerns was responsible for organizing administration aspects at UVIC.

The selection criteria for children to be included in the study consisted of the following:

1. Currently on the University of Victoria, Department of Psychology, Psychology Clinic waitlist for assessment by referral from MCFD.
2. Having a verified positive history of prenatal alcohol exposure
3. Living within the Capital Region
4. Be between the ages of 6 and 16

In terms of the intake procedures for the Pilot Project, the children selected were entered into the existing Queen Alexandra client database and their health records held in the health records department. All VIHA policies regarding information management (privacy and confidentiality, information sharing etc.) applied.

Fifteen children were assessed between September 2004 and May 2005. Eleven boys and four girls, with ages ranging from 7 years to 15 years. Only one family of two children involved

the birth mother (who has a care agreement with MCFD). All others children were in foster care with MCFD acting as legal guardian. The composition of the group was influenced by the admission criteria, specifically having to be referred from MCFD clients and on the UVIC neuropsychology waitlist. It is predicted that a more open referral would create a much more diverse group of children's situations.

The actual diagnostic and assessment process unfolded in the following manner. The team social worker, Carol Hale, identified the child to be seen based on the admission criteria in the contract, and communicated this information to the neuropsychologist, Dr. Kerns. The neuropsychologist assigned a PhD student to the child and this student arranged and conducted the neuropsychology assessment under Dr. Kerns' observation. A photograph of the child's face was taken. Data was prepared on a profile sheet, which was broken down by domain of brain functioning. Prior to the neuropsychology assessment, Carol Hale had contacted and often visited the family in their home. She had collected information from them, prepared them for the clinic day and assessed their needs. Carol Hale also spent a significant amount of time (approximately one day per child) obtaining and reviewing records from MCFD offices and hospitals.

The actual clinic day was on Fridays at the UVIC annex. The day included the following:

- The team met at 0830 and reviewed the information collected.
- The family and child arrived at 0900. The child then went either with the occupational therapist or the speech language pathologist, and then switched to the other
- The social worker met with family, and sat in on an interview with the paediatrician, the neuropsychologist and the family support worker. The interview was led by the Dr. Down and lasted 1.5 to 2 hours.

- When the interview was complete, the social worker gave the caregiver two questions from the occupational therapist to respond to while Dr. Down conducted a half hour physical assessment of the child.
- Meanwhile, the neuropsychologist, Dr. Kerns, used computer software to evaluate the facial measurements of the previously taken photographs.
- At 1200, the child and family left for lunch. The team spent this time completing the “FASD Diagnostic Form”. The categories of information used included: social and behavioural, growth, face measurement and score, and brain functioning. Each domain of brain functioning was evaluated and ranked (cognitive, academic and executive). All the team member’s discipline specific expertise was used in this process. Deliberations, at this stage, were complex.
- The team agreed on recommendations
- At 2300 the child and family returned. Information was shared and discussed with family and all team members.

After the diagnostic day, each team member prepared a report on their findings. The social worker then took the information from all the team members, as well as the information collected in the FASD Diagnostic Form, and created a multi-disciplinary report. The report included conclusions, other variables to consider, diagnosis and recommendations. The report was then sent to the child’s legal guardian, which in the pilot’s case was consistently MCFD.

#### D. Groups and Individuals Involved in the Project

The interdisciplinary team was designed after the FAS Diagnostic and Prevention Network at the University of Washington, Seattle. The team was made up of an occupational

therapist, a social worker, a developmental paediatrician, a speech language pathologist, a neuropsychologist, a team of graduate students, and a family support worker. Their roles are outlined in the Report on the Fetal Alcohol Spectrum Disorder Diagnostic Clinic—A Pilot Project by Michelle Fryer.

### Section III – Description of the Current Evaluation Study

#### A. Purposes of the Evaluation

The aim of the formative evaluation carried out by our research team falls under the second contract goal – to evaluate the process of the diagnosis and assessment, from the perspective of the caregivers and social workers. We sought to identify the services provided and the caregivers' level of satisfaction with these services, their concerns and needs as caregivers, and to evaluate the support they received while participating in the project. Social workers provided further feedback on the diagnostic and assessment process as it pertained to their relationships with caregivers. The ultimate purpose of the evaluation is to provide recommendations, based on caregiver and social worker input, for future diagnostic services and support for families of children suspected of FASD.

#### B. Background Literature

Fetal Alcohol Spectrum Disorder (FASD) is a birth defect syndrome that "results in a life-long disability profoundly impacting development and affecting individuals, families, and societies" (Wilson & Martell, 2003, p. 35). The terminology associated with this syndrome appears in many forms in the literature. FASD is the most recent label, describing the continuum of challenges and effects from intrauterine exposure to alcohol, but Alcohol-Related Neurological Disorders (ARND), Fetal Alcohol Effects (FAE), and Fetal Alcohol Syndrome

(FAS) are also common terms found in the literature (Sokol, Delaney-Black, & Nordstrom, 2003).

FAS is a pattern of malformations "identified by pre-and postnatal growth deficiency, dysmorphic facial features, and central nervous system dysfunction... described along a continuum according to the severity of their abnormalities" (Giunta & Streissguth, 1988, p. 453). More recent work differentiates alcohol-related neurodevelopment disorders (ARND) from FAS, with children diagnosed with ARND described as not presenting the physical and facial anomalies associated with FAS (Gardner, 2000). However, recent research suggests that the cognitive impairment accompanying ARND may be at the same level of that found in children diagnosed with FAS (Gardner).

FAS is now considered to be the leading cause of mental retardation in the Western world, with preschoolers affected by the syndrome generally scoring in the mentally handicapped to dull normal range of intelligence (Phelps, 1995). The severity of the syndrome is related to the individual's IQ level, with the lowest IQ levels found in the most severely affected (Giunta, 1999). Individuals with FASD may have multiple handicaps, requiring special educational, community, medical, and familial assistance and support. Impaired intellectual functioning and issues related to poor social judgement and independent living skills are key challenges. Therefore, many individuals with FASD require a structured living situation throughout their lifespan.

The common behavioural characteristics found in clients with FASD differentiate this disorder from other disorders effecting children's development (Giunta & Streissguth, 1988). The inability to make positive social judgements and weak socialization skills often plagues individuals with FAS. Without the awareness of social conventions and cues, children affected by FAS are often perceived as intrusive. This perception leads to difficulty in forming

friendships, often resulting in social isolation. The maladaptive behaviours of impoverished decision making, poor judgement, lack of self-direction, and lack of understanding of social cues continues into adolescence and adulthood (Phelps, 1995).

In terms of cognitive functioning, prenatal alcohol exposure affects the cerebellum, the cerebral cortex, the corpus callosum, and the hippocampus (Gardner, 2000). With so many important areas of the brain potentially affected, clients with FAS can exhibit a variety of cognitive impairment, including difficulty with memory, intelligence, attention, problem solving, and motor coordination (Gardner). Therefore, children and adolescents with FASD have special education needs. Small classrooms with structure and consistent guidelines have been shown to maximize the intellectual abilities of children and youth with FASD (Giunta, 1999). The cognitive deficits of children with FAS continue into their adolescent and adult years (Phelps, 1995).

Those individuals with FASD often require a structured living situation through their lifespan due to their level of intellectual functioning, problems in making positive judgements, and gaps in their independent living skills (Giunta, 1999). Individuals with FASD are at a higher than average risk for sexual abuse, physical abuse, and neglect, especially if they are being raised in an alcoholic home environment (Giunta & Streissguth, 1988). They suggest the need for close monitoring of children with FASD in these situations.

Caregivers of children with FASD "assum[e] a responsibility far beyond that normally associated with parenting" (Giunta & Streissguth, 1988, p. 458). These caregivers provide care for children, youth, and adults who often need constant supervision, requiring immense amounts of energy, time, consistency, and love (Giunta & Streissguth). The importance of foster and adoptive parents is illustrated by the troubling statistic that 69% of the birth mothers of children with FASD are dead before the child is four (Granitsas, 2004).

Raising a healthy child is time consuming and sometimes challenging, but the needs of an individual with FASD are diverse and numerous (Giunta & Streissguth, 1988) and complicate an already challenging task. The support system for caregivers of children with FASD needs to be broadened beyond the family to include social workers, physicians, educators, and other community professionals. FASD is a life-long disability that is completely preventable. The prevalence rates would decrease if helping professionals better understood FASD (William & Howard, 1994). The lack of understanding among professionals and society creates judgments on parenting techniques and limited tolerance for the caregiver's needs. Caregivers are often left feeling isolated. A study examining the stress levels of caregiver's of emotionally disturbed children (McDonal, Poertner, & Pierpont, 1999) revealed that the children's internalized and externalized problem behaviours caused high levels of stress for the parents. Therefore, it is important that caregiver's receive the appropriate supports to reduce burn-out from the high-stress involved in the care of FASD individuals.

A team approach to assessment and intervention is necessary for understanding the complex problems presented by a child suspected of FASD (Clarren, Olson, Clarren, & Astley, 2000). This complex profile of cognitive or behaviour issues can include a combination of ADHD, learning delays, language processing and usage problems, problems in planning and judgement, or an increase in soft neurological signs. If the child is school-age or older, "secondary disabilities" may have emerged in the face of years of frustration, failure, and social isolation. Professionals from the disciplines of medicine, psychology, speech-language pathology, occupational therapy, social work, public health nursing, and family advocacy are all important components of a diagnostic team approach.

### C. Evaluation Design

The design included two components: interviews with eight caregivers and a discussion group with social workers involved with the children diagnosed with FASD. An interview schedule, essentially a vocal questionnaire, was selected as the instrument used in the evaluation. The interview technique is flexible and adaptable and can be used with many different types of individuals such as those who may have difficulty in reading and writing. Additionally responses can be probed, followed up, clarified, and elaborated to achieve in-depth information. Interviews are particularly suitable for topics that concern personal qualities or emotional responses.

Research interviewers received the names and contact information of participants from Carol Hale, social worker on the assessment and diagnostic team. Participants were contacted and interview times arranged. Eight caregivers out of the possible eleven agreed to be interviewed. Interviews took place at the University of Victoria in an interview room (4 participants) or in the participant's homes (4 participants). Participants who travelled to UVIC received an honorarium of \$5.00 to cover the cost of parking or taking the bus to the university. Interviews ranged from 20 minutes to 90 minutes, depending on how willing participants were to speak of their experiences. The evaluation portion of the interview consisted of an opening preamble and 10 questions (Appendix A). Interviews were audio taped and the two research interviewers took field notes immediately after each of the interviews. The interviews were transcribed verbatim and participant's answers to each question were tabled using direct quotes.

The following table represents participant demographics, based on information provided by caregivers in the course of interviews.

<b>Participant: Foster caregiver or birth parent</b>	<b>No. of children in diagnostic service</b>	<b>Age &amp; Gender of child/children</b>	<b>Time child/children in caregiver's care</b>	<b>Other children in the home</b>
01 – Foster caregiver (Female)	2	Male, age 15 Male, age 11	All of the children's lives – except for periods when birth family reconciliation was tried	3 children: 2 birth sisters of the boys in the diagnostic service and one additional foster child
02 – Foster caregiver (Female)	1	Male, age 15	2 years – multiple previous placements	Caregiver has two birth children who live in the home. No other foster children in the home at this time although the boy in the diagnostic service did have a younger brother and sister who were also fostered in this home for a period of time.
03 – Foster caregiver (Female)	1	Female, age 11	4 years – since apprehended from birth mother	Foster child is the birth daughter of the caregiver's adopted niece. This caregiver also fosters the 3 year old birth sister of the girl in the diagnostic service
04 – Foster caregiver (Female)	1	Male, age 11	6 years – information about previous placements unknown	Caregiver has two grown children who don't live in the home. For the last 3 years they have not fostered any other children
05 – Birth mother	2	Male, age 9 Male, age 7	Both boys in Ministry care with home visits	No information about the foster caregivers

06 – Foster caregiver (Female)	1	Male, age 14	Just under 1 year – no information about previous placements	Caregiver has two birth children who are grown and living outside of the home. She also fosters 3 other teenage boys in her home.
07- Foster caregiver (Female)	2	Male, age 8 Female, age 9	6 months – no information about previous placements	These two children are birth siblings – no information about other children in the home
08 – Foster caregiver (Female)	1	Male, age 14	7 months – since child was apprehended from family caregivers	Caregiver also fostered this boy's 11 year old birth sister. Both children were returned to family caregivers soon after the diagnosis service was done

The second component of the evaluation included a Social Worker's discussion group, organized by Lynn Stretch. The meeting took place at the MCFD office on 1195 Esquimalt Road, Victoria. All seven social workers who worked with children in the Pilot Project attended as well as 3 field placement students who came with their social worker supervisors and sat in to observe the discussion group. Lynn Stretch introduced everyone and our researchers explained what our evaluation of the Pilot Project entailed. The social workers each signed a consent form to take part in the discussion group. (See Appendix B for the discussion group questions) The group lasted 60 minutes. Immediately after the discussion group, the researchers listened to the tape and took field notes. The tape was then transcribed verbatim.

#### Section IV - Results

##### Overview

The following section contains summarized results from the eight individual caregiver interviews and the social worker's discussion group. The qualitative approach taken provided an opportunity to record, in a less formal way, multiple understandings of the diagnostic and assessment process as it impacted the caregivers' lives and the lives of their children. The interview technique was flexible enough to allow caregivers an opportunity to explore and share their own unique experience in-depth with the research interviewer.

#### A. Caregivers Data

Were your expectations met?

Participants were generally pleased with the assessment and diagnosis process. Four of the participants were very satisfied. The remaining four participants were satisfied with the process but stated that they didn't know what to expect or they were called at the last moment. One participant (03-05) was pleased with the broad range of people conducting the assessment because the effects of FAS have such a broad spectrum of effect on the family and the child. Another participant (06-05) was satisfied because the assessment and diagnosis process clarified her concerns and provided her with a clear picture of the needs and abilities of her child. Participant (02-05) attributed her satisfaction to the fact that the process was so thorough.

What has been the most helpful for you as a family?

Participants appreciated receiving the diagnosis as it confirmed their experiences with their children. One participant (01-05) stated that her 15 year old son now understood the causes of his behaviour. "It's one thing to say you've got problems but it's another thing to know why you are acting this way and this is why you shouldn't drink and it's been really helpful for him." Another participant (04-05) noted how her confidence as a caregiver had increased as this assessment, "seems to see him in a light that I see him in . . . that has really made me feel more

confident in what I am doing with him.” Previously, other opinions of her child made this caregiver question her skills. Another participant (08-05) appreciated the opportunity to speak to professionals and to find out that she was taking the right approach with her child. Debriefing the experience and receiving support was reported as most helpful by one woman (05-05). An important learning piece for another participant (03-05) focused on the fact that a high IQ didn't mean the child wouldn't have struggles in other areas of learning. This participant also mentioned how helpful she found the occupational therapist's input on proprioceptive exercises. The clarity of knowing the child had FASD and the ways in which that opened doors to further investigation was helpful for other participants (06-05 & 07-05). Validation of on-going struggles with MCFD was important to one participant (02-05). Two participants (02-05 & 07-05) found the entire process to be very important to them in terms of learning and of support for their experiences as caregivers.

What was least helpful?

Participants responded in a variety of ways to this question. The diagnosis didn't change the situation at school where one caregiver experienced the majority of her struggles in raising her child (01-05). Another participant (05-05) reported that she would have liked the assessment and diagnosis process to be extended over a longer period of time which would give her more opportunity to be more involved.

What kinds of services did you receive or would like to receive to support you? Caregivers were asked to reflect on the type of support they had received and the types of possible support that the family support worker could provide to caregivers including working with school districts to obtain I.E.P. funding for next year, organizing a parent's support group, developing a volunteer mentorship pool, and organizing family placements at Whitecrow Camp. Two participants (05-05 & 06-05) shared their excitement about receiving support to facilitate their

child's participation in Whitecrow Camp. Two participants (04-05 & 07-05) noted how all support is a definite benefit and that just knowing that there is support and being able to choose when their family would access it was important.

Describe the services you received throughout and after the diagnosis that were supportive

Caregivers all noted a number of supportive services provided through the program, particularly the roles that Dr. Down and Dr. Kerns played in liaising with schools and Carol Hale's contact with caregivers. For one participant (01-05) having Dr. Down take the time to go to her child's school to speak to his special aid teacher was very important. She expressed appreciation that Dr. Down would speak to teachers at the middle school where her child would be going next year. The contact by Carol Hale and the invitation to go out for coffee with Janet Christie were seen as supportive by other participants (04-05 & 05-05). Another participant (03-05) who didn't drive spoke of how supportive and helpful it was to have Carol Hale pick them up and drive them to and from the diagnosis. De-briefing with the diagnostic team was also helpful as it confirmed her experiences and gave her further insight into her child. Carol Hale's willingness to drive to the caregiver's house to explain the process and to do the preliminary paperwork was viewed as supportive by one participant (02-05). "It was nice to meet somebody that you were going to be involved with for the day." Janet Christie's support and help in exploring different services was reported by another participant (07-05). Increased clarity about FASD was important to one participant (06-05) who spoke at length of the clearer picture she had of her child's capabilities, which allowed her to set realistic expectations. The firm diagnosis helped her to open a discussion with her children about FASD.

If you could change one aspect of the process what would it be and what is the reason it needs to be changed?

Participants provided a variety of suggestions in response to this question. The process was quite long for one caregiver's 15 year old son (01-05) who noted, "[W]hen he has to concentrate that long on something he has to go out and vent, so afterwards he was very angry, very frustrated and tired." One participant (03-05) wanted to have the diagnostic process expanded to adults as well as children. "I think the diagnostic procedure is going to be critical to the future of a lot of people." Although one caregiver (02-05) had initially thought that having her child be part of the de-briefing process would be a positive experience, she found the debriefing process uncomfortable for her son. "I could see his level of, not really anxiety, but almost embarrassment rising. . . I felt the information given by individuals was too long . . . for them to really learn how to talk to individuals affected by FASD . . . talking to them without grey areas, short concise sentences, not making them feel uncomfortable." Condensing the amount of forms to fill out was a suggestion by one participant (07-05) who found that the process took her hours of time. The entire assessment and diagnostic process was questioned by one participant whose children were to be returned to an environment that she didn't see as supportive. "What good is it when the kids go back into a situation where they came from and not have any services . . . It's just a waste of everyone's time and money. It's good in theory but if you don't, if you put kids back in the same environment that they came from then, what is the use?" (08-05). Three participants (04-05, 05-05, & 06-05) reported not wanting to change anything.

What should be continued with the service as it is now?

Having professionals go to the school with caregivers was seen as an important part to retain in the service by one participant (01-05). Two participants (02-05 & 04-05) noted that there were a lot of people out in the community that need this service so it just needs to continue. The six month follow-up to be done by Dr. Down was seen as being an important component to continue (05-05). One participant (06-05) encouraged the team to continue to adapt to each child

in terms of where that child would be comfortable working. "When you have a 14 year old who is very strong minded. . . Karen and the other ladies were so good because they gave him a choice of work places within the building . . . used a lot of good strategies to hold him there which is professionalism." Participant (02-05) also spoke of placing emphasis on the follow-up aspect of the service. "This partnership with the Ministry and the FASD Community Circle really needs to be jelled as a forever partnership and I really think the Ministry needs to start screening all youth that come into care... there is a reason why children are being put into care."

What could be dropped or left out of the service?

Six participants (02, 03, 04, 05, 06, & 07-05) didn't feel that anything could be dropped or left out. Another participant described the process of having the facial photographs taken as being hard for her 15 year old and she would like to see that dropped or handled differently. "He's a really good looking kid and that was really hard to hear for him that he had something different about his face. He spent the entire way home in the rear view mirror looking at his face trying to figure out why they would say that his face looked different from a regular person's face."

Do you feel your child has changed from being part of this diagnosis, assessment, & support process?

One participant (01-05) described her 15 year old as being more open and willing to tell his friends that he shouldn't drink because he has FASD. He has become a little more intellectual about his situation. For her 11 year old being the center of attention was enthralling. For another participant (04-05) her child was able to see that he could successfully complete something and deal with his anxiety around completing things. "He had fun. It was a great time for him." Another participant (05-05) spoke of Carol taking her boys out for lunch and how exciting it was for them. Change was an ongoing process for another participant (03-05). "I wouldn't say that

she has changed [from this process] . . . we had reached a point . . . coming to understand, both of us, what FASD is all about. The first two or three years, which was hell, but we both persisted and we both have gotten to a point where we can step back from the more difficult aspects of it and express our love for each other which is, to me, the basis of all human progress in the end.”

One woman (06-05) spoke of her child being shocked. “He knew something was wrong and that he wasn’t functioning in the school system; he wasn’t functioning well in society but what it was? I’ve seen a huge improvement . . . He’s no longer a ‘mental case’; he is a young man with FAS.” “Change happens everyday so he has changed and he enjoyed the attention but it has no effect on his daily routine – behaviours are behaviours” is how another participant (02-05) saw it. Another participant (05-05) didn’t think her children had changed through the diagnostic process. For one woman the children in her care were removed within a week of the diagnostic process and she did not have a chance to see any of the benefits that might have come about (08-05).

Did you as a caregiver change from being part of this assessment and in what way?

Although it was good to get the diagnosis it has not meant a big change for one family (01-05) because they were already very educated on the topic. “We do know what the birth mom was doing so we always knew it so now we just have a piece of paper saying it.” For another caregiver (04-05) there was a feeling of satisfaction in that other people were now seeing what she had seen all along. This experience has helped her to feel she can continue with this child. The process of learning about FASD has increased one participant’s (05-05) awareness and understanding about the source of aggression in her child. “When I see these professionals zeroing in on these small details of this problem both spiritual, mentally, emotionally it gives me a lot of hope and it makes me feel like together we can make progress (03-05).” The clarity of the diagnosis produced changes in her interactions with her child for one woman (06-05). Another participant (02-05) reported disappointment as the diagnosis indicated that her child’s IQ was too

high to qualify for service that she had hoped he could receive. She also shared that she had changed, “in that I hope I get a document that contains enough evidence for the school district and other community services to realize that he still has rights and that his needs need to be met based on those rights.” A participant (07-05) spoke of feeling that she and her husband have changed in the way they viewed their children. “We just understand more of what they are going through and we have learned more about FASD through the clinic.” This was a similar theme for another participant who reported that it was good to get the feedback and feel that her input was of value (08-05).

Do you have any other suggestions about the project that you have not mentioned?

Three participants (01-05, 03-05, & 05-05) felt that they wanted to see this process offered to more children. One participant (01-05) felt the school system needs to be better educated about FASD. Another participant (03-05) spoke of the need for early diagnosis because children don't get the support or encouragement they need. For her child, “There is no outreach program there for her and because of that her sadness descends on her, her sadness is like a shower that is showering these kids on a regular basis.” Being able to tell her story and receive feedback as a foster caregiver was important for one woman (06-05). A participant shared that she felt the process was backward in that having gone through the diagnosis they didn't see any new services opening up for them. “I would almost have preferred to see that services were in place [first] because we know there is a need and if funding was secure to go ahead with this project, either more funding needed to be secured to initiate services so that in the end of the process services were in place. . . . So now you have your piece of paper with your diagnosis but what does it mean?”

## B. Social Workers Data

How did you see your role in this process?

Social workers shared that their role included providing background information so that the child could be included in the Pilot Project. This included a time consuming search through records to verify maternal drinking during pregnancy. The social workers spoke of their frustration around meeting such a strict criteria and hoped that in the future more credence would be given to collateral information about maternal drinking. They also imparted a concern that medical records of the birth may not be accurate; that is, even when it is well known a birth mother drank during pregnancy this may not be noted. Social workers described, as part of their role, attending the de-briefing at the assessment day, attending meetings at the school, and using the report to advocate for services in the school and the community for the child and caregivers. They also reported that advocating for funding opportunities was another aspect of their role. Requesting personal electronic educational devices for use in the school, finding tutoring services, respite services for caregivers, and using the evidence contained in the report to find a supportive adoptive home for the child were mentioned as specific tasks they envisioned and were carrying out.

Do you see the need for this type of diagnostic and assessment service?

The social workers spoke of the need for the service to be expanded to more children, at a younger age, so services would be put in place early in the child's life. They also informed us of their opinion that ongoing assessment in line with a child's developmental growth was necessary. They saw an outcome of the service in terms of educating the school system on FASD because children are not receiving the support within that system that they need.

What if any challenges did you face carrying out your role in the process?

The time required to track down the information needed to have the child meet the criteria was reported as being the most challenging aspect of the process.

According to your understanding, what was the main concern caregivers with a child suspected of FASD had?

The social workers spoke of caregivers being confused about what were normal developmental issues and what was FASD. Caregivers were seen as struggling with the school system and were concerned about getting the school to understand their child's learning and behavioural needs. Caregivers were concerned about learning behavioural strategies that could be put into practice in the home and the school. Social workers perceived caregivers to have a concern about the need for ongoing support as their child grew older – into high school and beyond.

What did you understand to be the caregivers' initial reactions to having their child go through the diagnostic and assessment process?

The social workers stated that all the caregivers were excited and supportive of the Pilot Project and participated with enthusiasm. There was the perception that the caregivers wanted this type of information so they could put it to use in a concrete fashion within the school and their community.

What changes did you notice in the caregivers of children, pre and post assessment?

One social worker reported that her caregiver was much happier, much more accepting of the children's behaviour, and was actively looking at other strategies for dealing with behaviours. Another shared that the school was really pushing for the diagnosis and school personnel were extremely happy with what came out of the process. The birth mother was now seen to be questioning if she could cope with having her children in her care full time. She seemed to understand that things were not going to get easier and that her children would not grow out of

FASD. Her social worker reported she became better educated about FASD during the process. The debriefing component of the diagnosis and assessment was seen as an important educational moment and a number of the social workers stated seeing a change in the caregivers due to this process. One social worker conveyed that her caregiver felt validated by the process. The caregiver was now much more comfortable with caring for her child than she was prior to the assessment. Another social worker noted that one of the children had come to an understanding of how “special” he was and now he knew that certain things, like structure and an early bedtime, were necessary for his well-being. He had become an active member of his own caregiving team.

#### Section V – Discussion of Results

Caregivers reported some important changes for their children as a result of the diagnosis and assessment process. The children themselves gained clarity about FASD and the ability to speak about having FASD. One child was able to drop the label of being “a mental case” and another had come to understand the need to be vigilant in his own behaviour in reference to the use of alcohol. Another younger participant had become an active member of his own caregiving team because he now understood why he acted in certain ways and what needed to be done by himself and others to deal with his behaviours. Caregivers also spoke of how the day was long but one child was proud of his ability to complete the process. Sitting through the de-briefing process was not as productive for one child as his caregiver had hoped it would be and another child had problems with having his facial photo done and his perception that the team thought something was wrong with his face.

For the caregivers, change happened due to the clarity they gained about FASD and their child’s behaviours, the validation they obtained about their own perceptions and abilities to work

with their child, and an appreciation for the thoroughness of the entire process. As pointed out in the previous background literature, these caregivers provide care for children who often need constant supervision, requiring immense amounts of energy, time, consistency, and love. The personal contact and support of Carol Hale and Janet Christie were seen as having a large impact on caregivers, as was the willingness of professionals such as Dr. Down and Dr. Kerns to go into the schools and present information regarding the child's FASD diagnosis. Educating the school system was viewed as an important need by most caregivers. One caregiver spoke of the absolute need for the diagnosis and assessment to lead to concrete services for the child.

The social workers echoed the caregivers concern about the school system and the need for schools to better understand FASD. They saw the diagnostic and assessment process as educative and offering validation for caregivers, making them better prepared to care for their child/children.

The biggest challenge for social workers in the process was the time needed to search MCFD files to verify maternal drinking during pregnancy. The social workers saw their ongoing role as one of advocacy and the diagnosis allowed them to advocate for various services for the child and the caregivers. This is important as the background literature states that support systems for caregivers of children with FASD need to be broadened beyond the family to include social workers, physicians, educators, and other community professionals.

Section VI – Conclusions and Recommendations

A. Individual Caregiver Interviews

The following recommendations came out of the data obtained from the caregivers:

Objective	Participant input	Recommendation
Meeting the expectations of caregivers	Half of the participants spoke of not having specific expectations because they didn't know what to expect or were called at the last moment	More work in preparing caregivers for the diagnostic process before hand
Being helpful to caregivers	Many of the participants spoke of the educational component of the process – for them and for the children in their care. Validation, clarity, and increasing caregiver confidence were all mentioned.	Continue the educational component of the diagnostic/assessment process
What caregivers would change	<p>Two participants mentioned the process was too long for the children in their care.</p> <p>One participant spoke of the fact that the forms took too long to fill out.</p> <p>Another participant who requested her child sit in on the de-briefing spoke of the need for more expertise from professionals in speaking to young people about FASD.</p>	<p>Shorten or break-up the diagnostic process for the young people</p> <p>Streamline the process of forms to fill out</p> <p>Focus on creative ways for professionals to get information about FASD across to young people</p>
Make the service supportive for caregivers	<p>The personal outreach by Janet &amp; Carol was reported by participants as being very supportive.</p> <p>Having Dr. Down go into the school was supportive. De-briefing with the team and having a firm diagnosis was seen as supportive</p>	<p>Keep the personal outreach aspects of the program</p> <p>Place an emphasis on professionals willingness to go out into the family's world with their knowledge of the child – i.e. into schools and the community</p>

<p>Parts of the service caregivers want continued</p>	<p>Participants noted the flexibility and adaptability of the diagnostic/assessment process.</p> <p>Professionals going into the schools, and the follow-up by Dr. Down were seen as important aspects to be continued. One participant spoke of the school visit, saying,</p>	<p>Continue to adapt to meet the specialized needs of children</p> <p>Emphasize the ongoing support of professionals in the families world – schools and community.</p>
<p>What needs to be dropped from the service</p>	<p>The facial photos were a difficult part for one of the adolescent participants.</p>	<p>Create a way to handle the issue of facial photos with sensitivity, especially for adolescents.</p>
<p>Creating change in the child diagnosed</p>	<p>Caregivers reported that the children in their care were more willing to discuss having FASD.</p>	<p>Encourage caregivers and support workers to open the dialogue about FASD with the children.</p>
<p>Creating change for caregivers</p>	<p>One participant reported disappointment – the child in her care had a higher IQ than they expected and would not be eligible for certain funding.</p> <p>Another reported change coming about from having a document to take into the community.</p>	<p>Caregivers need something that will bolster their attempts to safeguard their child's rights to certain services in the community – validation. Whatever can be given to them that will help with this will create change for them.</p>
<p>What else is needed?</p>	<p>More services in place prior to the diagnostic service.</p>	<p>Caregivers need concrete information and supports and resources available to them after the diagnostic/assessment process.</p>



<p>Making the experience of the de-briefing positive for all</p>	<p>The de-briefing was seen as an important educational component for all involved. Adolescent FASD participants need this education too. The de-briefing experience may have to be tailor-made depending on the status of the caregiver – birth parent or foster caregiver. Concerns were also raised about the need to allow enough time for the de-briefing – so all the caregivers questions can be answered.</p>	<p>Members of the diagnostic team develop a special de-briefing model for adolescents</p> <p>An additional model of de-briefing be developed for birth parents that would emphasize sensitivity and ways in which this particular person can fully understand this information.</p> <p>Ensure that there is adequate time to carry out this valuable educational component.</p>
<p>Education in the community</p>	<p>Several social workers shared their frustration with the school system – the problems faced by FASD children is not taken seriously enough</p>	<p>Develop presentations and education for schools and parent groups</p>
<p>Challenges for social workers</p>	<p>The time involved in locating the information on maternal drinking to meet the criteria of the study</p>	<p>Give more credence to collateral reports of maternal drinking and allow the criteria to be based on strong suspicion of maternal drinking based upon observed lifestyle.</p>

### C. Recommendations Regarding Subsequent Evaluation of the Project

Future evaluation of this project is recommended based on the following components of the project that were seen to be important by caregivers and social workers: school issues, personal support, and psycho-educational services for adolescents.

The ways in which teachers, school support workers, and school administrators interact with FASD students is an extremely important component of a young person's life. Research indicates that often the learning needs of students with FASD are inadequately addressed as

educators lack necessary information for successfully recognizing and supporting the learning and behavioural problems experienced by these students (Premji, Serrett, Benzies, & Hayden, 2004). Further evaluation of this project could include interviews with the teachers, support workers, and school administrators of children who went through the diagnostic/assessment process. A suggested focus of these interviews would be the way the school will develop a care plan for the child in terms of having seen the final diagnosis/assessment report.

An important component of family support is to ensure that the basic needs of the caregivers are met (Premji, et. al., 2004). Caregivers found the personal support provided by Project Social Worker, Carol Hale and Family Support Interventionist, Janet Christie a vital part of the project. Further evaluative research focusing on the role of these two members of the diagnostic/assessment team could include additional in-depth interviews with families addressing how they responded to the support they received and how this support aspect of the project differed from other experiences they have had.

A number of caregivers reflected on the important educational component that the project provided for the children in their care. Two recommendations in this evaluation deal with the need to open the dialogue about FASD with young people, especially adolescents. Research indicates that during the adolescent period, close supervision, education about FASD, and supportive friendships are vital to avoid inappropriate sexual behaviours, or recruitment into stealing, gangs, and other risky behaviour (Premji, et. al., 2004). Further evaluation research could focus on a psycho-educational component of the project that would be directed toward adolescents, and would allow young people to begin to discuss and understand what having FASD means for them.

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## Appendix A

Opening preamble:

In order to help improve the FASD Diagnosis program we'd like to ask you to talk about your opinions of the program. We have some questions that may help get at what you liked, what didn't like, and what you think could be improved or should stay the same. I'd like to start with:

1. Were your expectations met? For example would you say you are: a) very satisfied, b) somewhat satisfied, c) not too satisfied, d) not at all satisfied.
2. What has been most helpful for you as a family? What was least helpful?
3. What kind of services did you receive throughout and after the diagnosis that were supportive?
4. The family support worker on the project has mentioned that her support will take place after the assessment and diagnosis. She will be working with school districts to obtain I.E.P. funding for next year, organizing a parent's support group, developing a volunteer mentorship pool, and organizing family placements at Whitecrow camp. Do you think any of these services will be of support to you?
5. If you could change one aspect of the assessment & diagnosis process what would it be? What is the main reason this aspect needs to be changed?
6. What should be continued with this service, just as it is now?
7. What could be dropped or left out of this service?
8. How do you feel your child has changed from being part of this diagnosis, assessment, and support process? Can you talk a bit about how the actual diagnosis and assessment day was for your child?
9. Did you as a caregiver change from being part of this assessment and in what way?
10. Do you have any suggestions that you haven't mentioned about the project that you would like to share?

## Appendix B

### Questions for the Social Worker's Discussion Group - June 1/05

1. What is your understanding of the main concerns of parents about their child who is suspected of FASD?
2. What did you understand to be the caregiver's initial reactions/perceptions to having their child go through the process?
3. What are your thoughts around the need for a comprehensive diagnostic and assessment, support model such as the one used in the Pilot Project?
4. How do you see your role in the overall structure of this diagnostic/assessment process?
5. What specific services will you provide for families with a child suspected of FASD?
6. What are the challenges, if any, in carrying out your part of the process?
7. Could you talk about any type of change you have noticed pre and post assessment for the families you work with?
8. Is there anything else you would like to add?

## Appendix C – Participant Sketches

### FASD P.P. – 01/05

Female foster caregiver of a 15 year old boy and his 11 year old birth brother who both went through the diagnostic process. She and her husband foster five children in their home at present. Four of these are birth siblings. The two boys have two birth sisters (one, a twin to the 15 year old) fostered in this caregiver's home. Both boys have been in this home since they were very young and the only breaks have been when attempts were made (unsuccessfully) to have them reunited with their birth family.

### FASD P.P. – 02-05

Female foster caregiver of a 15 year old boy. She and her husband have 2 birth children of their own who live in the home. Two years ago the 15 year old came into their home with his younger birth brother and sister. The sister was only able to stay for 6 months and the brother has just recently left the home. The 15 year old is now living in a suite in the caregiver's home. The 15 year old has been in several foster homes prior to coming to live with this caregiver.

### FASD P.P. -03-05

Female foster caregiver of an 11 year old girl. This girl is the birth daughter of the caregiver's adopted niece. The 11 year old has been in her home for 4 years, since she was apprehended. The 11 year old has a birth sister who is 3 and is also in the same foster home.

### FASD P.P. – 04-05

Female foster caregiver of an 11 year old boy.. He has been in the caregiver's home for 6 years. Over the last 3 years she and her husband have not fostered any other children and have concentrated on the boy who went through the diagnostic process.

FASD P.P. – 05-05

Female birth mother of two boys – a 7 year old and a nine year old. The birth mother does not have custody of the boys at this time. They are in the care of the ministry and she has them on the weekends and Wednesdays. No other information available from the interview about the boys foster care situation.

FASD P.P. – 06-05

Female foster caregiver of a 14 year old boy. She is also a caregiver for 3 other teenage males. The 14 year old has been in the caregiver's home just under a year.

FASD P.P. 07-05

Female caregiver of a birth brother (age 8) and sister (age 9). The children have been in the caregiver's home for 6 months.

FASD P.P. 08-05

Female caregiver in her mid-40's of a 14 year old boy and his 11 year old birth sister. They were both to go through the diagnostic process but a week after the 14 year old participated in the testing both children were returned to biological family members. She and her husband had these two children in their care for 6-7 months.