

**Fetal Alcohol Spectrum Disorder
Assessment and Diagnostic Clinic -
A Pilot Project**

Process Evaluation Report

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REPORT ON THE FETAL ALCOHOL SPECTRUM DISORDER DIAGNOSTIC CLINIC – A PILOT PROJECT

Executive Summary

In September 2004, a partnership between the Vancouver Island Health Authority, the University of Victoria and the Fetal Alcohol Spectrum Disorder Community Circle of Greater Victoria resulted in a 9-month pilot for the assessment and diagnosis of fifteen children with suspected FASD. This report describes the process used for the diagnosis and assessment, and provides 14 recommendations for consideration in future programs. Sources of information for this report include the members of the diagnostic team and their managers as well as documentation. This report is complimented by a qualitative evaluation from the perspective of the (foster) parents and legal guardians of the children assessed, done separately by a team from the University of Victoria. ¹

The recommendations for future planning are provided in the conclusion section, as well as throughout the text as they relate to the process of diagnosis. There are also a number of “considerations” in bold italicized text. These are areas requiring further exploration before a conclusive recommendation can be made. In summary, the diagnostic service was a much needed specialized service which had been previously unavailable on Vancouver Island. The pilot provided a valuable opportunity for trained professionals to experience the application of evidence based and comprehensive method for assessment and diagnosis in an interdisciplinary framework. The research and clinical collaboration has also supported the successful funding of grants to investigate interventions with children and families affected by FASD. The most significant gap in the service was the opportunity to follow through with the results into the child’s community, and in particular the schools. The involved foster parents reported the explanatory and affirming value of the diagnosis and emphasized the need for community supports, especially in schools.

¹ Shepard, B;Guenette,F and Crawford, C. Evaluation of the Fetal Alcohol Spectrum Disorder Pilot Diagnosis and Support Project, Caregivers and Social Workers Perspectives. University of Victoria, July 2005.

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Background

“Thousands of BC children have been affected by prenatal alcohol exposure. It is estimated that more than three out of every 1,000 infants will be affected in some way by FASD. The loss in human potential is immeasurable. The financial cost is formidable. Each child affected by FASD may require an estimated \$1 million to \$2 million over the course of their lifetime to support remedial medical, educational and social costs.”²

An early diagnosis is essential to allow access to interventions and resources that may mitigate the development of subsequent "secondary disabilities" (e.g., unemployment, mental health problems, trouble with the law, inappropriate sexual behaviour, disrupted school experience) among affected people.²² Furthermore, an early diagnosis will also allow appropriate intervention, counseling and treatment for the mother and may prevent the birth of affected children in the future.²³ It may also prompt caregivers to seek diagnosis and support for previously undiagnosed siblings. A review of medical and behavioural management of those with FASD can be found in other sources.^{3,24} Astley and Clarren²⁵ suggest that accurate and timely diagnosis is essential to improve outcome, as misclassification leads to inappropriate patient care, increased risk of secondary disabilities, missed opportunities for prevention and inaccurate estimates of incidence and prevalence. Together, these inaccuracies could hinder efforts to allocate sufficient social and health care services to the vulnerable populations and preclude accurate assessment of primary prevention efforts.³

Fetal Alcohol Spectrum Disorder: A Strategic Plan for British Columbia (2004)

As part of the provincial plan, a number of needs have been well documented after considerable consultation and review of research. They include:

1. Health promotion, and public awareness
2. Early identification of pregnant women in need of supports
3. Focused intervention to high risk pregnant women
- 4. Timely diagnosis, assessment and planning for children, youth and adults affected by FASD.**

² Fetal Alcohol Spectrum Disorder, A Strategic Plan for BC, <http://www.mcf.gov.bc.ca/fasd/>

³ Chudley, A. et.al. Fetal Alcohol Spectrum Disorder, Canadian Guidelines for Diagnosis, Canadian Medical Association Journal, March 1, 2005.

<http://www.acbr.com/fas/Canadian%20guidelines%20for%20diagnosis%20of%20FASD.htm>

5. Supports for people effected by FASD, and
6. Leadership and coordination at all levels, including local, regional and provincial

The fourth point, diagnosis, assessment and planning for children affected by FASD is the subject of the pilot project described in this evaluation. The University of Victoria, and Vancouver Island Health Authority (Queen Alexandra Centre) have partnered to conduct a pilot initiative to provide an interdisciplinary assessment and diagnosis of Fetal Alcohol Spectrum Disorder for fifteen children. Once a diagnosis is reached, interventions include medical and therapeutic, educational, training and support of caregivers. These are out of scope for the pilot project, but clearly recognized.

As a provider of local and regional health services for Vancouver Island and Greater Victoria, the Vancouver Island Health Authority, Queen Alexandra Centre provides developmental assessment and intervention for children with identified need. Children who have, or are at risk for developmental delay for any reason are referred to health professionals at the Queen Alexandra Centre. Dr. Jonathan Down, a developmental pediatrician with experience and expertise in Fetal Alcohol Spectrum Disorder has been providing leadership in this area. Children seen are typically those who may benefit from early intervention in the therapy services of physical and occupational therapy, speech and language and the support of social work and nutrition services. While there is a Neuropsychology clinic and mental health programs as part of the Queen Alexandra group of services, behavioral challenges alone do not meet the admission criteria to programs. For this reason, children suspected of Fetal Alcohol Spectrum disorder specifically would not be accepted for services at the Centre. There may be children with FASD in programs and services including mental health, Neuropsychology, Infant Development, and Intervention programs in both the pre-school and school age population, but their therapy needs would have been the reason for admission. The model of practice is multi-disciplinary.

The University of Victoria, Department of Psychology, Neuropsychology has provided comprehensive Neuropsychology assessments to children for years, and the service is part of the graduate education program in Neuropsychology. Dr. Kim Kerns is well recognized for her expertise in the area of Fetal Alcohol Spectrum disorder, and with her students has been doing

assessments in this area for some time. In an informal and unfunded way, a professional partnership has been in place between Dr. Kerns and her department and the services at QAC.

While these two partners have done a number of proposals to a number of funders, the FASD Community Circle in Victoria has been the first to provide funding specific to an **interdisciplinary** assessment for children specifically with suspected fetal alcohol spectrum disorder. With funding of \$44,942 from the FASD Community Circle, and in kind support from VIHA and UVIC of \$44,040 an agreement to provide specialized, interdisciplinary assessment and diagnosis for fifteen children was established. The initiative is a limited pilot project, intended to inform future planning and funding. The funding is one time and is concluded as of June 2005.

The contract between the health authority, the university and the FASD Community Circle was signed in the summer of 2004. The team members recruited and they attended training at the University of Seattle in early September 2004. The contract goals included:

1. To provide a comprehensive assessment and diagnosis for 15 children suspected of having fetal alcohol spectrum disorder 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 as appropriate.

The team

Using the experience of other FASD diagnostic models and the Canadian Guidelines,⁴ the team members included a developmental pediatrician, and neuropsychologist, occupational therapist, speech language pathologist and social worker. After the pilot began, a family support worker became available through the FASD Community Circle. The roles and functions of the team members are described later in this report.

⁴ <http://www.acbr.com/fas/Canadian%20guidelines%20for%20diagnosis%20of%20FASD.htm>

Roles

Occupational Therapy

- Screens for fine motor, gross motor and sensory processing as well as visual motor skills
- Conducts the QNST – soft neurological screening
- Provides recommendations in areas of expertise including emotional regulation and calming activities

Social Worker

- Coordinates the team
- Arranges for assessments (space, time and team)
- Collects needed information for team assessment from multiple sources
- Contacts and prepares and supports the child and their family.
- Writes final report integrating the contributions from each team member
- Admin support to clinic day (food, coffee, other tasks)
- Helping families with transportation needs (parking passes, getting to the clinic)

Physician

- Provides diagnosis in the medial context
- Recognizes additional risk factors, conducts a physical examination
- Provides differential diagnosis

Speech Language Pathologist

- Provides screening level assessment for language issues

Neuropsychology

- Assesses the level of brain damage by testing the cognitive function (intellectual, academic, and executive); adaptive and behavioral/social domains.

Family Support Worker

- This position reports to the FASD Community Circle, and does not have a role in the diagnostic process. Consent from the legal guardian is obtained prior to involvement in the diagnostic and information sharing process.
- Informs herself on the issues and needs of the child and family by attending the assessment and diagnostic clinic days
- Explores needs with families based on their requests, in the area of school system, social groups and ongoing education for both the child and the parent(s).
- Provides education to those in the child's community to reframe their approach to the child.

The Diagnostic Tool

In 1997, the Washington State FAS Diagnostic and Prevention Network developed a new, comprehensive, reproducible method for diagnosing the full spectrum of outcomes of patients with prenatal alcohol exposure. This new diagnostic method, called the **4-Digit Diagnostic Code**, provides more accurate and reproducible diagnoses than the gestalt method of diagnosis due to its use of quantitative, objective measurement scales and specific case-definitions. The four digits in the Code reflect the magnitude of expression of the four key diagnostic features of FAS in the following order: (1) growth deficiency, (2) the FAS facial features, (3) central nervous system (CNS) damage/dysfunction, and (4) prenatal alcohol exposure. The magnitude of expression of each feature is ranked independently on a 4-point Likert scale with 1 reflecting complete absence of the FAS feature and 4 reflecting a strong "classic" presence of the FAS feature. The 4-Digit Diagnostic Code has been used to diagnose over 2000 patients in the FAS DPN clinics to date. A patient's 4-Digit Diagnostic Code is derived after a thorough evaluation by an interdisciplinary team of professionals. The team typically includes a physician, psychologist, occupational therapist, speech-language pathologist, social worker, and family advocate. See Appendix B for the diagnostic framework.

The training

All five members of the team attended the 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 provides each discipline with the guidance of their peer, and the experience of going through a day at their diagnostic clinic.

- **Course Description**

This two-day training course introduces interdisciplinary clinical teams to the methods used by the Washington State FAS DPN to screen, diagnose and prevent FASD. A typical interdisciplinary team includes a pediatrician, psychologist, speech language pathologist, occupational therapist, and family / maternal advocate. The training includes didactic lectures, observation of a real diagnostic

evaluation, and hands-on practice sessions.

- **Course Objectives**

At the conclusion of this course, participants will:

- 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 this training the team attended a 2-day training program in January 2005, at the Asante Centre in Mapleridge. The program has been developing to support teams using the Canadian Guidelines for FASD assessment and diagnosis. The outline of the contents for this session is provided in Appendix A.

Experience of the team members in the area of FASD varies from being a recognized expert, to having no previous experience in providing services specific to FASD. All team members reported these experiences were key to their abilities to conduct FASD assessment and diagnosis in an interdisciplinary way.

Recommendation: That the team receives comprehensive training, together as a team, and that they are provided with peer professionals in other teams to consult with as they put their training into practice. This common training is viewed as important to all team members regardless of their experience with FASD diagnosis and assessment as it provides a common framework.

Infrastructure and process

Accountability within the Vancouver Island Health Authority for the pilot was placed with Early Intervention Services located at the Queen Alexandra Centre. The manager of those services is Phyllis Straathoff. The manager was the contract signatory and is connected to Island and Province wide planning and information in the area of FASD. Assisting in the day-to-day operations and support of the pilot was Audrey Gibson, Program Coordinator, school age and clinic programs. Audrey was support for day-to-day operations, administered the budget, did the

staffing and recruitment of the team and collaborates with the “seniors”⁵ for discipline specific clinical issues. Dr. Kim Kerns of the Neuropsychology section of the Department of Psychology (University of Victoria) supervised the administrative aspects of the pilot within the University.

Selection Criteria

The selection criteria for children included the following:

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

These criteria were selected to:

1. Support the needs of children in care of the Ministry for Child and Family Development and reduce the waitlist of children already needing a Neuropsychology assessment.
2. Maximize the likelihood that the child’s diagnosis would be related to alcohol exposure prenatally. It was important that the experience of assessing children with FASD was gained, rather than possible other behavioral problems.
3. Having the children reside in the Capital Region was important as an outreach model was not established, and travel of families not accommodated for. It also increased the ease of connecting the children to resources in the community.
4. The age grouping was selected due to the availability and knowledge base of the Neuropsychology assessment tools for that age group. (It is recognized that there are benefits to assessment and diagnosis before the age of 6)

Fifteen children were assessed between September 2004 and May 2005. Eleven boys and four girls were seen, 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 the Ministry for Children and Family Development). All others were foster children with the Ministry for

⁵ Each profession at the Queen Alexandra has an appointed senior, who guides the clinical practice in that profession. They advise members of the profession and the manager of the programs.

Children and Family Development being the legal guardian. The composition of the group was influenced by the admission criteria of being referred from the MCFD clients on the UVIC Neuropsychology waitlist. It is predicted that a more open referral would create a much more diverse group of children's situations.

Recommendation: It is desirable to expand the criteria for admission to future programs, beyond children in care of the Ministry for Child and Family Development, and into an earlier age group. Research shows that a diagnosis under the age of 6 years old is protective against the well-known secondary disabilities of FASD. It is recognized that the numbers of referrals will greatly increase, as will the diversity and needs of families when the criteria are expanded. It is also recognized that the Neuropsychology tools needed to assess younger children would also need to be addressed.

Intake

The Queen Alexandra Centre uses a coordinated intake service managed by a social worker. This role **was not** utilized for the pilot, due to the strict admission criteria of the pilot and the role of the FASD team social worker in the collection of information. Children seen were entered into the existing 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.

Recommendation: The intake process used by other programs in VIHA Early Intervention Services should be considered for this clinic in the future. The role of the intake worker in collection of information needed for the assessment process should be explored, as this is a helpful function in other clinics.

Recommendation: Records of information collected for the assessment, and records of the diagnostic process itself should be integrated into the Queen Alexandra Health Records system. This will allow access to the infrastructure based on health records specialists and will ensure the policies to provide access to information and protect privacy are applied.

The assessment and diagnostic process

Before the Clinic day

The social worker identified the child to be seen based on the admission criteria in the contract, and communicates this to the neuropsychologist. The neuropsychologist assigns a PhD student, who arranges and conducts the Neuropsychology assessment under Kim Kern's observation. The amount of testing depends on how much is already done, as the children were referred from an existing list within the Neuropsychology department. If previous Neuropsychology assessment has been done then an abbreviated battery of tests is selected. A photograph of the child's face is taken. Data is prepared in a profile sheet, which is broken down by domain of brain functioning.

Consideration: The comprehensive Neuropsychology testing including the involvement of doctoral students is a great strength in the process. This will be difficult or impossible to replicate in other communities. Future expansion will need examination of alternative approaches to achieve this.

Also, the social worker has contacted and visited the family often in their home. She collects information from them, prepares them for the clinic day and assesses their needs. The social worker has also spent a significant amount of time (approximately one day) obtaining and reviewing records from the Ministry for Children and Family Development offices and hospitals. The framework for this collection of information is provided in Appendix 2, the University of Washington FASD Diagnostic Form.

There is a great deal of information to collect about the child and their family. The information is from multiple sources and requires many hours to collect. The pilot was limited to the Greater Victoria region, which in itself limited sources. If a diagnostic service covered the entire Island it becomes more difficult to collect information and to be aware of sources and location of information needed. Options suggested include:

- Use the model used by other FASD centres such as the University of Washington and transfer all or part of the information collection responsibility to the parent or legal guardian.

- Budget for more social work or social workers time to collect information.

Consideration: The collection of information is a very time consuming part of the diagnostic process. The Seattle model requires others outside the team to collect much of this information prior to the referral, such as referring health care practitioners or parents. In order to focus the scarce resources and expertise of the diagnostic team, it may be necessary to shift the task of information collection to others.

There was no administrative support built into the pilot, and this meant that professional staff was left to perform such duties as:

- Making contacts with families to confirm appointments
- Arranging parking and assisting with transportation challenges
- Set up and maintenance of facilities
- Arranging for refreshments
- Follow up to obtain reports and documents
- Providing a contact point for families, MCFD and others.

Recommendation: It is recommended that administrative support models such as that used in the other Queen Alexandra Clinics be included in future planning.

The Neuropsychology assessment

A PhD student in Neuropsychology, under the supervision of Dr. Kim Kerns, does this comprehensive assessment. The Neuropsychology department had seen some of the children previously, and this affected the amount of testing required. Testing includes cognitive (intellectual, academic and executive), adaptive, behavior, social and emotional. The model from the University of Washington can be seen in Appendix B. While tested is done on each cognitive domain, the process relies on the parent or foster parent for behavior, social and emotional observations. It was noted that the school could be a valuable source of this information also.

Having Neuropsychology assessment done on a day previous to clinic spread out the demands on the child and family.

The involvement of students in the graduate program has provided an excellent training opportunity in the assessment of, and understanding the impact of FASD. This type of training is crucial for increasing the knowledge and understanding of this disorder in future neuropsychologist in BC, and in Canada. It has also allowed for an excellent collaboration between researchers and clinicians and their successful funding of 2 grant applications to investigate interventions with children and families affected by FASD, and basic research into some of the associated cognitive difficulties individuals with FASD experience.

Timeliness of information

The information collected by the social worker prior to the assessment day is very valuable to the conclusions and recommendations of the day. Team members reported a desire to have access to and review the information prior to seeing the child and family. Also, there is some redundancy of effort in collection of information that is done prior to or during the Neuropsychology assessment. Also, because the social worker is not involved in the initial interview with the parent, redundancy of information collected occurs. Team members each create a report following the clinic, and this requires the social worker to pull the information from each and create a final report. The first draft takes over 3 hours, and there is at times a delay in getting the reports from all team members.

Recommendation: Use flexible PDF forms (the FASD Diagnostic Form) to enter information prior to clinic, from multiple sources. Have as much of the information available shared with team members before the clinic day. Design in such a way that 3rd party personal information is not identifiable.

On the Clinic Day

Facility

The clinic itself was done on Fridays, in an annex at the University of Victoria. The facility was not satisfactory to all team members, and did not have easy access to supports such as kitchen, catering. The building used was an annex at the University of Victoria. The building had no windows, and was not equipped with medical diagnostic tools. It was originally planned that the clinic be held the Queen Alexandra Centre in the diagnostic clinic space, but scheduling difficulties precluded this. In future, a space such as this would be recommended not only for it's environment, but for all the infrastructure supports such as reception, washrooms (including handicap access), play area, food preparation area, cafeteria services, scales, scopes, etc.

Recommendation: That the Queen Alexandra Centre outpatient clinic facility be used for future clinics.

Team Meeting

- Team meets at 0830 and reviews the information collected. The team before will not have seen much of this information collected by the social worker and the Neuropsychology assessment.

Assessment Process

- Family and child arrive at 0900. The child goes with either the occupational therapist or the speech language pathologist, and then switches to the other so as to see both.
- Social worker meets with family, and then begins an interview by the pediatrician, neuropsychologist and family support worker. The interview is led by the Dr. and lasts 1.5 to 2 hours.
- When the interview is done, the social worker gives the parent two questions from the occupational therapist while the Dr. conducts a half hour physical assessment of the child.
- Meanwhile, the neuropsychologist uses computer software to evaluate the facial measurements of the previously taken photographs.

Diagnosis

- At 1200, the child and family leave and go for lunch. As the team starts completing the "FASD Diagnostic Form" (appendix B) with the information they have obtained. By this

time, there are multiple sources of information such as prenatal risk factors, postnatal, social history, hospital records and others. The categories of information use include:

- a. Social and behavioral
 - b. Growth
 - c. Face, measurement and score
 - d. Brain
 - i. Each domain of brain functioning is evaluated and ranked. (Cognitive, academic and executive) all the team member's discipline specific expertise is used to do this, as the pieces of information are linked and influences the final decision. Deliberations are complex and not straightforward.
- The team agrees on recommendations

Complexity of Diagnostic process

The diagnostic process is complex, requires consideration of multiple professional domains. Results are not discrete, but interrelated. Experienced professionals all over Canada still have questions about the diagnostic process. The new Canadian guidelines make it more difficult to come to a positive diagnosis even when that is what experience professionals recommend. The comprehensiveness of scores makes deliberations more difficult. Both parents and team members report that the objective nature of the diagnostic process can present challenges.

Recommendation: That ongoing support for the use of the diagnostic criteria be available for the team, such as suggested below.

- Participatory workshops on team diagnosis, even with made up data.
- Training must of active component, rather than passive.
- Use of consultative support with teams who have had more experience with interdisciplinary diagnosis.
- Provide more time for team development
- Be explicit about the process for decisions and resolution of clinical differences

It was also recognized that other specialists may be needed for assessment of the child, and this may include psychiatry and genetics. These professionals need to be formally linked to the clinic service, but would not necessarily be required for every child.

Recommendation: That the current team members are essential parts of an FASD team, and that consultative links should be developed with genetics, and psychiatry.

Family Meeting

- At 2:30 the child and family returns. Information is shared and discussed with family and all team members. (The Neuropsychology student may take the child for a few more assessment task and keep him occupied).

Information delivery to families

Sharing of information with parents or guardians is intense, time limited and holds complex and new information. There is no opportunity to provide more information later, to clarify when families have had time to consider the information or to assist them in sharing and interpreting the information to those in the child's world, such as teachers. Also, children involved may have difficulty understanding what they hear, and as reported in the interviews done by Blythe Sheppard and students, may cause them distress and misunderstanding.

Options:

- Use visual aides to explain the results to families
- Build in opportunities for follow up and assistance for parents in informing others about the assessment, diagnosis and recommendations.
- Create a summary of the final full report for parent to use
- Expand the role of the team to provide consultation in the community
- Involve more family or support persons in the meeting. Consider involving key school people.

After the diagnostic day

Reporting and Documentation

- Each team members prepares a report on their findings. The Dr. uses internal dictating systems, the others use secure email communications. The format of the various reports is not consistent.
- The social worker takes the information from all the team members, and the information collected in the FASD Diagnostic Form and creates a multi-disciplinary report. The report includes conclusions, other variables to consider, diagnosis and recommendations. Each team member signs the final report.
- Report is sent to parent (legal guardian), which in the pilot's case was consistently the Ministry for Child and Family Development. While the intended audience of the report includes school psychologists, parents and others, any sharing or the report beyond that is left up to the legal guardian.

Family Support Worker

- The Family Support Worker, from the FASD Community Circle contacts the family and provides information on community services, which may be helpful including parent training, social groups for the child, and assistance with the school system.

Six-Month Follow Up

- While this was not part of the original contract, the pediatrician has offered to see each of the 15 children 6 months following the diagnostic process to assess. This was viewed as very positive by the parents.

➤ Links to schools

Outside the pilot service, the pediatrician and neuropsychologist visited schools to discuss the child's needs with school personnel. Both the parents and the team members had strong messages about how important it was to have schools knowledgeable about the child's needs, and to have the resources to respond to them. Team members reported that a link to school both before and after the assessment and diagnosis could be stronger. There is a need for stronger information coming from the school in terms of assessments done, social and behavioral information and

others. Also, there is not current connection with the school therapists who would be in a position to support recommendations.

Recommendation: That team and school system is designed to ensure linkages both before and after the diagnostic process.

Follow up with community

While a comprehensive written report is provided to the legal guardian, it is a big step to put this information into action for the many people involved in the child's world. These people vary from friends and family, to care providers, teachers, and health professionals in the schools or other parts of the health system. Team members believe if they had the support (time and role) to follow up with the child, support the family and evaluate the effect of their recommendations then the diagnostic, assessment and recommendation process would be more likely to make a difference for the child, and help the parents "re-frame" the world the child lives in.

Recommendation:

In future developments, build in time for each team member to follow up with each child and family. This would involve meetings and connections with school professionals and support to parents in helping others understand the child's needs. This would need to allow for time for the parents and others to implement and try out the recommendations.

Recommendation:

Provide summary written materials, which can be used by parents to explain the child's needs and the recommendations in multiple contexts. (Family, caregivers, recreation, sports, etc.). It is often the case that the people (social works, foster parents and families) are not constant in a child's life, so the information needs to follow the child and the learning process continuous.

Budget

The contract between VIHA, the University of Victoria Department of Psychology and the FASD Community Circle specified cash and in-kind resources as follows.

NB: Costs for therapists and social worker include a 23.3% benefit cost and the hourly rate

ITEM	IN KIND	Budgeted cost	Actual expenses
Neuropsychology assessments	\$30,000 (\$2000 per child)		In kind
Consumables for Neuropsychology testing		\$3750 (\$250 per child)	\$4159
Digital Dymorphology Software		\$68	
Digital Camera		\$300	
Developmental Pediatric Assessment	15 days of \$936 per day. Total \$14,040		In kind
Speech Language Pathology services		\$8160 (10 hours per child at \$54.40 per hr)	\$31,972
Occupational therapy services		\$7344 (9 hours per child at \$54.40 per hr.)	
Case Coordinatation, social work and report writing		\$16,320 (20 hours per child at \$54.40 per hr.)	
Training for team of 5 professionals		\$7000	\$7100 for Seattle and \$996 for Asante Centre
Evaluation and report writing		\$2000	\$2000 (This was not charged to cost centre, but to program cost centre – not included in total)
Intake, report transcription, space, management, infrastructure	IN KIND		In kind
Misc (food, etc)			Approx \$150
TOTAL	\$44,040	\$44,942	\$44,377

Factors:

- Salaries budgeted for most senior, depended on salary scale of person hired
- Travel to Asante Centre in Mapleridge not in original budget or plans
- More time than anticipated needed for evaluation (interview of 8 people, coordination with UVIC and writing time)
- 3 staff attended a FASD conference in February which was not charged to this project

Conclusions

Through the assessment and diagnosis of 15 children, we have experienced both the value and the challenges of a truly multidisciplinary team. Due to the complexity of children with FASD, the expertise of the different clinical disciplines is the recommended way to both consider the multiple domains, and together with the multiple professionals consider the implications of findings in terms of recommendations, which will make a difference for the child. The training was a good start for the team, including those experienced with FASD as no team members had previously worked in an interdisciplinary team for the assessment of FASD. Even experienced members stressed the importance of ongoing active training and consultation with other teams. The information collection and organization are very large parts of this diagnostic process. A mix of clinical, social and behavioural information requires collection from a number of sources taking significant time and judgment. Schools are recognized as important sources of information, which need to be developed. As the multidisciplinary approach is better understood and more often experienced than interdisciplinary, this is a concept to be supported by both theory and team development. Included in the interdisciplinary approach is a report, which integrates the information from multiple disciplines. This is also an area for development, as current practice requires that the reports of each discipline are taken by the social worker and crafted into one meaningful report. This is very time consuming and presents logistical challenges and time delays. Parents and social workers were very appreciative of the comprehensive, specialized process, and emphasized the need to use the information from the process to effect change in the child's world of home, school and community. The Recommendations throughout the report are stated again here.

- 1. The team should receive comprehensive training, together as a team, and need connections with peer professionals in other teams to consult with as they put their training into practice. This common training is viewed as important to all team members regardless of their experience with FASD diagnosis and assessment as it provides a common framework.*
- 2. It is important to expand the criteria for admission to future programs, beyond children in care of the Ministry for Child and Family Development, and into an earlier age group. Research shows that a diagnosis under the age of 6 years old*

is protective against the well-known secondary disabilities of FASD.⁶ It is recognized that the numbers of referrals will greatly increase, as will the diversity and needs of families when the criteria are expanded. It is also recognized that the Neuropsychology tools needed to assess younger children would also need to be addressed.

- 3. The intake process used by other programs in VIHA Early Intervention Services should be considered for this clinic in the future. The role of the intake worker in collection of information needed for the assessment process should be explored, as this is a helpful function in other clinics.*
- 4. Records of information collected for the assessment, and records of the diagnostic process itself should be integrated into the Queen Alexandra Health Records system. This will allow access to the infrastructure based on health records specialists and will ensure the policies to provide access to information and protect privacy are applied.*
- 5. The comprehensive Neuropsychology testing including the involvement of doctoral students is a great strength in the process. This will be difficult or impossible to replicate in other communities. Future expansion will need examination of alternative approaches to achieve this.*
- 6. The collection of information is a very time consuming part of the diagnostic process. The Seattle model requires others outside the team to collect much of this information prior to the referral, such as referring health care practitioners or parents. In order to focus the scarce resources and expertise of the diagnostic team, it may be necessary to shift the task of information collection to others.*
- 7. Administrative support models such as that used in the other Queen Alexandra Clinics should be included in future planning.*

⁶ Streissguth, A and Kanter J. The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities, University of Washington Press, 1997.

8. *The Queen Alexandra Centre outpatient clinic facility should be used for future clinics.*
9. *Use flexible PDF forms (the FASD Diagnostic Form) to enter information prior to clinic, from multiple sources. Have as much of the information available shared with team members before the clinic day. Design in such a way that 3rd party personal information is not identifiable.*
10. *The current team members are essential parts of an FASD team, and consultative links should be developed with genetics, and psychiatry.*
11. *Provide ongoing support for the use of the diagnostic criteria for the team, including participatory workshops on team diagnosis, active training, and use of consultative support, time for team development and a process for decisions and resolution of clinical differences.*
12. *Design the team and school system links to ensure linkages both before and after the diagnostic process.*
13. *In future developments, build in time for each team member to follow up with each child and family. This would involve meetings and connections with school professionals and support to parents in helping others understand the child's needs. This would need to allow for time for the parents and others to implement and try out the recommendations.*
14. *Provide summary written materials, which can be used by parents to explain the child's needs and the recommendations in multiple contexts*

Appendix A
Training Program at the Asante Centre

Appendix B
FASD Diagnostic Form