BUILDING CLINICAL CAPACITY FOR FETAL ALCOHOL SPECTRUM DISORDER DIAGNOSES IN WESTERN AND NORTHERN CANADA

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ABSTRACT

Background
Fetal alcohol syndrome and fetal alcohol spectrum disorder are common problems. In response to this problem the Canada Northwest FASD Research Network was established in 2005 by the Canada Northwest FASD Ministerial Partnership. This study was conducted to determine the FASD clinical activity in Canada Northwest.

Methods
The Network identified all clinical programs via Internet sites, provincial postings and professional word of mouth references that purported to do FASD assessments regularly using a multidisciplinary assessment team. Each of these programs was sent a questionnaire asking about clinical capacity, aggregate diagnostic results, team composition, time of clinical assessment and cost of assessment.

Results
Of the 27 programs identified to receive the questionnaire 15 programs responded. These programs were determined to have evaluated about 85% of the patients evaluated by all the programs. The total 7 jurisdictional capacity for FASD diagnosis was 816 evaluations in 2005 and projected to be 975 in 2006. Selection methods for appointing patients for assessment seemed excellent as 23% of those assessed were found to have FAS or pFAS and another 44% had other forms of FASD. The most common professionals to participate in the team evaluations were Paediatricians, Clinical Psychologists, Speech and Language Pathologists and Occupational Therapists.

Interpretation
Clinics are developing in western and northern Canada to diagnose patients with FASD. Comparing the experiences of these clinics can help to determine the continued need to increase diagnostic capacity, standardize diagnostic approaches to assure consistency of approach and diagnosis across the sites and appropriately staff and fund the programs.

Key words: *FASD; diagnosis; Canada; clinics*

Fetal alcohol syndrome (FAS) is a specific birth defect syndrome defined by the presence of some growth deficiency, a specific set of facial features, and brain dysfunction leading to maladaptation in school, home and society in the context of prenatal alcohol exposure.[1] As is the case with most environmental agents that cause birth defects, alcohol can produce a complete, specific and recognizable pattern of malformation as well as partial expressions. This spectrum of abnormal outcomes is thought to be due to variations in exposure and gestational timing as well as maternal and fetal factors. Importantly in the case of alcohol teratogenesis, the same patterns and severity of brain dysfunction can be seen in individuals with both the complete and incomplete physical expression of FAS.[2] FAS and other prenatal alcohol related conditions are referred to, in the aggregate, as the fetal alcohol spectrum disorder (FASD). For most medical conditions, the true prevalence of the disorder is not established or monitored by population based studies or through broad community based screens but rather is inferred from the rates of diagnosis made within medical settings within the geographic area. It is assumed that most people made ill by a condition will be seeking care and the diagnoses will be reflected in various coding systems utilized in medical evaluations. Any change in the prevalence of the condition can then be tracked through diagnostic codes in active or passive retrieval systems.

The true prevalence of fetal alcohol syndrome (FAS) and fetal alcohol spectrum disorder (FASD) is not established neither in Canada nor anywhere else in the world. The difficulty of establishing the true prevalence for FAS/FASD is more complicated than for most conditions. The diagnosis rests in large part in evidence that a) brain dysfunction is integral to brain function/structure rather than due to temperament or environment problems and b) the possible observation of subtle physical finding and c) to the history of alcohol exposure when available. The determination and delineation of this complex form of brain dysfunction usually requires a team of investigators including a psychologist, speech pathologist, occupational therapist and possibly a psychiatrist as well as the physician each doing tests that are unique to their training.[3] Often the clinical situation requires the professional services of socials workers, nurses, educators and others to evaluate the environment of the patient and to help develop the treatment plan arising from the evaluation. Such interdisciplinary clinics do exist to some extent in all Canadian provinces and territories for evaluating developmental problems in children less than five years of age, but frequently the type of brain damage that is found in FAS/FASD patients is not fully detectable and hence not diagnostic until children's brains are more mature perhaps in the 6 to 10 year old range and then into adulthood. For children at those ages and adults, developmental teams are often not available for routine assessments. Without appropriate evaluation capacity, the fetal alcohol spectrum diagnoses are simply not made or not made in large enough numbers to reflect the truer prevalence. While the true prevalence of FAS/FASD is not known, it has often been estimated as FAS occurring in 1 to 3 live births per thousand based on a few prospective studies in the United States and Europe while individuals having some condition within FASD might occur as often as in 1 in 100 births in the United States.[4] These frequencies would make alcohol by far the most common specific cause of a known birth defect condition causing brain dysfunction. It would suggest that in western and northern Canada with a population just under 9 million, tens of thousands of people may have one form or another of this conditions and hundreds or possibly a few thousand new affected births occur annually. This is a hidden epidemic, since the clinical capacity to recognize and diagnose these conditions is simply not present. Since these affected individuals are not identified in clinical settings, they are by and large not counted in passive surveillance systems.

Even without the prevalence rates in hand, there has been significant political concern about the impact and the costs of FASD to society in western and northern Canada. In response to this concern, Ministers in the governments from seven jurisdictions (Alberta, British Columbia, Manitoba, Saskatchewan, the Northwest Territories, Nunavut and the Yukon) came together to form a group called the Canadian Northwest FASD Ministerial Partnership. One of their initiatives was the creation of the Canada Northwest FASD Research Network in 2004. The Network was to evaluate the activities in diagnostics, interventions and prevention ongoing in Canada Northwest so that data could be assembled and initiated that would aid in improving public policy.

In that same year, 2004, a group of physicians and psychologists with experience in the diagnosis of FASD were assembled to develop a consensus around FASD diagnosis. Those meetings resulted in the publication of “Fetal Alcohol Spectrum Disorder; Guidelines for Diagnosis” published in The Canadian Medical Journal in 2005.[5] “The Guidelines” stressed that the diagnosis is only securely made in most cases using an interdisciplinary team.[6] They also endorsed the standard diagnostic approach of The 4 Digit Diagnostic Code for FAS developed by the FAS Diagnostic and Prevention Network at the University of Washington.[7] This is a template for the appropriate development of diagnostic capacity, but the use of the Guidelines raises other questions critical to expansion of clinical capacity to diagnose more patients. We were interested to know how many patients were being seen now, what diagnoses were being made, what was the composition of the clinical teams and how much time and cost was involved in such a diagnosis? All this would help in planning and building increased capacity.

METHODS

In 2006, we identified 27 clinical programs that were actively engaged in making fetal alcohol spectrum diagnoses within the within Canada Northwest and they were in Alberta, British Columbia, Manitoba, Saskatchewan, and the Yukon via government lists, web sites, professional contacts and word of mouth recommendations. Each of the 27 programs was sent a 20-question questionnaire covering a 16-month period, January 1, 2005 through April 30, 2006 (Appendix 1). This period was chosen so that we could include programs that were just being initiated. We had previously determined that all of these programs were using the Guidelines in that they had developed some form of a multidisciplinary team and all but one was using the four-digit code in reporting their findings.

RESULTS

Fifteen programs completed and returned the surveys. These included all fully active programs in British Columbia, Manitoba, and the Yukon, and all but one new and small program in Saskatchewan. A long established program in northern Manitoba and a program in Yellowknife, NWT depended on both traveling teams of professionals as well as local professionals but had not been active or very active during the period of inquiry in the study and were not included for that reason in the tally of potential clinics. The reasons that one program in Saskatchewan and ten other programs in Alberta did not respond are not known. However, nine of the non responding programs in Alberta are new and/or small; the Province estimates that their capacity for seeing patients for FASD assessments in the period of this survey would have been approximately 50 patients altogether.[8] The final Alberta program that did not participate is relatively large and might have seen as many as 100 patients. No active programs were identified in the Northwest Territories or in Nunavut for this time period. In spite of the non responders, we believe that the survey then did capture 85 to 90 percent of the clinical experience with FASD in Canada Northwest in the period studied. The list of participating programs is found in Appendix 2. The group answers to the questions are found in Appendix 3. Answers to Questions 1 through 6 and 15 demonstrated that between January 1, 2005 and April 30, 2006, the 15 programs had a total capacity for FASD diagnoses of 1140 patient assessments. The total capacity was 816 in 2005 and was expected to climb to 975 in 2006). Some of these programs are specifically designed to diagnose alcohol related conditions. Other programs make FASD evaluations within the context of assessments in children with a variety of environmental exposures especially to “drugs and alcohol.” Others see children with complex behavioural problems in general and consider alcohol as one etiology. Within this 16-month experience, 260 patients were found to have FAS or partial FAS (pFAS) and an additional 496 had other conditions classified as FASD's. It is not clear if the remaining patient assessment slots were filled by patients who had other reasons for assessment or had come in for a consideration of FASD and were found to have something else. Assuming that those wishing consideration of an FAS diagnosis filled all slots, then 23% of referrals were found to have FAS/pFAS, and another 44% had other FASDs. Thus if all the patients evaluated in the 1140 slots had requested assessment for FASD then two thirds were found to have some form of the disorder and a third of those had the clinically obvious forms - FAS or pFAS. If some of the patients taking these slots did not have an FASD concern at assessment initiation, than the rate of finding FASD within the population seen would have been even higher.

This certainly suggests that the screening procedures for these programs, when taken as a whole, are very sensitive for appointing the appropriate patients. The screening procedures do not appear very complicated and largely involve a history of a history of gestational exposure to alcohol alone or in connection with a history of maladaptions or physical stigmata suggesting

FAS. Although the clinics as a whole are very efficient in making the FAS/FASD diagnoses, there are striking differences among clinics and provinces with the ratio of all FASD diagnoses/full clinic capacity ranging from 48% in one province to 79% in another and the ratio of FAS/all FASD ranging from 11% in one to 81% in another.

The FAS/pFAS population is found to be diagnosed at a younger age range than the other FASD patients (Questions 7 and 8). This is reasonable, since the diagnosis of FAS/pFAS is based on physical findings that may or may not be detectable from birth while the other FASD's are diagnoses of diffuse brain dysfunction associated with prenatal alcohol exposure and as such these brain differences would not be detectable until children are old enough to have fairly refined tests of cognitive ability. It should be noted that virtually none of the diagnoses occurred in the neonatal period and most patients were seen after the age of school entry. Only three programs routinely saw adults.

The Guidelines stress the need for a multidisciplinary team to make the diagnosis and develop the treatment plan. However, the details for how this recommendation is actually to be implemented by the clinical programs has not been previously detailed. All clinics did use a multidisciplinary team (Questions 9 and 10). Every clinic adjusted the number of professionals doing assessments in each case based on the patient's age and the presenting issues. The average team had 4 members (range 2 to 7) who saw patients more than 75% of the time. The most common team members were physicians (15), psychologists (15), speech pathologists (10), occupational therapists (9) and social workers (8). Other team members included psychiatrists, geneticists, nurses, education specialists, and family advocates. It is likely that all programs had some form of patient coordinator and some groups specifically mentioned them as team members when their role included the ascertainment of clinical information.

The time spent by professionals in the assessments was extremely lengthy compared to typical medical visits and generally even more than typical for multidisciplinary developmental assessments done in the preschool years (Questions 11 and 12). Generally older patients have more issues and history that need to be considered. Formal testing needs to be sampled in multiple areas to address and understand cognition, academic skills, language and especially social communication, sensory and motor function, memory and executive functioning and adaptive abilities.

All programs report that all professionals each spend many hours in direct and indirect care in reaching their conclusions although precise work times per patient could not be reliably determined through a retrospective questionnaire. The answers to these questions were not likely established by time motion studies, but rather reflected the best judgment of the team leader or the members. The mean time for direct patient care (time directly spent with the patient or family in assessment or in team discussion) was approximately 2.5 hours for Paediatrics, 2.5 hours for Speech and Language Pathology, 1.5 hours for Occupational therapy and 6 hours for Clinical Psychology. In addition the programs report that the professionals spend considerable time in indirect care which includes chart review, team discussion without the clients, scoring of tests and note preparations, consultations with primary physicians and referrals, etc. Mean reported times for these activities were a little less than 3 hours for Paediatricians and Speech Language Pathologists, and Occupational Therapist, and 4.5 hours for Clinical Psychologists.

The notes that were prepared from these lengthy assessments varied widely in format (Questions 13 and 14). One program produced isolated individual professional notes, 5 others produced individual notes that were collated with a summary letter of varying length and 4 programs produced a single merged note. Only 1 of the programs reported that their notes were formatted for immediate computer entry.

Eleven of the programs were administered directly through the provincial or territorial health systems including university facilities while 4 were administered through not-for- profit corporations (Question 18). There were no clear differences between the size of the teams or the amount of time spent on each case in comparing the public programs to those administered privately. Two of the NFP programs charged the families a fee that was less than their costs; the others did not charge families directly for the evaluation. Three of the public programs had estimated their cost of an evaluation at $2500 to $3500 with a mean and median of $3000. All 6 of the NFP private programs had an estimated cost for assessment ranging from $2000 to $5500 with a mean and median of $3500 (Questions 19 and 20). Finally, although the number of people in Canada Northwest who might deserve an FASD diagnosis is very high, the wait time for the clinics as a whole was not extremely onerous (Questions 16 and 17). Of the 10 programs that answered this question only 2 reported wait times of more than 6 months.

INTERPRETATION

To our knowledge this is the first report in the literature of a large, multi-jurisdictional region in any country that has organized itself to provide a significant capacity for FASD diagnosis and treatment planning. It is not clear that all of the appointment slots that were potentially available for FASD assessment were in fact used for that purpose. If all of the available clinical slots were used for patients with FASD as a referral question, these clinics are clearly able to select patients for assessment that resulted in a confirmation of an FASD over 67% of the time. If some slots were deliberately used for other diagnostic inquiries, than the selection of patients for assessment who were, in fact, found to have an FASD is even higher. There are differences among the clinics in the percentage of patients found to have FAS or pFAS relative to other FASDs. The reasons for this are not yet known. This could reflect true differences in prevalence. This could reflect the maturity of the programs as older programs have reported informally that they tend to see more FAS initially and then more other FASD over time as the sophistication of the referrers increases. It is also possible that variations in assessment and usage of the diagnostic code lead to different conclusions in different sites. This observation will be carefully evaluated in the future based on this report.

To our knowledge the capacity of Western and Northern Canada to provide FASD diagnoses at a rate of approximately 70 assessments per month in an area with a total population of just fewer than 9 million is the highest reported anywhere worldwide. The numbers would suggest that FASD is common and wide spread and if programs are built for appropriately evaluating the condition, appropriate people will come for evaluation.

Still, with an estimate of FASD prevalence at approximately 1% of the population of the area as a whole (90,000 persons affected), this regional capacity is woefully inadequate especially for adults. Further, the long distances that separate people in rural and remote sections of the region from these interdisciplinary clinics most likely make for added imbalance in the ability of some to access diagnostic services. The region is continuing to respond to this situation and further clinical capacity is actively planned in Alberta and in British Columbia. Ironically, it is likely that as clinics are built and hopefully as the benefits of a diagnosis are established, wait times may increase not decrease because demand is likely to increase faster than clinical capacity.

This report provides the first information on the “standard of care” for diagnosis of FASD’s reflecting experience in many different places with differing populations and organizational structures. The programs are reporting that the evaluation of these patients is very time consuming and expensive, reflecting the complexity in defining the breadth and scope of the patients' brain dysfunction and needs. The amount of time practitioners spend in assessment is only very roughly approximated here. One member of a team estimated the times for colleagues and imagined a “typical case”. This could be further studied through a time motion study. But the point is that these estimates consistently show that this is a very time consuming process in the hands of all programs.

Although all programs spend a large number of hours in assessment of FASD patients, there is also a wide range in the direct and indirect time spent by different professionals at different sites. This might reflect different diagnostic approaches that need to be compared. Are the programs that spend less time more efficient and as accurate, or are they less comprehensive but still adequate? Or are there differences not related to clinic assessment at all, but rather the fact that some programs rely more heavily than others on external testing by the schools or other private psychologists prior to clinic evaluation? The fact that nearly all programs endorse largely the same diagnostic approach and are achieving reasonably similar results is both reassuring and provides an opportunity for collective quality improvement.

There was no attempt to ask the clinics to report the ethnic backgrounds of their clients. However these programs are widely distributed throughout the region and it would be expected that they are generally offering services to the population as a whole. A diagnosis of FAS/FASD should lead to two things. First, the information obtained for defining the pattern of brain differences or disability can be used to develop a treatment plan for school, home, social services, psychological supports and so on. FAS/FASD are life long conditions and it is likely that there are as many if not more adults who have not been diagnosed as children. However, only three of the programs routinely diagnose individuals over the age of 18 as part of their mandate from their governing body. Second, an FAS/FASD diagnosis should lead to prevention by contacting the birth mother (even if she is not present at the time of the diagnosis) and working with her on issues in her life that might then lead to prevention of alcohol exposed subsequent births. This question was not addressed in the Questionnaire because we had already learned that this was not a component of any program.

CONCLUSION

In conclusion, Canada Northwest is developing a clinical system for FASD diagnoses. They are generally doing this within the broad context of the Canadian Guidelines in that they are using a multi or intra disciplinary team and largely using the four digit diagnostic code. They are not having problems in recruiting appropriate patients for diagnosis. They are finding that the diagnoses are complex and take much more time than typically allotted in medical clinics for many types of developmental assessments. The knowledge that is developing within these programs can be used as the basis for building a larger system for FASD patient evaluation within Canada Northwest, Canada as a whole and perhaps elsewhere.

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APPENDIX 1 CANADA NORTH WEST FASD RESEARCH NETWORK DIAGNOSTIC NAT QUESTIONNAIRE

1. How many potential FASD evaluation slots were available in your facility in 2005? ______
2. How many potential FASD evaluation slots will be available in your facility in 2006? ______
3. How many patients received an FASD diagnosis in 2005? ______
4. If your program began in 2005, how many months were you in operation? ______
5. How many patients received any FASD diagnosis between January 1 and April 30, 2006? ______
6. Among the patients who received an FASD diagnosis how many received an FAS or pFAS diagnosis? ______
7. How many patients, by age, received an FAS or pFAS diagnosis from 1/1/05 to 30/4/06?

   Newborn to 30 days ___
   1.0 months to 2.9 years ___
   3.0 years to 5.9 years ___
   6.0 years to 9.9 years ___
   10.0 years to 12.9 years ___
   13.0 years to 18.9 years ___
   19 years and older ___

8. How many patients, by age, received other FASD diagnoses from 1/1/05 to 30/4/06?

1.0 months to 2.9 years ___
3.0 years to 5.9 years ___
6.0 years to 9.9 years ___
10.0 years to 12.9 years ___
13.0 years to 18.9 years ___
19 years and older ___

9. What professionals in your program routinely evaluate potential FASD patients more than 75% of the time?

check all that apply ☑

Pediatrician ___
Family Physician ___
Psychiatrist ___
Other Physician ___
Clinical Psychologist (PhD) ___
Educational Psychologist (PhD) ___
Other Psychologist (PhD) ___
Master's level Psychologist ___
Speech and Language Pathologist (PhD) ___
Speech and Language Pathologist (MA) ___
Occupational Therapist ___
Physical Therapist ___
Recreational Therapist ___
Social Worker ___
Nurse ___
Family Support Worker/Advocate ___

Other ____

10. What professionals in your program routinely evaluate potential FASD patients less than 75% of the time?

check all that apply ☑

Pediatrician ___
Family Physician ___
Psychiatrist ___
Other Physician ___
Clinical Psychologist (PhD) ___
Educational Psychologist (PhD) ___
Other Psychologist (PhD) ___
Master's level Psychologist ___
Speech and Language Pathologist (PhD) ___
Speech and Language Pathologist (MA) ___
Occupational Therapist ___
Physical Therapist ___
Recreational Therapist ___
Social Worker ___
Nurse ___
Family Support Worker/Advocate ___

Other ____

11. When professionals in your program routinely evaluate a potential FASD patient how many **DIRECT minutes** are spent **ON AVERAGE** with the family/patient? (Include both assessment and conference time with the patient and family)

Pediatrician ___
Family Physician ___
Psychologist ___
Other Physician ___
Clinical Psychologist (PhD) ___
Educational Psychologist (PhD) ___
Other Psychologist (PhD) ___
Master's level Psychologist ___
Speech and Language Pathologist (PhD) ___
Speech and Language Pathologist (MA) ___
Physical Therapist ___
Recreational Therapist ___
Social Worker ___
Nurse ___
Family Support Worker/Advocate ___

Other ____

12. When professionals in your program routinely evaluate a potential FASD patient how many **INDIRECT minutes** are spent **ON AVERAGE** with the family/patient? (This might include chart review, case conference time without the family present, note preparation, referral letters, etc.)

Pediatrician ___
Family Physician ___
Psychiatrist ___
Other Physician ___
Clinical Psychologist (PhD) ___
Educational Psychologist (PhD) ___
Other Psychologist (Ph D) ___
Master's level Psychologist ___
Speech and Language Pathologist (PhD) ___
Speech and Language Pathologist (MA) ___
Occupational Therapist ___
Physical Therapist ___
Recreational Therapist ___
Social Worker ___
Nurse ___
Family Support Worker/Advocate ___

Other ____

13. Is the final note:

Individual assessments alone ___
Individual assessments with a short cover < 2 pages ___
Individual assessments with a longer cover >2 pages ___
A merged single assessment ___

14. Are your intake or clinic notes ready for computer data entry? Yes ___ No ___

15. What criteria are used to select patients for the clinic that sees FASD patients?

All referrals are accepted that come through approved providers
(i.e. from pediatricians in the catchment area) Yes ☑ _____

OR

<u>After referral, selection is then restricted to those with:</u> (check all that apply) ☑

Strong suspicion or documentation of alcohol exposure in pregnancy ___
History that is compatible with a finding of complex neurodevelopmental disorder ___
Prior testing and evaluation suggest that there will be a complex neurodevelopmental disorder ___
Physical stigmata described in words or in photo suggesting FAS ___
Other ____

How many criteria are required? ___

16. How long does the average patient wait to be seen?

less than 2 months ___
2 months to 4 months ___
4 months to 6 months ___
6 months to 1 year ___
greater than 1 year ___

17. How are patients prioritized on the wait list?

In order received alone ___
In order but also by indication of need or crisis ___
Other____

18. The program is managed:

Through a public health system ___
Through a private for profit health system ___
Through a private not for profit health system ___

19. Is there a direct patient fee? Yes ___ No ___

If **YES**, what is the average cost to the client? $________.00

20. What is the actual cost of an assessment? $________.00

Please return this questionnaire via email to Sterling Clarren: <u>sclarren@cw.bc.ca</u>

APPENDIX 2 DIAGNOSTIC CLINICAL PROGRAMS THAT COMPLETED ALL OR PART OF THE QUESTIONNAIRE

- **Manitoba**
    - Clinic for Alcohol and Drug Exposed Children
- **Saskatchewan**
    - Alvin Buckwald Child Development Program
    - Regina Child and Youth Services Clinic
    - Prince Albert Health Region, CDC and CYS
    - The FASD Centre, Regina
- **Alberta**
    - Alberta Children's Hospital
    - Glenrose Rehabilitation Hospital
    - Lakeland Centre for FASD
    - Renfrew FASD Diagnostic, Consultation, and Intervention Clinic
- **British Columbia**
    - Sunny Hill Health Centre for Children
    - Asante Centre for Fetal Alcohol Syndrome
    - Interior Health Children's Assessment Network
    - Vancouver Island Health Authority CDBC Clinic
- **Yukon**
    - FAS Society of the Yukon Adult Diagnostic and Assessment Program
    - Children and Youth FASD Diagnostic and Support Team (c/o Child Development Centre)

APPENDIX 3 RESULTS FROM CANADA NORTH WEST FASD RESEARCH NETWORK DIAGNOSTIC QUESTIONNAIRE IN WESTERN AND NORTHERN CANADA

Questions:

1. How many potential FASD evaluation slots were available in your facility in 2005?
2. How many potential FASD evaluation slots will be available in your facility in 2006?
3. How many patients received an FASD diagnosis in 2005?
4. If your program began in 2005, how many months were you in operation?
5. How many patients received any FASD diagnosis between January 1 and April 30, 2006?
6. Among the patients who received an FASD diagnosis how many received and FAS or pFAS diagnosis?

Questions 1 – 6 **Summarized Responses**

Jurisdiction	# of Programs reporting	Total Capacity	All FASD	FAS or pFAS	Other FASD	All FASD/ Capacity	FAS or pFAS / all FASD

Alberta	4	215	142	15	127	0.66	0.11
British Columbia	4	347	233	46	187	0.67	0.21
Manitoba	1	232	112	37	75	0.48	0.33
Saskatchewan	4	312	248	145	103	0.79	0.58
Yukon	2	34	21	17	4	0.62	0.81
TOTAL	*15*	*1140*	*756*	*260*	*496*	*0.66*	*0.34*

Question 7: How many patients, by age, received an FAS or pFAS diagnosis from 1/1/05 to 30/4/06?

Summarized Responses

	Manitoba	Saskatchewan	Alberta	British Columbia	Yukon	Totals
Newborn to 30 days	0	0	0	0	0	
1.0 months to 2.9 years	16	12	0	0	1	29
3.0 years to 5.9 years	10	38	1	7		56
6.0 years to 9.9 years	5	50	7	19		81
10.0 years to 12.9 years	2	35	1	16		54
13.0 years to 18.9 years	4	10	6	3		23
19.0 years and older	0	0	0	1	16	17
TOTAL	*37*	*145*	*15*	*46*	*17*	*260*

Question 8: How many patients by age received another FASD diagnosis from 1/1/05 to 30/4/06?

Summarized Responses

	Manitoba	Saskatchewan	Alberta	British Columbia	Yukon	Totals
Newborn to 30 days	0	0	0	0	0	0
1.0 months to 2.9 years	5	37	1	3		46
3.0 years to 5.9 years	11	25	16	43	2	97
6.0 years to 9.9 years	26	22	59	62		169
10.0 years to 12.9 years	16	13	15	39		83
13.0 years to 18.9 years	17	6	32	34		89
19.0 years and older	0	0	4	6	2	12
TOTAL	*75*	*103*	*127*	*187*	*4*	*496*

Question 9: What professionals in your program routinely evaluate potential FASD patients *more* than 75% of the time?

Question 10: What professionals in your program routinely evaluate potential FASD patients *less* than 75% of the time?

Summarized Responses

X means the professional met with all patients > 75% of the time
O means the professional met with all patients < 75% of the time

Jurisdictions (N of Programs)

Professions	Alberta (4)	British Columbia (4)	Saskatchewan (4)	Manitoba (1)	Yukon (2)	Total X , 0
Paediatrician	3x, 1o	4x	4x	1x	2x	**14x, 1o**
Clinical Psychologist	4x	4x	3x, 1o	1o	2x	**13x, 2o**
Speech/ Language	3x, 1o	3x, 1o	1x, 2o	1x	1x	**9x, 4o**
Occupational Therapist	2x, 2o	2x, 2o	2o		1x	**5x, 6o**
Social Worker	3x	3x	1x, 1o	1x	1x	**9x, 1o**
Nurse	2x		2o			**2x, 2o**
Family Support Worker	1x, 1o				1x	**2x, 1o**
Psychiatrist	2o					**2o**
Physical Therapist	1x, 1o					**1x, 1o**
Recreational Therapist	1o		1x			**1x, 1o**

Question 11: When professionals in your program routinely evaluate a potential FASD patient how many **DIRECT minutes** are spent **ON AVERAGE** with the family/ patient?

Summarized Responses

Most Commonly Utilized Professions

Jurisdictions	Paediatrician	Psychology	SLP	OT
British Columbia	240	420	120	120
	250	600	120	120
	150	420	150	-
	180	360	120	-
Alberta	60	300	45	30
	150	285	225	120
	180	240	240	90
	150	240	120	-
Saskatchewan	120	270	120	200
	75	390	120	60
	180	360	-	-
	60	360	-	-
Yukon	210	330	300	210
Mean	*150*	*352*	*141*	*106*
Median	*150*	*360*	*120*	*115*
Range	*60-250*	*240-600*	*45-300*	*30-210*

Question 12: What professionals in your program routinely evaluate a potential FASD patient how many **INDIRECT minutes** are spent **ON AVERAGE** with the family/ patient?

Summarized Responses

Most Commonly Utilized Professions

Jurisdictions	Paediatrician	Psychology	SLP	OT
British Columbia	120	240	120	120
	120	240	120	420
	180	180	120	-
	-	-	-	-
Alberta	180	180	210	180
	180	270	210	90
	300	720	300	300
	120	120	90	90
Saskatchewan	120	300	150	150
	150	400	45	45
	30	60	-	-
	120	-	-	-
Yukon	360	360	330	330
Mean	*165*	*279*	*169.5*	*172*
Median	*150*	*270*	*120*	*150*
Range	*30-360*	*60-720*	*45-330*	*45-420*

Question 13: Is the final note:

Summarized Responses

	N of Clinics
Individual assessments?	1
Individual assessments with a short cover letter (<2 pages)?	1
Individual assessments with a longer cover letter (>4 pages)?	4
A merged single note covering all assessments?	4

Question 14: Are your intake or clinic notes ready for computer data entry?

Summarized Response

Yes - 1
No - 9

Question 15: What criteria are used to select patients for the clinic that sees FASD patients?
(*14 Respondents answered the question and checked the selections that applied*)

Summarized Responses

All referrals from approved providers	2
After referral, selection of patients is culled from those with:	
Strong suspicion or documentation of alcohol exposure in pregnancy	8
History compatible with finding a complex neurodevelopmental disorder	3
Prior testing suggesting a complex neurodevelopmental disorder	2
Physical stigmata described in words or photos suggesting FAS	3
Others (location of the client)	1

Question 16: How long does the average patient wait to be seen?

Summarized Responses

< 2 months	1
2 to 4 months	1
4 to 6 months	6
6 months to 1 year	1
> 1 year	1

Question 17: How are patients prioritized on the wait list?

Summarized Responses

In order received alone	1
In order, but also by indication of need or crisis	14

Question 18: The program is managed through:

Summarized Responses

Through a public health system	11
Through a private for profit health system	-
Through a private no for profit health system	4

Question 19: Is there a direct patient fee?

Summarized Responses

No - 13
Yes - 2

If **YES**, what is the amount of the fee? *Range $1,000 to $3,500*

Question 20: What is the actual cost of an assessment?

Summarized Responses

Not known or not disclosed		7
Amounts (8 Responses)	*Range*	*$2,200 - $5,500*
	Mean	*$3,585*
	Median	*$3,500*

Competing Interests

The authors have no competing interests.

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