

B. BOURGET, BOURGET MANAGEMENT CONSULTING

Final Evaluation Report: EBBS FASD Project

October 31, 2010

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1. PROJECT OVERVIEW

FASD and Children in Care with FASD in North Western Ontario

The EBBS FASD Support Project is a two-year initiative, which was funded through the Child Welfare Secretariat until September 2010, to build capacity to support children and youth with FASD or probable FASD within the care of child welfare agencies in North Western Ontario.

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term that covers the spectrum of disabilities caused by prenatal exposure to alcohol.¹ It is the leading cause of developmental and cognitive disabilities among Canadian children² and the brain injury caused by alcohol exposure is permanent.³ Children and youth with FASD related disabilities are often misdiagnosed or never diagnosed.⁴ FASD has been called a “hidden disability” because the brain injury often manifests in the form of learning, behavioural and social problems unless there are distinct physical markers (which often there are not).⁵

Some of these problems worsen as children grow older and they are associated with the emergence of other disorders and disordered behaviours such as mental health issues, conflict with the law, substance abuse, unemployment, homelessness and difficulties with parenting.⁶ Many parents/caregivers are unable to cope with the challenges associated with FASD, placement breakdowns and difficulties with transitions are common for children with FASD in care, and long-term outcomes are often poor.⁷ However, there are effective, evidence-based interventions that can mitigate these effects.⁸ The economic and social burden of FASD is significant: conservative estimates place the cost at \$344 million in Canada annually.⁹

The exact proportion of children and youth with FASD in the child welfare system in the region is not clear, although it can be estimated. The proportion of children in care with FASD in Canada has been assessed as varying from 3.3% to 50%,¹⁰ although it is generally agreed that FASD is often undiagnosed or misdiagnosed.¹¹ This is particularly likely to be true in North Western Ontario, where capacity for diagnosis is extremely limited. Without proper diagnoses, specialized support may not be available for those children in need.

The prevalence rates for FASD in this area are considered high. For example, upwards of 60% of all children in the care of Kenora-Patricia Child and Family Services are suspected of having FASD.¹² Children with FASD in the care of child welfare agencies are more likely to become permanent wards than are children with no disabilities or different disabilities and they are more apt to have challenges with the transition to adulthood.¹³

Children in Northwestern Ontario are thought to be at increased risk compared to those living elsewhere for several reasons. The region has a significantly higher proportion of heavy drinkers and binge drinkers, both of which are linked to a heightened risk of FASD¹⁴, along with higher birth rates and teen pregnancy rates.¹⁵ Further, the high rate of

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positive diagnoses (77% of those referred) through the now closed North Western Ontario FASD Diagnostic Clinic confirm that FASD is very prevalent in the region.¹⁶

The area also has a high proportion of Aboriginal people—26.5% of the population compared to the provincial average of 1.8%,¹⁷ with higher rates of pregnancy.¹⁸ Historical trauma resulting from colonization and racism has given rise to issues of poverty, physical and sexual abuse and alcohol and drug abuse within Aboriginal communities.¹⁹ While FASD exists in all ethno-cultural groups, these factors combine to increase the risk of FASD for Aboriginal children, and Aboriginal children are also disproportionately represented in foster care in Canada.²⁰

System capacity for providing effective and sustainable interventions to respond to the complex needs of and improve outcomes for children and youth affected by FASD in the region has been limited and this project aims to close some of the gaps.

Goal and Objectives of the EBBS Project

The specific goal of the project was to maintain and enhance the stability of placements and improve outcomes for children and youth with FASD in the care of child welfare agencies. The primary objectives were:

- To enhance the understanding of caregivers and teachers about the neuro-developmental nature of conditions such as FASD so that affected children and youth experience less frustration and more success;
- To ensure that caregivers/teachers of children with FASD have ongoing access to support through project workers and support groups.

The project is a collaborative initiative between child welfare (one Aboriginal and one non-Aboriginal agency) and two children's mental health agencies in a large geographic area in Northwestern Ontario with high levels of need and limited resources, i.e. specialized services. Lake of the Woods Child Development Centre is the lead agency for the project and there is a Project Steering Committee comprised of a number of children's service providers and representatives from the education sector in the Kenora District.

The project partners contacted Diane Malbin, internationally renowned FASD consultant and trainer, about facilitating training sessions. The primary thrust of the training is to establish a new understanding of FASD as a brain-based, usually invisible, physical disability and to redefine childrens' behaviours as symptoms of the underlying disability. For children with FASD, challenging secondary behaviours are symptoms of chronic frustration that reflect a poor fit between the environment and the child's needs. Ms. Malbin trains workers in the use of a neurobehavioural (screening tool and introduces the approach to modifying environments in all settings, e.g., at home, school and in the community, to improve the fit between the child's strengths and needs and the environment. This reduces frustration, expands options and ultimately improves child outcomes. . The idea that brain function has something to do with behaviours is an obvious truism; the most effective accommodations based on understanding differently are simple. As Ms. Malbin has stated, adopting this understanding of FASD involves a significant paradigm shift for most people.

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Ms. Malbin travelled from Oregon to Dryden to provide a five-day training of Key Workers in September 2009, which was attended by 37 participants from a variety of community agencies; this was followed by a two-day training session in January 2010. .

The role of the Key Workers was to provide information and support to foster families, group home staff and educators working with and caring for children and youth with Fetal Alcohol Spectrum Disorder (FASD) or with probable/suspected FASD. Key Workers assist caregivers and educators in understanding FASD by providing education and information about FASD as a brain-based disability and suggesting specific environmental modifications to improve child behaviours and outcomes at home and at school. They also provide “train the trainer” sessions to community partners and do outreach and education about FASD across their communities.

To further assist with capacity building, the Patricia Centre for Children and Youth and the Lake of the Woods Child Development Centre hired three contract Outreach Coordinators; these staff have been responsible for conducting intakes for project participants, assisting with evaluation activities, community education, coordinating ongoing meetings of Key Workers and otherwise fulfilling the Key Worker functions.

Data pertaining to various aspects of project implementation and outcomes have been gathered and analyzed ongoing to assess the impact of the project in the Kenora region.

Limitations of the Findings

There are some limitations that need to be taken into consideration when interpreting the findings of the report. None of the instruments used to collect the data (e.g. assessment of secondary and tertiary disabilities among child participants, evaluation questionnaires for foster parents and teachers and survey questionnaires) have been formally tested for validity or reliability. The sample sizes were small and respondents' anonymity has been protected (e.g. key worker survey respondents did not identify themselves so there is no way of knowing whether the same individuals were responding to the multiple surveys) and therefore the results may not be statistically significant. However, the consistency of data trends that emerged across test points, different data sets and methods of data collection (i.e. quantitative and qualitative) lends credibility to the findings as presented.

2. RESULTS

2.1 Building Knowledge and Confidence of Key Workers

Thirty-seven individuals participated in the Key Worker training provided by Diane Malbin, FASD Trainer, in Dryden in September 2009. Since that time, the Outreach Coordinators have held regularly scheduled meetings with Key Workers once monthly to maintain engagement in the project and for mutual support. Depending on the location, these meetings occur in person, by videoconference or by teleconference.

Those who participated in Key Worker training have responded ongoing to evaluation surveys. September 11, 2009, just prior to the training, 26 prospective Key Workers responded to an on-line survey about their knowledge of FASD and FASD interventions and their level of confidence for implementing FASD interventions and training/mentoring others. The Key Worker Training commenced September 14, 2009 and involved 37 participants. A post-training survey was completed September 30, 2009 by 22 Key Workers. Another survey was completed by 32 Key Workers in January 2010, following a second round of training of FASD training by Ms. Malbin. The same surveys were completed again in March (n =19), June (n=14) and September 2010 (n=20). The total number of respondents for all of the surveys was 133.

Table 1 shows overall self-assessed knowledge of key workers about FASD at baseline and immediately after the FASD training. Because of ongoing training and relatively high levels of general knowledge of FASD, this question was not asked again.

Table 1 Overall Knowledge of FASD

Surveys	Dates	% of respondents reporting: ¹			Average Score ²
		Low level of knowledge	Moderate level	High level	
Baseline N=26	Early Sept 2009	24%	56%	20%	2.92
Post-training N=22	Sept 30, 2009	9%	23%	69%	3.59

Seventy-six per cent of trainees reported that their overall knowledge had improved quite a bit (43%) or a great deal (33%) as a result of the Key Worker training September 14-18, 2009.

Charts 1-4 show changes in the knowledge and confidence levels of key workers over the life of the project, based on averaged scores from all respondents using a 1-5 rating scale where 1 is very low and 5 is very high. A detailed breakdown of the data may be found in *Appendix A*.

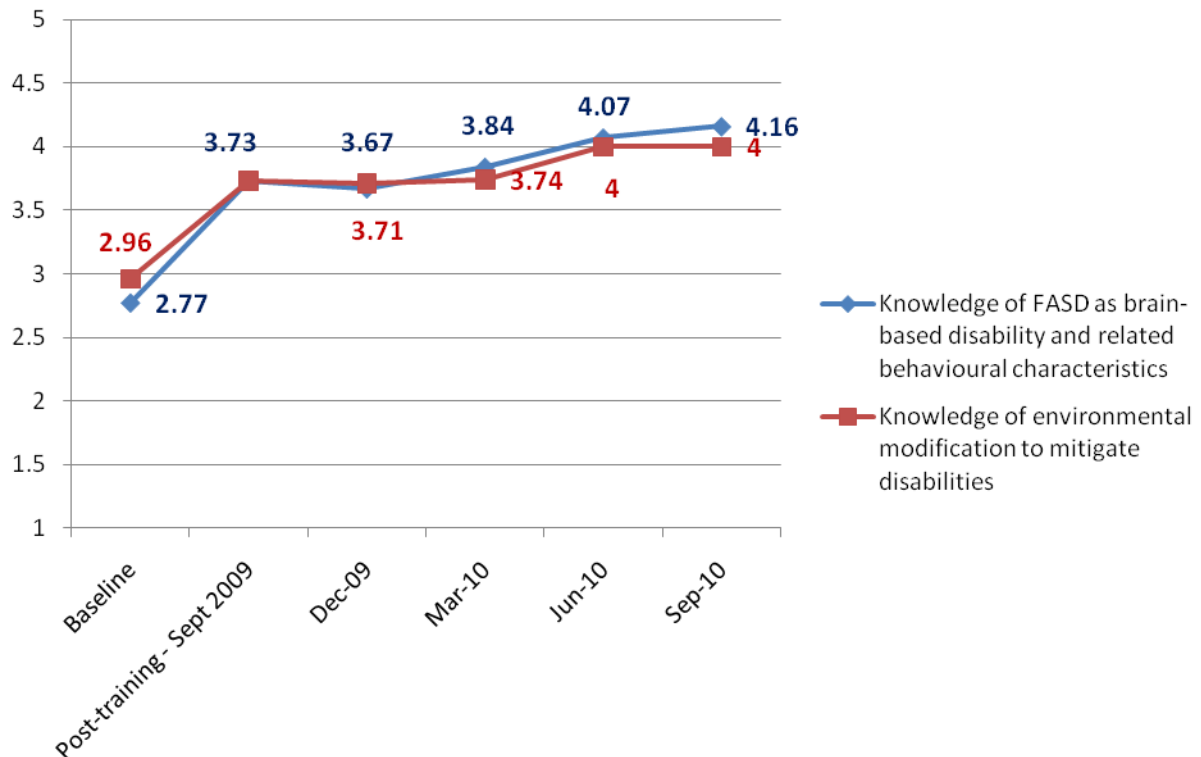
¹ Percentages have been rounded off.

² All average scores are based on a 1-5 rating scale, where 1 equals very low, 3 equals moderate, and 5 equals very high.

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Chart 1, below, shows self-reported knowledge of key workers about FASD and about relevant environmental accommodations to mitigate the effects of FASD-related disabilities.

Chart 1 Knowledge of key workers from early September 2009 (baseline) to September 30 2010

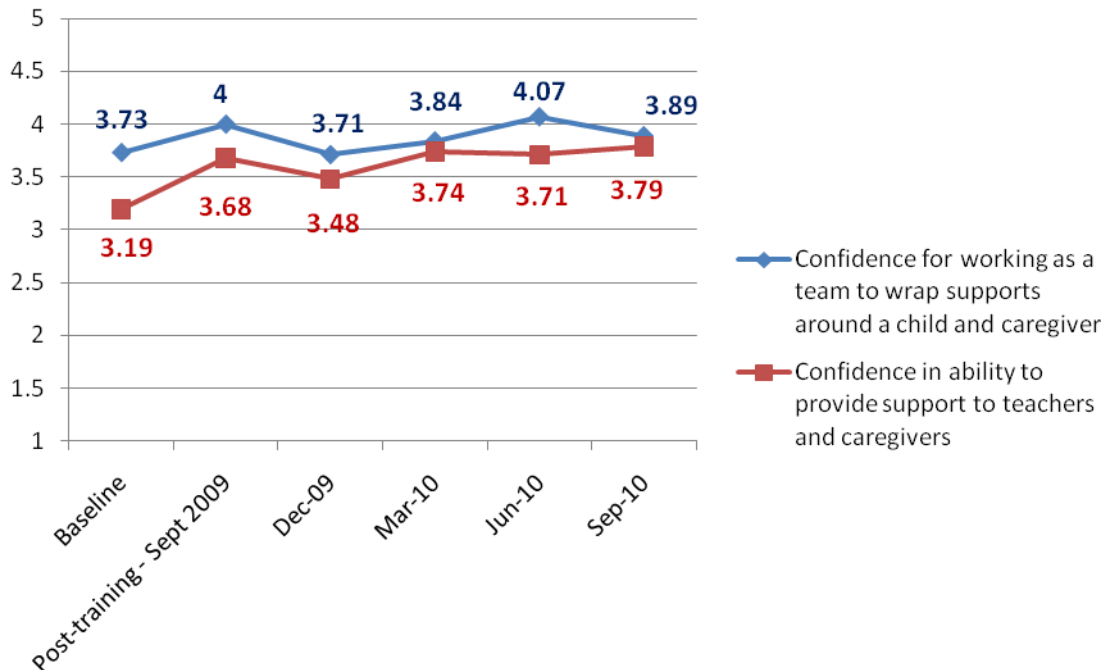


As shown above, self-reported knowledge of key workers has increased considerably since baseline, i.e. from just under 3.0/5.0 at baseline to 4.0 or more out of 5.0 by the end of the project. The upward trend has been consistent with the exception of a slight decline following the post-training assessment, which may have been due to a realization of the challenges involved in actually applying new knowledge “on the ground” or as one key worker noted, the challenge of integrating the tremendous amount of new information they had received.

Charts 2 and 3 below show self-reported confidence levels of key workers for: working as a team to wrap supports around a child and caregivers; providing direct support in making required accommodations to teachers and caregivers; doing public education work about FASD as a neuro-developmental disability; and training others to provide appropriate support to teachers and caregivers.

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Chart 2 Confidence of key workers for working as a team and providing support to teachers and caregivers from early September 2009 to September 30, 2010

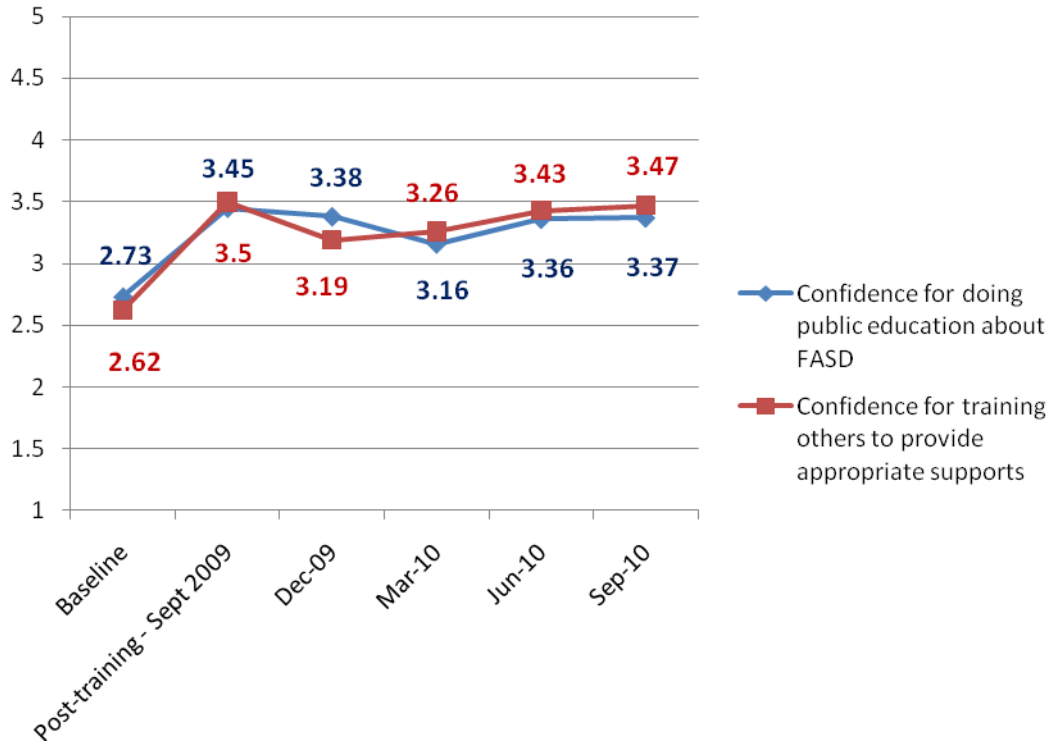


Confidence levels for working collaboratively to support children and caregivers and to provide direct support to teachers and caregivers (e.g. in making appropriate environmental accommodations) have increased from baseline, although the data demonstrated some ups and downs over the time period. Ratings for confidence in ability to provide direct support to teacher and caregivers increased the most from baseline from project end, although they were consistently lower than ratings for confidence for working as a team to provide supports to children and families.

Chart 3, below shows self-reported confidence levels of key workers for training others to support teachers and caregivers of children/youth with FASD and for doing public education work about FASD as a brain-based disability and related accommodations for mitigating the effects of the disability and improving outcomes.

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Chart 3 Confidence of key workers for training others and doing public education from early September 2009 to September 2010



Confidence for training other to provide appropriate supports was higher at baseline and remains higher at project end when compared to confidence for doing public education work about FASD. Both sets of data, however, show an upward trend over the life of the project, indicating that confidence levels are increasing.

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Chart 4 Changes on all measures for key workers from baseline (Sept 2009) to project end (September 2010)

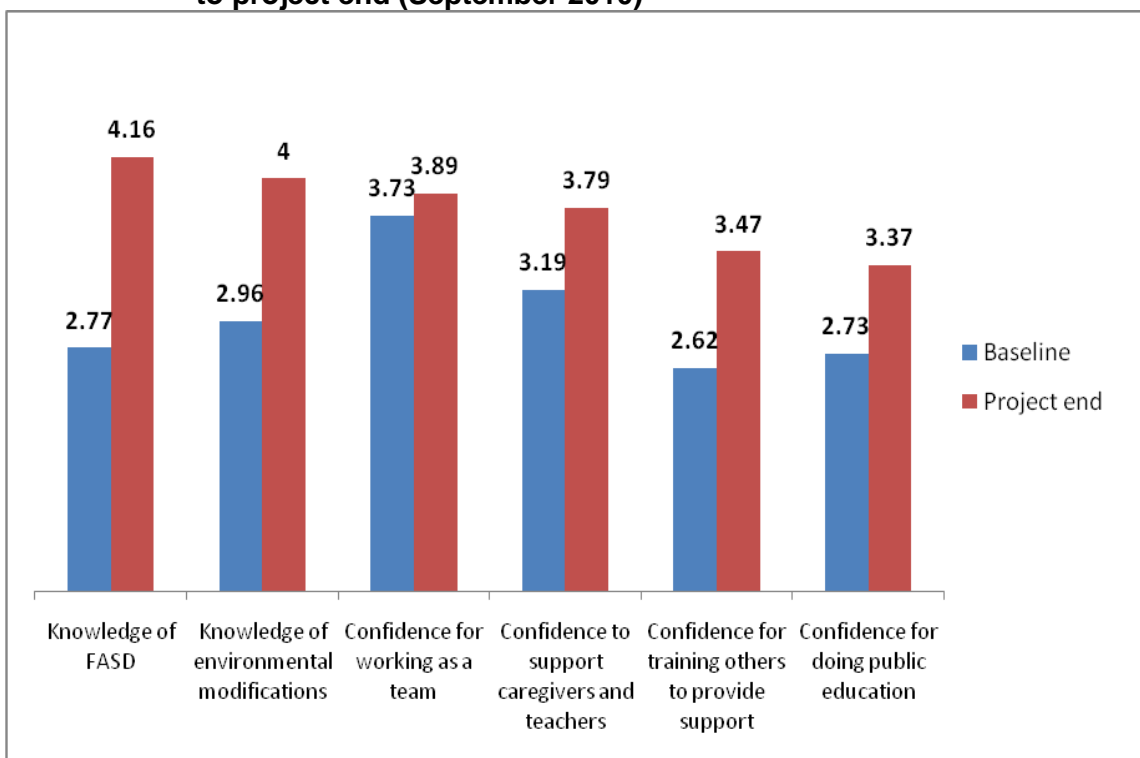


Table 2 Extent of changes from baseline to project end

Data element	Baseline Rating (using 1-5 rating scale)	Rating at Project End (1-5 rating scale)	Difference
Knowledge of FASD as a brain based disability and related behavioural characteristics	2.77	4.16	+1.50
Knowledge of environmental modifications to mitigate effects of disabilities and improve outcomes	2.96	4	+1.04
Confidence for working as a team to wrap supports around a child and caregiver(s)	3.73	3.79	+.16
Confidence for providing support to caregivers and teachers to make required accommodations	3.19	3.79	+.60
Confidence for training other service providers to provide supports to caregivers and teachers (train the trainer)	2.62	3.47	+.85
Confidence for doing public education work about FASD and related accommodations	2.73	3.37	+.64

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As chart 4 indicates, scores on all measures have increased from baseline. Table 2 shows that knowledge of FASD and knowledge of relevant environmental modifications to improve outcomes have increased the most over the time period. Confidence levels of key workers for working as a wrap-around team to provide support increased the least of all the items but it was relatively high to begin with, suggesting that key workers felt quite confident about this ability prior to engagement in the project. Confidence for providing supports directly to caregivers and teachers was higher at project end (3.79/5.0) than was confidence for training others to provide these supports (3.47/5.0). However, there was more of a jump in confidence for “training the trainer” over the time period (+.85) compared to the increase in confidence for providing direct support (+.60). Reported confidence for doing public education work, which received the lowest rating of all the measures, still increased by .64 from baseline.

These findings may not be statistically significant, as the sample sizes were small, the number of respondents varied across test points, and there was no way of ascertaining whether or not the same individuals were responding to each of the evaluation surveys. The consistent upward trend of the data however is strongly suggestive that capacity has been built among key workers with respect to understanding FASD, applying relevant supports and teaching others to provide appropriate supports. Further, self-reported knowledge of FASD remained higher than did confidence for providing support directly or doing training/public education work and this lends credibility to the findings—it makes sense that key workers would find it easier to gain knowledge than to apply it or teach what they know to others. Despite this, capacity for providing support and for training others has also increased throughout the life of the project, albeit to a lesser degree compared to knowledge gains.

Improvements in Working Relationships

In addition, key workers were asked if participating in the project has improved working relationships with other service providers. Baseline was established in January 2010 with 32 key workers who responded to the question through an online survey. Key Workers were asked the same question again in March, June and September 2010 with a total of 85 respondents. The average score of respondents across the four surveys was 2.5/3.0. On average, 55% said that relationship have improved, 37% said that relationships have improved “somewhat” and only 8% said that relationships with other service providers have not improved as a result of the project.

2.2 Behavioural Assessment of Children, Knowledge, Confidence and Stress Levels of Project Participants

This section of the report shows baseline and follow-up measures of project participants (foster parents, teachers and group home workers). Initially, 28 children/youth were put forward to the project staff by child welfare societies in the region as meeting the criteria for project participation, i.e. being between the ages of 8 and 18, being in the care of child welfare and having a diagnosis of FASD or probable FASD.

Of the 28 prospective participants, there were 22 cases where caregivers/children and youth were either able or willing to participate in the project and therefore the intake process was completed for 22 children/youth (representing 39 teachers and caregivers) by the end of January 2010.³ Over time, some of these individuals left the project for various reasons. For example, one child changed his mind and declined to participate after the initial intake. From intake to March 31 2010, two children were moved out of their communities to receive intensive treatment/medical services not available in their areas. By June 2010, there were 19 children and youth involved in the project along with 36 caregivers and teachers. Between June and September 2010, there was one foster family breakdown and the child was removed from the home. At project end (September 2010), there were 18 children/youth still involved and 18 caregivers. Teachers were not re-assessed in September 2010 as the children in their classrooms had moved on by that point and the project was almost at an end. Detailed demographic information about the project participants may be found in *Appendix B* and a copy of the evaluation questionnaire is in *Appendix E*.

The results section that follows shows the ratings of all project participants—foster parents, group home staff and teachers—from baseline (December 2009) to project end (September 30 2010) with respect to:

- neuro-developmental screening results for children and youth (secondary and tertiary behavioural symptoms linked to FASD);
- self-reported participant knowledge of FASD;
- participant confidence for managing FASD-related disabilities; and
- current levels of participant stress in working/caring for a child or youth with FASD.

Primary characteristics of FASD are learning, developmental and/or physical responses to the environment and other behavioural symptoms that have been associated with differences in brain function. They include things like attention difficulties, sensitivity to light, sounds or touch, difficulties processing information and speech and language challenges. When people with FASD are not identified as having a brain-based disability and do not receive support in the form of required accommodations to mitigate the effects of the disability, they often experience chronic frustration.

³ There were 19 completed or partially completed intakes (representing 19 children/youth and their teachers/caregivers) as of January 25, 2010. By March 31, 2010, there were 22 completed intakes. Because some intakes were not completed until mid-January to early February 2010, baselines were recalculated for the March 31 report.

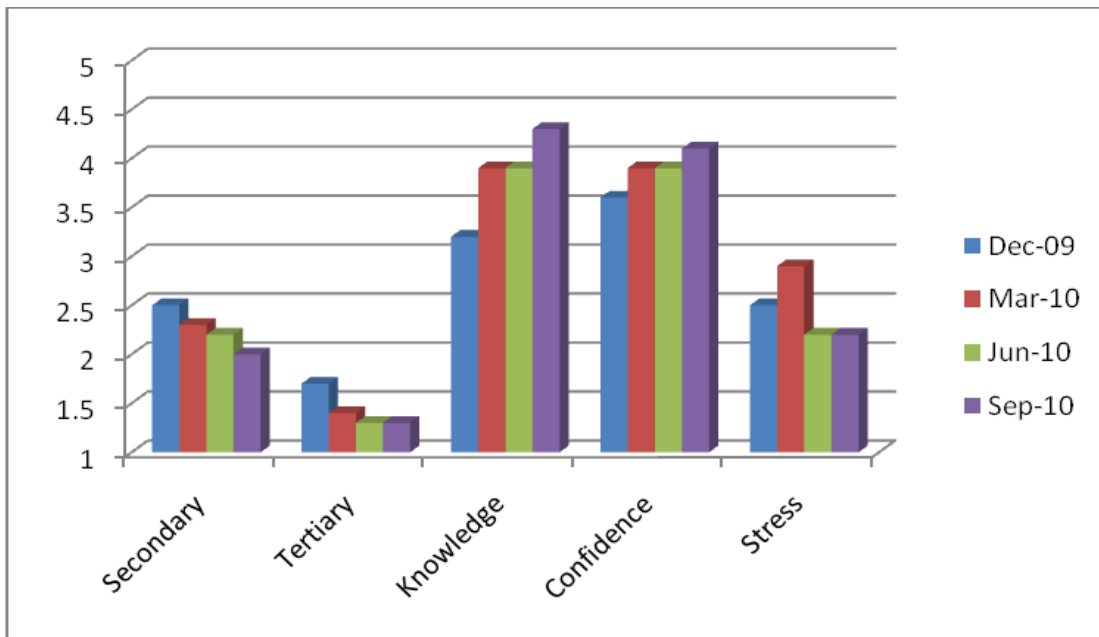
Over time patterns of defensive behaviours commonly develop. These are called **secondary characteristics** and they reflect a poor fit between the person and his or her environment. Examples of secondary behavioural symptoms are: anxiety, getting tired easily, which can manifest as irritability or over-activity, depression, aggression, disruptiveness, argumentativeness or withdrawal. **Tertiary characteristics** represent the net effect of chronic failure and frustration emanating from the brain-based disability and they tend to manifest as conflicts between the child and social norms. Examples are: criminal behaviours and involvement of the legal system, conflicts at home or at school, problems with substance abuse, etc. Secondary and tertiary characteristics are thought to be preventable or modifiable with appropriate support.

Results

The charts below show key finding from participant evaluations throughout the duration of the project. All ratings are averaged from the respondents' answers to evaluation questions using a 1-5 rating scale where 1 means "never" or "not at all" and 5 means "all the time" or "to a great extent".

Chart 5

Foster parent, group home workers and teacher ratings (combined) for December 2009 – September 2010 ⁴



⁴ September results are for foster parents and group home workers only as teacher were not re-assessed at that time. Foster parents and group home worker ratings have been combined, as there were only four group workers involved at the start of the project, and this had declined to one worker by June and September 2010.

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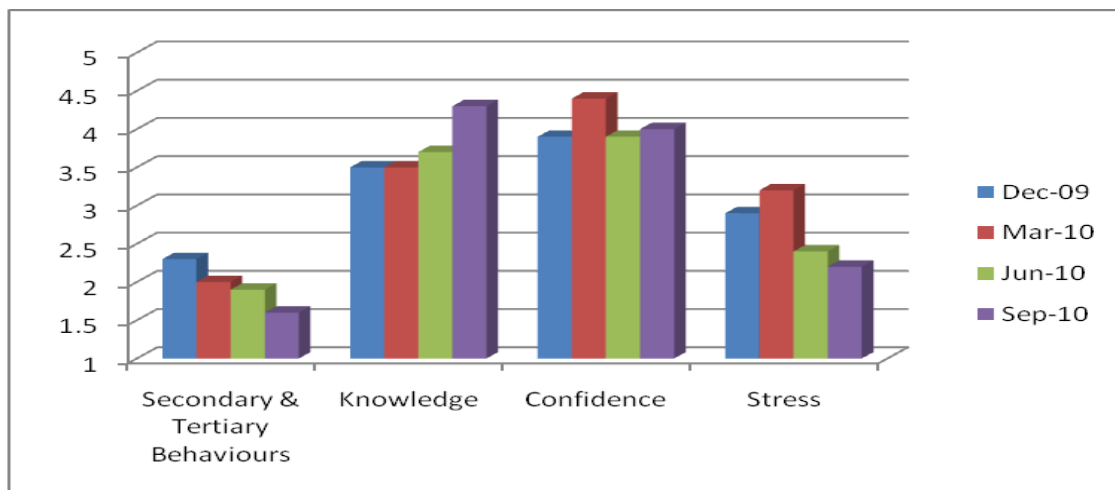
As the chart indicates, the observed incidence of secondary and tertiary behavioural symptoms associated with FASD declined from baseline in December 2009 to September 2010, with the largest decline in reported tertiary characteristics.

Caregiver and teacher self-reported knowledge about FASD and confidence in the ability to effectively care for/teach a child with FASD increased from baseline through to project end in September 2010. Stress levels of caregivers increased from December to March and then declined into June and through to September. According to the project's outreach coordinators, the temporary increase in stress was likely due to concerns of some parents about their foster children being returned to home communities by child welfare agencies due to funding cuts. This did not occur however and stress levels decreased once the situations were stabilized.

Charts 6 & 7 below show the differences between foster parent/group home worker ratings and teacher ratings on all items assessed across the time period.

Chart 6

Foster parent and group home worker ratings from December 30, 2009 to September 30, 2010

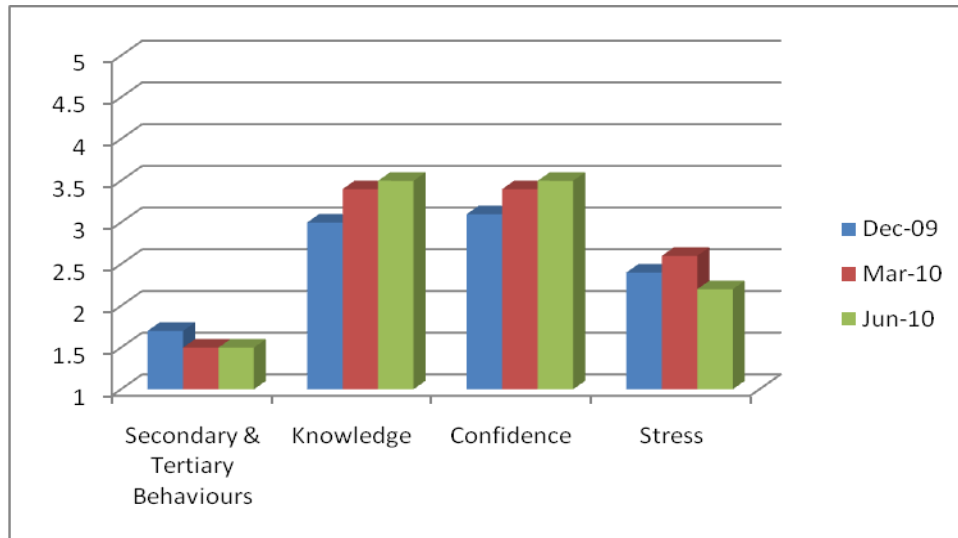


Reporting from foster parents and group home workers confirms that secondary and tertiary behaviours declined over the life of the project. Knowledge has increased from baseline as has confidence (albeit slightly) for working effectively with children with FASD. Stress levels are down from baseline.

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Chart 7

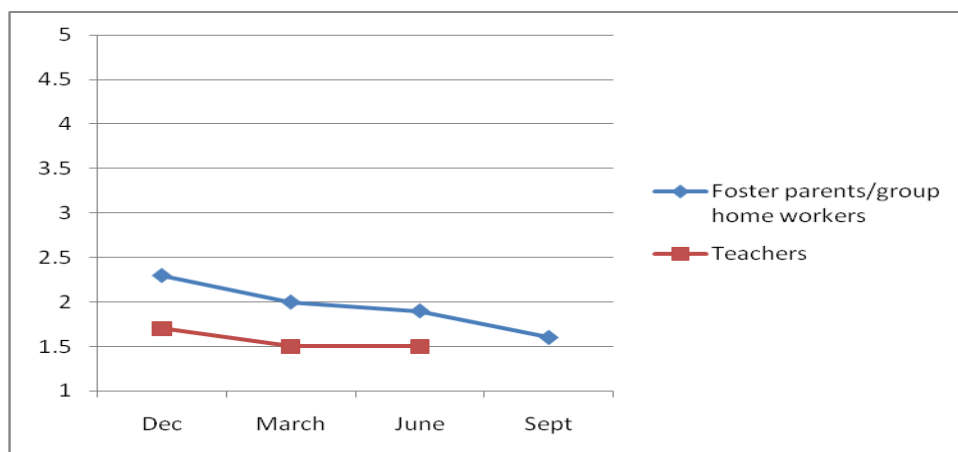
Teacher ratings from December 30, 2009 to June 30, 2010



Teacher ratings show the same trends as do the foster parent/group home worker ratings. Secondary and tertiary behaviours, while low to begin with, have declined. Knowledge and confidence increased over the time period and stress levels declined. Of interest is the temporary increase in stress levels of teachers in March, during a time when foster parents were under a great deal of stress due to concerns about the children being removed from their homes due to budget cuts.

Charts 8 through 11 show the average ratings for each of the various dimensions assessed, comparing foster parents/group home workers with teachers, from December 2009 to September 2010.

Chart 8 Secondary and Tertiary Behaviour Ratings by Foster Parents/Group Home Workers and Teachers Dec 2009 – Sept 2010



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Chart 9 Knowledge Ratings by Foster Parents/Group Home Workers and Teachers Dec 2009 – Sept 2010

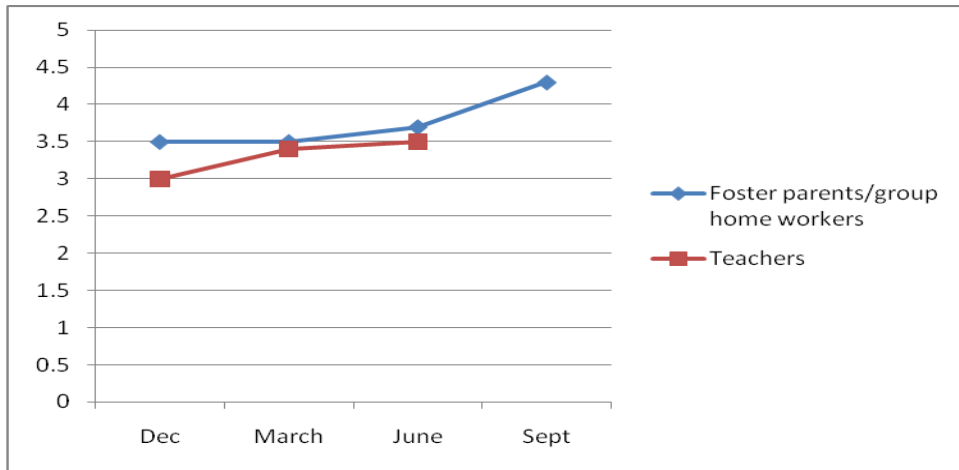


Chart 10 Confidence Ratings by Foster Parents/Group Home Workers and Teachers

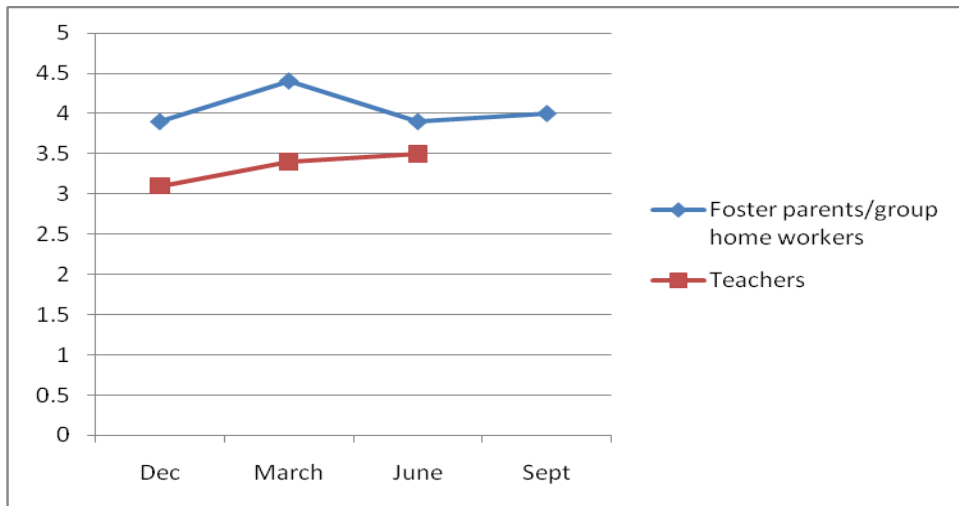
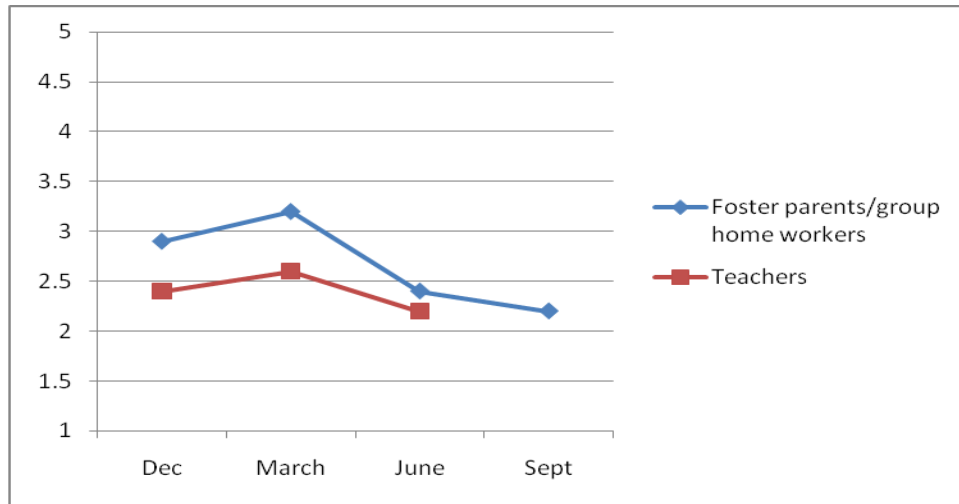


Chart 11 Stress Levels of Foster Parents/Group Home Workers and Teachers



Foster parents and group home staff generated the highest ratings on every dimension across the time period. This finding is not unexpected given that foster parents and group home staff spend much more time with children and youth than do teachers, so they may have more exposure to behavioural challenges, more knowledge and confidence to deal with children with FASD, but also more stress.

2.3 Outreach Work

FASD Training and Awareness Raising

Key Workers/Outreach Coordinators completed many FASD workshops and presentations between October 1, 2009 and September 30, 2010 and at least 1514 individuals from a wide range of agencies and organizations have received training from Outreach Coordinators and Key Workers. In addition to staff of children's services agencies, these include workers in remote First Nations, Chiefs and Councils, teachers and special education teachers, principals and vice-principals, students, staff of Native Friendship Centres, and representatives from corrections, youth justice and police. One of the Outreach Coordinators conducted a survey of 200 high school students, having trained three volunteer grade 10 students to survey their peers about FASD and to provide the correct answers if the wrong answer was given, to raise awareness. The volunteers received community service hours for their efforts.

Another Outreach Coordinator travelled to remote northern reserves throughout the spring and summer of 2010 to provide FASD training to foster parents and workers in those communities. Communities visited included: Sandy Lake, Lac Seul, Wapekeka (Angling), Kitchenuhmaykoosib Inninuwug (Big Trout Lake), Mishkeegogamang, Eabametoong (Fort Hope), Kasabonika Lake and Pikangikum. Foster parents and workers in the communities were very receptive to the information provided, which helped them to better understand the behaviours of children living with FASD. They would like to receive more training and support. *Appendix C* contains a full listing of the trainings provided by Outreach Coordinators and *Appendix D* shows a map of the area and the locations of these remote First Nation communities.

A number of organizations have made significant contributions to the project's outreach and training activities. As examples, the Keewatin-Patricia Public School Board is hosting a web page dedicated to the FASD project, which is available at <http://www.kpdsb.on.ca/education/fasd/edufasd.asp>. In addition, the Keewatin-Patricia Board is covered the costs for a final meeting of Key Workers in Dryden in October 2010 to share project outcomes and plan next steps. Tikinagan Child and Family Services covered the costs for one of the Outreach Coordinators to travel to remote northern reserves throughout the spring and summer of 2010. The Red Lake Friendship Centre covered some of the costs for two-day training sessions in that area, including three hall rentals. The Sioux Lookout Friendship Centre held a community potluck in September 2010 including an FASD presentation, which drew 60 participants. Anishinaabe Abinooji Family Services (Kenora area) has developed a plan for ongoing FASD training and support and has identified five staff to coordinate both internal staff training and trainings within AAFS' four First Nation communities.

The Coordinators also participated in special events to raise awareness of FASD through presentations and/or displays including community potlucks and barbecues, Farmer's Markets, etc. FASD day was held September 9, 2010. It was well attended and included school presentations and booths, a community parade and a barbecue. Over 100 trivia cards about FASD were distributed throughout Red Lake, Sioux Lookout and Dryden. These cards went into several restaurants, lobbies and also the police

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stations. The response received was very positive and in Dryden, two restaurants decided to keep the cards on the tables after FASD Day, as they noticed many of their customers were reading them.

The Coordinators visited two schools in Winnipeg that have modified classrooms to support the special needs of children with FASD and other neurological difficulties. This visit resulted in one of the Coordinators (who is also a teacher) developing a manual that describes how such modifications can be made in regular classrooms to improve the learning environment for children with FASD; the manual includes many pictures of these modifications.

As communities and service providers become more aware of the work and capacities of the FASD Outreach Coordinators, they are receiving more requests to share their expertise. For example, they are receiving requests to participate in case conferences for affected children and youth, for information sharing, accommodation/fit charting, planning for the students' special needs and safety, and planning for the transition to secondary school. This includes case planning for children/youth not on their caseloads.

Trainings continued into October including trainings with foster parents, employees of the Kenora Legal Clinic, Best Start Hub coordinators, etc.

Finally, the Outreach Coordinator for the Dryden, Red Lake and Sioux Lookout areas, along with several Project Steering Committee members, initiated a meeting in July with representatives from Health Canada's First Nation, Metis, Inuit Health Branch and Nishnawbe-Aski Nation (NAN), which represents 49 First Nation communities within the territory of James Bay Treaty 9 and the Ontario portions of Treaty 5. NAN has Health Canada funded FASD workers who provide supportive services on its northern reserves. The purpose of the meeting was to review current delivery services for individuals with FASD across the north, to review ideas for FASD accredited programming specific to the north, to explore possibilities for connecting FASD workers from NAN reserves to Key Worker monthly teleconferences in the North West or to initiate a similar model in the NAN area, and to develop opportunities for networking, support systems and added resources for NAN FASD workers. A letter of interest to follow up on these items is being prepared for FNIHB.

Foster Parent Support Groups

The Outreach Coordinators began facilitating foster parent support groups in Kenora, Dryden, Red Lake and Sioux Lookout in January 2010. In Kenora, bi-weekly sessions have occurred, involving approximately 32 foster parents. In Dryden, Red Lake and Sioux Lookout, three groups have been running with approximately 22 participants altogether. In Dryden, foster parents also received some clinical consultation from Diane Malbin, the FASD expert who provided the Key Worker training, over the telephone in July 2010. The foster parents reported that these sessions with Ms. Malbin were very helpful. Sessions in Kenora continued into June 2010; after that the Outreach Coordinator focussed more on supporting five foster families directly with case conferences to develop care plans. Currently, the Coordinator is seeking another key worker to continue facilitating the parent groups. Information about the foster parent support groups may be found in *Appendix C*.

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Level of Knowledge and Confidence of Key Worker Trainees

Those who received FASD training and who have access to email were asked to respond to survey questionnaires in December (n=13), March (n=19), June (n=11) and September (n=24) about the impact of the FASD trainings. September 2010 also included evaluation results from evaluation forms provided to 27 trainees by FASD Coordinators following training sessions. These were included with the online results, and the total number of respondents for September 2010 was 51. The total number of respondents—to online surveys and through on-site evaluations—was 94.

Averaged ratings from the training recipients for training outcomes are shown below in charts 12 to 14. Summary data is included in *Appendix A*.

Chart 12 Average self-reported knowledge levels of trainees from baseline (Dec 09) to Sept 30, 2010 (1-5 rating scale)

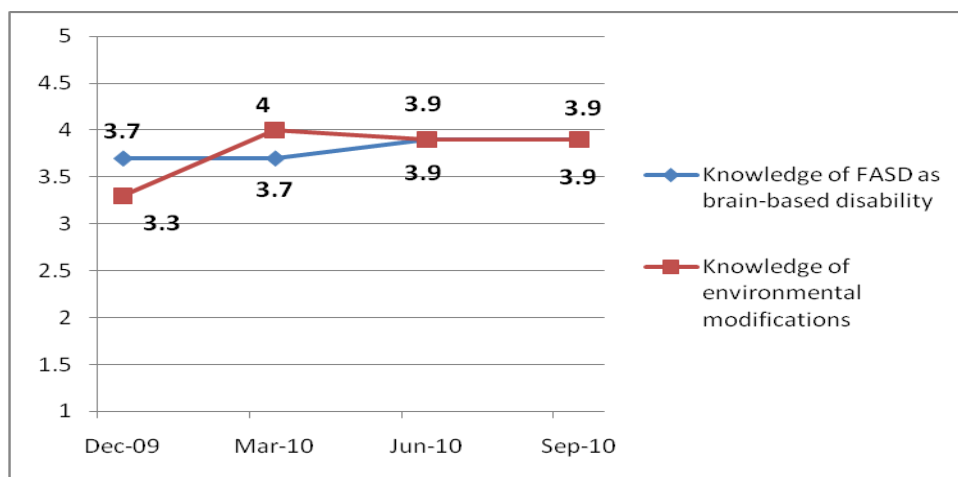
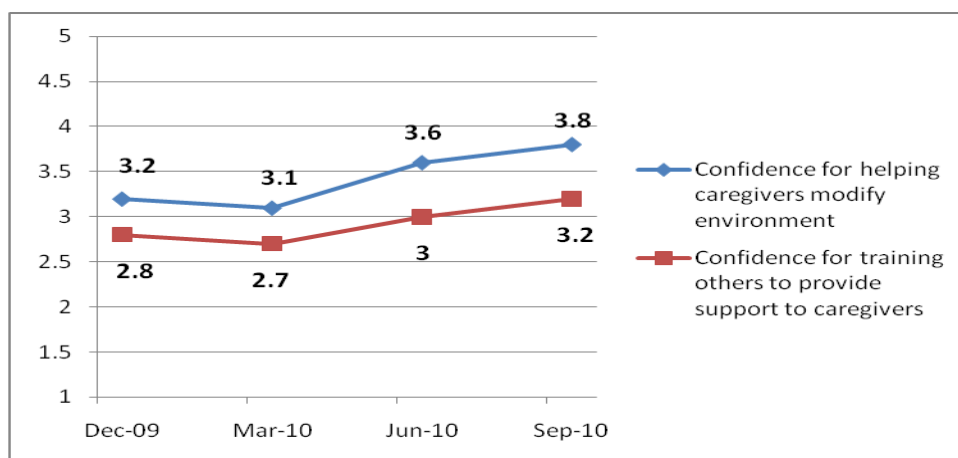


Chart 13 Average self-reported confidence levels of trainees from baseline (Dec 09) to Sept 30, 2010 (1-5 rating scale)



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Ratings on almost all items increased over time, suggesting that capacity has been developed among trainees for understanding FASD as a brain-based disability and required environmental accommodations, for working effectively with children with FASD, and for supporting caregivers in making needed modifications to improve outcomes for children with FASD. Further, the Key Workers and Outreach Coordinators have conducted many trainings and they have continued to learn about accommodations for children with FASD, e.g. through a visit to specially designed classrooms in Winnipeg. Thus, they have accumulated a body of knowledge over the life of the project and their skills with regard to providing trainings are likely increasing.

Among trainees, confidence for training others as Key Workers received the lowest rating of all of the items. This is not unexpected as the capacity for training others would normally require a higher level of skill than that required to implement modifications or to support caregivers in making modifications.

Chart 14 Average self-reported levels of knowledge & confidence of key workers and all trainees of key workers (combined) September 30, 2010 (1-5 rating scale)

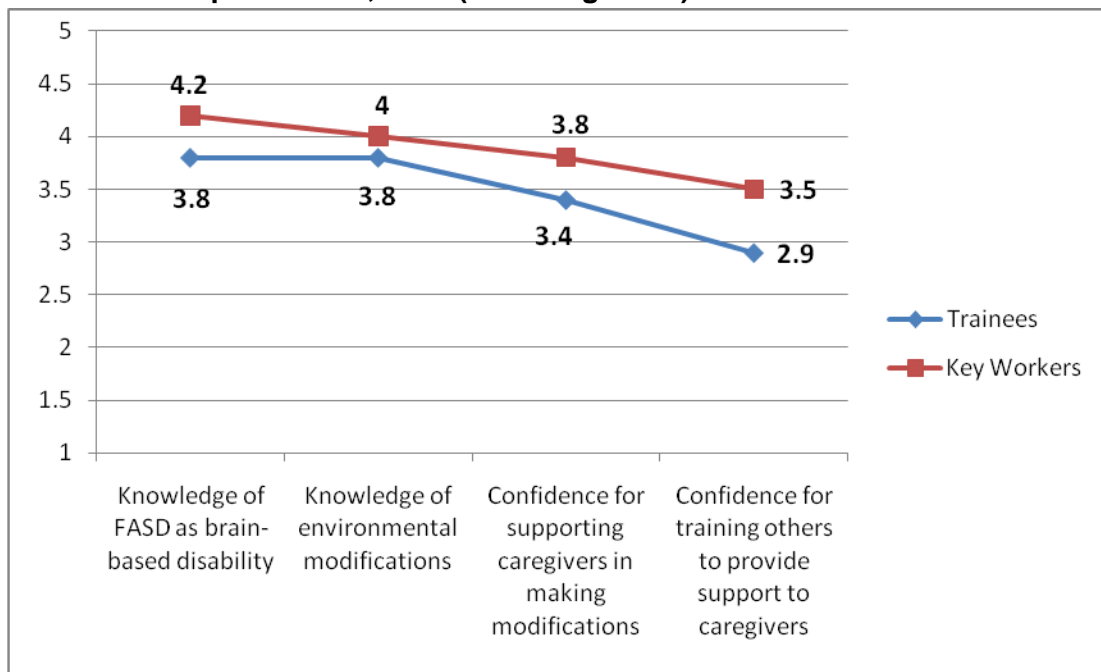


Chart 14, above, which compares the ratings of key workers and trainees over time, is of particular interest. Key Worker ratings are higher on every item compared to those of trainees and this would be expected, as the Key Workers have received training and support from a specialist trainer. Furthermore, the data trends are consistent for both groups, i.e. ratings are highest for knowledge, followed by confidence in ability to provide direct support and then confidence for training others to provide support. This “triangulation” of the data lends credibility to the findings.

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2.4 Focus Group Results

As part of the evaluation, four focused group discussions about the project were held with foster parents, teachers, key workers and members of the project steering committee. The questions were designed to elicit feedback about the impact of the project, including its strengths, successes and barriers to accessing services or to implementation. Twenty-three people participated in the discussions, including three foster parents, five teachers, eight key workers and seven members of the steering committee.

Understanding of the project and the role of the key workers

Foster parents felt that the primary role of the project workers was to gather information about their foster children and provide parents with information that would help them to support their children's needs and learning. They also thought that the project workers were to work with schools, to facilitate meetings with parents and teachers, and to educate teachers about working with children with FASD. In addition, they understood the role of the workers to include community outreach work to raise awareness about FASD and FASD prevention.

Teachers had a similar understanding of the project and the role of the workers, namely that the workers were to provide information as needed, to respond to questions or concerns and to help teachers to develop and implement strategies to support children with FASD. One of the teachers did not feel that she needed much support however, while another did not realize until recently that the worker would come in on request to provide resources and strategies to assist the teacher in working with students.

The **Key Workers** indicated that they understood their roles to involve supporting one another within and across agencies and working with schools and other community partners to "spread the word" about FASD as a brain-based disability and about required accommodations. For the most part, they thought that the role of the workers was well-defined and remained consistent throughout the project.

As would be expected, the **Project Steering Committee** members had a somewhat broader view of the project objectives and the role of the workers. They said that the project was aimed at supporting foster parents and teachers to improve outcomes for children and youth in care. However the project also had the objectives of increasing knowledge across the region in all areas and building a collaborative, multi-agency approach to ensure congruent implementation of support for affected children across all systems of care. One of the objectives, for example, was to develop a closer working relationship between children's mental health and child welfare agencies and staff.

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Key activities of project workers

Project workers include all of those persons who trained as Key Workers. However, most of these have full-time positions at service agencies and so three Outreach Coordinators (also trained as Key Workers) were hired on a contract basis to provide direct support to foster parents and teachers.

The **foster parents** reported that they speak regularly to the Coordinators on the telephone and that the Coordinators have also visited with them in person. The Coordinators have provided emotional support to the parents and have worked with them to brainstorm and review problem-solving strategies and needed accommodations for children/youth. Coordinators have also attended meetings between service providers or school personnel and foster parents.

“I talk to [the Coordinator] regularly on the phone. I thought she could give the school hands-on suggestions to make school less stressful for my child and she attended a meeting to give them suggestions and examples [of needed accommodations].”

“Mostly what we’ve done is work on problem-solving strategies and come up with a plan.”

“And we would try it and if it didn’t work, we would try something else.”

“I’ve had [the Coordinator] attend meetings with me with a service provider or she has attended at my house with a service provider.”

Foster Parents

Teachers have also met with the Coordinators to problem-solve in relation to FASD affected children in school. They have requested and received advice from the Coordinators over the telephone and by email. Meetings to propose strategies have been followed by meetings to review the effectiveness of the approaches and to implement required changes. In some cases, these meetings have occurred monthly or bi-monthly. Coordinators have provided teachers with resources (e.g. research papers on effective strategies for addressing challenging behaviours) which the teachers can share with other school personnel and they have helped teacher to access community resources and supports. Coordinators have also offered to provide presentations on FASD during PD days.

Key Workers and Coordinators have made presentations about FASD to various agencies and organizations in their communities. Other activities in which Key Workers/Coordinators have been involved include:

- Providing one-on-one support to staff in other agencies and to families, to review symptoms and behaviours and implement accommodations;
- Participating in case conferences to do brain-mapping and develop accommodation plans, including planning accommodations for Individual Education Plans.

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The Key Workers reported that as community awareness of their role increases, more requests are coming in for presentations, trainings and participation in case conferences, as a result, capacity is growing across the region.

Capacity has started to be built across communities but it will take longer than a year.

Education/knowledge is developing, but it's going to be a long process but the fact that groups are asking for presentations/workshops shows that awareness is being heightened.

And more and more requests are coming in every week – from early childhood education, probation, different agencies.

Key Workers

What difference has the project made to foster parents, teachers and children?

The **foster parents** said that one of the most significant things they have realized as a result of the project is that they are not alone—that there are many people who are struggling with the same challenges. It was also very helpful to them to have access to a support person who really understands the issues, as not many people do. Since the Coordinators have become involved, foster parents reported that teachers have become more knowledgeable and in some cases, things have improved for their children at school as a result of this.

It's invaluable and what a resource it would be for people who are just getting an FASD child – every community should have an FASD worker.

Foster parent

The **teachers** reported that the Coordinators have helped to raise their awareness of FASD and to understand some of the differences and challenges of FASD-affected children. The Coordinators have also helped them in tracking behaviour and developing strategies that can be applied on a daily basis. The surveys and diagnostic checklists provided by the Coordinators have helped in this regard. Having a support person to call on when needed was also very comforting. In some cases, especially when a child is from a remote, fly-in community, no diagnostic testing has been done and teachers sometimes misinterpret behaviours that are likely related to FASD. Once teachers understand what is going on, their own frustration subsides. As a result, they become more patient and understanding and more able to implement useful strategies to support learning.

...getting information from the FASD worker has allowed me to see signs in a lot of kids and given me tools in the toolbox for my daily practice with kids. Ignorance is bliss but when you know things, you can try them; if I don't know, I will just assume they are having a bad day.

Teacher

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.. one student we worked with showed high frustration levels when we challenged his learning level – I didn't realize that was FASD; I thought...he was being defiant, so understanding that FASD was a factor was a great insight.

When the child gets frustrated with learning material, at first it also caused me a lot of frustration and stress but by understanding more of what the child goes through and understanding their differences gave me a lot more patience. And my reaction has relieved her of her frustration.

It has given me lots of ideas and strategies about how to make accommodations for the students and from that I've noticed some benefits, like the use of headphones to block out distractions when the student is doing independent work; [and] little things in the day to day routine that could throw a child off, like having a visual schedule so they know what is coming up and know what is expected of them.

Teachers

Key learnings from the project

Foster parents reported that they have learned (and continue to learn) new strategies for supporting their children. They have also found it extremely helpful to have people to “bounce things off” and generate ideas. In this regard, the foster parent support groups have been very beneficial and these have also helped the parents to feel that they have support and are not alone. One parent noted that she feels that the project workers are “going to bat” for foster parents and children with the government and agencies, so that there is more recognition of affected children and their needs.

Teachers have also benefitted from the support provided by the project workers in terms of learning new strategies to support children. One teacher pointed out that there is a tremendous diversity in the way that FASD presents and being involved in the project has helped her to recognize related behavioural patterns in a variety of environments. In addition, the project has helped her with day-to-day planning for individual students and to make required changes to assist them when they are having a hard time. One of the teachers is new to the profession and has not had any experience working with children with FASD, so the information and support from the project workers has been very helpful.

Being a new teacher, I haven't had any experience working with FASD children so hadn't been educated at all about their difficulties and problems on a day to day basis, so all of the information provided has helped me quite a bit.

Teacher

Key workers said that they have learned to identify behavioural symptoms, to do mapping and to develop strategies, but they would like to learn more about specific accommodations and how to implement them. They really like the networking with other key workers, not only because of mutual support, but because it provides opportunities for information sharing and for learning from each other. This really promotes learning and builds valuable skills. There have been some strong connections developed as a result of the project and key workers really want to maintain those to build awareness,

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support prevention, and work collaboratively to build more capacity, e.g. to generate funding for diagnostics, to have FASD recognized as an exceptionality within the school boards.

Project steering committee members identified a number of important things that they have learned as a result of participating in the project. For example, the vastness of the geography, the uniqueness of the service population (i.e. many children are located far from their homes in remote communities), the number of agencies involved and policy changes over which providers have no control—all of these made for a complicated environment within which to implement project activities. Despite these challenges, steering committee members have been impressed by some of the shifts in understanding that have taken place due to the project. These include:

- An increased understanding of the knowledge and resources that caregivers already have and how much they can do help children function well, if they have appropriate support;
- An increased realization that caregivers and service providers need to work together;
- A growing understanding of the needs and challenges at all levels of the service system; and
- An increased understanding of the barriers to working collaboratively (across organizations) and of how to break down these barriers.

Further to this, steering committee members noted that there has been a real change with respect to organizations beginning to take on more responsibility and to work together. For example, there has been an improvement in terms of children getting easier access to needed services.

I've noticed a huge increase in a sharing of the responsibility and the load. I work 100% on FASD and it's incredible to watch other people and organisations taking on different pieces – it's been noticed by all the parents I work with. It's created a huge ripple effect and really increased the energy.

Steering Committee Member

One of the members, an educator, commented that the project has broadened his perspective in terms of how to look at child behaviours and respond differently based on the students' unique challenges.

It's made a difference for me with all sorts of children with behavioural issues, not just FASD, and in learning that the behaviours may not need to be addressed directly. We had a student last year with a brain injury with low functioning and lots of behaviours. He was using bad language but not really understanding what it meant, just that it would get a reaction. I was able to understand that this was a symptom of his frustration and how we works differently from other kids and this changed how I related to him. For me, it's been amazing.

Steering Committee Member

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Strengths and successes of the project

Foster parents said that the project has been an excellent support for them. In fact, they would like to see the service extended to all parents with affected children, especially new foster parents and including biological parents.

Teachers found the information, resources and support provided by the project workers very helpful. The evaluation surveys (which included behavioural checklists), while not intended as such, have helped teachers to better understand what is going on with their students. Some of the strategies applied (e.g. pre-class check-in with students to see how they are doing) have also been very helpful.

Another real strength of the project has been the consistency of support: knowing that there was one person to communicate with families, teachers and students.

When we are all on the same page we have a better chance of addressing the needs of these students – academically and personally and giving them the tools they need to live independent lives after high school.

Teacher

Teachers also found the project invaluable for simply raising awareness about FASD and the prevalence of it, and they noted that the support of the school boards for the project has been important in increasing recognition of children with FASD.

Finally getting some recognition for FASD kids is important – they are everywhere, in every single classroom. Having the school board on board with this is also wonderful.

Teacher

Key Workers thought that the project has helped to build awareness of FASD and that this has increased support for families. Providing them the opportunity to network with others who have the same training and knowledge base has also been very beneficial. Capacity continues to be built; for example, a presentation will be given shortly to all the Special Education Resource Teachers in Dryden, and community partners have also been invited. One respondent pointed out that having a group of key workers from different agencies has turned out to be a key strength.

Because we're all from different agencies, we come at it with a multi-disciplinary approach, and the different perspectives generate great ideas.

Key Worker

The **project steering committee** agreed that the networking, the empowerment of people “on the ground” who are working with affected children and the mutual support that these people are able to provide each other are key strengths of the project. Another benefit of the project is the legacy it leaves behind in terms of capacity building. For example, one person said that while it is unfortunate the project is ending, all of the trained staff will continue to work in their communities and to collaborate with each other. In addition, it has generated some advocacy work, e.g. agency workers have begun advocating within their agencies for enhanced rates for foster parents caring for affected children.

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It was noted that there was a lot of energy put into the developmental phase of the project (e.g. developing terms of reference, intake and evaluation forms, etc., and this helped to bring the group together. One member said that it felt like “slogging through mud” but it was necessary and it did help to build capacity.

New partnerships have developed as a result of the project, with new people coming on board along the way. For example, people who were not involved in the original key worker training are asking for information to bring back to their First Nations communities. A different level of cooperation has also arisen between agencies and school boards, and the boards have built capacity with their teachers, educational assistants and special education teachers.

The Coordinator role has been a key strength, in terms of having designated staff with resources that people can call on and who are able to bring the key workers together. The Project Steering Committee itself has helped to increase community support: having a larger body that is committed to the issue has given legitimacy and credibility to the work.

The key worker training has increased overall agency knowledge and commitment to the issue. For example, within one of the child welfare agencies, supervisors are very passionate about FASD, they have made sure managers are informed, and FASD is now a standing item at management meetings.

The respondents agreed that school board support has been critical in a number of ways. The project website, for example, which is hosted by the Keewatin-Patricia Board, will serve as a good legacy. Several steering committee members have noticed very positive changes within the Keewatin-Patricia Board due to its support of the project.

Within the Keewatin-Patricia school board, we've noticed a huge difference and I want to thank them. We've witnessed a real sea change in the understanding of school principals and vice-principals about child behaviours and a willingness to work with them. Special education staff have gained knowledge as well. There has been a large reduction in suspensions this year and I think it is due to the project.

And less suspensions will reduce the stress of foster parents.

Steering Committee Members

Barriers and challenges

Foster parents did not identify any barriers or challenges to receiving support from the project workers, although they feel there is still work to do to enhance the understanding and capacity of teachers to work effectively with children with FASD.

Teachers did not identify any barriers to receiving support either; they were able to get resources, information or support from the project workers as needed. However one teacher suggested that a “mini-workshop” format for training teachers would be helpful in

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terms of reaching larger audiences. Not all teachers were aware of the project, so some form of communication, like a newsletter, that outlined the purpose of the project and expectations of teachers and project workers would have been helpful. Similarly, it would have been helpful to provide teachers with a checklist of what they would be receiving from project workers.

Key workers cited several barriers and challenges that they have encountered throughout the project, including:

- The need to clarify the role of the key workers with agency managers
- Limited participation from some of the people who received key worker training
- Challenges getting everybody—parents, teachers, lunch monitors, coaches etc.—on the same page.
- Lack of attention to the needs of adults with FASD and the importance of engaging with adult services.
- Very limited diagnostic capacity in the area, which makes it more difficult to access services, especially within schools.

One of the biggest challenges for key worker with full-time jobs has been finding the time to function as a key worker. Most cannot spend more than a few minutes with people who need information and support, and this is very frustrating and upsetting for key workers. More support from management is required to allow the key workers to do the work they were trained to do.

For me, the big thing has been time. I was really excited to be a key worker—I wanted to do consultations with my co-workers, mapping and developing strategies within our agency. Our supervisors were going to ask our managers to free up a third to a half of our jobs to do this work but it kind of fell by the wayside. So, I have the knowledge base and don't have time to do anything with it. I think my supervisor really struggled with my role and what to do with me. In the future, if a similar project was done, it would be helpful to get the agencies on board – but the funding is not there for it.

Key Worker

There are also some concerns that momentum could be lost once the coordinator positions end. These positions have very important in maintaining the networking and some would like to see dedicated facilitator positions established within certain agencies to continue the work. However, again, limited time is a challenge.

More work still needs to be done in terms of education, raising awareness and prevention. For example, key workers would have liked to reach out more to probation and the medical profession but this has not yet happened to the extent that it could. There was a feeling that providing the information to probation officers, in particular, could affect sentencing of youth or adults with FASD, who are currently over-represented in the justice system. More education for schools and teachers is needed and also more diagnostic capacity, because if children are not diagnosed, they are not identified within schools and therefore do not receive required supports. At the same time, the key workers recognized that teachers are often overwhelmed with large classes that include many children with special needs.

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The **project steering committee** identified a number of barriers to successful implementation of the project's goals, one of the most significant being the short-term nature of the project. As a result, the full impact of the project may not be seen for some time, although they are pleased at what has been accomplished to date.

It would also have been helpful to extend the age range of the project participants and to have included a variety of age groups, as the needs of children change as they move through different developmental stages. In particular, transition periods (e.g. adolescence and early adulthood) are high risk periods for youth with FASD. It was a struggle for people working with transitional aged youth or adults to see how they fit into the project.

Some thought that the group should have engaged more partners on the steering committee earlier in the process, specifically the school boards. It was also suggested that including Elders in the key worker training would have been a good idea, given the questions and concerns that have been raised by some Aboriginal people and to ensure that project materials etc. were culturally appropriate.

It was also pointed out that the committee could have been more specific about the role of the key workers and what would be expected of them within their agencies. .

Like the key workers, the project steering committee members indicated that lack of diagnostic capacity has been and remains a serious challenge in the region.

The difficulty getting a diagnosis remains.

Those [project participants] who were diagnosed were diagnosed through the diagnostic clinic which is closed. If we were to repeat the project in 5 years it would be very hard to find children with diagnoses. This is a huge obstacle – there are hardly any children being diagnosed now. There is very little attention being given to this by the ministry responsible for clinical services.

And when services that require a diagnosis are needed, this is a huge barrier.
Project Steering Committee Members

Further to accessing diagnoses, one of the steering committee members pointed out that the project put everyone on “high alert” about the issue of FASD but if there is no diagnostic capacity, there is a risk that awareness will recede and the needs of people with FASD will go unaddressed. For example, children without a diagnosis are not eligible for any support services as adults and many of these children are crown wards. Within the child welfare agencies, there is a growing recognition of this barrier and they are trying to address it as best they can, but resources are very limited.

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We've allocated some psych money to buy four FASD assessments per year (it's not a lot but we weren't doing it a year ago) and Tikinagan has capacity now for three a year. This will help youth moving into adulthood get the services they need. But it's kind of a drop in the bucket.

Project Steering Committee Member

One of the positive effects of the project has been an increase in accommodations for children who have been diagnosed but were not previously receiving accommodations, as well as a capacity to identify children under six through application of the screening tool. As a result, there is a baseline now for these children and they are getting some supports. Agencies are also able to give schools a "heads up" about this. However, without a diagnosis, accommodations and transitions to school remain challenging, especially with regard to certain issues like toileting and sexuality.

What remains to be done: Next steps in capacity building

Foster parents were very sorry to hear that the project is ending. They expressed some frustration about the limited amount of funding that dedicated to supporting children with FASD, given their needs.

If there is money in our government for studying caterpillars or whatever, or paying for LCBOs, why can't they fund support for our kids?

I just think it's invaluable – every community should have a service like this – I'd like to see FASD get the same funding as AIDS does or autism. We need a famous person to speak for FASD.

Foster parents

The support from the Coordinators has been helpful for the foster parents and it would be more helpful yet for new foster parents. It could also help to prevent placement breakdowns. Support would be particularly useful when interacting with teachers and foster parents would like to see support extended to biological parents.

I like the support and it would be wonderful for someone just starting out.

I think there would be less chance of a [foster family] breakdown if the support was there.

...if they [foster parents] could have people go with them when they are talking to the classroom teacher who would back them up and explain that the child has FASD and provide support – a lot of times they [the teachers] look at you like you have two heads when you say he really can't help [his behaviour].

It would be nice to see more biological parents involved.

Foster parents

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In recognition of the heavy demands on teachers, foster parents would like to see more support in schools, including more educational assistants in classrooms. The transition to high school is particularly challenging and this is a time when many young people with FASD really struggle, especially if there are no specialized supports for them. In addition, they school administrators have to be educated and engaged to motivate teachers, as currently many teachers do not understand the nature of the disorder.

They [teachers] really don't understand that these kids have permanent, organic brain damage. It's not visible, they look normal and that's what the teachers see – there's no physical problems so they don't get what's going on.

.Foster parent

There is also a need more community awareness about FASD generally. For example, deterrents do not work with affected children and that is why so many are involved with the justice system. Foster parents would like to see more community outreach work, e.g. booths at different functions or at places like the hospital. They would also like more emphasis on prevention.

There are people out there who need to be educated on drinking when you are pregnant – there should be labels on the bottles, like cigarette packages, each bottle should be labelled like they do in BC.

Foster Parent

The **teachers** said that they hope the project is able to continue, as the needs are only increasing. The support provided through the project appears to be especially helpful for new teachers.

It would be of much benefit to carry on the program. I don't think I have enough knowledge and experience to carry on alone – it is very beneficial to have people to interact with who can give you a new set of ideas to try if you have run out of strategies. So that is key.

Teacher

Teachers would also like to see more supports put into place for educators, tailored to their backgrounds. These could include the provision of information and resources for First Nations schools, and mini-workshops on PD days or as part of a staff meeting. Modelling strategies for teachers (i.e. letting them observe strategies in action) would also be helpful. All teachers should be provided with information about the key worker network and about who to contact for information or support. .

Key Workers are sorry to see the project come to an end and they want to continue to meet to keep the momentum going. They would also like to meet regularly, e.g. every couple of months, to do joint community activities.

3. CONCLUSION AND NEXT STEPS FOR CAPACITY BUILDING

Conclusion

The EBBS North Western Ontario FASD Intervention Project has built community capacity to support children and youth living with FASD in the care of child welfare agencies in many ways. Conservatively, over 1500 people have been reached through training workshops, presentations and other events to raise awareness about FASD as a brain-based disability and the accommodations that can be made to mitigate the effects of FASD and improve child outcomes. The results of key worker and trainee surveys show improvements from baseline in the following areas:

- knowledge about FASD, related disabilities and helpful accommodations
- confidence for implementing environmental accommodations
- confidence for training others and doing public education work.

Evaluation questionnaires with foster parents, group home staff and teachers caring for or teaching affected children show increased knowledge, increased confidence and reduced stress since baseline. Secondary and tertiary behaviours of participant children have also declined. *It is worth noting that these improvements occurred over a nine month period and had the project participants been tracked for a longer period, more substantial changes may have been seen.*

All of these findings are congruent with the results of the focused group discussions with foster parents, teachers, key workers and project steering committee members, all of whom have validated the importance and the impact of the project and indicated a need to continue the work.

Some of the identified barriers to project implementation remain. Specifically, there is a need for dedicated positions for community outreach and training and for the provision of direct support to caregivers and teachers. Most of the key workers have full-time positions that limit their ability to do as much of this work as they would like. The contract outreach coordinators, who did a great deal of the outreach and training during the project, also took on the responsibility of organizing and coordinating key worker meetings, which helped to maintain cohesiveness and momentum. In addition, they organized and facilitated foster parent support groups, which were very well received. Agency support for the key worker role (which would involve managers and supervisors allocating some time for the work) is necessary but would likely not be sufficient to duplicate the work and successes achieved by the coordinators. There is a particular need for continued outreach and support to remote First Nations communities in the north, where the needs are very high.

Finally, the current lack of diagnostic capacity in the area, without which providing appropriate supports to affected children, youth and adults living with FASD becomes very challenging, is another critical barrier that must be addressed in order to further this work.

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Final Meeting to Determine Next Steps

The project partners convened a final meeting in Dryden October 28, 2010 which was attended by 45 key workers, agency supervisors, school board staff and other community partners. The purpose of the meeting was to review the project activities and evaluation findings, to share experiences that people have had with the project and to generate some ideas for next steps.

Testimonials

A number of guest speakers shared their experiences with the project. Highlights of their testimonials appear below.

Debbie Michaud – Kenora-Patricia Child & Family Services (Child Welfare Agency)

- I've been beating this drum alone for a long time so I'm glad that the project has recognized what we need to do and that we now have a common language.
- We have used the tools and information from the project to ensure that our staff are on same page. Having everyone sitting together and using the information has helped to create a paradigm shift. We have formed an "informal" assessment group including paediatric input, psychology and they have agreed to provide four FASD assessments per year as there continue to be waiting lists at Sick Kids and St. Mikes.
- The University Ottawa is compiling data on children in care and in 2008 FASD represented 21-23% of diagnoses of children at KPC&FS, compared to 7-11% in the rest of Ontario. This could be higher due to the misdiagnosis of ADHD.
- I recently spoke at a Kenora District Service Board meeting with Ontario Works/adult case managers, on what they might see with the adult population they are working with; the very fact that they invited me to come and speak shows that a paradigm shift is occurring. I hope this important work we have started doesn't end...

Graham Thompson & Judy Kay – Sioux Lookout Community Action Partnership for FASD: Judy is also with the Healthy Generations Family Support Program of the Dryden/Sioux Lookout Association for Community Living

- Graham is the facilitator for Sioux Lookout Community Action Partnership for FASD, involving 10-18 organizations and services through a project funded through CHEO (Centre of Excellence). Partners include schools, police, probation, CAS's etc...
- We are into our second year of funding; the first year we looked at where the needs are (overlaps and gaps). We are now building the pillars for action, including a number of teams to address: Service Integration, Legal Support Services, Prevention, Diagnosis and Education & Training.

**Judy Kay – Sioux Lookout Community Action Partnership for FASD.
Healthy Generations Family Support Program Dryden/Sioux Lookout Association
for Community Living**

- This key worker project has been amazing. For 15 years this issue has been at the forefront in Sioux Lookout, and the project has helped to enhance education and connections. Thank you to Catherine (EBBS Outreach Coordinator) for all of her energy.
- Community mobilization has increased: many more people are doing the work.
- An example of how coming together and finding innovative uses of resources for support is the story of a young fellow with an FASD diagnosis who was living on the street; various partners worked together to find him a stable place to live and to provide a solid safety net.

Jason McDonald – Keewatin-Patricia District Public School Board (KPDPSB)

- We have developed some great partnerships through the project. We are using a common language, have educated 300 people or more including the board trustees, administrators resource teachers trustees, administrators, special education advisory staff and volunteers, which is unbelievable given the geography our school board covers—more than 75,000 square kilometres.
- We are using the screening tool to identify gaps between chronological age and developmental stages.
- After this gathering, the project will not end; it will continue to move forward. Children’s mental health is a focus for our Board and we will be having a regional symposium on that in the spring.
- Thank you to Sean (Superintendent of Education) for his desire to bring this to the region – it was due to his fortitude to continue this and support it that we have accomplished so much.

Holly Szumowski – Hudson Public School

- I am a full-time special education literacy coach and trained as a key worker.
- The key worker project was wonderful; I’ve got the message out to other staff through three workshops (all school staff attended).
- It is hard for teachers to revise curriculum and attend training; this speaks to the need for support from “higher-up” for training, which will provide an opportunity to get the work into all classrooms.

Dianne Sidders – Patricia Centre for Children and Youth (Children’s Mental Health Agency, also Chair of KPDSB SEAC committee)

- Catherine (Outreach Coordinator) helped key workers and foster families in our area (Red Lake) to stay on track, get ideas, and generate enthusiasm. She took the focus off of child behaviours to what is behind them.
- There was an unbelievable effort on FASD day with the Red Lake Friendship Centre’s support and vision.
- Our SEAC wrote a letter to the Minister of Education about how important this issue is and we will follow up to see if a response occurs.

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- I am going to assist with the monthly key worker teleconferences, to make sure that these continue.

Rachel Bridge & Sarah Mekanak –Tikinagan Child & Family Services (Native Child Welfare Agency)

- We have 33 First Nation communities, with 760 kids in care and 400 foster homes.
- We travelled to a number of remote communities to provide FASD training and thank you to Catherine for her time and energy.
- The trainings were much appreciated by the foster parents in these communities.
- With training and case conferences we have seen placement stability increase.
- Rachel now has a new position in the agency but intends to keep the information alive.
- Sarah participated in the trainings with the remote First Nations and had to interpret the information into their language, which was a challenge because some of the terms/concepts are hard to translate.
- She learned a lot from the people we were training and they learned a lot too: some of the Grandmas now understand what is behind the child's behaviour and that the child is not "bad". There is a great desire to learn more.

Anne Shankowsky – Abinoojii Family Services (Native Child Welfare Agency) and Lake of the Woods Child Development Centre (Children's Mental Health Agency)

- I am doing clinical work at Anishinaabe Abinooji Family Services until March, 2011.
- I've been doing this work for 34 years and am seeing a paradigm shift but I'm also impressed by the resources caregivers have and how much they already know.
- We are working on modifying the training materials to make them easier for people to understand and to make them culturally safe.
- I will miss the project coordinators—funding dollars are essential to keep this going. We need to ensure that the powers that be hear the message and don't let the momentum stop!!

Diane Malbin, Key Worker Trainer – Closing Comments

A few comments about the context within which this project was conceptualized and implemented and the project itself:

The value of any project is measured by the degree to which it adequately recognizes and addresses the social issue at hand.

FASD is an emerging social problem. What is a social problem? Dr. Robert Holloway provided this definition: "It is one deemed such by a number of significant people, or a significant number of people and it is one *for which there is a solution.*" If there is no solution, there is no problem. No problem, no need for solutions.

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Early research on FASD, notably Streissguth's longitudinal study (1996), was a natural history design. Following diagnosis, all subjects were simply followed. Over the years, they continued to receive standard services—special education, counseling, treatment, jail. The findings of high rates of secondary disabilities contributed to a shared perception that emotional / behavioral deterioration was inevitable in this population, reinforcing parents' and professionals' sense of frustration and futility. The myth was established that “nothing could be done,” the “no solution” part of the equation. This has apparently inhibited identification and work toward prevention. If a problem cannot be named, can it be prevented?

Reviewing the early research through a neurobehavioral lens reframes findings: The power of Streissguth's research may be to show the limits of current practice. In spite of standard services, participants deteriorated. Why? Learning theory is the prevailing paradigm; practice and program design based on this theoretical foundation is seen across disciplines and in all systems. There is nothing wrong with the strategies, but learning theory fails to encompass brain *dysfunction*. Assumptions about cognitive abilities have not been examined for their relevance for those with FASD and other brain-based conditions.

FASD as an invisible, neurobehavioral condition is emerging as a social problem in a world that has yet to recognize the link between brain function and all behaviors. This limits perceptions and understanding, resulting in values-laden interpretations of neurobehavioral symptoms and, by extension, interventions designed to change behaviors. The resulting sad trajectory includes frustration, increasingly constrictive, coercive and expensive interventions, and poor outcomes. This is the macro context within which the EBBS project was implemented.

It is easy to say the brain has something to do with behaviors, and that research has clearly established FASD as a brain-based physical disability. The work is to unsnarl what this means intellectually, emotionally, and practically and then to factor this in to parenting, practice, program design and policy.

In this project, the role of Key Workers, conceptualized as change agents working across systems in diverse communities, has been to provide information, assure shared understanding, establish and sustain conceptual consistency and congruent application of the principles of a neurobehavioral approach in all settings. This is no small feat. Providing strategies is easy; supporting changing thinking for people with different educational backgrounds and cultures is very difficult, an art. Changing thinking from reacting to the person's behaviors as *being* the problem to understanding the person as *having* a problem is a paradigm shift, a different way of thinking.

“Problems are never solved at the level of thinking at which they were created.”
(Einstein) The project introduced way of thinking differently, asking a different set of questions based on research. It is from this thinking and understanding differently that frustration resolves, options expand, and person-specific accommodations emerge. In this project, on the basis of this approach, improvements were clearly seen, particularly in the tertiary characteristics. These findings break the “no solution” stalemate by clearly indicating solutions.

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Neurobehavioral theory, the conceptual glue of all project activities, is still not core curriculum for virtually all disciplines. The neurobehavioral approach holds some risk since it illuminates the limits of current practice and all the discomfort that potentially represents. Establishing a safe context within which people are able to learn and incorporate new information is also an art.

The work of the project is overtly simple—to educate—and in fact is multi-layered: Recognizing and indirectly addressing the social-emotional dynamics related to naming alcohol and brain dysfunction, understanding historical dynamics related to grief and loss, and effectively communicating a different way of thinking is enormously challenging

The power of this project has been to contribute to breaking the “no solution, no problem” stalemate. Systematically factoring in and giving equal weight to the idea that the brain has something to do with behaviors redefines problems and solutions in a manner consistent with research. The findings-- in such a short time-- of clear trends of improvement in the children *and* adults is a function of the skill and excellence of the work of the Key Workers and commitment of all community partners.

The success of the project is testimonial to the skill and grace of the Key Workers, their supervisors and community partners and the resiliency of parents and extended family who participated.

Further, the success of this project has established a template. The project design and implementation, clarified by evaluation, has provided a process that other systems and communities may replicate and emulate. A testimonial to the value of the project by community partners is in the endorsement by commitment to continue to sustain application of the project principles and further the ripple effect of change.

It has been an honour and privilege to be invited to participate in this project and to work with so many skilled and dedicated people. Thank you.

Working Groups

Following the guest speakers, the participants broke into four working groups to discuss the following topics:

- How to extend the work with children and youth during key transition periods
- How to extend the work within school boards
- How to extend the work within child welfare agencies; and
- How to extend the work within Aboriginal communities.

Extending the work during key transition periods

Key transition periods are considered to be: ages 0-1, moving from home to school, moving from elementary school to high school, and moving from high school to independence. These are critical periods that call for interventions to ensure smooth supports to children, families and systems, as with changes come difficulties.

Recommended steps include:

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- Identify the needs of affected children more thoroughly when they enter the school system, with school staff, and broaden the use of the neurobehavioral screening tool and who works with it. There is a need for more integrated assessments, looking at the child more holistically.
- Flag “at risk” children at school by the time they are 13. All children with FASD should/need to be flagged.
- Have social service providers tap into systems to find mentors for children and families during these periods.
- Increase trainings for workers across the social service system.
- Provide more respite for families during these times of transition, and train respite workers to be mentors, while ensuring that both the caregiver and respite worker are on the same page. If not, this could make things even more difficult. Mentors need to be coached on matched supports/interventions.

Extending the work within the school boards

- Develop partnerships with Treaty Schools, Catholic Boards and Public Boards, involving them all.
- Reach out to other social service providers
- Include teachers in all case conferences with affected children.
- Increase training for teachers and provide an allowance for hours to participate in training/networking and to provide training.
- Develop a stronger network of leaders in school, agencies, organizations etc, to provide a strong ‘backbone’ for the work.
- Encourage commitment from boards, not in word but in action, funding and time
- Ensure service provision and privacy
- Use a more holistic approach
- Ensure that there is an understanding of cultural safety for Aboriginal families and children, including an understanding of the rights of Aboriginal children as outlined by the UN and in human rights legislation.

Extending the work within the child welfare system

- Have an FASD focused worker in each community to ensure support, training and groups.
- Use a strength-based approach with families and children.
- Take better histories at admission
- Improve school preparation; work with the schools in developing plans of care and include child welfare workers in IEP planning
- Develop an FASD training module for all workers and new hires; this should be an extension of foster parent PRIDE training. The training needs to be mandatory (including managers and executive directors).
- Empower caregivers and consider and appreciate them as experts as they spend the most of their time with the children. No blaming: We all need to take responsibility and work together.
- Recognize when extra support is needed
- Change the standards by which we evaluate children and on what basis

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- Let foster parents and biological parents work together and develop a relationship, to increase future success
- Re evaluate our expectations of these children
- Educate the ministry, as their standards often get in the way of what child welfare workers do with affected children.

Extending the work within Aboriginal communities

- Ensure that the work, including FASD education and training, is culturally appropriate and sensitive.
- Provide school boards and school staff with information about who to contact at the grassroots level within Aboriginal communities.
- Provide cultural sensitivity training to non-Aboriginal service providers and teachers
- Share the responsibility – FASD is everyone's problem – it does not belong to any one group.
- Bring everyone together, on even ground that is culturally safe. For Aboriginal people, this may involve more informal settings.
- Work collaboratively to improve transition planning and make transitions easier.
- Recognize the impact of Residential Schools and ensure that service providers/teachers get more education on this so that we can all move forward together.

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APPENDICES

APPENDIX A: Key Worker Data Tables

i. KEY WORKER KNOWLEDGE AND CONFIDENCE LEVELS

Table 1 Knowledge of FASD as a Brain-based Disability and of Related Behavioural Characteristics

Surveys	Dates	% of respondents reporting:			Average Score/5.0
		Low level of knowledge	Moderate level	High level	
Baseline N=26	Early Sept 2009	39%	42%	19%	2.77
Post-training – N=22	Sept 30, 2009	0%	32%	69%	3.73
Post-training – N=32	Jan 2010	0%	43%	58%	3.67
Post-training – N=19	March 2010	0%	26%	74%	3.84
Post-training N=14	June 2010	0%	7%	93%	4.07
Post-training N=20	Sept 2010	0%	16%	84%	4.16

Table 2 Knowledge for Making Environmental Modifications to Reduce Disabilities and Improve Outcomes for Affected Children/Youth

Surveys	Dates	% of respondents reporting:			Average Score/5.0
		Low level of knowledge	Moderate level	High level	
Baseline N=26	Early Sept 2009	31%	39%	31%	2.96
Post-training – N=22	Sept 30, 2009	0%	32%	69%	3.73
Post-training – N=32	Jan 2010	5%	29%	67%	3.71
Post-training – N=19	March 2010	0%	37%	64%	3.74
Post training – N=14	June 2010	0%	21%	78%	4.0
Post-training N=20	Sept 2010	0%	16%	84%	4.0

Table 3 Confidence in Ability to Provide Effective Support to Caregivers or Teachers of Children with FASD

Surveys	Dates	% of respondents reporting:			Average Score/ 5.0
		Low level of knowledge	Moderate level	High level	
Baseline N=26	Early Sept 2009	23%	39%	40%	3.19
Post-training – N=22	Sept 30, 2009	5%	27%	69%	3.68

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Post-training – N=32	Jan 2010	5%	48%	48%	3.48
Post-training – N=19	March 2010	0%	37%	64%	3.74
Post-training- N=14	June 2010	0%	36%	64%	3.71
Post-training N=20	Sept 2010	0%	42%	58%	3.79

Table 4 Confidence Level for Training Other Workers to Provide Appropriate Supports to Caregivers and Teachers

Surveys	Dates	% of respondents reporting:			Average Score/5.0
		Low level of knowledge	Moderate level	High level	
Baseline N=26	Early Sept 2009	42%	39%	19%	2.62
Post-training – N=22	Sept 30, 2009	5%	46%	50%	3.50
Post-training – N=32	Jan 2010	14%	52%	33%	3.19
Post-training – N=19	March 2010	21%	37%	42%	3.26
Post-training N=14	June 2010	7%	43%	50%	3.43
Post-training N=20	Sept 2010	5%	53%	44%	3.47

Table 5 Confidence in Ability to Work as a Team to Wrap Services around a Child and Caregivers

Surveys	Dates	% of respondents reporting:			Average Score/5.0
		Low level of knowledge	Moderate level	High level	
Baseline N=26	Early Sept 2009	8%	31%	61%	3.73
Post-training – N=22	Sept 30, 2009	0%	14%	86%	4.00
Post-training – N=32	Jan 2010	0%	29%	71%	3.71
Post-training – N=19	March 2010	0%	26%	74%	3.84
Post-training N=14	June 2010	0%	7%	93%	4.07
Post-training N=20	Sept 2010	0%	26%	84%	3.89

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Table 6 Confidence in Ability to Do Public Education about FASD and Environmental Modifications

Surveys	Dates	% of respondents reporting:			Average Score
		Low level of knowledge	Moderate level	High level	
Baseline N=26	Early Sept 2009	35%	46%	19%	2.73
Post-training – N=22	Sept 30, 2009	5%	50%	46%	3.45
Post-training – N=32	Jan 2010	5%	57%	38%	3.38
Post-training – N=19	March 2010	16%	53%	31%	3.16
Post-training N=14	June 2010	7%	43%	50%	3.36
Post-training N=20	Sept 2010	10%	42%	48%	3.37

ii. KNOWLEDGE AND CONFIDENCE LEVELS OF KEY WORKER TRAINEES

Table 7 Did you learn something new about FASD as a result of the training?

Number of respondents	Date	Average Score (Out of 3.0)
Baseline n=13	Dec 2009	2.65
Round two n=19	March 2010	2.95
Round three n=11	June 2010	2.63
Round four n=24	Sept 2010	2.60
Total n=67	Overall average	2.71

Table 8 How effective was the training in helping you to understand how to work with children with FASD?

Number of respondents	Date	Average Score (Out of 5.0)
Baseline n=13	Dec 2009	3.6
Round two n=19	March 2010	3.8
Round three n=11	June 2010	3.9
Round four n=24	Sept 2010	3.9
Total n=67	Overall average	3.8

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Table 9 To what extent has your knowledge of FASD as a brain-based disability improved as a result of the training?

Number of respondents	Date	Average Score (Out of 5.0)
Baseline n=13	Dec 2009	3.7
Round two n=19	March 2010	3.7
Round three n=11	June 2010	3.9
Round four n=51	Sept 2010	3.9
Total n=94	Overall average	3.8

Table 10 To what extent has your knowledge improved for making specific environmental modifications to mitigate disabilities of children/youth with FASD, as a result of the training?

Number of respondents	Date	Average Score (Out of 5.0)
Baseline n=13	Dec 2009	3.3
Round two n=19	March 2010	4
Round three n=11	June 2010	3.9
Round four n=51	Sept 2010	3.9
Total n=94	Overall average	3.8

Table 11 What is your level of confidence for supporting caregivers of children/youth with FASD in making accommodations, following the training?

Number of Respondents	Date	Average Score (Out of 5.0)
Baseline n=13	Dec 2009	3.2
Round two n=19	March 2010	3.1
Round three n=11	June 2010	3.6
Round four n=51	Sept 2010	3.8
Total n=94	Overall average	3.4

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Table 12 What is your level of confidence for training others to support caregivers in making accommodations, following the training?

Number of respondents	Date	Average Score (Out of 5.0)
Baseline n=13	Dec 2009	2.8
Round two n=19	March 2010	2.7
Round three n=11	June 2010	3.0
Round four n=51	Sept 2010	3.2
Total n=94	Overall average	2.9

APPENDIX B DEMOGRAPHIC DATA & PARTICIPANT RESULTS

Demographics

Initial Intakes: Baseline January – March, 2010

In total, 39 individuals completed initial intake questionnaires. Of these, 18 were foster parents, five were group home workers, and 16 were teachers. At the time of initial intakes, these 39 participants were caring for or teaching 22 children/youth.

All of the children/youth involved were Aboriginal. Twelve were male and ten were female. Seven were between 7 and 10; six were between 11 and 13; and nine were 14 to 17 years of age.

Ten were from Kenora or the surrounding area; six from Dryden; three from Sioux Lookout; two from Balmertown; and one from Red Lake. All of the children and youth either had a confirmed diagnosis of FASD or FASD was strongly suspected. All were permanent wards. No reunification plans were reported. Current placement lengths ranged from 3 months to 14 years.

Round Two – March 31, 2010

For round two data collection and analysis, 35 people completed evaluation questionnaires, including 17 foster parents, 15 teachers and 3 group home workers.

There were 21 children/youth being cared for or taught by the project participants. All were Aboriginal; ten were female and 11 were male. Seven were between seven and 10 years of age, six were between 11 and 13 and eight were 14-17 years of age. Nine were from Kenora or surrounding area, six were from the Dryden area, three were from Sioux Lookout, two were from Balmertown, and one was from Red Lake. Other demographics remained the same.

Round Three – June 30, 2010

For the June 30 round of data collection, 36 people completed evaluation questionnaires, including 18 foster parents, 17 teachers and one group home worker.

There were 19 children/youth being cared for or taught by project participants. All were Aboriginal; nine were female and 10 were male. Six were between seven and 10 years of age; six were between 11 and 13; and seven were 14-17 years of age. Eight were from Kenora or surrounding area, six were from Dryden, two were from Sioux Lookout, two were from Balmertown and one was from Red Lake. Other demographics remained unchanged.

Round Four – September 30, 2010

By September 30, 2010 there were 18 children/youth being cared for by 18 project participants (17 foster parents and one group home worker). Teachers were not reassessed as all of the children/youth involved had entered a new school year with new teachers, none of whom had participated in the project. All of the children youth were e Aboriginal, with eight females and 10 males. Six were between seven and 10 years of age; six were between 11 and 13; and six were 14-17 years of age. Seven were from Kenora or surrounding area, six were from Dryden, two were from Sioux Lookout, two were from Balmertown and one was from Red Lake. Other demographics remained unchanged.

PARTICIPANT RESULTS

Participants (foster parents, group home staff and teachers) completed evaluation questionnaires about the impact of the project on: secondary and tertiary behavioural characteristics of children/youth, knowledge and confidence for working effectively with children and youth, and stress levels.

Table 1 Secondary and Tertiary Disability Scores of Children and Youth (average ratings using 1-5 rating scale)

Number of respondents	Date	Foster Parents & Group Home Workers		Teachers	
		Sec	Tert	Sec	Tert
Baseline n=39	Dec 2009	2.7	2	2.2	1.4
Round two n=35	March 2010	2.3	1.8	2.1	.9
Round three n=36	June 2010	2.2	1.8	2.1	.8
Round four n=18	Sept 2010	2	1.3	Not assessed	

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Table 2 Self-reported ratings of knowledge about FASD & related disabilities and for implementing required environmental accommodations (average ratings using a 1-5 rating scale)

Number of respondents	Date	Average Score (Out of 5.0)	
		Foster Parents & Group Home Workers	Teachers
Baseline n=39	Dec 2009	3.5	3
Round two n=35	March 2010	3.5	3.4
Round three n=36	June 2010	3.7	3.5
Round four n=18	Sept 2010	4.3	Not assessed

Table 3 Self-reported confidence levels for effectively caring for/teaching children with FASD (average ratings using 1-5 rating scale)

Number of respondents	Date	Average Score	
		Foster Parents & Group Home Workers	Teachers
Baseline n=39	Dec 2009	3.9	3.1
Round two n=35	March 2010	4.4	3.4
Round three n=36	June 2010	3.9	3.5
Round four n=18	Sept 2010	4	Not assessed

Table 4 Self-reported stress levels (average scores using 1-5 rating scale)

Number of respondents	Date	Average Score	
		Foster Parents & Group Home Workers	Teachers
Baseline n=39	Dec 2009	2.9	2.4
Round two n=35	March 2010	3.2	2.6
Round three n=36	June 2010	2.4	2.2
Round four n=18	Sept 2010	2.2	Not assessed

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**APPENDIX C
COMMUNITY TRAININGS COMPLETED BY OUTREACH COORDINATORS
AND KEY WORKERS AND FOSTER PARENT SUPPORT GROUPS**

September – December 31, 2009

Kenora Area

Date	Time	Organization	Number of People	Facilitator
Sept 24/09	10 am – 11 am	Youth Addictions	6	Hilary Jackson
Oct. 19/09	9 am – 9:30 am	KPCFS Child Care Team	8	Sarah Hicks
Oct.20/09	9 am – 9:30am	KPCFS Child Care Team	9	Cora Bennett
Oct. 21/09	9 am – 12pm	CDC Staff	14	Sarah Hicks Cora Bennett
Oct. 28/09	9 am -9:30 am	AOH Staff	5	Cora Bennett
Oct. 29/09	11:30 -1pm	Kenora Association for Community Living	19	Kerril Davidson-Hunt Andrea Brophy
Nov. 4/09	9am- 10am	Pineridge Group Home	8	Sarah Hicks
Nov. 6/09	8:30am – 9 am	Whitepine Group Home	6	Sarah Hicks
Nov. 13/09	10 am – 2pm	KPDSB EA's	140	Sarah Hicks Cora Bennett Kelly Schollie Jason McDonald Andrea Brophy Kerrill Davidson Hunt Cheryl Roffe
Nov 13/09	10am -1pm	KCDSB Special Education Resource Teachers	15	Shelly Tom

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Nov. 16/09	12pm – 2pm	Key Worker Luncheon	15	Sarah Hicks Cora Bennett
Dec. 9/09	9am-11am	CDC	11	Carole Roussin Anne Shankowsky
Dec. 15/09	7pm-8pm	KPDSB Administrators	10	Cheryl Roffe Jason Mcdonald
Dec 15/09	6-9 pm	Confederation College Child Dev Class	12	Cora Bennet
Total N of participants			278	

Dryden Area

Date	Time	Organization	Number	Facilitator
Oct 22/09	n/a	OACP Zone/OAPSB Police Chiefs and Board Members	48	Catherine H
Oct 29/09	n/a	Dryden KPCFS Unit Workers	4	Catherine H
Oct 30/09	n/a	Tikinagan CFS Unit Workers	5	Catherine H
Nov 9/09	n/a	Red Lake CFS Unit Workers	7	Catherine H
Nov 10/09	n/a	Sioux Lookout KPCFS Unit Workers	5	Catherine H
Nov 10/09	n/a	AOH – Lac Seul FN - Tikinagan	12	Catherine H
Nov 17/09	n/a	Mayor’s Committee for Prevention of Substance Abuse	9	Catherine H
Nov 26/09	n/a	Foster Parent’s Association	12	Catherine H
Dec 1/09	Full day	NW District School Board – all Spec Ed’s in each school received a day training session – FF, Atikokan, Dryden and Sioux Lookout	12	Catherine H
Total N			114	

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January – March 31, 2010

Kenora Area

Date	Time	Organization	Number of People	Facilitator
Jan 19/10	2 hours	KACL Kidzone Day care Staff	8	Andrea Brophy Kerril Davidson Hunt
Jan 29/10	1.5 hours 1.5 hours 1.5 hours	KCDSB PD Day	34	Shelly Tom And Sarah Hicks
Feb 9/10	Full Day	Shoal Lake teachers, EA's, Daycare Staff	22	Kerril Davidson Hunt Andrea Brophy
Feb 12/10	30 mins	Community Justice	7	Norine Van Breda
Feb 19/10	1 hour	SEAC (Special Education Advisory Committee)	13	Cheryl Roffe Jason McDonald
Feb 17/2010	1 hour	Probation Officer Brain Domain Discussion	12	John Baker Cora Bennet
February 23/10	2 hours	Hudson Public School	7	Holly Szumowski
March 3/10	2 hours	Group Home Training	20	Cora Bennett
March 8/10	2 hours	Hudson Public School	7	Holly Szumowski
March 16/10	9-11 am	Group Home Training	15	Cora Bennet
Total N to March 31			145	

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Dryden Area

Date	Time	Organization	Number of People	Facilitator
Jan 26/10	n/a	Presentation to student counsellors in Sioux Lookout, Dryden and Ignace areas, to develop a student led conference	2	Catherine Hutchison
Feb 10/10	n/a	Key worker teleconference - various	8	Catherine Hutchison
Feb 17/10	n/a	New Hires – Tikinagan Child and Family Services	17	Catherine Hutchison Sarah Nothing
March 5/10	n/a	Student led conference – students to continue training other students in the area.	18	Catherine Hutchison
March 9	n/a	Key worker teleconference	7	Catherine Hutchison
March 16-17	n/a	Presentation and Panel Speaker, Youth and Gangs Conference	105	Catherine Hutchison (presentation and panel speaker) and Sarah Nothing (presentation)
March 29/10	n/a	SEAC committee – presenting info regarding student placement	7	Catherine Hutchison
March 31/10	n/a	Sandy Lake FN presentation to foster parents/teachers/child care workers.	14	Catherine Hutchison with Sarah Nothing
Total N to March 31			178	

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April 1 – June 30, 2010

Kenora Area

Date	Time	Organization	Number of People	Facilitator
March 31, 2010	9 am -11 am	Group Home Training	20	Cora Bennett
April 29, 2010	9 am – 11 am	Group Home Training	16	Cora Bennett
April 30, 2010	1pm – 3 pm	AAFS	7	Sarah Hicks Anne Shankowsky
June 2, 2010	11 am – 1 pm	AAFS Train the Trainer	16	Sarah Hicks Anne Shankowsky
June 2, 2010	9 am -12 pm	Kenora Association For Communiy Living	15	Cora Bennet
June 4, 2010	9 am -12:30 pm	Foster Parent Support Group/ Workshop Catch Up	2	Sarah Hicks
June 14, 2010	12pm – 2 pm	Key Worker Lunch and networking opportunity	8	Cora Bennett Sarah Hicks
June 14, 2010	11 am – 2 pm	Kenora Social Justice Committee	25	Cora Bennett
June 30, 2010	11 am – 1:30 pm	AAFS Train the trainer	8	Sarah Hicks
May -June, 2010	2 months	Teen Survey Project with Beaver Brae Secondary School	3	Sarah Hicks
Total N to June 30			120	

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Dryden Area

Date	Time	Organization/ Location	Number of People	Facilitator
April 7	n/a	Wapekeka/Angling FN: Foster parents, CW staff and teacher's aide	7	C. Hutchison with Sarah Mekenack & Tannis Favot
April 8		Big Trout FN – Foster parents and staff	7	Same as above
April 13		Nodin Video Conference- variety of professionals – (locations included North Bay, Sault Ste. Marie, Sioux Lookout, New Post, Nipissing, Bearskin, Mish Slate Falls)	10	Same as above
April 16		Mishkegogamang/Missabay FN School-teachers	11	Same as above
April 28		Dryden – Regional Resource Teachers	26	Same as above
May 10		Fort Hope – foster parents and staff	13	Same as above
May 13		Dryden Anishinaabe Abinoojii Child and Family-CYW-Resource Workers	5	Same as above
May 26		Kasabonica FN	12	Same as above
June 8		Regional videoconference FASD family support groups	12	Same as above
June 28		Anishinabe Abinoojii Child and Family Mangers Training	2	Same as above
Total N to June 30			105	

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July 1 – September 30 2010

Kenora Area

Date	Time	Organization	Number of People	Facilitator
July 21, 2010	10 am -12pm	CDC KPCFS Key Worker Train the Trainer Meeting	5	Sarah Hicks
August 17, 2010	9 am – 11am	FASD Committee Meeting	5	Sarah Hicks Cora Bennett
August 24, 2010	11 am – 3 pm	Grassy Narrows School	20	Kerril Davidson Hunt
August 25, 2010	4pm – 7pm	Minto Family Resource Centre “Breaking the Barriers Community BBQ”	Public Information Display	Sarah Hicks Cora Bennett
August 30, 2010	9am – 11 am	FASD Committee Meeting	6	Sarah Hicks
September 1, 2010	9 am – 2 pm	FASD Awareness Display at Kenora’s Farmers Market	Public Information Display	Sarah Hicks Cora Bennett Kerrill Davidson Hunt
September 2, 2010	11 am – 12:30pm	CDC KPCFS Train the trainer meeting	5	Sarah Hicks
September 14, 2010	9 am -12pm	KPCFS Train the trainer	7	Sarah Hicks Connie Brown
September 15, 2010	9am -12pm	CDC Train the trainer	17	Sarah Hicks Carole Roussin
September 17, 2010	9am – 12pm	AAFS Train the	5	Sarah Hicks Anne

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		Trainer 3		Shankowsky
September 23, 2010	1.5 hours	KPDSB Special Education Resource Teachers	140	Cheryl Roffe Jason MacDonald Dr. Stambrook
September 24, 2010	1pm -3:30pm	Case Conference Information Sharing	5	Sarah Hicks Diane Malbin
			215	

Dryden Area

Date	Time	Organization/ Location	Number of People	Facilitator
July 19-20, 2010	n/a	Red Lake	7	Catherine Hutchison, Key Worker Michael Burton, Diane Sidders and Red Lake Friendship Centre Staff (new trainers)
July 26, 2010	n/a	Sioux Lookout	10	Catherine Hutchison
July 13&14, 2010	n/a	Fort Hope	13	Key Worker Sarah Mekenack
August 9 -10, 2010	n/a	Dryden	5	Catherine Hutchison
August 25-26, 2010	n/a	Pikangikum First Nation	50	Key Worker Tanis Favot
Sept 9, 2010	n/a	FASD Day – Red Lake, Dryden, Sioux Lookout		Catherine Hutchison, Key Workers, Parents/ Caregivers, Red Lake Friendship Centre Staff
		School presentation – grades 7&8	87	
		Information Booth	35	
		FASD Parade	80	

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		Sioux Lookout Friendship Centre Potluck & Presentation	60	Debbie Michaud – Key Worker
		Dryden Pancake Breakfast, Presentation & release of balloons in hope for those affected by FASD	7	Dryden Friendship Centre
September 21, 2010	n/a	Lac Seul Group Home Workshop	4	Catherine Hutchison Janice Wessel
			358	

Foster Parent Support Groups

Kenora Area

Dates	Times	Groups	Number Attending	Facilitator
Feb 3/10 Feb 10 Feb 17 Feb 24 March 3 March 10 March 17 Mach 24 March 31 April 7 April 14 April 21	2 hours each session	Caregiver Workshops/ Support Groups	Approx 14 per session.	Sarah Hicks Cora Bennett
Total N			32	

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Dryden Area

Dates	Times			
Jan 26 Feb 23 March 9		Dryden FP Support Group	6 2 2	Catherine H with support from other key workers
Jan 27 Feb 24 March 9		Red Lake FP Support Group	1 0 (cancelled due to meeting with director of CFS – children being returned to N communities 4	Same as above
Feb 9 March 9		Sioux Lookout FP Support Group	2 5	Same as above
April 26		Dryden Support Group	2	Same as above
April 27		Red Lake Support Group	2	Same as above
Total N			22	

Teen survey

In April, May and June 2010, the Kenora-based Outreach Coordinator was in contact with a resource counsellor at Beaver Brae Secondary School, in Kenora. Together they selected three Grade 10 students to assist the Coordinator to survey 200 of their peers, aged 14-18, on their knowledge and thoughts about FASD and factors that may or may not contribute to it. The three students received FASD training from the Coordinator prior to distributing the surveys. The results of the survey are shown below.

FASD TEEN SURVEY 2010

1. What substance when taken while pregnant can cause lasting brain damage in babies?

ALCOHOL

(Alcohol, unlike other substances, when injected during pregnancy affects the development of the babies brain, leaving permanent brain damage.)

142/200 or 71 % of the teens surveyed answered this correctly.

Other common answers were: drugs, meth, cocaine, crack, LSD

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2. Do you know what FASD stands for?

FETAL ALCOHOL SPECTRUM DISORDER

110/200 or 55% of the teens surveyed answered this correctly or mostly correctly. The other 45% indicated that they did not know.

3. How much alcohol is safe to drink during pregnancy?

NONE

(There is no SAFE amount of alcohol during pregnancy. The brain damage caused by the effects of alcohol is irreparable.)

169/200 or 84% of the teens surveyed answered this correctly. The other 16% indicated that a little bit, or a glass a day is ok.

4. True or False: I'm a teenager, I don't have to worry about FASD.

FALSE

(FASD is something to be aware of at all age levels. This knowledge can guide your future decisions. If you are female and if you are sexually active and drink alcohol, even occasionally, you are at risk of becoming pregnant and having a child born with Fetal Alcohol Syndrome.)

171/200 or 85% of the teens surveyed answered this correctly.

5. What kinds of women are most likely to drink during pregnancy?

ALL KINDS

(This is not just a problem with poor women, alcoholic women, or minorities. Half of all women are drinking at the time they get pregnant. And half of all pregnancies are unplanned. Alcohol consumption during pregnancy occurs in all ethnic groups and across all age spans.)

37/200 or 18% of the teens surveyed answered this correctly. 38/200 or 19% thought only Alcoholics are the only ones to drink during pregnancy and 47/200 or 23% thought teenagers. Other common answers were uneducated women, prostitutes, Aboriginal, welfare and depressed women.

6. True or False: All women who drink during pregnancy are alcoholics?

FALSE

(While there are women who do have an addiction to alcohol and continue to drink during pregnancy, there are also a great deal of women who were unaware of their pregnancy and are able to stop once they are aware. There are also countless occurrences of binge drinking before becoming aware of one's pregnancy.)

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176/200 or 88% of the teens surveyed answered this correctly.

7. Complete this sentence (In relation to FASD): Young women who are not pregnant but are sexually active should.....
ABSTAIN FROM ALCOHOL

99/200 or 49.5% of the teens surveyed answered this correctly or mostly correctly. Most thought that they should only use protection, some did say 'drink less' or 'be careful'.

8. True or False: FASD can be prevented.
TRUE
(In fact, FASD is the leading most common preventable birth defect!)

177/200 or 88% of the teens surveyed answered this correctly.

9. True or False: Men can't do anything to prevent FASD in children.
FALSE
(Men can do a lot by not drinking and providing support for pregnant women not to drink!)

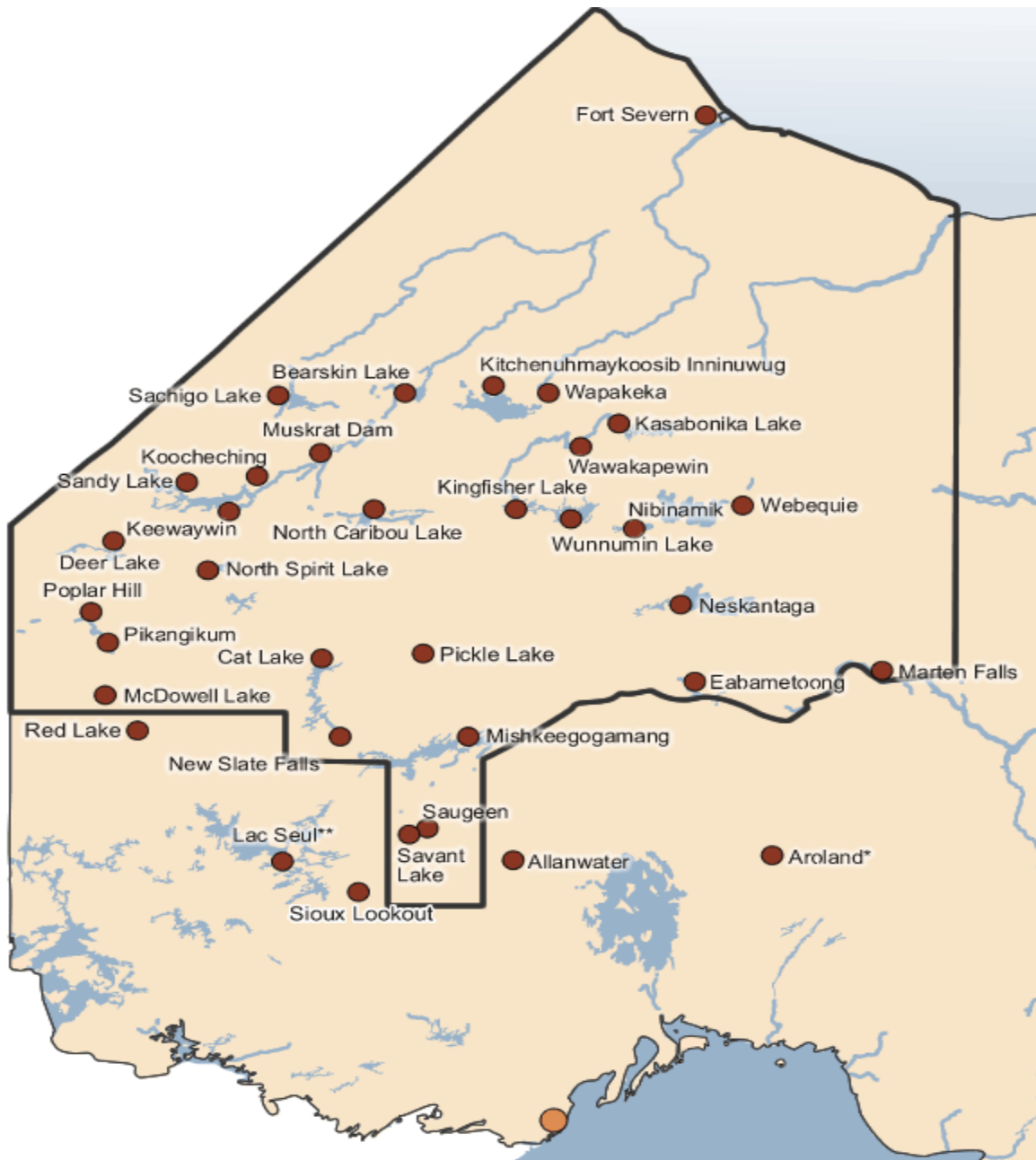
158/200 or 79% of the teens surveyed answered this correctly.

10. Do you know how to prevent FASD?
DON'T DRINK
(It is important for both the man and the woman to stay alcohol free before, during, and after pregnancy.)

163/200 or 81% of the teens surveyed answered this correctly.

APPENDIX D

Map of the area north of Sioux Lookout showing remote First Nations communities, a number of which were visited by the project Outreach Coordinator for education and training about FASD in the summer 2010. Communities visited included: Lac Seul, Wapekeka (Angling), Kitchenuhmaykoosib Inninuwug (Big Trout Lake), Mishkeegogamang, Eabametoong (Fort Hope), Kasabonika Lake and Pikangikum. The map was taken from Tikinagan CFS website. For perspective, Fort Severn is on Hudson's Bay. The communities range in size up to 2,000 people and most are regularly accessible only by air



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**APPENDIX E
EVALUATION QUESTIONNAIRE FOR FOSTER PARENTS, GROUP HOME
STAFF AND TEACHERS**

Baseline Evaluation Questionnaire for Caregivers/Teachers

Introduction

The EBBS FASD Support Project is a two-year project aimed at supporting caregivers and teachers of children and youth with FASD or suspected FASD who are in the care of a Children's Aid Society or Native Child Welfare organization. Foster parents, group home staff and teachers will be able to access ongoing support from Key Workers – workers who are trained in understanding FASD as a brain-based disability and in developing strategies to help affected children and youth succeed at home and at school.

The overall goal of the project is to maintain and improve the stability of placements and improve outcomes for children and youth aged 8-18 with FASD in the care of Child Welfare. This evaluation questionnaire will help us to determine if the project is meeting its goal.

SECTION 1: Background Information

ID #: _____ Initials of child: _____

Date: _____
D M Y

Home Community of Interviewee: _____

If a Teacher:

Name: _____

Name of School: _____

Grade Level Taught: _____

If a Caregiver:

1. What is your role in relation to caring for child(ren) who may have FASD?

- Foster parent
- Group home worker

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2. Are you the primary caregiver?

- Yes
- No

If not, who is?

3. What is your age?

- 20-34 years
- 35-49 years
- 50-64 years
- 65 or older

4. What best describes your ethnic origin?

- European (Caucasian)
- Aboriginal
- Other _____

5. What is your level of education?

- Elementary
- Secondary
- Post-secondary

For both teachers and caregivers:

6. Have you ever accessed support from a service provider who is dedicated to providing ongoing information and training about supporting children with FASD?

- Yes
- No

If yes, please explain.

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**SECTION 2: Secondary and Tertiary Behavioural Symptoms of Child
(Pre-project participation)**

Primary characteristics of FASD are learning, developmental, and/or physical responses to the environment and other behavioural symptoms that have been associated with differences in brain structure and function. They include things like attention difficulties, sensitivity to lights, sounds or touch, difficulties processing information and speech and language challenges.

When people with FASD are not identified as having a brain-based disorder, they often experience chronic frustration. Over time, patterns of defensive behaviours commonly develop. These are called **Secondary behavioural symptoms** and they reflect a “poor fit” between the needs of the person and his or her environment. They are preventable. **Tertiary characteristics** are the net effect of chronic failure and frustration and are also preventable.

Please indicate to what extent the child you are caring for/teaching exhibits the following:

Scale:

0=Not assessed 1=No 2=Rarely 3=Sometimes 4=Usually 5=Always

Secondary Characteristics:

- 0 1 2 3 4 5 Gets tired, easily exhausted; may show as over-activity, irritability, and/or tantrums
- 0 1 2 3 4 5 Anxious
- 0 1 2 3 4 5 Lonely, isolated
- 0 1 2 3 4 5 Easily manipulated and set up by others
- 0 1 2 3 4 5 Chooses “wrong” friends (people who are accepting)
- 0 1 2 3 4 5 Self-harming behaviours
- 0 1 2 3 4 5 Shut down; flat affect
- 0 1 2 3 4 5 Fearful, avoidant, withdrawn
- 0 1 2 3 4 5 Frustrated, short fuse, angry
- 0 1 2 3 4 5 Depressed
- 0 1 2 3 4 5 Remarkable sexual activity; multiple partners; unplanned or teen pregnancy
- 0 1 2 3 4 5 Aggressive
- 0 1 2 3 4 5 Destructive (not due to curiosity or just taking things apart)
- 0 1 2 3 4 5 Disruptive in class or at work
- 0 1 2 3 4 5 Talks back, is argumentative

Tertiary characteristics

- 0 1 2 3 4 5 Delinquent; criminal involvement
- 0 1 2 3 4 5 Runs away
- 0 1 2 3 4 5 Trouble at home
- 0 1 2 3 4 5 Trouble at school or in the community
- 0 1 2 3 4 5 Social services involvement
- 0 1 2 3 4 5 Legal system involvement
- 0 1 2 3 4 5 Alcohol / drug problems
- 0 1 2 3 4 5 Other mental health problems.

SECTION 3: Participant Knowledge and Experience (Pre Project Participation)

The following statements deal with being a teacher/caregiver of a child or children with or suspected of having FASD. For each statement, please indicate the extent that you agree or disagree.

1. I believe I have the information I need to be an effective teacher/caregiver of children with FASD.

Strongly disagree		Neither agree nor disagree		Strongly agree
1	2	3	4	5

2. I feel I have a good understanding of FASD and of the primary, secondary and tertiary characteristics associated with FASD.

Strongly disagree		Neither agree nor disagree		Strongly agree
1	2	3	4	5

3. I have a clear understanding of how to change the environment to make it a better fit for a child with FASD.

Strongly disagree		Neither agree nor disagree		Strongly agree
1	2	3	4	5

4. Overall, my confidence level in my current ability to effectively teach/care for child(ren) with FASD is:

Low		Moderate		Great
1	2	3	4	5

5. On a scale of 1-5, my stress level in working with/caring for the child(ren) with FASD is.

No stress		Moderate stress		Maxed out
1	2	3	4	5

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