

KYM CRAWFORD

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EDUCATION of Students with Fetal Alcohol Spectrum Disorder.

Prepared by;

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Signed

Dated 26/09/2008

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Table of Contents

Acknowledgements.....	5
Introduction	6
Project Description.....	7
Executive Summary.....	8
Program	9
What is Fetal Alcohol Spectrum Disorder?	11
Diagnosis	14
Education.....	17
Overview	17
Attention Deficit Hyperactivity Disorder and Fetal Alcohol Spectrum Disorder.	18
Post Traumatic Stress Disorder and Fetal Alcohol Spectrum Disorder.....	19
Best Practise and Research.....	19
Relationships.....	20
Structure and routines.....	21
Sensory Processing	21
Students with FASD and an Intellectual Disability.....	22
Eligibility for Special Education Services.....	23
Placement of Students with FASD	23
Specialist Classes	23
Program Features	25
Whole School Change	27
Regular Classes.....	29
Winnipeg	29
British Columbia First Nation Schools.....	31
Resources for Educators.....	33
Utilising Resources and Knowledge in your own Context.....	33
Building the capacity of educators.....	34
Presentations and lectures.....	34
Conferences.....	35
On line Learning.....	36
Tertiary Qualifications in FASD.....	37
A Resource for Schools working with Parents	37
Supporting Families impacted by FASD	38
Overview	38
Winnipeg	38
Interagency FASD Program, Winnipeg.....	39

Structured For Success Program. Northern Health, Prince George, British Columbia.	39
Whitecrow Village.....	40
Lakes District Campus of College of New Caledonia. Burns Lake, British Columbia.....	42
Healthier Babies-Brighter Futures, A FASD prevention program.....	43
Focus Employment Program.....	43
Community Day-care	44
Early Intervention and Community Therapy Services	45
Kids Edge: Support and Advocacy for Vibrant Youth, (SAVY).....	45
Capacity Building of Others.....	45
British Columbia Ministry of Children and Family Developments Key Worker and Parent to Parent Support Programs.....	45
Indigenous Families	47
Resources for working with and supporting First Nations People:	49
Conclusion	50
Education Recommendations	51
Appendix	52
Bibliography	55

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Introduction

The damaging effects of *in utero* alcohol exposure are beginning to be researched and reported in Australia.

As an educator I have worked with families who have experienced the extreme difficulties of raising children who have been exposed prenatally to alcohol. The needs of the children have been great. They are often the neediest and most challenging children in our schools. They have often presented the greatest challenge to myself and colleagues who have endeavoured to teach them in the past with our standard education toolkit. The toolkit didn't work particularly well. The children didn't learn well and make the academic and social gains we expected.

We realised we needed to do things differently. Supportive parents and staff saw the beginnings of my exploration of what will make a difference to the educational and life outcomes of a child exposed *in utero* to alcohol.

The parents I have worked with have all wanted what is best for their child.

I hope as you read this your understanding and knowledge grows of what life is like for a person with Fetal Alcohol Spectrum Disorder and their families.

Project Description

The Churchill Fellowship was undertaken to gain knowledge about the best practises in educating children with a Fetal Alcohol Spectrum Disorder (FASD).

This included learning more about how students who may have FASD are educated in Western Canada.

I have investigated ways that we can build the capacity of educators to successfully work with students who may have FASD.

I have located and reviewed many resources which I'll be endeavouring to share with others to assist them to build their knowledge.

Most importantly, the project has involved learning the best ways to collaborate with families to build their capacity to assist their children achieve success. I was able to spend time learning how other non education service providers work with families affected by FASD.

I sought guidance and information from Canadian First Nations people and others who worked closely with Indigenous families, to learn more of how to work with understanding and respect with Indigenous families and FASD.

I hope my report will provide encouragement and motivation to others to learn more about FASD and to begin to make changes that will mean a more positive future for many Australians.

Executive Summary

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Project Description

- Build knowledge about the best practises in educating students with a Fetal Alcohol Spectrum Disorder (FASD).
- Learn how to develop the capacity of educators to work with students with FASD.
- Learn how we can best work with families impacted by FASD.

Highlights

- Meeting people whose work I'd read and finding them extremely willing to share their knowledge and experiences with me. They were incredibly helpful, exceptionally humble and were themselves very keen to learn about the progress Australia is making towards addressing the complex issues surrounding FASD.
- Seeing practical examples of successful education and family programs.

Conclusions

- There is a pressing need for identification of FASD so that cross agency planning and intervention processes can be implemented for children and adults with FASD.
- We need to consider how children and adults with FASD can access appropriate lifelong support to enable their needs to be met. We need to implement this.
- The capacity of educators and professionals in other service provider areas, (disability, health, justice, welfare) needs to be developed to effectively work with children 0-18, with FASD.
- Education programs and environments need to be adapted to meet students with FASD's needs. Adjustments to the curriculum to be inclusive of best practises relating to structure, routines and sensory adaptations.
- Schools, families and communities working together with strong support from the government will be key to moving forward in addressing FASD issues.

Implementation and Dissemination

The knowledge gained from the Churchill Fellowship will be implemented and disseminated through the following means:

- In my role as Principal of Karratha Education Support Centre, where I am responsible for leading and providing educational provision for students including some with FASD.
- In discussions with key Department of Education and Training of Western Australia personnel.
- In professional learning programs implemented by various Districts and Directorates: Inclusive Education and Aboriginal Directorates of the Department of Education and Training.
- Through my membership of the Western Australian Education Support Administrators, the Australian Special Education Principal Associations and The Dare to Lead Coalition I will promote and discuss best practises in FASD education.
- Through presenting my findings at the Department of Communities event to mark the International Day for the Eradication of Poverty.
- Through distribution of the present paper to education colleagues and to the broader community.

Program

Date	Name	Position Institution or organisation
May 21-24		Canada Northwest FASD Partnership Conference. http://www.cnFASDpartnership.ca/
May 22 plus in Winnipeg	Janet Thompson and Dorothy Schwab	Conference session: A Model for Educating Children with FASD.
May 22	Carman Rasmussen and Olivia Lestideau	Conference Session: Brain Imaging and Executive functioning in children with FASD.
May 22	Dr Sterling Clarren	Conference Session: The diagnoses of FASD: Where we are and where we need to be.
May 23	Myles Himmelreich	Conference session: Having FASD.
May 23	Drs D and V Massey and Dr J Pei	Conference session: Neurocognitive performance of Individuals with FASD across the lifespan: Executive functions, Memory and Learning.
May 23	Dorothy Schwab, Shelley Proven and Brenda Fjeldsted	Conference session: Strengthening Circles of Support, Before, During and after diagnosis.
May 23	Catherine Walker and Marnie Pearce	Conference session: What's worth fighting for: how to advocate effectively for school success.
May 24	Dwayne Souveny	Workshop: Embrace your beliefs-Release our potential.
May 24 and September 13	Sue Patterson	FASD specialist, Calgary Board of Education, Calgary, Alberta. Meeting and telephone interview.
May 26	Catherine Walker	Senior Resource Manager, Learning and Teaching Resources Branch, Alberta Education, Edmonton, Alberta.
May 27	Evelyn Good Striker	Director, First Nations, Metis and Inuit Services, Alberta Education, Edmonton, Alberta.
May 27	Maureen Yates-Millions	Principal, Amiskwaciy Academy, Edmonton, Alberta. http://amiskwaciy.epsb.net/home/index.html
May 27	Gerry Wright	Safe Communities Leader, Edmonton, Alberta.
May 27	Sandra Roberts	Safe Communities Leader, Edmonton, Alberta.
May 29	Kathi Hughes, Stacey Wakabayashi	Educators, POPFASD, Provincial Outreach Program for Fetal Alcohol Spectrum Disorder, Prince George, BC. http://www.FASDoutreach.ca/
May 29	Dr Cindy Hardy	University of Northern British Columbia, Prince George, BC.
May 29	Rob Crobar	Teacher, Connections Program, Centre for Learning alternatives, SD57, Prince George, BC. http://cla.demo.sd57.bc.ca/index.php?id=1563
May 30	Craig Brennan	Vice Principal, Carney Hill Elementary School, SD57, Prince George, BC.
May 30	Elle Ambrosi and Karla Carr	CDBC Key Workers, Northern Family Health Society, Prince George, BC. http://www.nfhs-pg.org/
May 30	Tricia Wright	CAPC Program coordinator, "Healthiest Babies Possible", Northern Family Health Society, Prince George, BC.
May 30	Chrissie Gertzen	Program Manager, Structured for Success Program, Northern Health, Prince George, BC.
June 2, 3, 4	Anne Guarasci	Family Programs & Training Coordinator, CNC Lakes District-Burns Lake, BC. http://www.cnc.bc.ca/Campuses/Lakes_District_Campus.htm
June 2, 3, 4	Joan Conlon Corrine Swensson	Support Workers, Healthy Babies, Brighter Futures Programme, CNC Lakes District-Burns Lake, BC.
June 2, 3, 4	Sandy Haskett	Occupational Therapist, CNC Lakes District-Burns Lake, BC.
June 2, 3, 4	Ken Peters Barbara Hagreen	Program Coordinator and Assistant, Focus Employment Program, CNC Lakes district-Burns Lake, BC.
June 2, 3, 4	Wanda Giesbrecht	Coordinator, Day care, CNC Lakes District-Burns Lake, BC.
June 2, 3, 4	Waneta Nealis	Instructor, Adult education class, CNC Lakes district-Burns Lake, BC.

June 2, 3, 4	Helen Cunningham	ECE Worker and Foster parent of children with FASD. CNC Lakes district-Burns Lake, BC.
June 2, 3, 4	Barb Martens	Student, CNC Lakes district-Burns Lake, BC.
June 5	Dr Deborah Rutman Carol Hubberstey Sharon Hume	Research Initiative for Social Change Unit School of Social Work, University of Victoria, Victoria, BC.
June 5	Jennifer Phipps	Teacher in Charge Youth Custody Centre, Victoria, BC.
June 6	Bill Standeven	Educator, Accountability Department, Diversity and Equity Unit, Ministry of Education, BC.
June 9,10	Kee Warner	Director, Whitecrow Village, Nanaimo, BC. http://www.whitecrowvillage.org/
June 9	Jennifer-Leigh Gould	Program Director, Whitecrow Village, Nanaimo, BC.
June 10	Ron Jorgenson	Educator, Port Alberni, Vancouver Island, BC. Phone interview and correspondence.
June 11	Sharon Lund	Program Supervisor, Alderwood Family Development Centre, Vancouver, BC. www.childrens-foundation.org
June 11	Jag McMillan	Key Worker, Parent Support Program, Alderwood Family Development Centre, Vancouver, BC.
June 11	John Gotowiec	Coordinator, West Coast Alternate, Pacific Community Resources, Vancouver, BC. www.pcrs.ca/Content/Program%20Pages/Youth%20Services/SSST/SSST%20Home.asp
June 11	James George	FASD Change Manager, FASD Collaboration Roundtables, Vancouver/Surrey, BC.
June 12	Dr Elizabeth Bredberg	Education Consultant, Sunny Hill Health Centre for Children, Vancouver, BC.
June 12	Dr Sterling Clarren	CEO and Scientific Director, Canada and Northwest FASD Research Network, Vancouver, BC.
June 12	Dr Sandra Clarren	Educator and Psychologist.
June 13	Jan Lutke	Clinical Research Manager, Canada Centre for Community Child Health Research, Vancouver, BC. www.FASDconnections.ca
June 16	Bev Wahl Deb Thordarson	Principal and staff. David Livingstone School, SD1, Winnipeg, Manitoba.
June 17	Shelley Proven	Clinic for Alcohol and Drug Exposed Children, Winnipeg, Manitoba.
June 17	Dorothy Schwab	FASD specialist, Winnipeg, Manitoba.
June 18	Brenda Pundyk and staff	Principal and staff. Shaunessy Park School, SD1, Winnipeg, Manitoba.
June 19	Anita Posaluko Betty Wiebe Hosein	Program Counsellors, Interagency FASD Program, Winnipeg, Manitoba.
June 20	Dr Susan Astley	Director, University of Washington FAS Diagnostic and Prevention Network Clinic, Seattle. Washington State. http://depts.washington.edu/FASDpn/index.htm
June 25	Dr Jim Luetzgen	Senior Consultant, Children and Youth with Special Needs Policy, BC Ministry of Children and Family Development, BC. Phone Interview
June 25, August 7	Deb Evensen	FASD Educator and Director, Fetal Alcohol Network on the Yukon (FASSY), Yukon. Phone Interview and ongoing correspondence
June 23, 26, 27, 28	Diane Malbin	Director, Fetal Alcohol Syndrome Consultation, Education and Training Services, Inc. Portland, Oregon. 3 day course and meeting. http://www.fascets.org/index.html
September 10	Madeline Price	Special Education Consultant, First Nations Education Steering Committee (FNESC) www.fnesc.ca First Nations Schools Association (FNSA) www.fnsa.ca Phone Interview and correspondence
September 13	Stan Dyck	District Behaviour Specialist, Surrey School District, BC. Phone Interview and correspondence.

What is Fetal Alcohol Spectrum Disorder?

Fetal Alcohol Spectrum Disorder (FASD) is a term that describes a wide range of effects that can occur in an individual who was exposed to alcohol in pregnancy. (Chudley C. C., Fetal alcohol spectrum disorder:Canadian Guidelines for Diagnosis, 2005)

Fetal Alcohol Spectrum Disorders occur as a result of the effect of alcohol, a teratogen, on the fetus. **Alcohol freely crosses the placenta and can damage any developing fetal cells.** The fetal brain is vulnerable to damage during the entire nine months of development. The changes in brain development are permanent.

The effects can include physical, behavioural, emotional and cognitive disabilities that last throughout the lifespan.

FASD is an umbrella term under which specific medical diagnosis can be made. The term FASD is not a diagnostic term and includes the following diagnoses:

- Fetal Alcohol Syndrome (FAS)
- Partial Fetal Alcohol Syndrome (pFAS)
- Alcohol Related Neurodevelopment Disorder (ARND)
- Alcohol Related Birth Defects (ARBD)

In the USA and Canada diagnosis is made by a multidisciplinary assessment team typically consisting of physician, psychologist, occupational therapist, speech therapist, social worker and family advocate.

In Australia in 2008 we do not have capacity to diagnose Fetal Alcohol Spectrum Disorders through a multidisciplinary assessment.

The establishment of FASD diagnostic clinics in Australia and the use of the University of Washington Diagnostic Code were discussed at a National FASD workshop (supported by the Department of Health and Ageing and the intergovernmental committee on drugs FASD working party) in August 2008. Recommendations from this workshop will be published.

For more information on the diagnostic process see:

- Canadian Guidelines' for Diagnosis. (Chudley C. C., Fetal alcohol spectrum disorder:Canadian Guidelines for Diagnosis, 2005)
- University of Washington's 4-digit Diagnostic Code. (Washington)

The incidence of FAS in the United States of America (USA) has been reported as 1–3 per 1000 live births. (Sampson PD, 1997)

The Canadian guidelines for diagnosis cite the estimate from the United States of the rate of FASD as 1 in 100 live births or 1%. (Chudley C. C., Fetal alcohol spectrum disorder:Canadian Guidelines for Diagnosis, 2005)

"Behind FASD..."

Call them root causes, life conditions and experiences or determinants of health ... they are the factors that set the stage for women's use of alcohol during pregnancy. Factors that contribute to women drinking during pregnancy include, among others:

- Family violence - physical, psychological or sexual abuse
- Poverty, unemployment and homelessness
- Stress, and lack of knowledge of strategies for coping with stress
- *Role of alcohol in society*
- *Social pressures* to drink alcohol and *poor role models* for some women
- *Low self-esteem* and social isolation faced by some women
- *Poor knowledge about the impact of alcohol* - many people don't know that even small amounts of alcohol consumed during pregnancy can affect the developing fetus.

Clearly, women have an important role in preventing FASD. What is equally important, and not as clear to many, is that family, community, governments and society have a vital role in understanding and dealing with the root causes of women's use of alcohol during pregnancy". (Public Health Agency of Canada, 2005)

The Australian paediatric surveillance unit has identified the Australian FAS rate per annum was 0.58 per 10⁵ children aged <15 years or 1.14 per 10⁵ children aged <5 years, but have indicated they believe the incidence of FAS is underestimated in Australia (E J Elliott, 2008) as under diagnosis of FAS by paediatricians is suspected.

In 2008, in further Australian research it stated that “It is likely that many affected children with FAS, ARBD and ARND will never receive a diagnosis.” (Elliott, 2008)

There were 265,900 births registered in Australia in 2006. (Statistics, 2007)

We could anticipate an incidence of

- FAS-(1 to 3 per 1000 live births) = 265 to 797 births.
- FASD-(1 per 100 live births) = 2659 births.

It has been recognised in Canada that FASD is a leading cause of preventable brain damage and developmental delay.

The draft National Health and Medical Research Council Australian alcohol guidelines for low-risk drinking (2008), recommend that **no drinking in pregnancy** is the safest option.

Fetal Alcohol Syndrome (FAS). A child with FAS will have confirmed prenatal alcohol exposure, a set of characteristic facial features, central nervous system dysfunction and growth restriction.

Alberta Education provides the following explanation for educators of other FASD terms:

Partial Fetal Alcohol Syndrome (pFAS) indicates confirmed maternal alcohol exposure. A child with pFAS exhibits some, but not all of the physical signs of FAS, and has learning and behavioural difficulties which imply central nervous system damage.

Alcohol related birth defects (ARBD). A child with ARBD displays specific physical anomalies resulting from confirmed prenatal alcohol exposure. They may include heart, skeletal, vision, hearing and fine/gross motor problems.

Alcohol Related Neurodevelopmental Disorder (ARND). A child with ARND exhibits central nervous system damage resulting from confirmed prenatal alcohol exposure. This may be demonstrated as learning difficulties, poor impulse control, poor social skills, and problems with memory, attention and judgement.

It is important to note that:

- Neurological damage can be seen in individuals with FAS, pFAS, ARND and ARBD.

“Consider, as well, the following information about the birth mothers of children with FASD:

- Some are social drinkers.
- Some are alcoholics.
- A great many have FASD themselves.
- Many are survivors of some form of abuse.
- Many of those are survivors of sexual abuse.”

(Yukon Department of Education, 2006)

- Individuals with pFAS and ARND may be at greater risk because they do not have physical signs of FAS and are less likely to be diagnosed and have appropriate supports.
- **Individuals with pFAS and ARND and pFAS may have significant brain damage but the only identified signs without multidisciplinary assessment, may be behavioural difficulties.**

Terminology

In Canada and USA the conditions of FASD were always referred to by the initials of the term. FAS was always referred to by the letter names 'F' 'A' 'S' not FAS as one word. Likewise FASD was referred to by the letter names 'F' 'A' 'S' 'D' not the word FAS 'D'.

A Provincial Plan for British Columbia 2008-2018

“Cross-government Strategic Objectives

- British Columbians are aware of the risk of alcohol and substance use in pregnancy and of FASD as a lifelong disability.
- All women of childbearing age and their partners and support systems have access to early support and follow up.
- All pregnant women and mothers experiencing substance use problems, and their partners and support systems have access to focused intervention and support.
- Children, youth and adults living with FASD have access to timely diagnosis and assessment.
- Children, youth and adults living with FASD and their families and support networks have access to comprehensive and lifelong intervention and support.
- Service systems are coherent, integrated and coordinated, and benefit from strong research and evaluation.”

(Ministry of Children and Family Development, 2008)

It is estimated that one in 160 children will have an Autism Spectrum Disorder.

The estimated incidence of FASD is 1 in 100 live births.

Diagnosis

As a special educator I knew I needed to make some adaptations to maximise learning for students who were diagnosed with a specific disability.

Prior to the Churchill Fellowship, working with students with FASD and engaging in relevant professional learning highlighted the tremendous need to ensure my educational practises were adapted to meet the needs of students with FASD. Otherwise these students were not very successful in life.

Once I became aware of FASD around 2000, like many educators I have spoken to in Canada and the USA I reflected that some of the very challenging students I had previously taught could possibly have a condition on the FASD spectrum. It was then looking at the life outcomes for these students that I realised many of the secondary disabilities identified by Streissguth, (1996) had in fact already occurred in these children. Many had left school early, not found employment, became involved in the juvenile justice system and were using alcohol and drugs. It was this salient realisation that what I had done previously hadn't been particularly successful for many of these students.

From this I realised that I, along with other educators and the families and communities that surround these children, would indeed have to do things differently, if we wanted success for these students.

I consider that diagnosis would be a vital first step forward towards improving educational outcomes and preventing secondary disabilities for these children.

Diagnosing these children would mean that I and other educators would view the children as having a neurobehavioural brain injury and that we would teach in a more supportive and appropriate style.

Diagnosis will mean that the government and non government agencies that support children and families in our communities will view these children as having a neurobehavioural brain injury so they will adapt their practises to be more supportive.

A multidisciplinary diagnosis that investigates the child's language, learning, and sensory characteristics, will provide teachers with an understanding of the particularities of the spectrum disorder and enable realistic and effective programming that builds on the student's strengths while accommodating his/her areas of weakness.

Whilst overseas on the Churchill Fellowship I met with FASD experts, Sterling and Sandra Clarren and attended FASD diagnostic clinics and learnt much more about why a diagnosis is important for the birth mothers, families, carers, individuals and what diagnosis means for educators and schools.

Australian Birth Mother

“So while doctors are right in their belief that the obvious affect of diagnosing FASD in a child would be a tremendous disturbance to the family-it is a responsible disturbance, and one which they must be prepared to make. I would have given my life to know about Fetal Alcohol Syndrome before Seth was six. A diagnosis prior to age six can mitigate some of the secondary disabilities in affected children.”

(Russell, 2005)

Why diagnose

- **Early diagnosis is a protective factor associated with fewer secondary disabilities (Streissguth et al., 1996).**
- **Diagnosis assists families and the person with FASD understand their behaviours in terms of neurological damage, and not that they are wilfully misbehaving.**
- **A diagnosis helps parents and caregivers set realistic and appropriate expectations for their child.**
- **Diagnosis can be a dual diagnosis of child and birth mother. The birth mother may be able to receive counselling from this point.**
- **Diagnosis of one child may mean successful intervention with the mother to prevent the birth of another child with FASD.**

Diagnosis involves a multidisciplinary team assessment which provides considerable quality information about the individual; it identifies areas of strength and challenges in the person's brain functioning.

The specific information provided at the point of diagnosis along with knowledge of FASD as a brain based disability makes effective interventions and support possible. This makes a significant difference to the life outcomes of the individual with FASD.

Within a school setting diagnosis provides educators with more specific knowledge from which to effectively plan for the students. Likewise this knowledge allows improved supports across the life span for the individual. The supports each person needs as they grow older will continue to change, but when the interventions fit the disability a much better match happens. Multidisciplinary diagnosis provides quality information about the person's disability.

Diagnostic clinics are located throughout Canada and the USA. I visited the Clinic for Alcohol and Drug Exposed Children (CADEC) in Winnipeg that has operated since 1999. It has developed the capacity to do remote diagnosis with other communities in the province through the use of the Telehealth Network, and video conferencing. A journal article about Telemedicine Diagnosis in Manitoba is available at www.cmaj.ca/cgi/content/full/172/5_suppl/S1

I visited the University of Washington FAS Diagnostic and Prevention Network Clinic which has pioneered FASD diagnosis. Of note here is the screening program to identify children with FAS that are placed in foster care. Since 1999 children coming in to long term foster care in Washington State are screened for FAS.

Numerous professionals I met advocated the benefits of the establishment of local diagnostic teams in regional communities. The service is considerably easier for families to access.

Australian Research;

"..early diagnosis allows for prevention within families. A salutary finding in our study was that where information was available, 51% of cases were reported to have a sibling with FAS, indicating missed opportunities for prevention. (E J Elliott, 2008).

Diagnosis is beneficial for the individual professionals in the regional diagnostics teams. Members get to build their own knowledge of FASD and to learn from diagnosis and the recommendations they make. They are more easily able to see the results of the recommendations as they continue to see the individual over their life span. This is particularly important as the area of FASD is a relatively new one and professionals involved are still gaining knowledge. Professionals I met indicated the current body of knowledge is dynamic and growing from the experiences of practitioners in the field.

After assessment, an educator, or a person very experienced in education and in interpreting the results of the FASD assessments has an important role in developing appropriate supports for the student at school. They will explain about FASD as a brain based disability and interpret the diagnostic results to the class teachers. They will work with the teachers' and education assistants' to develop appropriate strategic interventions suited to the student.

Liz Bredberg, who has this role, provided additional insight.

"It is critically important that this person, become at least to some extent, familiar with the school and the community of origin of the child. Programming should reflect both the diagnostic findings and the community and culture of the child. Schools vary in the particular strengths that they can bring to bear to support a student with a FASD diagnosis and it is critically important to integrate both the diagnosis and the schools' capacities to support the student."

A diagnosis helps parents and caregivers set realistic and appropriate expectations for their child.

Education

Overview

Around 75% of school aged children who have a Fetal Alcohol Spectrum Disorder (FASD) do not have an intellectual disability but will have specific neurological damage that will make learning and managing their behaviour at school challenging. There is the possibility of a range of other birth defects or physical disabilities. However, it is the specific brain damage that has considerable impact on their success at school and in adulthood.

Children with FASD have complex learning difficulties, behavioural challenges and difficulties understanding and expressing language.

There are characteristics in the behaviour and learning profiles of people with FASD that are very similar but there are significant differences as the degree and timing of the prenatal alcohol exposure, family genetics, nutrition and life experiences all influence the individuals development.

Primary disabilities associated with FASD as a result of “Brain Function deficits may include:

- **Neurological impairment:** The I.Q. may vary from well below average to above average.
- **Information processing deficit:** This results in gaps and inconsistencies in understanding, sequencing, and auditory processing of information.
- **Memory and attention deficit:** this results in spotty or faulty memory and limited attention span.
- **ADHD Behaviours:** It is estimated that 80 percent of children with FASD demonstrate hyperactivity.
- **Delay or dysfunction of language skills:** This may result in limited vocabulary and comprehension, problems with clarity of speech or speech impairment.
- **Other deficits/delayed development:** The result may be late walking, late talking, tremors, or problems with balance, coordination, and fine motor skills

Adapted from (Yukon Department of Education, 2006)

For more detailed information on profiles of students with FASD refer to Alberta Learning (Alberta Learning, 2004) pp10-14.

Secondary Disabilities associated with FASD may develop over time as there is often a real discrepancy between expectations for a person with FASD and their ability to perform. One researcher, Striessguth (1997) noted that adolescents and adults with FASD often experience secondary disabilities, or emotional and societal problems related to their difficulty managing typical expectations. Secondary disabilities that were identified included: Mental health problems,

“Only a fraction of affected children present with identifiable facial features. Most children’s impairments are invisible, but they are profoundly challenged, especially in areas of social skills and common sense. These are the children who “pass the tests but fail life”

“Dr Ab Chudley,
(Healthy Child
Manitoba, 2007)

disrupted school experiences, trouble with the law, confinement, inappropriate sexual behaviour and alcohol and drug problems.

Canada's provincial ministries of education are beginning to recognise that many more students in a class may be on the FASD spectrum than those with diagnoses.

“Not all children born with FASD are diagnosed, but they all go to school.” (Yukon Department of Education, 2006)

“There may be students in your classroom affected by prenatal exposure to alcohol who may never be diagnosed. It is extremely important that educators are aware of this fact and develop an understanding of this often unrecognized disability.”

(Saskatchewan Institute on Prevention of Handicaps., 2004)

Because of our lower rate of diagnosis in Australia it is highly likely we have many students with FASD currently in our schools. Awareness of FASD is only just emerging in Australia. Education, along with areas such as health, welfare, disability, justice does not have a well developed understanding of FASD and its impact on individuals, families and their communities. Existing policies, structures and strategies across government and non government sectors do not yet recognise FASD and are therefore not as supportive of the FASD population as they could be.

By comparison, students with an Autism Spectrum Disorder and those with Acquired Brain Injury also have significant deficits in their neurological functioning and benefit greatly by government and community awareness, knowledge, funding and positive strategic initiatives.

In the school setting, support provided in Western Australia (WA) by the Department of Education and Training (DET) allows students with Acquired Brain Injury and Autism Spectrum Disorder to be eligible to access “Schools Plus” resourcing, opening gateways for additional Teacher and Education Assistant time based upon their individual level of need across 11 domains. Those students benefit from Teachers and Education Assistants being or becoming knowledgeable and skilled about their disability and to most importantly to implement strategies that will be of assistance in developing each student's varying abilities. Educators have learnt over the past years that they need to make adjustments to the learning environment for a student with Autism Spectrum Disorder or Acquired Brain Injury to learn and develop the skills for success in life.

Attention Deficit Hyperactivity Disorder and Fetal Alcohol Spectrum Disorder.

Many students with FASD also present with ADHD. Estimates are as high as 80% of children with FASD have ADHD.

“Children with FASD do not purposefully choose to go to school and make the same mistakes (academic, behavioural, or social) that they have been making for some time, just to get in trouble or make the teacher angry. They don't want to feel embarrassed or stupid, or become socially isolated. Unfortunately, many children with FASD are treated as though their behaviour is intentional. In reality, they are doing the best they can with the understanding they have.

Now consider yourself in the classroom with a student who is not progressing. You may feel frustrated. You may feel inadequate as a teacher. Then consider: if the student has FASD, the instructional tools may not be appropriate. Like the student, you may be doing the best you can with the understanding you have.

In both situations, the solution is not for the student or teacher to try harder. They need to try something different.” (Yukon Department of Education,

“Consider the neurological basis of behaviours. It is critical to understand the many behavioural difficulties of students with FASD. While many act in ways that could be considered erratic and irresponsible, their behavioural difficulties may be due to memory problems, an inability to problem solve effectively or the tendency to become overwhelmed with stimulation—all factors related to neurological damage associated with prenatal alcohol exposure.” (Alberta Learning, 2004)

It is worth considering the insightful information of Dr Kieran O'Malley an Irish Psychiatrist who worked in Canada and Seattle for many years. His work on ADHD, early brain development, Complex Post Traumatic Stress Disorder in relation to FASD was consistently referred to whilst I was on the Churchill Fellowship.

"FASD are the true clinical masqueraders' and ADHD is their most likely disguise".

"The commonest clinical presentation of patients of whatever age was a picture most aptly described by ADHD".

"The ADHD resulting from prenatal alcohol exposure is an acquired form of brain injury."

"The FASD population may also come from chaotic, violent backgrounds, but they may also not come from these backgrounds. Their ADHD - like behaviors may, in fact, directly reflect the effect of neurotoxic brain damage on the developing central nervous system." (K.D.O'Malley, 2007)

Post Traumatic Stress Disorder and Fetal Alcohol Spectrum Disorder.

For some children and adults living with FASD their life experiences have contributed to high levels of stress. These environmental factors compound the difficulties of living with FASD. It has increasingly been realised that some within the FASD population are experiencing high levels of stress commensurate with Post Traumatic Stress Disorder. This was inclusive of children. Educators and service providers need to consider this in all interventions.

Best Practise and Research

The use of best practise for teaching students with FASD is vitally important if they are to succeed at school. Success at school is the starting point for success as an adult.

What is regarded by educators as best teaching practise for students with FASD has developed in Canada since the early 1990's. The practises are acknowledged by educators as effective and essential. At this time there have begun a number of research studies which are evaluating the success of specific practises.

Louise Nadeau the Chairperson of the Canadian Foundation on Fetal Alcohol Research in her address at the 2007 Research Roundtable on the establishment of the Canadian Research Foundation stated:

"It's really, really key that in a country like ours we do not blame people for disabilities, but on the contrary we help and helping means finding what is the most effective enabling strategy.

Understanding is one thing, having an effective intervention is the key.....Understanding is one thing, doing the best thing available is

"FASD are the true clinical masqueraders' and ADHD is their most likely disguise"

(K.D.O'Malley, 2007)

where we need to go.....What research is about is doing the best thing to be most effective and only research can do that, and that's why we are here."

The Center for Disease Control and Prevention in the USA recognises that interventions for children with FAS/ARND, "lack scientific evaluation or validation". They are working with researchers to identify, develop, and evaluate effective strategies for intervening with children with FAS/ARND and their families. (Department for Health and Human Services).

The key question of the Fellowship was to investigate effective teaching practises. Each FASD educator I met was asked the question of "What makes a difference to a child with a Fetal Alcohol Spectrum Disorder, success at school." The replies were very similar.

The first was the absolute need to establish a *positive relationship* between teacher and student.

The second: Educators, who successfully engaged and taught students with FASD, articulated that viewing the child and their learning styles and behaviours as a result of specific brain damage, helped them. They then viewed what they saw at school within a context of a *brain based disability* and this significantly altered how they supported the student.

They all spoke of the need for huge levels of *structure and routine* in the student's daily life and of the need for *adapting the sensory environment*.

Education manuals on FASD produced in Canada provide excellent information about these key factors. The written material matches what experienced educators were advising me and what I observed to be working in classrooms.

I will provide only a brief overview in this report as what has been written in manuals is both easily accessible and of a very high standard.

Relationships

A positive relationship between the teacher and student was seen as a key factor for success at school. In many ways it was a bottom line that had to be met. If the teacher and student didn't have a positive relationship, engagement in the learning process wouldn't happen. Teachers said when this relationship didn't exist they had very little impact on the student. Once established they were able to work with the student. In the section of this report on working with Indigenous families this factor for success is extended to include the educator's respectful relationship with the students' family as being of equal importance.

Center for Disease Control and Prevention study with University of Washington

"University of Washington—Seattle, Washington.

The purpose of this project is to explore two intervention models for school-age children. One consists of an individualized, supportive, behavioral consultation intervention for school-age children (aged 5 through 11 years) with FAS or ARND. Consultation includes FAS education, emotional/practical support, teaching child management strategies specific to children with FAS/ ARND, advocacy assistance, and school consultation. The second intervention is a school-based social communication intervention provided directly to children with FAS/ARND. This intervention targets critical deficits in social communication and peer relations and is designed to teach children (aged 8 through 12 years) how to use an interactive checklist to guide them through resolution of peer conflicts. An intervention and a control group will be compared using pre- and post-test measures, with post-tests occurring at the conclusion of the intervention and at a 9 month follow-up." (Department for Health and Human Services)

Structure and routines

Changes to any aspect of a school or home routine may present the student with FASD with major challenges. Sometimes very small subtle changes can cause anxiety and be a trigger for negative behaviour or simply the student becoming confused with what is expected. An inability to generalise learning means these students may not be able to figure out what will be the next piece of the event, activity or day. Poor memory contributes to this.

Some adjustments:

- Put structure in place to allow the student to move step by step through their learning using schedules and timetables,
- Prepare students for changes to their day: use visual schedules and remind them of changes. When changes occur, be certain not only to explain change, but also what will remain the same. This can be at the level of, “We’re going to the park today instead of gym. We’ll go to gym tomorrow like we usually do.” (With illustrations.), or “We’re moving Norbert’s desk, but the bathroom will still be where it always was.” (And walk Norbert through this)
- Teach classroom routines through direct instruction and practise: e.g. coming in to the classroom, using unstructured time, requesting teacher attention for doing everyday tasks.

Sensory Processing

Sensory Processing Disorder is a complex disorder of the brain that affects many students with FASD.

“Students who are alcohol-affected often experience difficulties in processing the different sensory information they receive... For most individuals, the processing of sensory information is automatic. Most individuals can screen, filter, and selectively attend to different sensory information. However, children who are alcohol-affected often have difficulty with these processes. They may be over-responsive to some forms of sensory input and under-responsive to others. They may become overloaded by the sensory information they receive and, as a result, are unable to organize their behaviour. (Manitoba Education, Training and Youth, 2002)

Classrooms can be overwhelming for students as there is much to see, to hear, to feel, to smell. This is particularly so when there are lots of colourful displays on walls or from ceilings, open shelving and crowded tabletops. This can affect their sense of calm, their ability to organise themselves and to process information the teacher presents. Students appear disorganised, confused, upset, shut down or out of control. Teachers can easily misinterpret these behaviours as hyperactive, defiant, and aggressive. In fact it is their nervous systems having difficulty making sense out of their world. Occupational Therapists have had a role in assisting educators to

For a person who can see similarities and differences easily, minor changes may hardly seem significant; for the student with FASD, change may present major problems. For example, an educator may decide to change the classroom routine one day and not understand why the student with FASD seems so anxious. The ability to generalize information from one setting to another requires what Jan Lutke, an FASD specialist from British Columbia, calls “moveable parts in the thinking process.” Students with FASD are highly rigid thinkers. Without the ability to generalize learning, these students may be unable to figure out what will happen next when one piece of the daily schedule is changed. The key to helping students with FASD cope with change is to create structure and routine that accommodate their learning differences.”

(Yukon Department of Education.

understand how to accommodate the needs of students with FASD who have sensory processing difficulties.

All FASD education manuals have excellent information on addressing sensory processing difficulties. Educators considered environmental adaptations a key factor that needs to be included in planning for a student. Some educators included space for the environmental adaptations to be listed in the students Individual Education Plan documentation.

The effects of the environment can have a very significant effect on a student with FASDs' behaviour. **It needs to be considered when analysing a student's behaviour and developing management strategies.**

Some adjustments:

- Environmental adaptations to create a calm and quiet learning environment.
- A quiet place for individual seatwork.
- Less visual items etc in a room are best. Reduce amount of information on walls, store resources in cupboards or behind fabric to reduce visual clutter.
- A safe quiet place or calming space should be available for the student to retreat to, calm and organise themselves.
- Provide structure and routine.
- Deep pressure and large muscle activities can be calming. Activities like: carrying heavy items such as books, pulling and pushing carts with added weight, pounding and rolling play dough, hanging from monkey bars, obstacle courses.
- Movement and activities like walking, running, swinging and using scooter boards, therapy balls and slides.

Students with FASD and an Intellectual Disability.

"..Prenatal alcohol exposure, and the resulting FASD, is recognized as the commonest preventable cause of intellectual disability."
(K.D.O'Malley, 2007)

Students with FASD and an Intellectual Disability make up around 25% of people with a FASD diagnosis. It is likely that many students already with a diagnosis of Intellectual Disability could also in fact be on the FASD spectrum. If 1 in 100 students could be affected by FASD then we could estimate approximately 1 in 400 students to have an Intellectual Disability and a Fetal Alcohol Spectrum Disorder.

Educators working with the group of students with both an Intellectual disability and FASD indicated that the same FASD strategies were needed but the student would need even more repetition and support to achieve success. They indicted many of the programs implemented with students with both Autism and an Intellectual

"..Prenatal alcohol exposure, and the resulting FASD, is recognized as the commonest preventable cause of intellectual disability."

(K.D.O'Malley, 2007)

Disability would be suitable. The structure of these programs would suit the students' needs.

Eligibility for Special Education Services

British Columbia has expanded their eligibility for special education to include those with a FASD diagnosis exhibiting an array of complex needs with two or more domains being impacted. They have included FASD in the Special Needs category E.8 Physical Disabilities or Chronic Health Impairments. (Ministry of Education. BC)
www.bced.gov.bc.ca/specialed/ppandg/planning_8.htm

Alberta Education has included funding for students with severe FASD under the category SEVERE PHYSICAL OR MEDICAL DISABILITY (Code 44). A diagnosis of FASD along with significant impairment in functioning levels is required. (Alberta Education, 2007 2008)
www.education.alberta.ca/media/841679/hdbk_severedisabilities_2008-2009.pdf

Currently students enrolled with the Western Australian Department of Education and Training who have an Intellectual Disability or one of seven other indicated groups are able to access the gateways to additional support. A FASD diagnosis is not an indicated group.

We need to consider the inclusion of FASD as a gateway for additional support to better meet these student's needs.
Inclusion of FASD as a separate indicated group with 'Schools Plus' needs to be investigated.

Placement of Students with FASD

In Western Canada there has been a policy of inclusion for many years. Most students with disabilities, FASD included, are in mainstream classes.

However, where students have severely challenging behaviour they may be in specific classes for this.

Students with FASD, given appropriate programs and adaptations appear to cope a little better in the primary years but there are much greater challenges for all once students' reach adolescence and progress to the high school years.

Specialist Classes

There has been the establishment of some specialist classes for students with FASD in Canada. These are usually the initiative of the local school division and in a few cases they are the result of interagency co operation. I visited some classes and others I learnt about through phone interviews and correspondence.

"Severe Physical or Medical Disability (Code 44)

Special Education Coding Criteria

A funded student with a severe physical, medical or neurological disability is one who:

a) has a medical diagnosis of a physical disability, specific neurological disorder or medical condition which creates a significant impact on the student's ability to function in the school environment (note: some physical or medical disabilities have little or no impact upon the student's ability to function in the school environment); and

b) requires extensive adult assistance and modifications to the education environment in order to benefit from schooling. A student with severe autism (or other severe pervasive developmental disorder) is included in this category.... A student diagnosed with severe fetal alcohol spectrum disorder (FASD) may have fetal alcohol syndrome (FAS) or alcohol-related neurodevelopmental disorder (ARND) and is included in this category. A clinical diagnosis by a psychiatrist, registered psychologist with specialized training, or medical professional specializing in developmental disorders is required. A clinical diagnosis of FASD is not necessarily sufficient to qualify under this category. Eligibility is determined by the functioning level of the student with FASD. Students with severe FASD who exhibit significant impairment in the areas of social functioning, life skills, behaviour, learning, attention and concentration will need extensive intervention and support."

(Education, Alberta)

School Division 1, Winnipeg, Manitoba

In School Division 1 in Winnipeg, Manitoba specialist classes for students with FASD have been operating for over 10 years. David Livingstone School has “The Bridges Program” and Shaunessy Park School has “The Right Program”. They are low enrolment specialist classes within the mainstream school for students who have a FASD diagnosis and present with behaviours that would make it very difficult for them to manage in a regular classroom and so require a specialist setting. Students in these classes do not have an Intellectual Disability. There are six classrooms with eight students in each. A teacher and two education assistants work with each class. When in the classrooms you see the environmental adaptations: the rooms are quiet, organised and visually plain in order to meet the students’ sensory needs and the huge need for calmness, structure and routine that many students with FASD have. The emphasis is on assisting students through the use of proactive supports structures such as visual timetables, social stories and schedules. Underlying all aspects of the teaching program is the understanding that the students have differences in the structure of their brain that will often require different accommodations by the teacher so learning can happen.

Because of the need for information of how best to teach students with FASD, classes such as at David Livingstone receive many visitors.

Port Alberni School District, Vancouver Island, BC

Port Alberni School District in BC supports a number of classrooms specifically for students with FASD. They are typically highly structured environments that support each student’s individual needs. The class for High Schools students have an employment and life skills focus. It was reported that the students in the class continued through most years of High School, they were students who would previously have likely become disengaged from school at a young age. The consistent core classroom throughout high school provided for a stable relationship and a family-like support environment on campus. This supported some students to engage in core area classrooms of the High School while others completed work placements and apprenticing skills in the community leading to School Leaving Certificates (Completion of 12 years in school) or their Dogwood Certificate (Meeting academic standards for Grade 12). For students this class was their home at school for three years and enabled their success.

Key Workers, who focus on students with FASD in the community, in conjunction with the school, have transitioned students into College, more stable housing environments, and supported their negotiating of the community at large. Transitions between settings are a major concern for students with FASD.

“By speaking about their disability with grace, perseverance and courage, the students and teachers of the Bridges FASD Program at David Livingstone Community School demonstrated that they were deserving of the Manitoba Human Rights 2007 Commitment Award. This year the award recognized activities that are advancing human rights by overcoming discrimination based on mental disability. This is the first time that children have been the recipients of the Commitment Award. The students and teachers of the Bridges program host dozens of guests from around the country, and as far away as Australia, each year in their classroom. The students speak articulately about how their disability was caused, and openly about their limitations. They also reveal the many gifts and talents that they possess. Those who have learned about FASD from them have said that their own personal beliefs have been changed. .. Last, but certainly not least, they have completed a two-year project writing and illustrating a book and DVD titled “Jilly’s Story: Living with FASD.” This book is now being published. Schools across the country are taking notice of this program and these amazing students.” (Manitoba Human Rights Commission, 2007)

Surrey School District, British Columbia

Surrey School District in BC is recognising the need of students with FASD with more extreme behaviours and have formed specific classes (FAS-Track) for a small number of these students. Surrey School District has over 66,000 students and had 17 classes across the district for students with severe behaviour issues. The classes had been organised around behaviour practises applicable for students with conduct disorders. They begun to be aware that the classes included some students with FASD and they were aware that the management style suited to the students with Conduct Disorders was not suited to students with FASD. The School District identified the students already in the behaviour classes with FASD and along with some other students with FASD from the mainstream, has turned a few of the original 17 classes for students with behavioural difficulties into classes for students with FASD. The students in the classes do not have an intellectual disability.

The classes are in the Elementary and Junior High areas with plans for a Senior High School Class underway.

- The classes are “low key” with structure and routine.
- Classes have 10-12 students, a teacher, 2 education assistants.
- They do not do typical integration back into mainstream classes as this doesn't work well for this group of students: for example practises like going back into the regular class for a whole class art activity or joining in for group science lessons doesn't often work because the environment isn't conducive to this groups learning style. They have developed alternatives that suit the learning styles better. The student may go back to the mainstream class for a reading lesson that is suited to their ability and is a quieter and more structured lesson.
- The program for older students has a very practical component that includes life skills, skills for independence and job skills.
- They teach to the student's strengths and try to develop these as much as possible. Many students have strength in the arts; music, dance and visual art. Success in these builds self esteem.

The Surrey School District Behaviour specialist, Stan Dyck told of the considerable benefits of having the classes in the district. From the benefits to students in the program to benefits for the whole district.

He told of a student with FASD who had severe behavioural issues requiring regular restraint but when placed in one of the classes, with appropriate environmental adaptations, these behaviours stopped and the most challenging issues now, were to get the student to engage in more reading.

Stan also said that the classes have been invaluable as a leaning tool for staff in the program and for outside staff. The classes have enabled best practices in FASD to be implemented and evaluated on

FAS-Track

Program Features

- Small class size
- Extra staff
- Environmental adaptations
- low stimulus
- calm down zone
- Individualized academic and behavioural program
- Staff training specific to the diagnosis needs
- Class integration into school community
- Minimal student integration into regular class



Photos and text from FAS-Track brochure. Surrey School District

an ongoing basis. Other educators are learning from the educators within the program. This is similar to what I learnt in Winnipeg. The mainstream teachers could actually see the environmental adaptations and strategies working, so began using the same set of strategies and adaptations in their own mainstream classes with students with FASD. Stan has utilised the practical knowledge gained from these classes as an integral part of Professional Learning sessions on FASD presented in the School District.

Like the experiences in Port Alberni they believe the creation of classes for older students with more challenging behaviours associated with FASD is actually keeping these students engaged in school and learning skills for a more positive future.

Prince George School Division, British Columbia

In Prince George, BC I visited a number of alternative education classes that existed around the city. They were co located in community buildings with other community agencies having a major partnership in their operation. They catered for students who were not able to succeed in the regular school system and in many cases had stopped attending. Eligible students had presented with significant social, behavioural and educational challenges in the regular school and the general community environment and had not been previously successful in traditional school settings despite interventions. Through discussion with educators it was apparent that some students in the programs did have a FASD diagnosis and it was suspected that others also had one these conditions, but the diagnostic process had not occurred. The classes were low enrolment classes of 10-12 students. The classes were structured and supportive with the emphasis on behaviour support rather than behaviour management. Teachers had adopted many of the best practises in working with students with FASD. It was apparent the staff had good relationships with students. In the classrooms at one setting I was able to see;

- At the front of the class a clear timetable with lesson blocks and pictures of clocks. The teacher indicated the students use it; they stick to it and rely on it.
- A schedule where positive incentives are built in to the learning program so that students may do 20 minutes work, 10 minutes computer work, 20 minutes work etc
- Desks are separated and spread out so students have plenty of personal space. There existed a range of alternative work areas like study carrels for students to choose to work in if they required it.
- The rooms were not visually crowded so sensory overstimulation was reduced.
- Students had individualised education programmes.
- Teachers repeatedly indicated that it was essential to have good rapport with the students.

Connections

Location: Native Friendship Centre

Age Range: 12 to 13

Philosophy:

The philosophy of Connections is that of behaviour support as opposed to behaviour management. Positive behaviours are taught, modelled, shaped, and cued in conducive environments. There is an attempt to:

- understand the “why” or “function” of the behaviour, and
- to alter the environment to eliminate the need to use that behaviour, and/or
- determine how adults and peers can support the student in using an identified positive replacement behaviour that meets the same or similar need.

Objectives:

The objectives are to:- develop an interagency behaviour support plan that focuses on functional analysis of behaviour and environment, and the teaching of alternate acceptable replacement behaviours. Whenever possible, the plan includes connection to therapy, counselling and/or support for the student and/or family in the community,

- connect children to programs/services available through the Native Friendship Centre and community, depending on their readiness, maturity, and growth,
- develop an Individual Education Plan which takes into account the abilities and needs of the student, and
- create a transition plan for successful entry to programs/services available in a regular secondary setting or another community based alternative program.

From the School Guide
(Centre for Learning
Alternatives. School District 57)

Whole School Change

Some schools across Canada have been attempting to address FASD through whole school changes. One of these is Carney Hill Community School in Prince George, British Columbia.

I visited Carney Hill School. The students come from very low socio economic backgrounds with an identified at-risk population of 79%. The school administration has been endeavouring to improve the educational outcomes for students, many of whom have a FASD diagnosis. Many others students are likely to have been exposed to alcohol prenatally as they exhibit behaviours typical of FASD. A primary focus has been on putting into practise the philosophies around appropriately managing a “Brain-based disability”.

The school-based team (learning assistance, english second language /english as a second dialect (ESL/ESD), counselling, Aboriginal education, administration) identified areas that presented difficulties to large numbers of students and have been addressing these with whole school change. Additionally, smaller target groups have been identified and targeted with specific interventions to bring positive change for individual students and their families.

On the visit to the school I was impressed with the way they had a wide range of services to support students and staff.

The whole staff engaged in ongoing professional learning about FASD. This initially was in the form of training provided by both provincial and local specialists. Ongoing support now comes from the teachers and support workers at the Provincial Outreach Program FASD (POPFASD) located in Prince George. Through an action initiative project involving a yearlong specific case study and ongoing data collection and guided analysis, staff achieved an understanding of what a brain based disability presents as in their classrooms. They now understand that there is a neurodevelopmental injury that affects how the children learn and teachers know they need to put in place a supportive learning environment.

The staff now recognises and demonstrates the need for structure, routine and organisation in the classroom and throughout the school to assist the students in making the connections they need to make in order to be successful. Students with damaged neural pathways need structure as it helps keep the many pieces of a day in order. Further, a calm and uncluttered learning environment reduces their stress and anxiety resulting in pro-social behaviour.

Specifically:

- Events in a day are planned for and changes are minimised.
- Classes have clear visual timetables so students know what's happening next.
- Items in a classroom are kept organised. Items not in use are put away to reduce visual distractions

A calm and uncluttered learning environment reduces their stress and anxiety resulting in pro-social behaviour.

There is a Neurodevelopmental injury that affects how the children learn and teachers know they need to put in place a supportive learning environment that will assist in meeting these children's needs.

- Old style recess where whole school goes out together is finished. Teachers take own class out at slightly different times and supervise.
- Hallways are tidy and low in visual stimulation to reduce distractions.
- Two alternative smaller classes for the most challenging FASD students.

The principal indicated that these strategies have positively impacted on both student learning and behaviour.

The school has employed youth workers and counsellors. The youth worker interacts with students and adds another professional to assist the teaching staff. The youth worker engages with students in a very positive way. This rapport helps in the daily positive interactions and especially in times of crisis when students have behaviour ‘meltdowns’. Youth workers interact with the students throughout the regular school day and in the implementing of life skills programs at the school and during community access excursions. Youth care workers in British Columbia complete are required to complete a degree course. Having additional staff experienced with child and family trauma on site is an invaluable support to the school community.

The most significant change for the school was the recognition that some of the more challenging behaviours that students sometimes exhibited were viewed as a “behaviour meltdown” rather than just bad behaviour because the child is being naughty. When meltdowns occurred the child was supported. The administration, staff, counsellors and youth workers all had a role in calming the students. For example, a student had had a melt down earlier in the day I visited. After he was calm, an impromptu meeting with the school vice principal, school counsellor and parent was convened. The purpose of the meeting was to review the student’s behaviour support plan to determine if changes were required due to several recent incidents.

In September 2008, Carney Hill Community School began working with families and their children ages zero to five with the addition of a Strong Start classroom. Strong Start BC is a no cost early learning opportunity for parents, caregivers and children. Adults must attend with their child. The program is funded by the Ministry of Education and provided in elementary schools. Many of the young children and parents/ caregivers are impacted by FASD.

The local Carney Hill Neighbourhood Centre is on site and provides a range of programs inclusive of after school and day care programs. They offer a Developmental Preschool, Group Daycare, After Kinder care, and After School Care. Each program delivered by the Centre is in response to an identified Community need. They work with the residents to find solutions.

The school’s theme from last year was
“Thinking Differently”
and this year’s is
“Alignment of Practise”.

Carney Hill Community School is trying to locally develop successful programs that target families affected by FASD and generational poverty. The positive results from the 2007-08 school year have the school community united and excited about continuing this work. The school's theme from 2007-2008 was "Thinking Differently" and the 2008-2009 year is "Alignment of Practise". By developing a high performing team with specific goals, there is an air of confidence in the school community that they can close the achievement gap for some of the most disadvantaged youth in the province.

Regular Classes

One of the greatest challenges for the provincial systems I visited was to implement appropriate quality inclusive practises for students with FASD within a regular classroom. This is where the majority of students with FASD are educated. There are limited specialist FASD class placements.

Winnipeg

In Winnipeg, Manitoba I met with Janet Thompson who is the Special Education Support Teacher in the inner city School Division. She was able to outline for me both the processes that surround a family and child obtaining a diagnosis and the subsequent changes this has on the child and their classroom. The diagnosis of a FASD disorder is recognized by educators who then endeavour to accommodate the needs of students. Only those students who are more severely affected by FASD may receive additional assistance such as Education Assistant time.

Janet's involvement usually starts when students are initially assessed for FASD by the Clinic for Alcohol and Drug Exposed Children (CADEC). The School Division has established very close links with CADEC which facilitates support for students and their parents from the point of diagnosis. Those involved have tried hard to develop a seamless process. After diagnosis Janet meets with teachers and assistants to assist them improve the diagnosed student's outcomes. Much of the focus is on building the teacher's capacity to support the student. Features of the process described by Janet:

- Spend time observing the child in their class prior to planning with the teacher.
- Work on the strengths the teacher already brings to the table that will be supportive of a student with FASD. Focus on the many skills a good teacher already has that will assist.
- Focus on good quality existing regular teaching skills such as being well prepared and organised, as they are key for success.
- Utilise knowledge and skills the teacher already has, such as understanding and skills for working with students with autism, as there are many similarities in the approaches.
- Encourage teacher to try some new strategies, not to try just once to see if it works but to try a few times as students with FASD are

Utilise knowledge and skills the teacher already has, such as understanding and skills for working with students with autism, as there are many similarities in the approaches.

not consistent in what they can do, but perform differently on different days and with different situations.

- Indicating to adapt how they give instructions- not relying on verbal instructions as these children are not verbal learners.
- Emphasise any adaption's they make for the child with FASD can also benefit other kids in the class.

Janet does regular presentations to schools about FASD. They vary from short introductory sessions to full day workshops. The sessions work towards assisting educators to move towards understanding the disability as a brain based disability and being able to think differently about the behaviours and learning styles of students with FASD, and to apply more appropriate teaching and learning adjustments. Janet often works alongside Dorothy Schwab, who, as well as being the CADEC Family support worker is an Occupational Therapist who specialises in FASD. Workshops have a focus on reducing sensory stimulation; they are very much practical experiences where teachers can feel how it is to have FASD. The workshops are interactive so educators can fully discuss strategies and concerns regarding teaching children with FASD. They use information such as:

“When behaviors are used as cues, as symptoms of the disability, a different focus for interventions is identified. (Malbin, 2002)

Viewing Behaviours Differently:

Behaviour	Misinterpretation	Accurate Interpretation
Non-compliance	<ul style="list-style-type: none"> • wilful misconduct • attention-seeking • stubborn 	<ul style="list-style-type: none"> • difficulty translating verbal directions into action • doesn't understand
Repeatedly making the same mistakes	<ul style="list-style-type: none"> • wilful misconduct • manipulative 	<ul style="list-style-type: none"> • can't link cause to effect • can't see similarities • difficulty generalizing
Not sitting still	<ul style="list-style-type: none"> • seeking attention • bothering others • wilful misconduct 	<ul style="list-style-type: none"> • neurologically-based need to move while learning • sensory overload
Doesn't work independently	<ul style="list-style-type: none"> • wilful misconduct • poor parenting 	<ul style="list-style-type: none"> • chronic memory problems • can't translate verbal directions into action
Does not complete homework	<ul style="list-style-type: none"> • irresponsible • lazy • unsupportive parents 	<ul style="list-style-type: none"> • memory deficits • unable to transfer what is learned in class to a homework assignment
Often late	<ul style="list-style-type: none"> • lazy, slow • poor parenting • wilful misconduct 	<ul style="list-style-type: none"> • can't understand the abstract concept of time • needs assistance organizing
Poor social judgment	<ul style="list-style-type: none"> • poor parenting • wilful misconduct • abused child 	<ul style="list-style-type: none"> • not able to interpret social cues from peers • doesn't know what to do
Overly physical	<ul style="list-style-type: none"> • wilful misconduct • deviancy 	<ul style="list-style-type: none"> • hyper- or hypo- sensitive to touch • doesn't understand social cues regarding boundaries

Stealing	<ul style="list-style-type: none"> • deliberate dishonesty • lack of conscience 	<ul style="list-style-type: none"> • doesn't understand concept of ownership over time and space • immature thinking ("finders keepers")
Lying	<ul style="list-style-type: none"> • deliberate • sociopath behaviour • lack of conscience 	<ul style="list-style-type: none"> • problems with memory and/or sequencing • unable to accurately recall events • try to please by telling you what they think you want to hear
Self-centredness	<ul style="list-style-type: none"> • selfishness • only cares about self 	<ul style="list-style-type: none"> • only see the superficial or concrete level of social behaviour • doesn't link cause and effect
Volatile	<ul style="list-style-type: none"> • poor parenting • aggressive nature • short-tempered 	<ul style="list-style-type: none"> • exhausted from stress of trying to keep up • extremely over- stimulated
Inconsistent performance	<ul style="list-style-type: none"> • manipulating • sneaky • not trying hard enough 	<ul style="list-style-type: none"> • chronic memory problems • inability to generalize learning from one situation to another
Unmotivated	<ul style="list-style-type: none"> • poor parenting • lazy • doesn't care 	<ul style="list-style-type: none"> • can't project into the future and see what will happen • doesn't connect today's decisions with future opportunities • doesn't understand cause and effect

Developed by Deb Evensen

British Columbia First Nation Schools

Madeline Price is a Special Education Consultant with both the First Nations Education Steering Committee (FNEESC) and the First Nations Schools Association (FNSA). She supports First Nation Schools in British Columbia develop and deliver quality and culturally appropriate program for First Nations students with special needs and FASD.

We spoke of how she works with educators to assist them make the crucial shift towards thinking "What can I do to change what I do to support the child?" rather than thinking "How can we change the child". Madeline has found when a teacher begins to view the changes that they personally need to make to their teaching, along with changes they can make to the learning environment of the student, then real support for a student comes into place and learning begins.

Madeline works with educators to help them understand many of the behaviours they see. Students with FASD often present with behaviours considerably less mature than their peers. Madeline explains to teachers that even though a student's age may be 12, their social functioning level can be much lower at maybe that of a 7 year old. Their social understandings are at the same level. If teachers can see that the 12 year old is socially more like a 7 year old they can adjust their expectations for social behaviour. This makes a significant difference.

“What can I do to change what I do to support the child?” rather than thinking **“How can we change the child”**.

Madeline sees that developing involvement between home and school is essential for a positive school - family relationship. She advocates bringing all stakeholders together as the students "team". A vehicle for this is the development of supportive Individual Education Plans (I.E.P). Madeline uses and advocates a very collaborative approach to IEP development. All IEP participants sit in a half circle and are facilitated to contribute towards what they see as important for the student to achieve in the year. A few priorities are selected by a "team-decision" and made into achievable goals. The responsibilities of all the members of the student's team are recorded along with the strategies they will use to meet the goals. The role, name and contact information of all members of the students support team are also documented.

When goals are well beyond what the student is capable of doing the student becomes unable to realistically achieve the goal often resulting in frustration, failure, loss of confidence and self esteem, and frequently escalation of inappropriate behaviour. (Madeline Price, 2008)

Resources for Educators

Resources to assist educators work effectively with students with FASD or even suspected FASD have been developed in Canada and the USA.

The first FASD education resource book, "Teaching Students with Fetal Alcohol Syndrome/Effects: A Resource Guide for Teachers" was developed in 1996 by the BC Ministry of Education and is still a very good resource.

A feature of almost all of these resources is that they can be accessed on the internet, downloaded, saved to a computer and can be printed out as a resource book. For Australian educators this is a bonus as we do not need to "reinvent the wheel". We can utilise the existing knowledge in the manuals, learn and trial what works for us in the Australian context and over time build up our knowledge and skill base so that in the future we can develop texts specifically for students with FASD in our own context.

The manuals are very user friendly. The education systems and language of Canada are similar to our own and so much can be easily translated in to our schools.

The downloadable manuals which were constantly referred to by educators whilst I was on the fellowship were:

- Programming for Students with Special Needs Book 10: Teaching Students with Fetal Alcohol Spectrum Disorder: Building Strengths, Creating Hope. Alberta Education. 2004
- Towards Inclusion: Tapping Hidden Strengths - Planning for Students who are Alcohol-Affected. Manitoba Education. 2001
- Making a Difference: Working with Students who have Fetal Alcohol Spectrum Disorders. Yukon Department of Education, 2006.

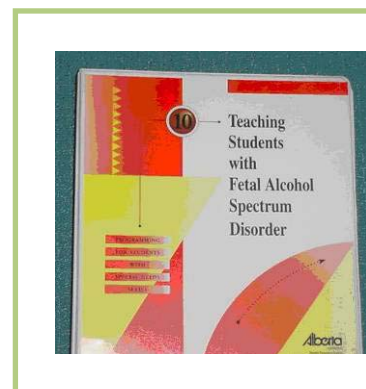
Understanding FASD as a brain based disability is essential when working with students with FASD. To assist educators and others gain this understanding the work of Diane Malbin is extremely important. Her short book, "Trying Differently Rather Than Harder", Fascets, 2002 is very informative.

DVDs have been produced that are both informative and powerful in communicating an understanding of FASD. Most are not designed specifically for schools. There are an ever increasing number of titles available.

In Appendix 1 there is a comprehensive list of resources.

Utilising Resources and Knowledge in your own Context

Strategies for FASD are highly supportive of students with other neurological based disabilities such as Autism and Acquired Brain Injury.



An action learning approach where a few strategies can be trialled with a student is an excellent way to begin:

- Select a strategy and trial it over time.
- Don't try just once as students with FASD have very intermittent performance, they can do some things one day and not the other. Some days they will react a certain way and others will react quite differently to the same activity or strategy.
- Reflect and make adjustments.
- Gradually build up a repertoire of strategies you know works.
- A strategy or accommodation for one student may not always work for another.

A very experienced teacher gave the advice of time: spend time observing and learning about the individuals' strengths and needs; what works for them and what doesn't work for them. Often simply asking a person with FASD this is a useful way of obtaining information. With this knowledge you can build personalised supportive strategies and accommodations around the student.

Another teacher indicated the benefits of teaching the student with FASD for more than a single year. It takes time for the teacher to get to know the students strengths, weaknesses and behavioural triggers. The more the teacher knows the more likelihood of a supportive learning environment.

Building the capacity of educators

When an educator has a solid understanding of FASD as one where the individual can have a permanent brain injury they can then view the student and their behaviours through this lens and are more able to determine and apply suitable teaching and learning adjustments and environmental adaptations.

A range of strategies has been useful in building the capacity of educators in Canada and the USA. How schools and educators have achieved this within classrooms and schools has been described. The following will add a system perspective to this.

Presentations and lectures

Presentations about FASD are readily available and have been for over a decade. Only some of these presentations are aimed specifically at educators.

Presentations specifically for educators appear to be:

- Organised at a provincial level (state level)

Or

- Organised by a particular school district or school

Alaska began with state wide Professional Learning through "FASD Summits" in 1999. Teachers were provided with scholarships to travel

When an educator has a solid understanding of FASD as one where the individual can have a permanent brain injury they can then view the student and their behaviours through this lens and are more able to determine and apply suitable teaching and learning adjustments and environmental adaptations.

to Anchorage for 3 days of intensive training. Since then FASD presentations: FASD 101 and FASD 201 have been available by trained presenters.

In Alberta in 2004 the manual, "Teaching Students with Fetal Alcohol Spectrum Disorder" was developed. Copies were sent to all school principals in Alberta, encouraging them to share the resource with staff in their school. Eight one-day workshops were offered across the province through a Regional Professional Development Consortium. The training materials for these workshops were also posted on the web so that individual school jurisdictions could adapt the material for use with their own school staffs. The in depth facilitator notes can still be downloaded from the website.

British Columbia (BC) developed a provincial teacher education strategy in 2005 through the establishment of the Provincial Outreach Program for Fetal Alcohol Spectrum Disorders. (POPFASD). They are a small team of 2 teachers with a computer support person. They have developed capacity to provide Professional Learning for BC educators through the use of presentations, on line learning and capacity building of a key teacher in each School District. POPFASD has developed a 2 day Professional Learning course for school staff which the team travel all over BC presenting.

POPFASD has established a support model where each School District has a key teacher, known as a District Partner, who is the key person in their district for promoting FASD education. The POPFASD team liaises closely with the District Partners through newsletters and training opportunities. They assist with resources and material preparation so that the District Partners can present professional learning sessions in their own schools or districts.

In Portland, Oregon, courses by Diane Malbin, a respected authority on FASD and director of FASCETS have often laid the ground work for the educational programs that have been developed for students with FASD. Many educators have completed these courses. In the course the model of FASD as a brain based disability is fully developed. This concept is now well understood and inherent in the educational provision of students with FASD.

Conferences

Initial knowledge about FASD for professionals, inclusive of educators, tended to come from attending FASD Conferences. They spoke very highly of all Conferences as they provided participants with the latest information. The knowledge from early conferences provided most with a starting point. People told of going back to their places of employment and beginning to trial and develop and learn about effectively working with people with FASD.

On line Learning

On line learning as a tool to inform and build the capacity of educators about FASD, is promising. There is some limited on line material available on FASD specifically for educators.

There is considerable more health and community information available. Webcasts relating to FASD are available.

The first FASD modules were initially developed on CD rom in Alaska in 1999. In 1999 Alaska passed the Binkley Law (Alaskan Statute 14.20.680) which required all teachers and other professional staff to have training on drug and alcohol related disabilities within 45 days of being employed. Since this time the modules have been reviewed and updated regularly and are available on line for educators in Alaska. They are 3 ½ hour courses that can be completed over a number of sittings. The program is viewed by the Alaskan education department as cost effective, especially as it continues to have many users. As with other online learning programs use can be readily tracked. The two courses which comprise the training are available for others to access for a fee.

www.eed.state.ak.us/eLearning/FASD%20module.html

The British Columbia Ministry of Educations Provincial Outreach Program for Fetal Alcohol Disorder (POPFASD), have developed short online learning modules about aspects of FASD.

In September 2008 there were fifteen modules ranging in length from five to fifteen minutes. More modules are planned. Modules are presented mainly in lecture style with some simulated classroom situations. Slideshows and additional written information is available with many presentations. I was very interested to learn POPFASD can track from which region in Australia "hits" on the site come from. The website is: www.FASDoutreach.ca/

Alberta Education is developing a series of online learning modules to support educators. They will be developing ten modules per year for the next three years. The first online posting will be April 2009 on the Alberta Education website and will be available for all to access. Other FASD resources from Alberta Education are of a very high standard so it is expected that these would also be of a high standard.

Webcasts on a variety of topics about FASD exist.

Current research is presented in short twenty to thirty minute sessions at the webcasts of the Fetal Alcohol Canadian Expertise Research Roundtables. Webcasts from 2002 through to 2007 are available online at the website

knowledgenetwork.ca/fas/home.html

The presentations do not have a school focus but provide quality information.

POPFASD on line learning modules. Current titles of sessions:

- What is FASD? Overview
- Alcohol Effects on the Developing Brain.
- Primary Disabilities. The impact on learning and behaviour.
- Paradigm Shift. Changing our thinking to foster more appropriate supports and less frustration
- Secondary Disabilities. Secondary behaviours can be prevented.
- Environment. How to set up a classroom learning environment.
- Classroom Routines. How to establish classroom routines.
- Relationships. The importance of understanding students through developing "relationship".
- School Experiences. Youth with FASD and a parent speak about their school experiences.
- Cause and Effect and Impulsivity. Provides strategies Memory Difficulties. Samples of accommodations for the teacher to use to support students with memory difficulties.
- Slow Processing Pace. Samples of accommodations for the teacher to use.
- Dysmaturity. Explains the developmental "gaps" between the student's chronological and developmental age in different domains.
- Case Study-LEIC and IEP's. How to understand the learner and then make appropriate accommodations to the environment, instruction and curriculum.
- Complex Disorder Behavioural Conditions Assessment Network. Canadian Support Network.

Tertiary Qualifications in FASD.

Burns Lake campus of University of New Caledonia offers an Advanced Diploma in FASD, which provides professionals with the skills to improve service, impact policy and understand the complex challenges facing individuals, families and communities impacted by FASD. They have had students from Australia and overseas completing or who had completed the course.

A Resource for Schools working with Parents

Alberta Education has developed a resource for agencies and families working with schools. The resource is titled: Together We Succeed, A team approach to advocating for and supporting students with FASD. To view this document, visit the Alberta Education website.

This resource is valuable for families and for those advocating for students with FASD as it provides ways that families and schools can more effectively work together. It has a very useful Tool Kit at the end of the resource which is 35 pages of “tools’ such as:

- What School Staff Need to Know About FASD.
- Parents’ Tips for Helping My Child Feel Better.
- Planner for a Solution Focused Meeting.
- Circle of Friends.

Supporting Families impacted by FASD

Overview

I visited numerous agencies that supported families where parent or a child or both (intergenerational FASD) were affected by prenatal exposure to alcohol.

Families who are supported are more likely to be successful.

The successful programs I visited were family focussed. I spent most time learning about programs to support the group of families, impacted by FASD who are most disadvantaged in our society. These families lived in poverty and had struggled with addiction issues, employment and homelessness. **They are also the families who are least able to successfully advocate for their children and in particular their children's education.**

It is vital to remember that not all families impacted by FASD come from socially disadvantaged families.

Successful programs supported families to more effectively manage and nurture their children. This included assisting parents to work with their children's school.

Support to families varied, it could be assisting them to have the basic needs of food and shelter met, assistance to access medical care or legal advice or help to get things in order at their house, all these go towards which improving the quality of life for the family and ultimately means children have a better chance of success and in engaging in education.

Other family support was direct with schools. This varied but included: talks to staff about FASD to raise their awareness and knowledge and meetings with teachers to plan for a child with FASD.

Indirectly agencies supported education by the ongoing support they provided families.

Support for families that are impacted by FASD helps stabilise the family and builds the base from which children can be nurtured. Without support directly to families the work of education is much more difficult and outcomes that are achieved are less likely to be sustainable.

Winnipeg

Winnipeg, Manitoba has been at the forefront of developing preventive, diagnostic and support structures around individuals, families and communities affected by FASD.

Winnipeg has been working on developing a holistic approach across agencies for many years.

"Woman at high risk for substance use often face major social and health issues that limit their ability to successfully access and utilize support. These factors include a lack of supportive housing, unresolved trauma from violent and abusive relationships, unrecognized and untreated mental health problems, and a fear of losing custody of their children. In order to address these issues, support must be provided through specialized holistic services using a non-judgmental, harm reduction approach." (Ministry of Children and Family Development, 2008)

I was impressed with the depth of commitment to FASD across education, child protection, health and family development organisations I visited.

The range of services available was extensive.

Interagency FASD Program, Winnipeg.

This is a home based service for families caring for children 0-6 who have been prenatally exposed to alcohol or other substances. Interagency FASD work as a team with parents and professionals to develop individualised support programs that meet the need of children and parents. They are a family-client led service where once they build a relationship with the parent they walk alongside the family supporting them.

Their work is to:

- Assist families understand the strengths and challenges of FASD.
- Assist and advocate for families in matters of housing, child care and daily living issues.
- Provide information about disabilities associated with FASD.
- Provide strategies for managing at home.
- Provide information and assistance to families to adapt environments to meet the needs of children with FASD.
- Support families to access other services.
- Support families accessing FASD diagnostic services.
- Provide Information and strategies to schools and daycares.
- Present workshops and training for parents and professionals.
- Develop FASD resources to inform and educate others.
- Manage the Manitoba FASD Information line.

The staff are highly skilled in working with people with FASD and have trained and coached staff from other disciplines in developing their skills and expertise. The staff comes from a range of professional backgrounds: social work, education, child welfare, psychology and counselling.

Structured For Success Program. Northern Health, Prince George, British Columbia.

A program that supports families affected by suspected or confirmed FASD. This program works both with parents who have FASD and parents who have children with FASD. The program has worked to establish support around individual families from the families own support network rather than relying on professional support.

The team uses a multi disciplinary approach to provide in home support and learning with the goal to keep families safe and healthy. They focus on adaptations to the environment surrounding the family rather than changing the individual. Interventions used to strengthen

“The SFSP begins work with families from a place of hopefulness, empathy, respect and mutuality and continues with a strength-based approach to achieve the desired outcomes.”
(Structured for Success Program)

the family are based on a neurocognitive model of learning that utilises concrete, experiential, kinaesthetic, context based learning. The aim of interventions is to build a successful structure for the family. The table below demonstrates the differences between this program and traditional family support programs.

“Difference from Traditional Family support Program Models

Traditional family Support Program Model	SFSP Family Support Model
Parent education based on learning theory, motivational insight model	Parent education based on neurocognitive developmental model
Works to change the parent in their environment	Works to change the environment for the parent and thereby achieves changes for the parent.
Uses psychological methods, behavioural modification, insight-based therapy to support the parent	Uses concrete, context-based experiential and kinaesthetic learning tools to support the parent
Encourages the parent to use own resources to access community supports	Creates a support system that keeps family safe and healthy
Works in isolation from other services the family is using	Develops wraparound services for the family based on the family’s needs”

(Structured for Success Program)

Structured for Success has worked with many high risk families with considerable success.

Practical supports within the program include:

- 12 step alcohol addiction groups tailored for parents with FASD.
- Family celebrations.
- Cooking club.
- Learning group.
- Parenting group.

They work closely with other community organisations to provide the programs. This was a pilot program and has been extensively reviewed with excellent results. (Northern Family Health Society, 2005).

Whitecrow Village

It was with great anticipation that I visited “Whitecrow Village”. I had heard much about what this team of people with and without FASD working together has achieved in assisting and supporting families affected by FASD and how they had also influenced many service providers and government policy. Other professionals I met paid credit to the work of Whitecrow Village.

The aim of interventions is to build a successful structure for the family.

Whitecrow Village respects the individual nature of each person's disability, but their emphasis is on sharing a belief and creating an environment which celebrates each person's unique abilities and strengths. Whitecrow Village recognises the strengths and individuality of each person and has a strong philosophy underpinning it: *"we all need to work together as a community to support and nurture each other"*.

The Whitecrow Village aims to build healthy and stable 'communities' for people with FASD as this provides a holistic and stable basis for the person and family. This means educational interventions along with all the other supports for the family will likely be most effective. Whitecrow Village believes all members of a community benefit from and contribute to the communities' well-being, when they share a common understanding of FASD.

From early beginnings as a summer camp suited to children with FASD Whitecrow Village has grown to demonstrate year-round success and belonging for families, children and youth with FASD and professionals in all social service fields.

Whitecrow Village runs L.I.F.E. (Live in FASD Education) week-long camps which are workshops for families and service providers together where they build links, relationships and understanding between both, that will enhance the outcomes for the person with FASD, their families and those who support them. From this foundation, Whitecrow Village also runs year-round employment, addiction recovery, housing and education projects.

Whitecrow Village has been involved in building the capacity of others for over twelve years. Their FASD training presentations ideally run over at least four days. It includes presenters living with FASD to ensure people have a thorough understanding of FASD and that they can effectively work alongside individuals with FASD. Like many others presenting on FASD they are no longer willing to do short one to two hour presentations about FASD. They feel many participants left short presentations still knowing very little about FASD and certainly not enough to begin effectively working with people with FASD. They believe a solid, experiential, and practical understanding is required for people to effectively support others with a brain injury and that a connection from a heartfelt relationship opens the mind to this understanding.

The Whitecrow Village education programme is actively involved in consultation, mentorship, and advocacy to support both students and educators. This includes working with students, their families and their schools on such topics as Individualised Education Plans, lesson planning, daily structure, practical application of assessments and classroom environments.

The Education Team offer a 4 - 5 day series of Professional Development sessions for educators, giving an in-depth and practical



The figure of the white crow appears in the traditional stories, myths, and legends of many world cultures. Initially shunned for its differences, with understanding the white crow comes to be valued for its unique contribution to community. The allegory of the white crow serves as a reminder to look to the gifts and strengths that exist in everyone. Its journey speaks to the vision of Whitecrow Village, offering hope as we work toward a society in which the diverse perspectives and abilities of all members are recognised and valued as important and equal.

Reprinted with permission of Whitecrow Village

understanding of FASD, from which educators can form strategies which suit their particular situations and needs.

Whitecrow Village has a Peer to Peer Education Program that is designed and run by youth with FASD. It gives students with FASD the opportunity to learn about themselves and to share their knowledge with their classmates, peers and teachers in a setting where they are mentored and supported by successful adults with FASD.

Information about Whitecrow Village is available at their website at www.whitecrowvillage.org

Lakes District Campus of College of New Caledonia, Burns Lake, British Columbia

I spent 3 days at Burns Lake at the Lake District Campus of New Caledonia working with both staff and students learning about the wrap around programs they have developed since the early 1990's to support families and individuals that may be affected by FASD. Their ongoing work has been recognised in the British Columbia FASD Provincial Plan 2008-2018.

Anne Guarasci, coordinator of the FASD programs at the Lake Campus said they started from small beginnings which they have built on. In the early nineties they were offering regular college courses to their community but realised it wasn't effective for many students. They heard about FASD and so organised workshops with "FASD experts" to educate themselves and interested people from the community.

With this knowledge and awareness that some clients were likely alcohol affected they tried new ways of working. At the same time knowledge and diagnosis of individuals with FASD begun across BC. They accessed funding and gradually designed more programs to meet the needs of the community. They realised a need to internally train staff and built training packages for themselves, which extended over time to a range of training courses for other agencies. The College now offers family support programmes alongside the more traditional college courses. The traditional subjects are offered in a way that is conducive to the learning needs of an adult with FASD.

I observed part of the programs whilst visiting, and interacted with adults with FASD who gave me a greater personal understanding of how FASD affects adults of normal intelligence and makes it so hard for them to do so many things we take for granted.

The learning environments were respectful and supporting. The students were very open in telling me how much they valued these programs and how it had made a huge difference to the success of their lives.

The learning environments were respectful and supporting.

The staff has extensive knowledge in working with people who have FASD and this showed in how professional and focussed they were in supporting students.

The website has information about the programs offered.

www.cnc.bc.ca/Campuses/Lakes_District_Campus/FASD_Programs__Services__Training.htm

Some of the services and programs available:

Healthier Babies-Brighter Futures, A FASD prevention program.

“One woman enrolled in HBBF has been in the program a number of years. When she entered the program with her first baby she was actively drinking and was not accessing prenatal care. Throughout her time in HBBF she has learned about FASD and has become a champion for FASD prevention. She educates her friends, family and fellow participants on the dangers of prenatal alcohol exposure. She can identify behaviours and characteristics of FASD and therefore she accepts the person for who they are and doesn’t blame if there is an unexplained behaviour. She feels individuals with FASD can be successful and being affected is not hopeless. She offers support to other mothers by:

- *babysitting to give a break,*
- *cleaning others’ houses to lighten the load, and*
- *feeding families that don’t have enough food. (Even though food is often scarce at her home)*

She no longer drinks alcohol and when others are she makes sure there is a safety plan in place for their children. With her last two children she abstained from alcohol. Four days after her arrival, she brought the baby to the program. Baby feeds well, is gaining weight, has regular sleep patterns and appears happy and easy to settle. This mom is an example of what this program is intended for - FASD education and prevention!” (College of New Caledonia, Lakes District Campus, 2008)

This program is sponsored by the BC Ministry of Children and Family Development to work closely with families living with FASD with the overall aim to reduce further pregnancies where there is alcohol and drug exposure. The support workers advocate and support mothers. I participated in an end of year session with the mothers in the program, who all spoke extremely highly of the assistance the program has provided them.

Focus Employment Program

Focus Employment is a fulltime program for adults with FASD that assists and supports the development of skills. It recognises that it takes most people with FASD longer to develop skills for employment and so some students are in the class for a number of years. Students have ongoing access to counsellors; often their lives can be very chaotic. Many students experience the secondary disabilities associated with FASD.



Focus classroom

The program:

- Develops individual strengths.
- Is structured, calm and quiet.
- Provides an environment low in visual stimulation.
- Utilises a concrete hands on learning style.
- Recognises that the brain damage makes sitting and concentrating for even short periods, very hard and tiring. Periods of concentration are broken up with activities.
- Fosters the development of a close working relationship between students and staff. This is viewed as critical.
- Teaches the traditional subjects of english, maths, computing, craft, job skills along with daily living skills; advocacy for housing, justice and health.
- Provides processes to reduce disruptions which are unsettling for the students. For example a sign on the door indicates to visitors to go to the front office rather than come directly to the room.
- Offers a limited program over holidays to allow continuity for the students who rely on stable structure and support.

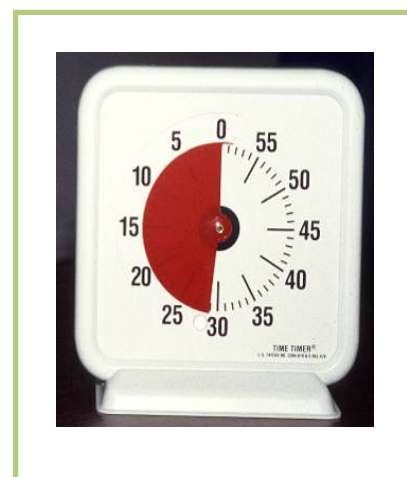
Community Day-care

Families accessing programs at the College can have their children at the onsite day-care. Using the philosophies and practices of an Early Childhood Education program and combining it with the FASD knowledge and skills the staff, they have created a childcare environment that suits the learning needs of all children, including those that have FASD behaviours and characteristics.

Wanda Giesbrecht, the Early Childhood Education Teacher in the day-care indicated success has been built from having staff well trained in FASD. She spoke of the need for ongoing refreshing of staff to have them continue to focus on the best FASD strategies to use and not revert to old practises.

Adaptations used at the day-care include:

- Drop off time not rigidly fixed- mums can bring kids when ready, to accommodate the poor organizational skills of adults with FASD. Initially they had asked parents to phone to let them know they would be late...this didn't work so they stopped expecting it.
- No or few pictures an display on walls and windows.
- Visual timetable for whole class-pictures with line drawings, for some students they use photos and individual timetables. Ensures the day is predictable .Children with memory deficits don't cope with changes as rely on the sameness of each day to cope.
- Hand Signing. An extra visual cue is to support comprehension, especially as oral comprehension can be poor.
- Children with FASD can do less circle time, they use pictures and objects during circle time to increase attention.
- "Time timers" are used as Visual timers. A timer where as time elapses so does a red bar. When children need to calm down or



stop an undesired behaviour the child sits out till the red disappears: they sit out and do deep breaths, when the red disappears they return to the activity. Very concrete and visual.

- Use of activities and materials to reduce sensory integration dysfunction. They incorporate “heavy work” as part of programme; incorporate into songs, movement activities and in small tasks.
- If child becomes overstimulated (often viewed by others not familiar with FASD, as demonstrating unacceptable behaviour), they take the child for walk or try to reduce noise in room.
- Material over cupboards to reduce visual overstimulation. Objects such a books, pencils etc are away when not in use.
- When high numbers of children with FASD are in the centre they reduce outside community visitors, like firemen, as the children don't cope with changes to the structure of the day.

Early Intervention and Community Therapy Services

The Lakes Campus is fortunate to have therapists on site. Parents who attend the College and whose children may have FASD can be directly referred.

Kids Edge: Support and Advocacy for Vibrant Youth, (SAVY).

I spent the afternoon with youth from SAVY who were keen to learn what young people in Australia like to do. This group meets three times a week after school. The youth, 13-18 years, have been diagnosed with FASD or display behaviours and characteristics consistent with FASD. They were all young people at great risk. They are supported by two youth counsellors. The counsellors aim to improve the quality of life for the youth by assisting them in a hands on practical way with issues that may be affecting them. (Housing-homelessness, justice issues, drug and alcohol misuse, mental health, joblessness) The afternoons are structured and the key to success is the positive relationship between the counsellors and the youth.

Capacity Building of Others

The experience gained in building the capacity of their own staff CNC Lakes Campus has enabled them to assist others develop their staff's capacity. They now offer a range of recognised training courses for service providers and caregivers in health, education, justice and social services developed.

British Columbia Ministry of Children and Family Developments Key Worker and Parent to Parent Support Programs.

In 2005 the Ministry of Children and Family Development (MCDF) began development of a support program, specifically for families of children and youth with FASD and /or other complex developmental behavioural conditions similar in impact to FASD. Key Workers have been employed throughout the health regions of BC to support families dealing with the long term behavioural challenges associated

with their children's conditions. Parent to Parent Support Programs have also been established as part of this initiative.

The programs:

- Aim to maintain and enhance the stability of families to improve the child's long term outcomes.
- Aim to increase parent and professionals' knowledge of FASD so the children experience a better fit with their environment and experience more success.
- Provide the families with a network of support and assist them to access additional support services.
- Work towards families developing their own skills to advocate for their child.

Programs are based upon FASD expert Diane Malbins' work that views FASD as a brain based physical disability with behavioural symptoms that can be best supported by adaption's to the child's environment. (Malbin, 2002)

I met with Dr Deborah Rutman and her colleagues who are completing ongoing reviews of the Key Worker and Parent to Parent Support Programs. These reviews are available at British Columbia's Ministry of Children and Family Development website at www.mcf.gov.bc.ca/FASD/partnership.htm

The reviews confirm positive outcomes have been achieved and provide information on both content and future direction of the programs.

Key Workers recognize that each family is unique and understand their role as one that builds on a family's strengths.

Indigenous Families

FASD is not an issue of Race or Culture.

“A common misconception is that FASD is associated with ethno-cultural background. In Canada, First Nations are the hardest hit by FASD, but this is not because of racial or cultural characteristics. It is important to remember that FASD is a symptom of the fallout from an assault on Indigenous cultures: if anything it is the loss of culture rather than the cultures themselves that is related to the predominance of FASD.” (Wemigwans, 2008)

Throughout the Churchill Fellowship I was able to meet a number of First Nations people who shared both their professional and personal stories around FASD with me.

I was able to meet with a number of non Indigenous educators that have very closely worked alongside Indigenous communities, families and individuals for many years developing an educational response to FASD.

Whitecrow Village has already been described. The Whitecrow Village Team includes people of many nations. The members' Indigenous Nations include Carrier, Kaska, Umatilla, Sliammon, Akisgnuk, Metis and Cree; of Coast Salish, Dene, Columbia Plateau and Prairie territories. The program is guided by Elders, Georgina and Harold Amos, Coast Salish.

Kee Warner from Whitecrow Village explained: “In all our traditions, we view each child as a gift. Many of our elders' stories frame apparent hardship as an invitation to an important teaching, which is why we speak of the ‘gift’ of FASD.”

Evelyn Good Striker is a First Nations lady who was Director of First Nations, Metis and Inuit Education for Alberta Education before retiring. Evelyn has worked as a teacher in communities and done grassroots community work on FASD. She also spoke of the traditional belief that children are a gift from the creator. ‘What we learn from children with FASD are patience and endurance.’ Evelyn spoke about how children with FASD can become important contributors to their culture. They can be taught important roles, be valued culturally for what they do and personally grow. Evelyn talked of a young man with FASD who has a role as a ‘helper’ to elders, during ceremonial occasions he was there assisting the elder, showing great respect, and at the same time his own self worth and dignity and his relationship to others within his community grew.

Evelyn has worked in communities in the early stages of learning about FASD. Each community is unique and the approach for learning about and moving forward with FASD has been to individually work with each community. Evelyn stressed the pivotal importance of working first with community Elders.

“Disabilities as Gifts

Aboriginal worldviews recognize that each student has a unique pattern of learning. Traditionally, each individual was seen as having a gift. The whole community helped individual young people determine how to use their strengths and gifts to serve the community.

The concept of learning disabilities is at odds with the basic framework of Aboriginal education. Even the term identifies only a part of the child, the part that does not function well as a learner within the education system.”

(Alberta Education, 2005)

I sought Evelyn's views on working with Indigenous communities, families and students who may have FASD. Evelyn strongly expressed the view that the critical role a teacher has is to establish a relationship with a student and to come to understand that student through observing and learning about them as an individual and being there to assist the student to grow spiritually, physically, mentally and emotionally. She advocated a First Nations view that education needs to be holistic. Evelyn also stressed the absolute importance of extending this understanding and relationship to parents/care givers, as you need to be able to work with them very closely at all times to bridge home and school, so there are no gaps. **When teachers work closely with families the students' relationship with the teacher becomes stronger and the likelihood of positive outcomes significantly increases.**

Evelyn was very proud of her teams' development of the Alberta Education book, "Our Words, Our Ways, Teaching First Nations, Metis and Inuit Learners". They have written a chapter on Teaching Aboriginal Students with Learning Disabilities: Recognizing Gifts and Strengths. The chapter assists educators learn of the Canadian Indigenous perspectives around disability and how it can be understood with students and families affected by FASD. The book is available on the Alberta Education website.

http://www.education.gov.ab.ca/k_12/curriculum/OurWords.asp

Many of the experienced educators I met had many years working with indigenous communities. Madeline Price and Debra Evensen both believe **the relationship between school and family is essential for indigenous students if they are to be successful.**

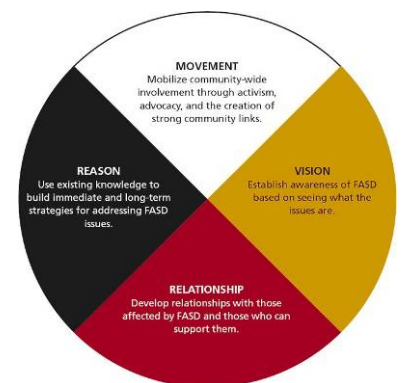
The Medicine Wheel was frequently referred to as of key importance moving forward with FASD. The Medicine wheel is respected as a holistic model for considering issues such as FASD. It allows people to approach the issue with sensitivity and with respect to traditional ways of thinking and being. It allows people to first learn for themselves what FASD is, before moving forward, it involves the establishment of relationships and trust. Only once this is established can the person move forward with others to begin addressing FASD issues. This then moves to the next sector which is working with others as part of a community towards the creation of strong community links to support FASD. The 4 sectors that you can move through are Vision, Relationships, Reason and then Movement. The end cannot be achieved till the stages are worked through that build the structure for support and understanding.

The FASD toolkit provides an excellent overview of this. (Wemigwans, 2008).

I met with James George a First Nations man, who is the FASD Change Manager for the FASD Collaborative Roundtables in Vancouver and Surrey in British Columbia. James has firsthand

"The relationship between student and teacher is the heart of Aboriginal education..... Teacher/student relationship is the foundation of that student's success in the classroom."

(Alberta Education, 2005)



experience as the parent of adopted children with FASD. He is working on intersectorial systemic change with regards FASD. He discussed with me how the population of people with FASD can be challenging and the rates of burn out/ compassion fatigue in workers across all sectors is high. James is working towards systemic change so appropriate practises are implemented that better fit the client groups needs and reduce the fatigue of front line workers to ensure quality and sustainable services.

Resources for working with and supporting First Nations People:

Some excellent resources are available which can be viewed on websites and printed for use.

The website of the Ontario Federation of Indian Friendship Centres has excellent resources.

- Aboriginal Approaches to FASD
www.ofifc.org/ofifchome/page/Document/UP_FILE/2008041510570USV.pdf
- FASD toolkit for Aboriginal Families
www.ofifc.org/ofifchome/page/Document/UP_FILE/20080415105432ABM.pdf

Yukon Education has a book that has a strong focus on working with First Nation students and families.

- **Making a Difference: Working with Students who have Fetal Alcohol Spectrum Disorders.** (Yukon Department of Education; Claire Earner et al) 2006
http://www.education.gov.yk.ca/pdf/fasd_manual_2007.pdf

Aboriginal Australian from the Pilbara,

“During the 1950’s and 1960’s we didn’t see or experience the destructive assault of alcohol on our societies. It didn’t seem to me that there were kids with developmental or behavioural issues stemming from FASD.

FASD was a non issue.

A person with a Fetal Alcohol Spectrum Disorder has it for all their life.

The people who teach and work with these kids (and later adults) need to help them create a meaningful existence for themselves.

Conclusion

FASD is a serious lifelong disability affecting individuals and communities. Recommendations that will make a difference to families impacted by FASD need careful development so a planned and strategic response to FASD can be implemented. The effects of FASD exist across all social groups.

Families impacted by FASD need ongoing support.

Young children with FASD need support from birth and throughout their lifespan. We need to strategically consider how to best develop intervention from the earliest age so as to maximise each child's potential.

School aged children need appropriate support throughout their schooling experiences. The support will be both in how we manage their learning environments and in additional support they may require to be successful learners. We need to particularly consider how to successfully engage these students in schooling until Year 12.

Supports for people with FASD need to be available for them across their lifespan.

FASD is in every culture where alcohol is consumed. We need to ensure a broad approach that supports all.

A very strong message I received from many of those I met was the issue of FASD is so vast no one Department can address it in isolation. A state wide response to FASD needs to be developed by Government Departments working collaboratively to address the issue.

Recommendations

I make the following recommendations to support individuals and families impacted by FASD:

- Provide the earliest possible intervention to children at risk of having a FASD.
- FASD be identified as a separate indicated group or as part of another indicated group within 'Schools Plus' framework.
- Educators be provided with Professional Learning on educating students with FASD.
- School Psychologists be provided with Professional Learning on educating students with FASD to enable appropriate support to educators, and students with FASD.
- The Department of Education and Trainings current specialist support services be expanded to provide support to Principals, Teachers, Education Assistants and Aboriginal and Islander Education Officers assisting students with an identified FASD diagnosis.
- That a DET representative work closely with those establishing diagnostic capacity to develop a supportive system immediately after diagnosis, similar to the Service for students with Acquired Brain Injury, where a Specialist Teacher can liaise with those making the diagnosis and who can interpret the multidisciplinary assessments into a language that teachers will understand so that they can make appropriate adjustments to the students educational program to accommodate the specifics of the FASD diagnosis.
- People with FASD be able to access appropriate supports across their lifespan.
- Specialist support be provided to families who are impacted by FASD to achieve the best outcomes for the family.
- Processes be developed to enable multidisciplinary diagnosis of FASD.

Further discussions and consultation are imperative to determine the very best ways of achieving the above recommendations.

Although my recommendations focus on the education of children with FASD it is the prevention of this avoidable condition that will provide the best solution.

Appendix

Manuals / Books on FASD related to Education

Programming for Students with Special Needs Book 10: Teaching Students with Fetal Alcohol Spectrum Disorder: Building Strengths, Creating Hope. Alberta Learning, 2004. Also download the "Sample Professional Activities" to support educators learn about FASD. To download: www.education.alberta.ca/admin/special/resources/FASD.aspx

Teaching Students with Fetal Alcohol Syndrome/Effects: A Resource Guide for Teachers, BC Ministry of Education 1996. To download: www.bced.gov.bc.ca/specialed/fas/

Making a Difference: Working with Students who have Fetal Alcohol Spectrum Disorders. Yukon Department of Education 2006 To download: www.education.gov.yk.ca/pdf/fasd_manual_2007.pdf

Reach to Teach: Educating Elementary and Middle School Children with Fetal Alcohol Spectrum Disorders. Center for Substance Abuse Prevention, Substance Abuse and Mental Health Services. To download: www.fasdcenter.samhsa.gov/publications/reachToTeach.cfm

Towards Inclusion: Tapping Hidden Strengths - Planning for Students who are Alcohol-Affected. Manitoba Education. 2001. To download: www.edu.gov.mb.ca/ks4/specedu/fas/pdf/intro.pdf

Challenges and Opportunities: A Handbook for Teachers of Special Needs with a Focus on Fetal Alcohol Syndrome (FAS) and Partial Fetal Alcohol Syndrome (pFAS). (Vancouver School Board; P. Lasser) 1999 To order: www.fasbookshelf.com/

Supporting Positive Behaviour in Alberta Schools; Part 3: An intensive individualized approach. 2008. Provides information and strategies for providing intensive, individualized support and instruction for the small percentage of students requiring this level of intervention. Particularly relevant for students who may have FASD. To download: www.education.alberta.ca/admin/special/resources/behaviour.aspx

Planning for Students with Fetal Alcohol Spectrum Disorder A Guide for Educators, Saskatchewan Learning, 2004. To download: www.sasklearning.gov.sk.ca/branches/curr/special_ed/docs/misc/fasd2004.pdf

FASD strategies not Solutions, Edmonton Region 6 FASD Committee.

To download: www.faslink.org/strategies_not_solutions.pdf

DVDS

Parenting with FASD. Challenges, Strategies and Supports.

Parenting-related experiences and challenges faced by people with FASD. To order:

www.fasbookshelf.com/

Computer programs

This is me: A Tool for Learning and Working with People who have FASD. Particularly suitable for use with children who have a FASD diagnosis. www.mefasd.com

Obtaining resources

www.fasbookshelf.com/ -Online store located in Canada. Books, DVDs, posters are available.

Amazon – range of DVDs and books

Fascets.org – book and resources

Zeus publications –Australian books

Websites

Iceberg is a quarterly international informative newsletter on FASD.

www.fasiceberg.org/index.htm

FASD Connections: Critical Issues & Related Links.

www.fasdconnections.ca/

The National Organisation for Fetal Alcohol Syndrome and Related Disorders Inc, Australia. www.nofasard.org/

Telethon Institute for Child Health Research: Alcohol and Pregnancy Project

www.ichr.uwa.edu.au/alcoholandpregnancy

FASCETS: Providing An Alternative Paradigm for Understanding Behaviors

www.fascets.org/

Public Health Agency of Canada: FASD Information site

www.phac-aspc.gc.ca/fasd-etcaf/index.html

Canada Northwest FASD Partnership

www.cnfasdpartnership.ca/

The Asante Centre for FAS

www.asantecentre.org/

FASD Connections

www.fasdconnections.ca/

Fetal Alcohol & Drug Unit Washington

www.depts.washington.edu/fadu/

FASD – Centre for Excellence

www.fascenter.samhsa.gov/

The FASD Canadian Guidelines for Diagnosis and Identifying Fetal Alcohol Spectrum Disorders in Primary Care

www.cmaj.ca/cgi/content/full/172/5/628

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