Living With FASD

Spring 2006

Saskatchewan Fetal Alcohol Support Network Inc.

Inside this Special Edition

Feature Articles highlighting a series of workshops: Community and Social Services, Justice, Mental Health and Addictions, Education and Employment

Saskatchewan Fetal Alcohol Support Network

The Board of Directors of the Saskatchewan Fetal Alcohol Support Network is comprised of both parents and professionals from communities throughout the province. The board works diligently toward the vision of creating a community where persons with FASD, their families and circles of support feel safe, supported and valued. Each board member contributes unique ideas and insight and together they provide leadership and direction to the staff of the Network. Much has been accomplished; we celebrate the successes, yet recognize that more remains to be done.

Board Members
2005-2006

Treasurer: Terry Hellquist, Trudy Shingoose, Sandy Overs, President: Marion Tudor, Shelley Kolisnek, Sylvia Nagy, Kim Skidmore.
Missing from picture: Marilyn Macdonald, Rae Mitten, Sarah Guenther, Jonina Male.

Greetings from the staff of the Saskatchewan Fetal Alcohol Support Network!

Angela Schmolke, Executive Director

I'd like to take this time to fill you in on some of the exciting and positive work that we are doing here at the Network. As we approach our fiscal year end, we are nearing the completion of a number of projects and are looking at new grants and funding opportunities for the upcoming fiscal year.

One of the projects that we've been involved with this past year is the Supported Housing Project for Persons with FASD in Saskatoon. Eunice Bergstrom has been employed as the Project Developer. In addition to researching supported housing for persons affected by a Fetal Alcohol Spectrum Disorder, Eunice has been involved in capacity development initiatives in Saskatoon through the delivery of a number of workshops and trainings geared to frontline workers. We're so pleased with the quality of work and insight that Eunice has brought to the Network and thank Eunice for her commitment and hard work! We would also like to thank Connie Jones, Office Coordinator for the Network, who has played an instrumental role in pulling together eight workshops in a three week time span.

In addition to the Supported Housing Project, the Network has been involved with a number of other projects. These projects include the delivery of several eight week parent support groups in Saskatoon and Regina, a provincial post secondary FASD Awareness & Prevention Project, and the development of additional FASD strategy sheets and pictorial brochures. Within the next few weeks we will be launching our newly developed website. We would encourage you to visit our website for more detailed information about all of these projects! www.skfasnetwork.ca

In the meantime, I hope you enjoy the publication!
Sincerely,
Angela

Network Staff: Connie Jones, Eunice Bergstrom, and Beverly Palibroda

President's Message

by Marion Tudor

In the past month I have had the opportunity to participate in two of the workshops put on by the Saskatoon Supported Housing project. I found the workshops useful and empowering. We've come a long way in the past five years or so. When we go to workshops now, we hear about strategies that work for children, youth and adults. Previously, the focus tended to be on the damage itself and the challenges faced by our young people. It's interesting to note that the most important strategy we have is to change our own attitudes. It is vital that we view individuals with FASD as having a permanent disability which requires us to change the environment for that person.

However many workshops and presentations I attend, I still find it hard to hear about the secondary characteristics associated with FASD. I find it hard because they are secondary, and therefore we should be doing a better job of providing services to individuals with FASD at an earlier age, so that some or all of these characteristics could be avoided.

I want to share with you an overview of a piece of writing by Jan Lutke. Jan lives in B.C. She is a parent of many children and adults with FASD and is a very strong advocate for them. You can find the entire article, entitled 'Hard Issues for Parents of Adolescents and Adults with FASD – Playing Lifeguard' at www.fasdconnections.ca – click on 'Feature Articles'.

In this article, Jan talks about adolescents and adults with FASD not knowing that they cannot swim, and those that provide supports to them, as the lifeguards. Our sons and daughters may get into their 'boat' without the proper equipment (lifejacket, flashlight, map, radio…). Once in the boat, they cannot predict when a storm will come up, and therefore may be found floundering in the water. We rescue them. The next time they may remember some of the items needed, but still not recognize when a storm is coming, and again they need to be rescued.

My experience has been that every 'boat trip' is a little bit different, and thus it's very difficult for the individual to predict what's going to happen. How many times do we throw out the life ring or a rope? Jan mentions that lifeguards are found everywhere in society, and we all use them. Beaches and pools have them of course. Job sites have first aid attendants, mechanics inspect public transportation, food handlers wear gloves, red lights and speed limits control traffic…..and so on.

Now I'd like to quote the last part of the article:

"The issue, and where it can conflict with our own personal beliefs and definitely with that of society, is who, exactly, should have a lifeguard? Why should they have a lifeguard? What is the role of the lifeguard? How do you lifeguard effectively? How much life guarding should be done? Where and under what circumstances? How does one decide? Who decides? Who should the lifeguard be? Who pays? Who has ultimate responsibility? What happens when the lifeguard goes home? Does providing a lifeguard take away the rights of the individual?

And finally, what happens when there are no lifeguards for those the very most in need? And the answer to that, I think, is obvious. Look around you."

I find this excellent food for thought. As we try to put supports into place for our children, there are many things to consider….but we must do it, because they need those lifeguards.

Highlights of this Issue:

Network
Materials and Resources

7 New FASD Tips in Pictorial Format

A well chosen picture along with a clear message written in plain language is an extremely effective form of communication. The sharing of ideas and messages through pictures is in fact an ancient means of communication found in several cultures as well as an early means of communication for youngsters. Evidence of communicating with pictures can be found in the rock paintings of Northern Saskatchewan, the crayon drawings of very young children, or the high priced ads on billboards. These examples illustrate the value of communicating with pictures. Abstract ideas are made concrete through images. The audience is able to receive an entire message in an easily understood way and is more likely to be able to recall the information when it is needed. Because the need for advanced language skills is not a barrier to understanding, the message is received by a greater number of people.

Creating effective pictorial materials is not a simple process. The FASD Tips in pictorial format distributed by the are developed by an experienced team of individuals with a great deal of expertise in this process. In addition to the expertise of the design team, the materials go through several phases of testing and improvements. Focus groups comprised of community members are consulted, as are subject matter experts such as parents and professionals.

Sort Fact from Fantasy

How to Help Children and Teens Deal with Change

The FASD Tips in pictorial format have been well received by users. Persons with lower literacy, those whose first language is not English, busy parents and caregivers, as well as persons with FASD who are parenting, all find the pictorial versions of the FASD Tips for Parents and Caregivers to be helpful.

The Network will very soon have a set of 10 FASD Tips for Parents and Caregivers in a handy pictorial brochure format. We have recently received funding to create an additional 10. Call the office to order your copies.

The creation and printing of the pictorial materials has been funded by the Saskatchewan Liquor and Gaming Authority. We are grateful for the financial assistance and pleased that we can offer high quality parent support materials to people throughout the province.

Do You Need Information about FASD?

For information about FASD, give the Network a call. We have a variety of ways of providing information to community members. A print based information package can be tailored to meet a specific need or area of interest. We have information sheets and an excellent set of FASD Tips for Parents and Caregivers. If telephone support or consultation is what you need, call our toll free number: 1-866-673-FASN (3276). If it is a knowledgeable guest speaker or a training opportunity, we can help you make those arrangements.

Whether your need is for personal reasons, a school project, staff development, or information for a community group, we will do our best to help you to access resources. Remember, we are a provincial organization and we are committed to providing resources province wide. See contact information on page 16.

Saskatchewan's Action Plan for Citizens with Cognitive Disabilities

You may have heard of this Government Strategy. At present there are 4 Cognitive Disability Consultants in 4 regions of the province. In the next year, additional consultants will be hired to help individuals and families affected by FASD access funding and resources in their communities. For more information contact the Network; see contact information on page 16.

Articles, Reviews, and Websites

Book Review:

Finding Perspective...Raising Successful Children Affected by Fetal Alcohol Spectrum Disorder: A Parent's Guide to Creating Prevention Strategies and Intervention Techniques Using the OBD (Organic Brain Dysfunction) 3 Step Plan of Action
(2005) Liz Lawryk

Review by Kim Skidmore

In chapter one, the author lays a strong foundation by comparing the struggle that many parents of children with FASD are having, with the struggles parents of children with Down Syndrome had 25 years ago. She explains that years ago parents were told that their children with Down Syndrome "would likely require a special school" and "may need to be placed in a group home or institutional care." She states "in this day and age as a society we wouldn't dare discuss these options with parents of a child with a different medical issue that resulted in brain damage. In our desperation to initiate and accumulate services, we have created a dissimilar standard for children and families affected by alcohol related brain injury, one of overt and public labelling that not only involves a medical circumstance but a social condition as well—alcoholism."

After thinking about this, I realized that as parents we are breaking ground for our children; we insist that our children deserve the right to live at home with their family, go to their neighbourhood school, be members of a community and have many successes in their lives. I truly got the sense that the author had walked in my shoes.

While I found the book dragged at first, once Ms. Lawryk was explaining why some of my children reacted strongly to smells (one of my guys gags and throws up around anything that smells like dog food) or why some of my kids are toy breakers (I wish they manufactured toys for 13 year old boys that would last longer than 2 days) I was hooked on this book.

I wished I would have read a book like this when I was starting on my parenting journey. Strategies...I wanted strategies that worked. In fact, I was desperate for simple ideas on how to help my children not just survive their day, but actually enjoy their day. Ms. Lawryk's book is full of strategies.

I wished I would have read a book like this when I was starting on my parenting journey.

One of her strategies made me laugh out loud. She wrote "allow the use of a palm pilot...the one where they come home with their homework agenda written in ink on the inside of their hand. They have a slightly less chance of losing it as opposed to the other kind."

I found the OBD (organic brain dysfunction) 3 Step Plan of Action breaks behaviours down in a simple yet interesting way.

Step 1 Speaks to the behaviour
Step 2 Possible societal misinterpretations of the behaviour
Step 3 Central Nervous system issues that translate to behaviour

Ms. Lawryk then lists prevention strategies and intervention techniques that are wonderful.

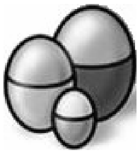
There are many, many nuggets in this book. At $42.95 plus I found it pricey, but it would be a valuable resource for parents, teachers, or anyone in a child's circle of support.

Kind thanks to Kim Skidmore for her review and to Liz Lawryk for providing a copy of her book to the Network for the review. We appreciate the focus on practical strategies that are so valuable to families. For ordering information, contact the Network.

Thank You.

Websites of Interest

National Database Of FASD and Substance Use During Pregnancy Resources
www.ccsa.ca/fas
The Database is a partnership project with the Canadian Centre on Substance Abuse. The information is relevant and easily accessible.



Directory of FASD Information and Support Services in Canada (2005).
This directory is the most comprehensive listing of services that is available. The directory can be ordered online or by writing to:
Canadian Centre on Substance Abuse
300-75 Albert Street
Ottawa, ON K1P 5E7
Or by email: fas@ccsa.ca

Provincial FASD News and Research

FASD Diagnosis and Assessment Information in Saskatchewan

by Beverly Palibroda

Many families in Saskatchewan find themselves seeking diagnosis and assessment services for a child or adult they suspect has been affected by prenatal alcohol exposure. Seeking a diagnosis can be a complex, time consuming and daunting process. In addition to having limited diagnostic services there seems to be a lack of information about how to access the services that do exist. Compounding this, many individuals and families have mixed feelings about whether a diagnosis will be beneficial to them.

Diagnosis and assessment can be done throughout the lifespan. Early diagnosis is advisable when this is an option. The process is less complex for children; it may be easier to establish evidence of maternal alcohol consumption and recommendations can be implemented in the child's life early on. Studies have shown that children who receive an early diagnosis are much less likely to develop secondary disabilities. Common secondary disabilities include: academic struggles, mental health or addictions issues, conflict with the law, unemployment and homelessness. **Reference: Streissguth, A., & Kanter, J. (1997). *The challenge of fetal alcohol syndrome: Overcoming secondary disabilities.* Seattle, WA: University of Washington.**

Early diagnosis may not always be an option. Individuals often begin the diagnostic and assessment process during adolescence or adulthood due to increased struggles with daily functioning, social difficulties, and the previously mentioned secondary disabilities. Regardless of when an individual is diagnosed, there are benefits for the individual, the family, and their circles of support.

Diagnosis must be made by a qualified physician. Ideally, a team of professionals, which may include an occupational therapist, physiotherapist, psychologist, social worker, and speech and language pathologist, are involved in the process. Together, the team gathers family history and conducts a thorough assessment of the individual to determine a diagnosis. The term Fetal Alcohol Spectrum Disorder is not a diagnosis. This is an umbrella term that encompasses the range of disabilities caused by prenatal alcohol exposure. The diagnostic terms that you will hear are: Fetal Alcohol Syndrome (FAS), Partial Fetal Alcohol Syndrome (pFAS), and Alcohol Related Neurodevelopmental Disorder (ARND).

Following assessment, it is possible that the individual may not receive a diagnosis within the spectrum of FASD. They may have a different disability or in some cases they may have an FASD as well as a co-existing diagnosis.

In Saskatchewan, diagnostic services are presently available in Regina, Saskatoon and Prince Albert. What follows is a brief overview of some of the services available at the present time; not all services are necessarily presented in this overview. There may be a waiting period at each location though the time period will fluctuate.

Saskatoon
Alvin Buckwold Child Development Program, Kinsmen Children's Centre
Contact: Anita Grosse for information on the diagnostic process.
(306) 655-1085
Support provided through diagnosis, assessment, and follow up for children birth to 18 years. Medical referral required.
A travelling clinic will also provide diagnosis in northern communities 3 times each year.

The FASD Centre at Regina Community Clinic
Contact: Cheryl Charron, FASD Case Coordinator for information on the diagnostic process.
(306) 543-7880 ext 268
Diagnosis of persons ages 6 through adulthood. Guidance is provided to the individual and family during the process of appointments, scheduling, and follow-up.

Regina Child and Youth Services
Contact: Intake Office
(306) 766-6700
Specialized assessment service for complex cognitive disorders for persons aged 6-24.

Wascana Rehabilitation Centre
(306) 766-5100
Children's Programs offers services accessed through referral by family physician.

Prince Albert
PA Health Region, Child and Youth Services
Contact: Lori Janzen for information on the diagnostic process.
(306)765-6333
The focus of services is for children up to 12 years; they are looking at expanding services to meet the needs of those over 12. The diagnostic team meets with the family to discuss options and recommendations.

Contact the Network with questions; see page 16 for contact information.

Provincial and Community Activities

Upcoming FASD Conference:
Sharing Our Stories, Strengthening Our Supports and Supporting Our Circle

by Marion Tudor

The Canada Northwest FASD Partnership is an alliance of the governments of the four western provinces and three territories. Since its inception in 1998, the goal of the partnership has been to develop an inter-provincial/territorial approach to the prevention of FASD and the care and support of those affected by FASD. The partnership holds conferences every two or three years. This year, Saskatchewan is the host province to what is promising to be an exciting event. The theme of the conference: Sharing our Stories, Strengthening our Supports and Supporting our Circles, creates a sense of hope and encouragement. When we work together on both individual and governmental levels, positive changes can be made.

This is an event you will want to attend. Whether you are a parent, caregiver, professional, direct service provider, or someone who wants to learn more about FASD prevention or strategies, there will be sessions of interest to you.

A pre-conference day of workshops is followed by two days of plenary and concurrent sessions on a wide variety of topics related to FASD.

Renowned speakers will be presenting over the three day event. Dr. Sterling Clarren, known internationally for his work with FASD, will bring the keynote address. Dr. Clarren is currently the Scientific Director and CEO of the Canada Northwest FASD Partnership Research Network. Other speakers to address plenary sessions at the conference are Dr. Tim Feeney, Dr. Don Bartlette and Dr. Lewis Mehl-Medrona.

Specifically for parents, caregivers, and family members, there will be presentations facilitated by experienced parents. The sessions will be related to strategies to help your child succeed, how to reframe our view of this disability from the negative to a more positive approach, and other information about what works for individuals with FASD. Other presentations will focus on supporting adults with FASD, diagnosis, education, advocating and developing services for individuals with FASD, women and substance use, public awareness, prevention and more.

The board and staff of the Saskatchewan Fetal Alcohol Support Network are looking forward to meeting many parents/caregivers at this conference. There will be opportunities to share experiences, learn from each other, make lasting connections, and even have some fun! Make sure you come and find us when you arrive – we will have a display table and will be easily identified by the sunflower logo wherever we go.

For more information about the conference and speakers visit the website at:
www.cnfasdpartnership.ca
Or www.preventioninstitute.sk.ca

A Special Note to Parents and Caregivers of Persons with FASD:

The Canada Northwest FASD conference is for **YOU.** Whether you are a birth, foster, adoptive parent, grandparent or anyone caring for an individual with FASD, we invite you to join us at this event. Although this will be a large conference and it may seem intimidating to some, the Network will do its best to ensure that parents, caregivers and families feel comfortable and supported. We want you to come out, share your stories, learn, meet others, strengthen your circle of support, and find out more about our organization and how we might be able to support you and your family.

Several of our board members, some of them parents, some professionals, will be presenting at the conference. They will share years of experiences, wisdom, and practical strategies that work for them. There will also be opportunities for parents and caregivers to get together for informal discussion. The board members and staff of the Network look forward to meeting you in Regina in May.
Registration and Network contact information can be found on page 16.
**If the registration fee is a barrier for you, please contact Angela at the Network.

Supported Housing Project Workshop Series:

When it comes to FASD, think Brain, not Blame

by Connie Jones

Brenda Bennett is the Executive Director of FASD Life's Journey, Inc., an organization in Winnipeg, Manitoba. At a recent workshop held in Saskatoon, she introduced her audience to the concept that "people may be born with disabilities, but society causes handicaps." Over the course of a two day workshop, participants had the opportunity to:

- understand FASD as a brain based disability,
- examine the current systems of social support,
- learn about and identify alternative means of support, and
- recognize that while each of us is a part of the "society" that causes "handicaps" by blaming persons with FASD for their struggles, we can indeed be a part of the change that is so clearly needed.

Most of us have been brought up to believe that we should punish intentionally bad behaviour. "What about socially unacceptable behaviours that come as a result of a disability?" asked Bennet. Unfortunately, this belief system is one of the greatest barriers to understanding and accepting Bennett's idiom, 'brain, not blame'. Bennett continually challenged workshop participants to understand the notion of 'brain, not blame'.

"FASD is not a cultural, racial, or mental health issue," explained Bennett. Alcohol has specific effects on the developing brain. The cognitive processes used to regulate conduct and adapt to social situations are located in the anterior frontal lobe of the brain. "This region doesn't develop sufficiently to allow the FASD affected individual to appropriately control his [or her] actions," explained Bennett.

Once we understand how these brain changes affect behaviour, we can begin to consider the support principles that work. "Support must be based on respect and dignity," said Bennett, especially since many people with FASD have not found favour within society. Caregivers should remember to include the individual in decisions regarding their supports. "If they're not amenable to the support you're providing, you don't have a hope of helping them," said Bennett.

The central nervous system damage that causes behaviours such as an inability to engage in meaningful conversation, frequent failure in social situations, inability to understand the concept of time, and poor predictive skills all make it difficult to provide effective support utilizing traditional approaches. It's often difficult for people with FASD to receive respectful health or other care, because they are perceived as 'throwaway people', said Bennett; consequently, she recommends implementing a clinical case management advocate who could lead the coordination and integration of care across all services and programs. An individualized habilitative plan would include a solid understanding of the individual's unique patchwork of needs, strengths, and disabilities across the individual's lifespan.

A case management advocate could help ensure successful approaches for supporting persons with FASD are implemented within each sector of social service provision. Successful approaches usually provide predictable, realistic expectations, consistent routine, impulse control assistance, de-stressing activities, fiddle devices such as squishy balls or a pocket full of elastic, reducing stimuli, and providing 1-1 support whenever possible. The adaptation of the environment by structuring the day, creating routines and rules, modifying caregiver expectations and expression of emotions is also vital to success.

Finally, all approaches must be overlaid on a foundation of a trusting relationship with a person who is knowledgeable about FASD. It is within a trusting relationship that skills such as appropriate behaviours for conflict resolution and identification of feelings and concerns are modeled. These skills are not learned in the classroom but through daily interactions.

FASD is not a cultural, racial, or mental health issue.

"Traditional social work interventions don't work for this population," she said. "Where are the people who understand this disability? It's a huge black hole."

Bennett stressed the importance of support workers taking a caring, not a curing, approach. "We can't cure them, but we can provide adaptations to support them to succeed."

Workshop proceedings will be available from the Network in May.

Supported Housing Project Workshop Series:

FASD and the Justice System: A Journey of Understanding

by Beverly Palibroda

In January of this 2006, Tina Antrobus traveled to Saskatoon to speak on the topic of supporting youth and adults with FASD who are involved with the justice system. Ms. Antrobus is a vibrant speaker, and an enthusiastic advocate for persons with FASD. Early on in her opening remarks Ms. Antrobus promised the audience, "I am going to take you on a journey of understanding," and indeed, over the two day workshop, she did guide participants on a journey of understanding. Participants gained an appreciation of the complexities of the relationship between persons with FASD and the justice system.

In Canada we do not have definitive data to suggest that the rates of incarceration or involvement in the justice system are higher for persons with FASD than that of the general population. However, we do know that there are persons with FASD involved at all levels of the justice system. The specific needs of persons with FASD are not being met because the brain based disabilities associated with FASD are not being recognized. The reasons why the needs of persons with FASD remain unrecognized are:

- FASD is for the most part, an invisible disability.
- Most persons affected by prenatal alcohol exposure do not have a diagnosis.
- Much of what families and professionals see is interpreted as wilful negative behaviour rather than disability based behaviour.

Persons with FASD have an odd relationship with the justice system. On the one hand, the system is based on the notion that one has to identify a problem, work through a process of remorse, face the consequence and take the necessary actions to make changes. Due to the disability based impaired reasoning of persons with FASD, they struggle each step of the way in this process. However, the other side of this relationship is that many persons with FASD are quite successful when incarcerated due to the structure, routine, limited choices and limited decision making required by the system.

Tina Antrobus, workshop facilitator

Professionals working within the justice system include law enforcement personnel, judges, lawyers, court workers, correctional workers, probation officers, and service providers from community organizations. Ms. Antrobus encourages professionals to look at the behaviour they are seeing in the situation and ask "why am I seeing this behaviour? Can the behaviour be traced back to the primary disability?" We know that we can not change the primary disability because the damage to the brain is life-long. What we can do is to change the environment around the person with FASD.

Again, we are to ask ourselves, "What can be put into place to externally compensate for impaired reasoning?" By asking these questions we are forced to look at things from a different standpoint. We start with an understanding that the brain has been injured by prenatal alcohol exposure and that much of what we see can be related back to impaired functioning in reasoning, language difficulties, adaptive behaviour, attention problems and impaired memory.

While participants were promised to be taken on a journey of understanding, Ms. Antrobus made it very clear that she was neither going to provide participants with quick solutions nor a "recipe book" means of providing support. A theme running throughout the two day event was that as professionals working within the justice system, participants were to take the information, ideas, strategies and concepts to work toward changing our thinking and to create a "lens" from which to determine how we can best serve each unique person with FASD.

As a complement to the information presented by the facilitator, a panel of local community members shared their experiences of what has worked for them in their particular area of the justice system. The input from community members rounded out our understanding of FASD and the justice system.

Workshop proceedings will be available from the Network in May.

Supported Housing Project Workshop Series:

Persons with FASD have a Right to Effective Mental Health and Addictions Services

by Beverly Palibroda

Over the course of a much anticipated workshop on the topic of mental health and addictions, Dan Dubovsky, FASD Specialist, generously shared his knowledge as a professional and a parent. His experiences raising his son Bill, were interwoven with sound research and proven strategies.

Mr. Dubovsky challenged workshop participants to support persons with FASD not in isolation, but in cooperation with families and circles of support. He stressed the need for service providers to be open to changing their thinking about FASD, to identify the strengths of individuals, and to be willing to "find another way" when traditional treatment strategies prove ineffective. Participants in the two day workshop were guided toward an understanding that persons with FASD don't simply need better services, they have a right to fair and effective services, and that it is imperative that the services be made available in our communities.

Research shows that persons affected prenatally by alcohol exposure are at greater risk of mental health and substance abuse problems. The disabilities caused by prenatal alcohol exposure, along with social factors such as lack of success, feelings of inadequacy, exposure to trauma, violence, disrupted lives and lack of family stability can lead to mental health issues like depression or anxiety. More problematic though, is the question as to how to provide effective mental health and addictions services for persons with FASD and their families. Professionals understand that traditional approaches for the treatment of addictions and mental health issues do not work for those with a significant brain injury caused by prenatal alcohol exposure, but they do not have an alternative.

Typically, when a traditional program fails the individual is blamed and dismissed as being unmotivated and non compliant. By blaming and dismissing the persons with FASD, service providers need not make necessary changes to their own thinking, interactions or treatment practices. When left without effective mental health and addictions treatment, lives are lost and people do not reach the incredible potential that could have been. The daily lived experiences of persons with FASD and their families provide ample evidence that this is happening.

There are no simple answers, but there are strategies that can be incorporated into treatment practices in mental health and addictions so that persons with FASD can receive the effective service that is their human right. What follows is a selection of strategies presented.

EDUCATION: According to Mr. Dubovsky, education and ongoing training for service providers, families, and community members should be a priority. All involved need to recognize the disability based behaviour is not purposeful. Along with education and training, families need respite services to avoid burnout. Service providers must recognize that even if families are struggling in the care of the person with FASD, it does not mean that they have nothing to offer.

ADAPTATION AND ACCOMODATIONS: Traditional approaches require adaptations. Service providers must be willing to be creative, flexible, and develop truly individualized programs that are strength based. Accommodating learning styles and adapting the environment of persons with FASD will improve outcomes. Examples include: one to one role modeling, practicing skills, videotaping activities, a simplified environment to reduce stimuli, and the use of plain concrete language to aid in communication. In addition, appointment times and locations should remain consistent to develop predictable routines. Meetings may need to be shorter and more frequent than typical. Plans should include achievable goals with a limited number of interventions. A support person can help to provide reminders to attend meetings and be a reassuring one to one presence. They can also assist with follow up and aftercare. All strategies mentioned can be implemented to create an alternative treatment approach.

RELATIONSHIPS: Safe relationships are beneficial to all of us, and especially so for persons with FASD. Role models, structured friendships, and well chosen community members can provide a consistent positive presence and lessen feelings of loss and grief. Mr. Dubovsky reminded us that persons with FASD are "very social but often socially inappropriate" and because of this may have limited meaningful connection and have likely experienced isolation. For this reason, treatment approaches must maximize relationships and physical presence and avoid isolation tactics. A positive relationship is a key element to the success for a person with FASD.

Workshop proceedings will be available from the Network in May.

Supported Housing Project Workshop Series:

Making it Work—Successful strategies for employment

by Connie Jones

In 1992, Marsha Teichman and her husband promised their newly adopted son that they would be a family por siempre – Spanish for forever.

“When the dream came true, the nightmare began,” recalled Teichman, an educator with the Access Program for People with Disabilities at Kwantlen College in Abbotsford, BC. “I realized that our kids grow up, but FASD stays. We need to adapt and change the world around them.”

We must remember that parents play an important role in the lives of their grown children, and their opinions count.

Kwantlen’s program offers career awareness, job preparation and vocational skills training to students with disabilities exiting high school. Research shows that up to 80% of people with FASD struggle to secure and maintain meaningful employment. “Our job is to look for the structures that our folks need in order to be successful,” she said. The trick is to shift our thinking from avoiding negative behaviour to modelling visual cues and creating successful physical environments. “It’s not that people with FASD can’t [be employed successfully],” said Teichman. “It’s that they need support, and that’s okay.”

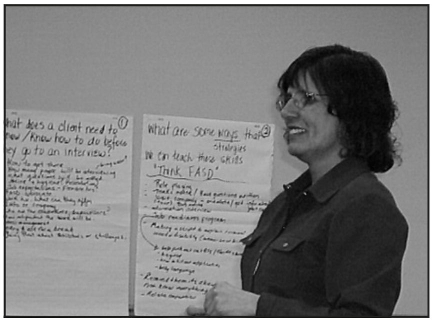
In a recent workshop held in Saskatoon, Teichman outlined several strategies to help individuals with FASD get the most out of a work placement or maintain meaningful employment. Here are just a few:

- Show, don’t tell: People with FASD are hands-on learners. “If you can touch it, you can learn it” is a motto that works.
- Employee self-disclosure: Individuals should identify their disability to their potential employer. Feel free to describe the disability in ways that the employer can support while respecting the individual’s sensitivities (i.e.: “I have a learning difficulty”, etc.).
- ‘Discovery’, not ‘failure’: Classify unsuccessful work experiences as ‘discoveries’ - valuable reference points to help learn what is and is not a good match, and why.
- Consider part-time employment, as full-time work is often too taxing.
- Offer interview support: Be present, and act as an interpreter to communicate idioms of English language into understandable linear meaning.
- Understand daily job requirements: Avoid memory issues by carrying a pen and notebook.
- When readying for an interview, enlist the help of a parent to help with the details, such as hygiene, outfit choices, and transportation planning. Study the interview questions in advance, and practice the answers. Remind them that it’s okay to not know everything.
- ‘Fair’ is not ‘same’: What works for one may not necessarily be workable for another.

There is no provincial transition plan; therefore people with FASD are dependent upon building relationship with principals, frontline teachers and parents, said Teichman. Making the leap from school to work can be made easier if students begin the process as early as Grade 10. Job coaching can begin during their last summer holiday to form linkages.

“When I promised that judge in Puerto Rico that I’d be his mother por siempre, I meant it,” said Teichman. “This is a cradle to grave commitment.” We must remember that parents play an important role in the lives of their grown children, and their opinions count. “The goal is successful interdependence,” she said. “Why should we expect anyone to be independent when they hit 19? “No one should be - No one is.”

For more information, visit www.fasdconnections.ca.



Marsha Teichman leads the group in an interactive employment session.

Workshop proceedings will be available from the Network in May.

National FASD
News, Research and Stories

Article Review: The FASD Toolkit for Aboriginal Families

Jennifer Wemigwans & Mary Cunningham. Ontario Federation of Indian Friendship Centres (OFIFC) (September 2005)

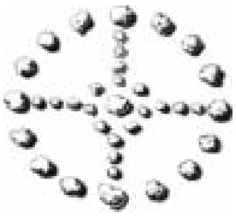
Review by Sylvia Nagy

The FASD Tool Kit for Aboriginal Communities was prepared by The Ontario Federation of Indian Friendship Centres. Author Jennifer Wemigwans has prepared a “user friendly” resource, along with main contributor, Mary Cunningham, who works out of the Northwestern FASD Clinic. The expertise of both has produced an excellent tool kit designed to be used by the front-line workers who are supporting Aboriginal families affected by FASD. The Tool Kit is divided into four sections:

1. **Vision**
2. **Relationship**
3. **Reason**
4. **Movement**

The four sections are based on the Medicine Wheel concept. This holistic model has been adapted to create an understanding of FASD.

The first section, Vision, highlights the need for those working with FASD in the community to have a vision for their community. The Tool Kit emphasizes that in order to have that vision one begins with a basic awareness of FASD and an awareness of the broad issues that need to be addressed by the community. FASD and culture is addressed and the author makes the point that: “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 one 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 than predominance of FASD.” (Wemigwans, 2005).



It recommends that when planning a community event to play down the FASD issue and play up other aspects such as ‘Developmental Difficulties’ or ‘ADHD’ in order to bypass the stigma attached to FASD and hopefully reach a wider audience.

The next section on the medicine wheel deals with Relationship. The front line worker is in the unique position of developing relationships with both the affected family and the resource people who can support them. This involves developing trust among all parties. The Tool Kit walks through the diagnostic process. Clearly the diagnostic process is one that can benefit from a relationship built on trust. The relationship can help families prepare for and accept a diagnosis. The Tool Kit stresses the importance of the team approach.

A full time job in itself is the role of advocacy. If a front line worker has been involved in supporting diagnosis, he or she may also become that individual’s chief advocate. Although because the front line worker already has many roles to play; it is recommended that the family would be better served if they are shown how to become advocates for themselves.

The third section, entitled Reason, provides strategies to parents and teachers. It explores what is being done for students with FASD. A comprehensive chart on characteristics and expectations taken from the work of Diane Malbin is on page 17. This is useful information for parents and teachers alike.

The final section of the tool Kit, entitled Movement, contains a lot of practical information on taking action and mobilizing the community to address the issues of FASD. The author suggests starting an FASD task force to help the various agencies work together since the work involved will take more than individual effort or single agency involvement.

While this Tool Kit is “user-friendly” it could become more so by using a larger font for the text. The pages could have been designed to be pulled out and used as handouts or worksheets to provide information to clients, whether parents or teachers. But, for anyone who takes the time to go through this document, they could find much useful and interesting information to assist them in finding and applying appropriate tools and supports to address FASD at the community level.

Kind Thanks to Sylvia Nagy for her review of this resource.

Wemigwans, J., Cunningham, M., (2005 September). *FASD tool kit for Aboriginal families available at* www.ofifc.org

New 'Eye Movement' Test may Help Treat Fetal Alcohol Syndrome

Queen's University
Public release date: 11-Nov-2005
Contact: Nancy Dorrance
dorrance@post.queensu.ca
613-533-2869

KINGSTON, Ont. - A simple test that measures eye movement may help to identify children with Fetal Alcohol Spectrum Disorder (FASD) and ultimately lead to improved treatment for the condition, say Queen's University researchers.

At present there are no objective diagnostic tools that can be used to distinguish between children with FASD - which affects approximately one per cent of children in Canada - and those with other developmental disorders such as Attention-Deficit Hyperactivity Disorder (ADHD).

Researcher James Reynolds and graduate student Courtney Green, of the Department of Pharmacology and Toxicology and the Centre for Neuroscience Studies, will present their findings next week at the annual meeting of the international Society for Neuroscience in Washington, D.C.

"Having a set of tests that can be used as diagnostic tools for fetal alcohol syndrome and all of the other behavioural disorders classified under the broader term fetal alcohol spectrum disorder is tremendously valuable," says Dr. Reynolds, who is part of a $1.25-million Queen's-led team focusing on fetal alcohol syndrome, funded by the Canadian Institutes of Health Research. "Now we can begin to identify specific deficits in these children."

Many of the behavioural tests used to assess children with FASD are geared to white, middle-class English-speaking people, notes Ms. Green. "The biggest problem [in current tests] is cultural insensitivity," she says. "By measuring eye movement we can cut across cultural barriers and provide objectivity in identifying the disorder."

In a pilot study involving 25 girls and boys aged eight to 12, the Queen's team found that children with FASD have specific brain abnormalities which can be measured with eye movement testing. Defined as "birth defects resulting from a mother's consumption of alcohol during pregnancy", fetal alcohol syndrome is associated with hyperactivity, difficulty in learning and deficits in memory, understanding and reasoning, as well as problems dealing with stressful situations. The next stage of the Queen's research will be to make the eye movement test mobile and transport it to targeted areas, such as northern and rural parts of Ontario, where FASD is believed to be more prevalent. The researchers envision this as a multi-centre project, in which other participants will work from the same set of pooled data.

"There is a clear need to develop new tools that can be used to reliably and objectively measure the brain injury of FASD," says Dr. Reynolds. "Ideally, these tools need to be mobile, inexpensive, and easy to use, for both diagnosis and the long-term evaluation of therapeutic interventions. Eye movements are ideally suited for this purpose."

Using the new functional MRI facility at Queen's, the team will then be able to measure differences in brain activity between children with fetal alcohol syndrome and those with other developmental disorders such as ADHD.

"Having access to this facility will have a huge impact on our research program," Dr. Reynolds says. "It allows us to create an integrated research strategy for carrying out studies to provide functional brain imaging data that can be directly related to neuro-behavioural deficits in individual children with FASD."

The cost of FASD

According to a news release the annual cost of Fetal Alcohol Spectrum Disorder to Canadians is upwards of $344 million a year. This research can be found in the February 28, 2006 issue of the *Journal of FAS International* on the website:

www.motherisk.org/JFAS/

International FASD News, Research and Stories

International FASD Awareness Day September 9, 2006

In Canada and around the world, September 9th has been designated as International FASD Awareness Day. The significance of September 9 is that this is the ninth day of the ninth month of the calendar year. This reminds us of the 9 months it takes for the growth and development of a baby.

It is time to start thinking about how your community might recognize International FASD Awareness Day. Throughout the world communities recognize the day in a number of ways. Last year many Canadians joined others throughout the world, from locations such as the United States, South Africa, France, and Germany to take part in range of events.

The events are intended to increase understanding, awareness and compassions for those affected by prenatal alcohol exposure.

Inspiration and ideas for community events can be found on the FAS World website at: www.fasworld.com. You can also obtain a copy of FASD Awareness Day guide from the Saskatchewan Prevention Institute at: www.preventioninstitute.ca or by calling 655-2512. Once you have decided what to do to mark September 9th, contact the Network office for help in promoting your event.

There are many creative ways of recognizing FASD. An interesting campaign that began in the United States last year is the Nine Zero Campaign. We have all seen the colourful silicone bracelets adorning wrists. This campaign introduced a bright red wristband. The red is symbolic of a stop sign. The message is to stop drinking alcohol for nine months, for the safety of the growing baby. Along with the wristbands, there are several versions of the poster pictured here. You can download the poster at www.ninezero.org and insert relevant community information to promote your event.

The Nine Zero wristbands are available to order in quantities to sell or to give away to promote awareness.

An event that complimented the Nine Zero campaign in 2005 was a poster contest. School aged children throughout Alaska had the opportunity to design a poster promoting the message of zero alcohol for nine months. Clearly people in all regions of the world and of all ages can contribute to FASD awareness.

Let creativity be your guide as you think about how you might mobilize your community to recognize FASD Awareness Day this coming September. Good Luck.

FRANCE

WARNING labels will soon appear on bottles of alcohol sold in France. The labels are expected to be in place by early 2006. The labels will include a pictogram warning of the dangers of prenatal alcohol exposure to a developing fetus.

syndrome of foetal alcoholization SAF

GERMANY

A COMMUNITY based project in Berlin is providing support and housing for young adults with FASD. The project arose because people with FASD identified that they did not feel like they belonged in the community. They also identified that because FASD was not accepted as a disability they could not access services needed for independent living. Sound familiar??

IRELAND

RESEARCH shows that almost one-in-10 pregnant women in Ireland are putting the health of their unborn children at risk by consuming more than six alcoholic drinks a week. The Department of Health insists there is no known safe level of alcohol use in pregnancy and recommends stopping completely until the birth of the child.

FASD: Questions and Answers

How To Choose A Criminal Lawyer For Your Child or a Person With FASD

by David Boulding

These few sentences are intended for parents and caregivers of persons with the brain based birth defect often called Fetal Alcohol Spectrum Disorder. Social services staff, probation officers, teachers and like-minded folks might also find some comfort here.

I have some 15 years experience as a criminal lawyer, both prosecution and defence. Like many lawyers, I have made many mistakes as a lawyer when dealing with clients with fetal alcohol issues. I intend here to suggest ways you and your lawyer can avoid some of the mistakes I have made.

Choosing a lawyer can be difficult because most people touch the law when they sell or buy their house, or have a will made or interpreted. Most members of any public audience have formed their impressions of what a lawyer does and is from these mild encounters.

I trust you know that neither Hollywood, nor the million-channel TV universe, has much reality when it comes to law and lawyers.

A criminal defence lawyer usually only does criminal work. He or she may have a few side areas of law, but the focus is always on defending people who have criminal problems. Thus, ALWAYS avoid a lawyer who says he has a general practice of real estate, family and corporate law.

Start looking in the yellow pages of the phone book. A quick scan will reveal that most lawyers that advertise indicate their practice is restricted to personal injury work. Then, notice that a few say their work is restricted to criminal defence. This gives you a list from which to choose.

If you have friends who have contacts in the police department or at the courthouse ask them. It is a universal truth, quietly acknowledged, that the police always know who the good lawyers are. When police, lawyers, court staff, probation officers, by- law enforcement staff, and other such ordinary people get in trouble they seem to use the same lawyers—good defence lawyers. Asking your local constable is a good start. In addition, take the advice carefully, remembering how much you paid for it.

From the short list you have gathered from the yellow pages, phone a few. Choosing a lawyer should consume more time and energy than buying a new car or truck. So phoning five or six lawyers is a good start, but probably not enough to make an informed decision. You may have to speak to ten and you may have to ask probation officers or friends at work. Think especially of those who have had occasion to use a criminal lawyer.

Rarely will lawyers tell you much about themselves or their practice over the phone. After you have tried the above methods, you need to interview lawyers in their offices.

The trick is to find a competent criminal defence lawyer you like and trust—LIKE AND TRUST.

These words must be your standard. If you like her, your communication will be excellent. If you trust him, you will have the sense of being heard, of being seen in your problem and you will understand what is happening to your child.

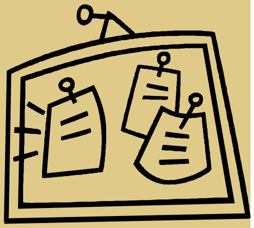
Do not worry if your lawyer knows nothing about FASD. You can educate a criminal lawyer quickly. No ones learns as quickly as a criminal lawyer does with a file in hand.

Do not gauge criminal lawyers by the furniture in the waiting room. Do not expect her to be gushing, emotional or use fluffy social language at your arrival in the office like a commission sales clerk. The business of criminal law is deadly serious and your lawyer will get immediately to business.

Money matters need quick clarification and agreement. Lawyers are expensive, and few and fewer are accepting legal aid. Here you will be guided by your income. If you cannot pay for the one you have selected, she will gladly suggest one suitable to your ability to pay.

Disclaimer: ***Living with FASD*** offers this question and answer column as general information. It is not intended as a substitute for professional advice on medical, behavioural, educational, or legal matters specific to your situation. This response has been printed with consent from the Mr. Boulding. The Network thanks him for generously sharing his knowledge. If you have a question, concerns, or would like more information on this topic, contact the Network office; see contact information on page 16.

Upcoming Events And Learning Opportunities



For event information contact the Network

Saskatchewan Fetal Alcohol Support Network
John V. Remai Centre
510 Cynthia Street
Saskatoon, SK S7L 7K7

Toll Free:1-866-673-FASN (3276)
In Saskatoon: 975-0884

fasdnetwork@sasktel.net
www.skfasnetwork.ca

The vision of the Saskatchewan Fetal Alcohol Support Network, a parent-led organization, is for individuals with Fetal Alcohol Spectrum Disorder and their families to recognize themselves as safe, supported, valued and contributing members of the community.

To reach this vision we provide support to people with Fetal Alcohol Spectrum Disorder, their families and circles of support by:

- Providing information and education
- Promoting early assessment, diagnosis and intervention
- Advocating for the development of life-long support services for individuals with FASD
- Establishing partnerships
- Working to increase awareness of FASD

The Network creates this publication, *Living with FASD*, as a benefit of membership. Memberships are available for $15. Please contact the office to become a member.

Living with FASD
Publication Committee
Beverly Palibroda, Shelley Kolisnek, Jonina Male, Kim Skidmore, and Sylvia Nagy.

Understanding Learning Disabilities and the Assessment Process

Saturday, April 29, 2006
To register in this or other Learning Disabilities Courses by VISA or MASTERCARD, contact the Extension Division Registration Office at (306) 966-5539.
If you wish to be added to a mailing list for courses on Learning Disabilities, please call Marilyn at 966-5575.

See My Pain! Helping Children & Adolescents Who Self Injure

Sponsored by: Child & Youth Services - Sun Country Health Region
April 28, 2006
Weyburn, SK
Contact Information:
Holly Power/Sharon Mulhall
Phone: (306) 842-8665

Adults with FASD 2006 Conference:

"Navigating the Rapids: Doing What Works In Practice"
May 4th - 6th, 2006
Vancouver, BC
www.interprofessional.ubc.ca
or call the Network for a copy of the registration form.

Canada Northwest FASD Partnership Conference Sharing our Stories, Strengthening our Supports, Supporting our Circle

May 17-19th, 2006
Queensbury Convention Centre
Regina, SK
$400.00 3 full days
$250.00 3 full days reduced fee for parents, caregivers, and students
For registration information visit:
www.www.cnfasdpartnership.ca
www.preventioninstitute.sk.ca
(306) 683-3663 or call the Network.

Pathways to the Future "Nikanihk mesa kanahkewina"

Gathering of the Saskatchewan Aboriginal Literacy Network Inc.
Saskatoon, Saskatchewan
May 9 – 11, 2006
Call Tammy Forrester @ 384-6044
We welcome all learners, Elders, practitioners, and people interested in Aboriginal literacy to consider attending this rich and rewarding experience.

Saskatchewan Fetal Alcohol Support Network

Annual General Meeting
June 3, 2006
Details to be announced.

Article Submission

The next issue of *Living with FASD* will be distributed in the Fall of 2006. The deadline for submissions is August 1, 2006. The Network welcomes personal stories, poetry, photos, article reviews, or research findings.

Please contact Beverly at 975-0806 to discuss submissions or to pass along story ideas.