Living With FASD

Spring 2008

Featuring Articles by Nathan Ory, Brenda Knight, Diane Malbin and Annette Cutknife

FASD Support Network
of Saskatchewan Inc.

Always be on the
lookout for the
presence of wonder.

E.B White

FASD Support Network of Saskatchewan

Board Members and Staff

Board Members 2007-2008

Back row: Beverly Palibroda (staff), Kim Skidmore, Lisa Brownstone, Sandy Overs, Angela Schmolke (staff), Rae Mitten, Trudy Shingoose. Front row-Marilyn Macdonald, Shirley Hellquist, Marion Tudor, Sylvia Nagy. Board members not pictured: Sharon Taylor, Ingrid Friesen and Tracy Breher.

Staff Contact Information

Angela Schmolke
Executive Director
Toll Free 1-866-673-3276
In Saskatoon (306) 975-0884
fasdnetwork@sasktel.net

Megan Wood
Employment Support Coordinator
(306) 975-0806
Cell (306) 717-0589
fasdmentor@sasktel.net

Beverly Palibroda
Communications Coordinator
Toll Free 1-866-673-3276
In Saskatoon (306) 975-0806
fasdcommunications@sasktel.net

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Living with FASD
Editor Beverly Palibroda

Living with FASD is published twice yearly by the FASD Support Network of Saskatchewan Inc. This publication is a benefit of membership. Memberships are available for $15.00. Please support us by contacting the office to become a member of the Network.

Article Submission

The next issue of *Living with FASD* will be distributed in the Fall of 2008. The deadline for submissions is August 15, 2008. The Network welcomes personal stories, poetry, photos, article reviews or research findings. To discuss submissions or story ideas please contact Beverly at 975-0806 or by email at: fasdcommunications@sasktel.net.

We are Online!

To access additional articles, information and resources prepared by the Network please visit our website:

www.skfasnetwork.ca

President's Message

by Trudy Shingoose

> "Advocating for funding and resources for a group as diverse as those living with FASD is a challenging task."

Spring is finally upon us! In conjunction with Mother Nature's rebirth, the Network is busy planting the seeds for a renewal of our own. The Board of Directors is currently beginning the process of developing a five-year strategic plan. Just as each of us in our own lives must engage in self-reflection and analysis from time to time, so too must an organization. There are numerous benefits to periodically stepping back. This process allows the board of directors to evaluate previous accomplishments, examine current issues, consider future directions, and identify and prioritize goals for future programming. We expect that the resulting five-year plan will provide us with a clearly defined path on which to move forward to best represent individuals and families living with FASD.

The five-year plan will take into account the valuable suggestions and concerns shared by parents, Network members, individuals with FASD and the community at large. I would like to thank all of you, on behalf of the Network, for the insight and input we have received. Advocating for funding and resources for a group as diverse as those living with FASD is a challenging task. However, this task was easier because we heard from so many of you.

You have voiced concerns over issues as diverse as diagnosis and assessment, access to educational supports, involvement with the justice system, the necessity of support through the life-time, difficulties accessing funding, availability of respite services and access to trained mentors. Clearly, individual needs and experiences vary greatly. Our task it to reflect on the individual needs and identify the common themes that have been expressed.

Well, as you can see we will be busy in the upcoming months. We intend to have a clear plan of action to share with our readers in the Fall 2008 issue of *Living with FASD*. The board and staff are excited about this opportunity to help make dreams into reality.

While we reflect on the big picture, please remember, the Network will still be there for you as you experience your daily struggles and successes. Our toll-free line is easily accessible for support and we have a range of information about FASD available to every community and every individual who may have questions.

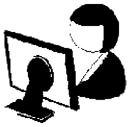
I hope each of you has a great spring and summer.✺

Trudy

International FASD Awareness Day

As many of our readers know, September 9th is International FASD Awareness Day. The Network is exploring ideas to promote this day throughout the province. We understand that many communities already recognize this day with a variety of events and activities. As a provincially based organization it would be great to hear how your community plans to mark this day.

Let us know your plans; we would love to hear from you and help to promote your events. Please see contact information on page 16.✺



Around the Network Office

Become a Member of the FASD Support Network of Saskatchewan

You can support the work of the board of directors and Network staff by becoming a member. Membership is $15.00 annually and includes E-mail notices of events and resources, copies of all new materials as they are produced, receipt of our quarterly newsletter, *Network News*, as well as our biannual publication, *Living with FASD*. Your membership is important to us. Please call the office for information on how to become a member; contact information on page16.❋

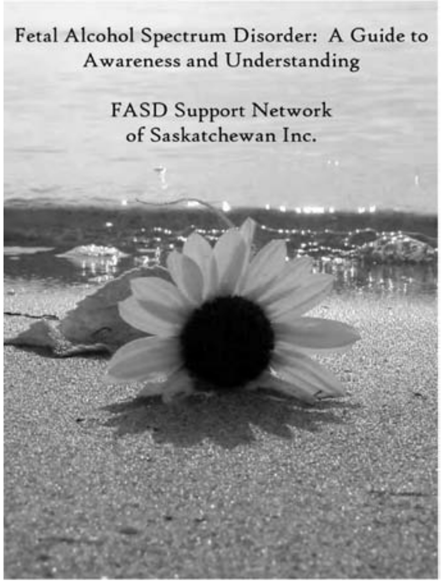
A New Resource now Available!!

One of the primary goals of the Network is to educate community members about FASD. We provide education through workshops, presentations, displays at events and meetings, E-mail distribution of materials, website based information, and by mailing out information packages on request. The Network is proud to provide quality education to individuals and groups throughout the province and across Canada.

As an organization, we recognize there is an ongoing need for awareness and understanding of FASD and we continually strive to meet this need in new and creative ways. We handle many requests for information related to diagnosis, characteristics of FASD, and effective parenting or support strategies. In response to such requests, we have produced a booklet titled, *Fetal Alcohol Spectrum Disorder: A Guide to Awareness and Understanding*. This booklet brings together a collection of information sheets and articles along with the entire set of 20 FASD Tips for Parents and Caregivers.

While this resource is quite new, response so far has been incredibly positive. The information contained is suitable for families, professionals, support personnel and the general public.

If you are interested in receiving a copy, or multiple copies, please contact us. Individual copies will be sent at no cost; for orders over 5 copies we will charge the cost of shipping; contact information on page 16.❋



Fetal Alcohol Spectrum Disorder: A Guide to Awareness and Understanding

FASD Support Network of Saskatchewan Inc.

Notice of FASD Support Network Annual General Meeting

Be sure to watch for notice of the next Annual General Meeting of the FASD Support Network of Saskatchewan. The AGM is planned for late spring and will be held in Saskatoon. This is a great opportunity to come out and learn more about our organization and the work we do. We look forward to meeting with new members and to visiting with those we have not seen for awhile.❋

Information and Resources

The Best I Can Be

Revised 2nd Edition
by Liz and Jodee Kulp

Thoughts by Beverly Palibroda,
Megan Wood and
Liz Shoofey Stabler

There really is something quite magical about an introduction to a formerly unknown book. *The Best I Can Be* is not your conventional volume about Fetal Alcohol Spectrum Disorder; it is not written by a researcher or professional or even a team of researchers and professionals. *The Best I Can Be* is a book written as a collaboration between a young woman with FASD and her mother. This is the kind of book that, as you are reading, you want to jot down phrases to help you remember the ideas. That impulse to write down ideas was the motivation for this article. I asked my colleagues to choose a compelling passage and explain why this specific passage was meaningful to her. If you choose to read this book, I suspect you too will find a passage that is meaningful to you.

Here are a few of our thoughts on *The Best I Can Be* .

Liz Shoofey Stabler, mentor advocate:

Each of the stories in this book hit home in terms of insight into some of the difficulties faced by the individuals with FASD that I have had the pleasure to get to know. I chose Family Gatherings (17) because of the unique strategies this family found to help their daughter cope with the excitement of family gatherings. It is a well-established observation that individuals with FASD have difficulties in situations that are loud, crowded or overly stimulating. What I found most interesting about this story was the extent that this family went to enable their daughter, Liz, to experience family celebrations yet make it work for her. Suggestions like dining under a table and peeking out from under a tablecloth or eating dinner in the bathroom are wonderful ideas.

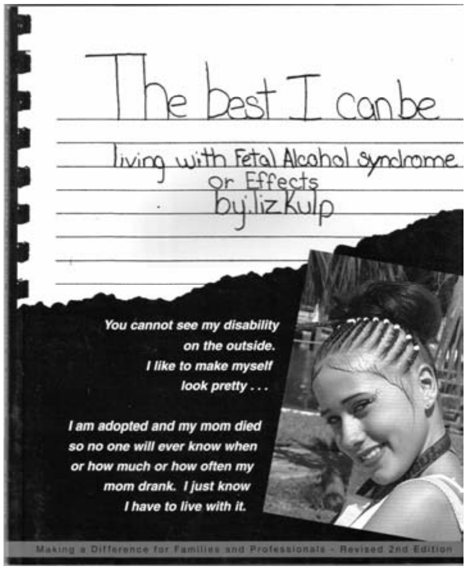
These strategies helped Liz to feel safe enough to participate in important occasions and feel a sense of belonging while avoiding the temper tantrums or meltdowns she would often have when she felt overwhelmed. The Mom comments that to others it seemed like they were appeasing her with the strategies and essentially showing lack of control. In reality, they were maintaining control with the strategies that worked for her. I too have noticed the reactions of well-meaning but uninformed people who think some of the behaviours exhibited by children with cognitive disabilities are due to poor parenting when this clearly is not the case.

Megan Wood, Employment Support Coordinator chose the following passage:

“Today, she can manage the grizzly bears in her brain when her hormones are balanced, she is rested, not stressed, and is properly fed. We managed Liz’s environment as much as possible and watched for the danger signs. Most of all we didn’t judge the brainstorms. We loved the child.” (39)

This passage embodies the spirit and message of the entire book. With support, an individual with FASD is able to learn, grow and manage her behaviours. When the people who surround a person with FASD understand that the individual will need accommodations, that individual can be then be successful. This passage also speaks to an issue I have been slowly learning about over the past year - the importance of helping an individual with FASD manage vital human needs and functions like diet, sleep and stress management. The author recognized the effect of this balance on her daughter’s behaviour and that her daughter may not be able to recognize nor address an imbalance without the help of others.

As well, it is incredibly important that the family didn’t judge Liz for her behaviours. They accepted those behaviours as a part of her disability and helped her to deal with them as best as she could.



Community News and Activities

Exploring Motivation and Employment

by Megan Wood, Employment Support Coordinator

The FASD Support Network of Saskatchewan has been presented with an exciting venture over the past 6 months. The Opportunities Fund provided funding for employment support for individuals with FASD in Saskatoon. Along with individualized support, new connections have been made with a variety of employers. The intention is to increase the employment of people with FASD thereby creating opportunities for individuals to experience the benefits of meaningful work. This includes a decreased reliance on outside financial assistance, a sense of belonging and an increased sense of self-worth.

Those involved in the Employment Project have taught me a great deal about how to discover what type of work will best suit each individual. As a starting point, we must first examine strengths, weaknesses, skills and areas of interest. I have also learned that the issue of personal motivation to work is just as important and frequently overlooked. When we do not question why someone would want to work, and simply assume that work is something that we all do, we miss information. All people are motivated to work for different reasons. For example, some people with FASD think in very concrete ways and will only recognize the concrete gains from working, usually from earning money. These individuals will probably not last in a workplace if they do not see the financial gain. If the individual is currently receiving social assistance careful planning must occur in order to ensure that the individual can experience a financial benefit.

Others with FASD value the connections with coworkers and a feeling of accomplishment. Many people with FASD need the support of others in their life, so it can be particularly gratifying to feel needed by an employer and to contribute to a workplace. These individuals will do well in jobs where they have connections with other employees and tasks that result in regular success and positive feedback.

Another group of people may be motivated by a need to be busy and active. These individuals have a high level of energy and will be suited for physical work.. They may get into trouble if they are unoccupied as they seek outlets for their energy. One such individual has been involved in the Employment Support Project and he recognizes how being active helps him stay on track..

Individual motivations also help determine the type of job accommodations and support needed. If someone is motivated by money, the support worker may need to help with budgeting or setting up a trustee. If an individual is motivated by a need for belonging, the support worker will do well to provide positive feedback and develop natural workplace supports. For those motivated by a need for activity, recreational support outside the workplace is a good addition to the physical labour.

> "I have also learned that the issue of personal motivation to work is just as important and frequently overlooked."

There are other reasons to work or not to work; in fact there are usually combinations of motivations for each individual. When supporting those with FASD to enter the workplace, be certain that you listen and consider these motivations—even when they do not fit with your own values or ideas. Finding a job that meets these various needs will ensure a greater likelihood of success and longevity in the workplace for an individual with FASD. ❁

Regina FASD Community Network

The Regina FASD Community Network is an intersectoral group with approximately 25 members. This cooperative group is comprised of parents, family members and agency representatives. Together members work to maintain the dedication needed to address the issue of FASD in and around Regina. A major initiative of the Regina FASD Community Network is the partnership with Regina Community Clinic to develop the FASD Centre. The group has worked to build supports and create access to various services for families and individuals living with FASD.

For those interested in getting involved, monthly meetings are held at 4-Directions Community Clinic. Meetings are on the last Thursday of each month from 9:00AM-11:00AM. Please feel free to drop in to participate in the next meeting. For more information contact either of the group co-chairs:Lisa Workman at 766-7546 or Cheryl Charron at 543-7880. ❁

Community News and Activities

First Ever Parent Retreat —A Great Success

The parent and caregiver retreat, hosted by the Network in the fall of 2007, was envisioned as time away from the multiple responsibilities, tasks, stresses and routines of every day life. We wanted parents and caregivers of persons with FASD to feel that this was time set aside just for them to be with others who might understand their experiences.

When the Network sent out the invitation to the first ever retreat we were cautiously optimistic. We hoped that parents and caregivers would see the value in this gathering and want to come, but we were unsure as we had not tried an event like this before. The retreat was promoted as a time to laugh, share and learn. Well, the response was amazing! Very quickly emails, faxes, phone calls and letters came into the office. Evidently parents and caregivers were interested!

Local performer, Krystle Pederson, delighted the crowd with her charm and talent.

Dr. Patricia Blakely presented and responded to many questions from participants of the parent retreat.

As a way to help parents and caregivers feel special and pampered a massage therapist was on site, healthy and tasty meals were served, hotel accommodation was provided for out of town guests and fabulous door prizes presented. Each participant received a gift bag with information about FASD, resources, treats and much to everyone's excitement —chocolate!
In addition to all the mentioned comforts, we arranged several excellent presenters and performers. There was a blend of practical information, fun and pleasure.

An expected outcome of the event was the forming of new friendships and connections among others who understand both the joys and struggles of raising a child, teen or adult with a life-long cognitive disability. We believe that important connections were made and for that we are incredibly gratified. Huge thanks to all participants and invited speakers, guests and performers. ✺

FASD Speakers Bureau Expands to Meet Needs in Northern Saskatchewan Communities

In 2004 two provincial organizations, the Saskatchewan Prevention Institute and the FASD Support Network of Saskatchewan, collaborated to establish the FASD Speakers Bureau. Each speaker is well qualified and has an area of expertise in FASD. Several regions of the province are represented by speakers. Thanks to additional members recently joining the Northern Speakers Bureau, the more remote northern communities will have better access to information about FASD. The members of the Speakers Bureau are available to present at a variety events.

Since 2004 and to the present day, members of the Speakers Bureau have successfully assisted communities and organizations to increase awareness and understanding of FASD. Whether the goal is to reach a specific audience or the general public, there is likely a speaker to meet your needs. The individuals involved in the Speakers Bureau can share expertise, inform and inspire your group, and help work to promote social change around issues related to FASD. If you are interested in booking a speaker please contact the Saskatchewan FASD Speakers Bureau Coordinator at the Saskatchewan Prevention Institute
E-mail: info@preventioninstitute.sk.ca
Phone: (306) 655-2512
Fax: (306) 655-2511 ✺

A Story about Trying Differently

by Diane Malbin

Good parents and professionals often try harder and harder to change behaviours of children and youth with FASD. Frustration is a common outcome. "Trying differently rather than harder" is less of a technique or strategy, more a way of asking different questions and finding solutions based on understanding of FASD as a brain-based physical disability. The following story illustrates how this works:

My wife and I have a 15 year old foster son with FASD. We were really frustrated with him because his chore was to do the dishes, and it took him nearly 2 hours to do the dinner dishes. We always had to spend another hour cleaning up after his cleaning up. While he was doing his chore, he'd work for a while, stop, come into the living room, and we'd ask him to go back and finish his job. We were frustrated because we thought he was just trying to get out of doing his chore.

After the training on FASD, my wife and I decided to watch and see what was happening when he did the dishes. The first night we observed him here's what we saw: He was the last one done with dinner. He went into the kitchen and started filling up the sink with hot water. He also started pouring liquid dish soap into the sink. While he was pouring the soap, he looked out the window over the sink and spotted someone walking on the sidewalk, then a cool car drove by, and someone else went by. All this time he was pouring the soap into the sink. By the time he looked down, he got a look of amazement on his face when he saw that the water was nearly to the top of the sink and there was a huge mound of bubbles in the sink. He turned off the water, took a big scoop of bubbles out of the sink, put them on his head and came out into the living room to show everybody his crown of bubbles. The other boys were laughing hysterically. He went back into the kitchen, started washing dishes and water splashed out of the sink onto the counter and floor. A few minutes later he came out and we redirected him back to the dishes. Again, we thought he was just trying to not finish his work.

> "We could have tried for months to teach him to do the dishes, but that wasn't the whole picture."

When my wife and I talked about it later, and thought about his FASD, we realized a few things. At 15 he's more like 5 in some ways (how many 15-year-olds put bubbles on their heads?), he has trouble doing multi-step tasks, has trouble remembering things, and he's very distractible -- particularly visually. On the plus side, his strengths, he's a visual learner, willing, determined, is a hard worker, does well with structure, and has a great sense of humor.

We came up with a plan. The next night, before he was done with his dinner, my wife went into the kitchen and closed the curtains on the window over the sink. She filled the washing and rinsing sinks with hot water and added *a little* soap. When my son was done with dinner, he went into the kitchen and started washing. A few minutes later when he came out, we realized he just needed to know what the next step was. We simply asked, "How about the salt and pepper shakers?" He put those away. We now understood that his coming out wasn't because he was trying to avoid doing his job; he couldn't remember what came next. We said one thing at a time, he finished the dishes in 45 minutes and we didn't have to clean up after him.

We could have tried for months to teach him to do the dishes, but that wasn't the whole picture. He was able to do the dishes with a little structure. We were less frustrated and so was he.

Comment: The beauty of this story is that it shows the value of observing behaviours through a different lens. Recognizing strengths and challenges identifies points of prevention. Linking brain function with behaviours provides a way to reframe behaviours. In this case, the shift in perceptions went from seeing him as "not trying" to understanding he needed one step at a time guidance. This example also demonstrates solutions are usually win-win. Problems are solved and future problems prevented. It also indicates that working with people with FASD is not about finding the right "technique," it is about observing, asking questions, identifying points of accommodation, and from this, preventing problems. ✽

Contact Information:
© FASCETS.org
dmalbin@fascets.org

How to divert someone you cannot confront without an explosion?

by Nathan E. Ory, M.A.

Many individuals with organic brain dysfunction experience extreme emotional arousal when they feel “cornered” by a question or an expectation.

They may be confused by the language used with them or may be unable to resolve the conflict implicit in having to make a choice.

Avoid pressuring a person with FASD for an immediate response. Always try to give the person a “way out” of the situation.

When confused or uncertain, some people immediately become threatening and aggressive as a means of protecting themselves from the feeling of anxiety and confusion, and not knowing what else to do.

Your suggestion or correction may feel like criticism or disapproval and they may react against their perception of being rejected. They don’t know what else to do. Instead of reacting to their threat or aggression, use a variety of methods to divert and defuse the situation.

For a person with FASD, it is helpful to remain “in-the-moment” with them and to give them a “way out” with a concrete prop.

For example: Appeal to his self-interest:

- Hand a TV guide: “What is on tonight. Is there any hockey?”
- Hand a blank grocery list: “What do we need for supper?”
- Hand a pool schedule: “What time are we going tomorrow?”

Use a pre-rehearsed method that you have worked out with the individual for using the “right way” out of a situation. For many people it works to print these options onto cards that you can show them the “right answer” rather than tell them to do.

- Go think in your room.
- Go hit the heavy bag in the garage
- Go for a walk by the river.
- Give XXX a phone call.
- Never mind, just sit by yourself for a minute.
- Tear up this card and come have a cup of tea.
- It can be helpful for the support person to model, “I’m ok, but I need a break.”

> “Your suggestion or correction may feel like criticism or disapproval…”

For people who live, “in the moment”, make a catalogue of similar, relevant, off the cuff comments and questions that you can ask to interrupt their current action and redirect them without causing them to feel confronted.

Offering help to some individuals can be interpreted by them as, “I’m a failure and I can’t do anything for myself.” If he or she “shuts down” when upset they may become even more reactive to verbal guidance. Use visual guidance to offer a way “out” of the situation:

- Hand a CD or MP3 to prompt him to go to a private place to listen to music.
- Hand a box of pens to encourage her to be alone and do a project.
- Hand a box of tea bags to encourage taking a break and to involve in sense of smell and taste.
- Hand a cut out heart or heart shaped pillow to remind her to “come have a hug when you are ready.”
- Hand him a card with the words, “Come see me when you are ready.”
- Hand him a photo album of pictures doing activity associated with positive memories.
- Ask him to play a piece of music on his keyboard.

Appeal to her sense of being positively regarded and respected:

- So you don’t have to “remind” them, (this feels like nagging) write things down for them to self-remind.
- What is on her mind is important. Give her a white board so that she can write down what she wants to say when she first thinks of it. Then she won’t be frustrated that she forgot.

Never say “no,” “not allowed,” “not here,” or “I won’t.” Say what he is allowed, where, and what you will do. Suggest what he is allowed to do and what you will do with him.
For example:

- Do not say, “Don’t call me all the time.” Instead, say “Call me every day, after super. I want to tell you that I love you.”
- Do not say, “You can’t sleep over tonight.” Instead, say “You can sleep over for two nights every 21 days.”

All of these are methods that have been useful in avoiding explosive episodes in persons with organic brain dysfunction.

Contact Information:
© Nathan E. Ory, M.A. (2007)
Registered Psychologist (B.C.)
Challenging Behavior Analysis and Consultation, Ltd.
543 Marine View, Cobble Hill, BC, Canada V0R 1L1
challengingbehavior@shaw.ca
Phone: 250-743-1667

I am not the person that I used to be...

by Brenda Knight

I am a high energy person. I am a very loving and caring person with a lot of patience who rarely gets mad. I am very well organized and can balance my life successfully.

I am exhausted. Depleted. I have become a cranky mean old bag with no patience who always seems to be angry. My life is in chaos and there is no balance.

Who are these two people?

These two are one. The before and the after.

The first is the optimistic, enthusiastic person who was ready to have a family because he or she felt that they have so much to offer. The second person is the later product of living with little emotional or professional support in a complex Relationship, with a child with FASD, who likely has not been Diagnosed, and is having a hard time coping with life.

I see this person in my practice weekly. Competent, caring people who are at the end of the rope wanting to find a way to recapture themselves and to build their relationship with their child.

Eighteen years ago that was me. My teenage daughter had not yet been diagnosed and I was living in a state of exhaustion and self-loathing. I was wondering why I was capable of helping others and was such a loser as a parent myself. Gradually the understanding and healing set in and I am now a comfortable parent of a thirty-two year old daughter who is a wonderful mother and wife.

> "I see this person in my practice weekly. Competent, caring people who are at the end of the rope wanting to find a way to recapture themselves and to build their relationship with their child."

Living with a child with FASD can be manageable and delightful An early diagnosis, informed medical and professional support, respite options, community resources, appropriate education services and knowledgeable and supportive friends and family, makes this possible. If these services were not available when the child was young, the ensuing difficulties may not be resolvable but they may be entrenched with little hope for resolution. These are the tragedies that happened to families who care and love deeply and are living with the challenges of how to protect and support themselves and their children.

When the depleted parent appears, she needs to be listened to fully with respect and empathy. She needs the opportunity to lay out the story from beginning to end. Often the parents I see have experienced years of frustration and invalidation and muster enormous courage to one more time pursue professional help. It is my responsibility to make it a positive and hopeful experience. Regardless of the outcome with our children, gaining perspective and having support makes it much more manageable and a less isolating experience.

Often it is apparent that the parent is burnt out and requires medical treatment for depression and anxiety. In addition, they need to develop a therapeutic relationship with someone who has the skills to support the parents and treat the child.

This requires the therapist to recognize the value of working together.

Keeping the parent in the loop and not seeing the child in isolation is a necessity. Professionals need the parents as a reality check because often the child or adult-child is not capable of accurately reporting events or symptoms nor adequately advocating for themselves.

When I presented workshops last fall in Moose Jaw and Saskatoon, I met courageous parents, grandparents and caregivers who have braved the isolation and the trauma and demonstrated at times impossible commitment and consistency to their children. Against all odds, so many had withstood the frustration and now have found support and solace in the Network to help them continue or let go, knowing that there were people who cared for them and their children.

I deeply respect those parents who can continue and those who recognize that they have to let go. ❋

Contact Information:
Brenda M. Knight
Registered Psychologist CPBC #00694
Private Practice
325-1200 Burrard Street
Vancouver, BC V6Z 2C7
604-662-7755 Fax 604 662-7215

Raising Daniel

by Annette Cutknife

Daniel Allan Lloyd Cutknife was born 6:04 a.m. one cold October morning in 1988. He did not make a sound when he was delivered by forceps; I knew instantly something was wrong and that he was not healthy. I knew this the second he was born because of his silence. Later, my fears were confirmed that something was wrong, when he made a funny squeaky noise when he was feeding. I knew then that the drinking that I had done during my pregnancy greatly affected my son.

Following Daniel's birth, I denied his condition and my alcoholism. I was still a practicing alcoholic until he was going on eight years old. I seemed to manage my consumption during the first 3 years of his life because he was constantly hospitalized and I was tending to his needs. Then, in April of 1991 tragedy struck our family when my brother was killed. That year I kept myself extremely busy so I would not to feel the loss of my brother and then on the first anniversary of his death, it struck me very hard and thus I drank heavily for four years. I finally sobered up in April of 1996.

Daniel has had many health problems. From the age of 2 months until he was about 5 years old, Daniel was hospitalized regularly. He had many respiratory ailments, ear infections, and various surgeries including tubes in his ears, dental problems, G-Tube, plastic surgery to repair his outer ears, wandering eye problem, restorative hearing surgery, removal of extra teeth (prior to braces) and removal of wisdom teeth (post braces). He has been under anaesthetic at least 16 times in his lifetime.

When Daniel started Kindergarten, I could not deny his condition any longer. His teacher confronted me with concerns about his behaviour almost immediately. She listed all his deficits to me, such as inability to follow simple instructions, hyper-activity, short attention span, hard to understand, and disappearing from class. She commented, "I don't know what is wrong with him, although, I'm sure you have an idea, so why don't we get him assessed and get him the right supports in place. "I made an appointment and he was assessed and received a diagnosis of mild to moderate FAE. This was a good start and because of this he had his personal aide to assist him in the classroom from that point on until grade 4.

He received that diagnosis because I was not honest with my alcohol intake at the time. When Daniel was 14, I deciphered my shorthand notes from college. For some unknown reason, when I became pregnant in college I recorded my alcohol intake. My notes indicated that I had 14 sittings in total where I had consumed 8 or more drinks. This information was helpful when he was re-assessed at the age of 16. Daniel's current diagnosis is pFAS with static encephalopathy – alcohol exposed, severe receptive and expressive language delay and poor speech intelligibility.

Even though Daniel has been diagnosed with an FASD, has experienced many medical concerns and will likely continue to have medical concerns, he has also achieved a lot. Daniel is presently in grade 12 and will be graduating from high school in the Spring. I am so proud of him.

I do not know what the future will bring for Daniel. My immediate concern for him is that he keeps talking about drinking with his peers. I keep reinforcing to him that drinking is very dangerous for him, and he keeps reassuring me that he will not drink. However, I know about the impulsivity and lack of cause and affect thinking that may lead him to experiment, which terrifies me.

I keep positive and work hard on my recovery and do my ultimate best to be there for Daniel at all times. I love him dearly. ✺

Contact Information:
Annette Cutknife
acutknife@samsoncreenation.com

National FASD
News, Research and Stories

FASD friends: a foundation for fighting a preventable condition

by Louise Nadeau

Every Sept. 9 for the past eight years, a growing number of Canadian communities, researchers and social and health-care practitioners have gathered to mark International Fetal Alcohol Spectrum Disorder Day. The concept is to educate the public about the far-reaching effects of FASD and to highlight the importance of efforts to curb this highly preventable condition.

The effects of FASD, the result of a woman's alcohol consumption during pregnancy, are physical, mental and behavioural and can have lifelong implications for the affected person, the mother, family and community. In many cases, it has been shown that persons living with it develop secondary disabilities, such as depression, obsessive-compulsive disorder and alcohol and drug addictions, all of which may directly contribute to negative social and economic outcomes.

As Sept. 9 comes and goes, we are left to contend with the reality that FASD is a serious health and societal concern for all Canadians. About 300,000 Canadians are already living with negative consequences related to FASD, and it's estimated that nine out of 1,000 babies are born with it each year. There is still a large need for additional research into all aspects of the fetal effects of alcohol during pregnancy and as the affected children become adolescents and adults. With this in mind, a broad-ranging group of experts and concerned parties have come together to create the Canadian Foundation on Fetal Alcohol Research, a not-for-profit granting body aimed at promoting new research and facilitating the dissemination of information on the consequences of FASD.

> Together, we can position Canada at the forefront of funding research.

The foundation will be officially launched at this year's annual Fetal Alcohol Canadian Expertise conference, held in conjunction with International FASD Day.

As its chair, it is my hope that the foundation will help launch a new generation of Canadian researchers dedicated to increasing our understanding of the biological, psychological and social processes of alcohol consumption during pregnancy. CFFAR will also increase our understanding about the children, adolescents and adults who live with FASD, and the tools and strategies that can be developed to help them cope.

Of course, CFFAR and its research can never replace a network of support and education. It can't be a substitute for the courage that love and spiritual experience can provide. But research is the key ingredient to understanding the causes and effects of FASD, and to developing ways to address them. If and when we can demonstrate scientifically that the psychological and social problems of people affected by FASD are a result of their biological condition, then as a society, we will be better able to understand and assist those in need.

Governments have tried to support research and awareness on the prevention and treatment of FASD, especially in high-risk first nations communities. The foundation will be supported with an initial investment from the Brewers Association of Canada of $1-million over the next five years, making it by far the largest non-governmental investment in FASD research support in Canada. While this funding will provide a starting point, much more is needed

As foundation chair, I am challenging government and others to meet and exceed the brewers' commitment. Together, we can position Canada at the forefront of funding research.

The foundation will be a compliment to the Motherisk initiative of the Hospital for Sick Children, affiliated with the University of Toronto and the annual Fetal Alcohol Canadian Expertise Research Roundtables. Each of these initiatives has been partly or wholly funded by the Brewers Association of Canada.

Almost 35 years after officially recognizing the existence and effects of FASD, I believe we have reached a turning point. Our new foundation ultimately hopes to decrease the incidence of FASD and prevent many communities from experiencing a reality that is still far too common across the country. ✻

Louise Nadeau, PhD, is chair of the Canadian Foundation on Fetal Alcohol Research and a professor in the department of psychology at the Université de Montréal.

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National FASD
News, Research and Stories

The Annual Fetal Alcohol Canadian Expertise (FACE) Research Roundtable Webcasts are Available Online!!

The Annual Fetal Alcohol Canadian Expertise (FACE) Research Roundtable is held each year in September to mark International FASD Awareness Day. Presentations from 2002 to 2007 are available as online webcasts on the Knowledge Network website. Each webcast is a tremendous opportunity to view presentations made by leaders in FASD research. To view the most recent webcast, search the phrase — FASD Webcast 2007— with your internet browser or visit the website at:

www.knowledgenetwork.ca/fas/index.html

The 2008 FACE Research Roundtable will be held on September 9, 2008 in Montreal, Quebec. Planning is still underway but each year the most current research findings are presented. Watch for more information as September draws nearer. ❋

The Alcohol and Substance Use Helpline

1-877-327-4636

The Alcohol and Substance Use Helpline offers information and counseling to pregnant and breastfeeding women, their families, and health care providers. Helpline information is based on continuing research and study by Motherisk's specialized team of physicians, psychologists, pharmacologists and counselors.

You can reach the helpline:

- Monday to Friday, 9 a.m. to 5 p.m. in each of Canada's time zones
- toll free within Canada
- in English or French

Call for information on:

- the possible effects of alcohol and other substances on your baby
- referrals to services in home communities
- Fetal Alcohol Syndrome assessments at The Hospital for Sick Children
- laboratory tests for drugs and alcohol in babies ❋

The FASD Ontario Justice Committee Website

http://fasdjustice.on.ca/

With funding from the Public Health Agency of Canada, the Ontario Justice Committee has developed a website to be used as a resource for justice system professionals and others who are grappling to understand FASD.

This is an excellent Canadian website that brings together a large amount of useful information including case law, legal resources, background information, and practical tips. The committee hopes the site "will offer strategies for dealing with the unique problems presented by offenders, victims and witnesses with FASD in compassionate, fair and effective ways." (http://fasdjustice.on.ca/)

While most of the listed resources are within Ontario the intention is to eventually include resources from across Canada. The Case Law section of the site is updated with new legal decisions that refer to FASD. ❋

International FASD News, Research and Stories

Elephant Domains™

By Michael L. Harris M.A., L.P.
Indian Health Board of Minneapolis, Inc. Article 2 of 3

Please Note: The FASD Elephant™ article 1 of 3 by Michael L. Harris was reprinted in the Fall 2007 issue of *Living with FASD.* Contact us for a copy or visit Michael's website at www.FASDElephant.com to view all three articles plus additional information. Article 3 will be published in the Fall 2008 issue of *Living with FASD.*

The previous article discussed the six wise men who couldn't see the elephant they were describing. Each formed a different belief based on the part of the elephant he'd touched. Each belief *felt* right, but all were wrong. This metaphor reminds us to consider the whole FASD Elephant™—especially brain damage—when facing FASD behavior challenges.

To solve these challenges, though, one must be able to see *all* parts of the FASD Elephant™—the Ten Brain Domains of Functioning. Here is a brief overview of each "Elephant Domain™:"

1. **Achievement** —Ability to learn and use reading, writing, and arithmetic skills

2. **Adaptive Behavior**—Using daily living skills for home, school, and community

3. **Attention**—Ability to maintain selective, sustained, and focused attention

4. **Cognition** —Verbal and nonverbal IQ, thinking abilities, processing efficiency

5. **Executive Functioning** — Self-regulation, decision-making, planning, prediction, inference, deduction, organizing skills

6. **Language**—Speaking and understanding grammar, syntax, sentence structure

7. **Memory** —Long and short term capacity to encode, store, & retrieve information

8. **Motor** —Ability to use and coordinate small/fine and large/gross muscles

9. **Sensory/Soft Neuro** — Sensory integration and processing problems or a weakened nervous system

10. **Social Communication** — Capacity to communicate in social situations by reading and using social cues

When an FASD challenge arises, immediately identify which Elephant Domain™ is causing the problem. See the whole elephant —not just behavior—and think about the brain damage. Ask yourself, "What does this person's FASD brain need to be successful in this situation?"

Use your ideas to try different interventions and accommodations, rather than just repeat the same ones over and over. Otherwise, if you only try harder, then you'll only get the same negative results. Think differently.

Remember, this is just an introduction. You can read more about the Ten Brain Domains and a practical method to use the domains at www.FASDWheel.com. ✺

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FASD: Questions and Answers

by Sandy and Mike Overs

Q. I have a daughter who is affected by an FASD. My family just doesn't seem to understand my situation and I end up feeling like they think I am a bad parent. I would like their support and understanding but I am afraid to ask for help. Do you have any ideas about what I could do?

A. We also encountered the same issue with a few members of our family. Parenting children with an FASD requires structure and consistency along with a good dose of patience. Sometimes members of our family saw, and continue to view our actions, as too strict and that we should lighten up on the rules. As you may well know, to get the best out of the children and minimize outbursts, disruptive or destructive behaviours, a consistent approach to discipline and behaviour control is required.

One of the strategies that has worked to get the community and extended family on board with us was to provide education on the issues we were coping with in working with the children. This can be done by open and frank discussions with them and providing them with information like pamphlets, books, internet sites. A good source of information for families dealing with FASD is available from the Network. Another approach was to have them attend workshops that dealt with the issues we were encountering (FASD, ADD, ADHD, opposition defiance, etc…) When talking to our family members, they stated that having first hand experience with the children helped them to comprehend the issues we were dealing with.

> "Try to keep and encourage the positive relationships and minimize those that aren't."

When certain behaviours become evident as your child is around other family members, you can explain why the children have these behaviours and the best strategies that work to resolve or counter the behaviour. As your family gets to know and understand the children, you may be able to start using them as a major part of your support system. Parenting children with an FASD can and will be very stressful so this could be helpful.

Be prepared though, that no matter how much some family members get to know your children or how much you try to educate them, some will still not understand the issues and will remain critical of the way you parent. Remember, you parent these children 24 hours a day, seven days a week, and you will know the best way to deal with them and the resources required. Until they have walked in your shoes for a good length of time they will not fully understand what you or your children need.

Our children have a great relationship with their aunts, uncles, cousins, and grandparents and that is what all children need. Keep your family members involved with your family and like all relationships, it will take time for them to get to know and understand your children. This will help you and your children and lessen the stress in your life. Above all, keep a positive outlook… ❁

Sandy and Mike

Sandy and Mike Overs are parents of two young adults affected by FASD. Sandy is also a member of the FASD Support Network Board of Directors. Together Sandy and Mike have gained insight into many common parenting issues and struggles. They have generously agreed to share their understanding about gaining the support of extended family members in response to this question. Thank you to Sandy and Mike for your thoughtful response.

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. ❁

Upcoming Events
And Learning Opportunities

For further event information contact the Network

Third National Biennial Conference on Adolescents and Adults with FASD—FASD and Mental Health: The Wisdom of Practice
April 9th – 12th, 2008
Vancouver, British Columbia
Contact: Yolande Chang Phone: (604) 822-7524 Fax: (604) 822-4835
Email: ipad@interchange.ubc.ca Website: www.interprofessional.ubc.ca

Adoption Support Centre of Saskatchewan
Growing Attachments Conference
Guest Speaker Deborah Gray
May 5, 2008
Saskatoon, Saskatchewan
Contact: Cindy Haftner Phone: (306) 665 -7272
Website: http://adoptionsask.org

Canada Northwest FASD Partnership Conference Building on our Strengths: Stone by Stone
May 21-24, 2008
Banff, Alberta
Website: http://www.cnfasdpartnership.ca/index.cfm

The 3rd Saskatchewan Aboriginal Literacy Network Gathering 2008
Building Our Future Through Literacy
May 20 - 23, 2008
Waskesiu, Saskatchewan Prince Albert National Park
Keynote Speakers: Dr. Don Bartlette and Tom Roberts
Contact: Mari James at (306) 763-8258 or (306) 960-3646
Email: Gathering2008@sasktel.net

Community Development Society - Annual International Conference
June 22-25, 2008
Saskatoon, Saskatchewan
Website: www.comm-dev.org
Email: cloden@heartofwi.com
Phone: 1-715-423-1830

12th Biennial Symposium on Violence and Aggression
June 22 - 24, 2008
TCU Place, Saskatoon, Saskatchewan
Phone: (306) 966-1382
Fax: (306) 966-5567
E-mail: va.symposium@usask.ca

FASD Support Network of Saskatchewan Inc.

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 FASD Support Network of Saskatchewan, 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