Living With FASD

Fall 2006

FASD Support Network
of Saskatchewan Inc.

In my own limited experience
I have found that the more
we care for the happiness
of others, the greater is our own
sense of well being.

The Dalai Lama

FASD Support Network of Saskatchewan
The Board and Staff

Board of Directors 2006-2007

The Network relies on the unique gifts contributed by each volunteer member of our board of directors. The volunteer board members give freely of their time and expertise in order to make a difference. Countless hours of hard work, planning and meetings go into the efforts and successes of the Network. The board has seen some recent changes; we want to acknowledge and give thanks to outgoing board members: Jonina Male, Terry Hellquist, Sarah Guenther, and Shelley Kolisnek. As well, we extend a warm welcome to new board members: Lisa Brownstone, Anita Grosse, Sharon Taylor, and Trudy Shingoose. These individuals are already hard at work and their efforts are appreciated.

Board Members at a recent gathering: Sandy Overs, Shirley Hellquist, Lisa Brownstone, Marion Tudor, Sharon Taylor, and Kim Skidmore. Not pictured: Marilyn Macdonald, Rae Mitten, Sylvia Nagy, Trudy Shingoose and Anita Grosse.

Living with FASD
Fall 2006

Publication Committee
Beverly Palibroda, Kim Skidmore, and Sylvia Nagy.

Living with FASD is published twice yearly by the FASD Support Network of Saskatchewan. This publication is a benefit of membership. Memberships are available for $15. Please support us by contacting the office to become a member.

Article Submission
The next issue of ***Living with FASD*** will be distributed in the Spring of 2007. The deadline for submissions is February 15, 2007. The Network welcomes personal stories, poetry, photos, article Reviews or research findings. Please contact Beverly at 975-0806 or skfasnetwork@sasktel.net to discuss submissions or to pass along story ideas.

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President's Message

by Marion Tudor

I am writing this in the middle of August with the sun streaming in through the window beside me….and I'm thinking about all that will happen this fall and winter related to FASD and the Support Network. I know it will be a busy time, with interesting and exciting projects starting up. The Network continues to grow, providing information, support and training for parents, service providers and professionals across the province.

Not only does the Network grow – so do our children. My daughters are now in their late twenties, though I find that hard to believe! Looking back over the past two or three years, I see a noticeable change. I am much less involved in the daily activities and details of my daughters' lives. This is a good thing, and I have my friends who understand FASD to thank for it.

Ten years ago, when Karen and Dawn were in their teens, life was pretty crazy. You name it – it happened! I was completely tied up in crises and worrying about what would happen next. I wasn't ready to let go and was sure that if I did, things would get worse. I think I was right – Karen and Dawn needed to know that I was there and would try to rescue them when they needed it, even if they didn't want me around most of the time. I like to think that my heavy involvement at that time made a difference and has contributed to the increased stability in their lives now.

As my daughters reached their mid-twenties, my friends pointed out that I was exhausting myself, I couldn't keep up this pace forever, and I couldn't control their actions or decisions. It was time for me to step back and time for Karen and Dawn to take their own journey. It took me a while to digest this. It's really hard to step back and see the big picture when you've been totally engrossed in something for years. I was so used to keeping track of what was going on and offering to help; I wasn't sure what would happen if I didn't – perhaps things would fall apart again.

> It was time for me to step back and for Karen and Dawn to take their own journey.

Now, several years later (I'm a slow learner!), I see that I've distanced myself somewhat from the daily involvement I once had. There are times when I consciously let things go that previously I would have rushed off to do. Because of this, Karen and Dawn find ways to do those things without me. My daughters live close by, so I still see them often and talk to them every few days, but often they call me rather than the other way around. Later this month I'll help one of them move – but I won't be lifting the heavy furniture or finding a truck for the move….

I suppose the realization that we should step back comes to different people at different times, and it will depend on the individual situation. It's a challenge to find a balance between letting our children take their own journey and providing the support they still need because of their disability. Parents have their own journeys too, and sometimes we lose track of that, don't we? I've often said to other parents 'you can only do what you can do', meaning 'you can't do everything!' However, I've realized there comes a time when we can, and should, step back and not do. I don't mean that I won't help or be involved, but I will give my daughters the room to do what they want to do, even when it doesn't seem right to me. It is their journey. Also, I have given myself permission to set some boundaries for my life.

At the Network we often hear from parents of adult children with FASD. Many are struggling with the things I've mentioned above. The recognition that we each must travel our own path is something all parents and caregivers should think about no matter how old their children are. All parents, will come to this point in the journey sometime.

"I am only one, But still I am one.
I cannot do everything, But still I can do something;
And because I cannot do everything
I will not refuse to do the something that I can do."
-Edward Everett

FASD Support Network Materials and Resources

Tackling the Tough Issues Faced by Youth and Adults with FASD

Youth and adults affected by FASD can feel like they walk a tightrope each day. Issues such as sexuality, dating, drugs, alcohol, peer pressure, staying out of trouble with the law, and healthy self esteem commonly create difficulties. The difficulties most often spiral outward and create additional stresses and strains for various family members and those in the circle of support.

With funding received through the National Crime Prevention Strategy, the Network has been creating the latest in our series of Tips for Parents and Caregivers. The Tips address tough issues in practical and candid ways and provide parents, caregivers, and mentors with actual ideas and strategies that can be used to support loved ones with FASD.

While we recognize that it is hard to face the challenges of living with FASD, the teen and young adult years can especially be a struggle. However, as one parent has suggested, if a teen doesn't learn about healthy and safe sexuality or drug and alcohol use from parents and trusted family, mentors, or support persons, they will learn from others. The lessons gained from others will not likely maintain their health and safety nor be in the best interests of the vulnerable young person with FASD. The risks of secondary disabilities for persons with FASD are extremely high and the consequences of not tackling issues are dangerous. The Network is hopeful that our new FASD Tips promote positive outcomes for young people by providing tools to begin discussions around some of these tough issues.

The most recent titles:

- How to help a teen or adult avoid trouble with the law
- How to help teens and adults avoid drug and alcohol use and abuse
- Healthy and safe sexuality for teens and adults
- Understanding FASD

With the release of the most recent Tips in text and pictorial versions, the Network will have a set of 20. Members will receive the tips by mail in the very near future. Alternately, visit our website to download copies of the text version.

Check with your local Association for Community Living. Resources and materials are available on a variety of topics. The resources on sexuality and transitioning into adulthood are particularly helpful.

We are Creating a Poster!

Many gains have been made in the level of public knowledge about FASD. Community members are more aware of the issues faced by persons with FASD and with increased awareness, comes a greater understanding of the nature of this disability. The Network continues to work with communities to establish support and acceptance for families affected by FASD. Knowing how far we have come, it is surprising when members of the public indicate that they have not heard of the Network.

As a means of addressing our apparent low profile in some communities, the Network is developing a poster. The intention is to increase public awareness of the services and support that are available. Of particular importance is our toll free telephone warm line. Parents, caregivers, professionals, and persons affected by FASD can call the toll free line to speak to staff of the Network. All calls are confidential and every effort is made to provide respectful and effective telephone support. In many cases callers receive print information, referral to other sources of service, or are linked to a board member for further discussion of parenting strategies and advocacy issues. Whatever the reason for the call, all callers are met with kind words and understanding.

Watch for our poster. We will distribute posters widely in hopes that more community members will be aware of the FASD Support Network and will access our services.

Articles, Reviews, and Websites

Let's Talk FASD: Parent Driven Best Practice Strategies in Caring for Children and Adults with FASD.

Victorian Order of Nurses VON Canada; 2005
Review by Shirley Hellquist

This publication, funded by the FASD National Strategic Projects Fund, Public Health Agency of Canada, is printed in both English and French. As it says in the introduction "VON Canada has developed parent-driven best practice parenting guidelines for children and adults with FASD … These parent-driven guidelines have evolved from the first hand experience of those living with FASD and those that care for them and respond to a community need for tips, techniques and strategies that are empirically proven by parents themselves."

As a parent of two young adults with FASD I heartily endorse this book…

In my opinion this is a valuable resource for parents and caregivers of individuals with FASD. The material is well-organized and very practical. Since the suggestions and strategies come from parents themselves, they all carry with them a great deal of authenticity. Although every strategy will not work with every individual or in every situation they give each family a place to start when caring for a child with FASD. In my experience, if one strategy doesn't work in a given situation then another one probably will.

The book is divided into four sections. The first covers Routine and Consistency, Managing Behaviour, Learning Strategies, Making and Keeping Friends, Getting a Diagnosis, Secondary Effects of FASD, Helping Adults and Teens with FASD, Connecting with Others, and Care for the Caregiver. The second, Educating Professionals and the Public, contains separate information sheets in a pocket on: What You Need to Know about Me, What You Need to Know about the Child with FASD, and FASD – What You Need to Know. These information sheets can be photocopied and given out at the parent's discretion as needed. I think most parents will find this very helpful.

The third section headed In The Community has three topics: Advocacy/FASD and Professionals; FASD and the School System; and FASD and the Public. Here too there are many practical suggestions from parents specific to each of the three topics. The fourth part of the book is titled Resource Toolbox and is a compilation of publications, websites and information regarding access to workshops and conferences. Some of the contact information in this section is in pale blue print which I found a little difficult to read. The book is also printed on shiny, white paper and so it might be difficult for some people to read in bright sunlight or artificial light due to glare on the page.

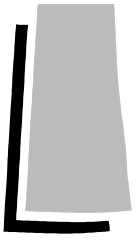
As a parent of two young adults with FASD I heartily endorse this book as an excellent resource which I would have found very useful had it been developed earlier! Although useful to all families regardless of the age of the individual with FASD, I think it will be even more valuable to families starting their FASD journey. By using a tool such as Let's Talk FASD, the strategies can be implemented as soon as possible after diagnosis or when there is even some suspicion that FASD might be what the family is dealing with.

Let's Talk FASD is available online as a pdf document. Visit the website at www.von.ca/FASD/index.html to download your copy.

Website of Interest
www.hayskids.com
"Pathways to Understanding"

The HaysKids website is intended to be a means of sharing the visions, goals and information used by the organization, HaysKids. The site is user-friendly and contains several categories of information. The website owners are parents of children who have been diagnosed within the spectrum of disorders related to prenatal alcohol exposure. Of particular interest are the following sections:

- Parenting Techniques
- Audio Visual Seminars
- Life Planning



Provincial FASD News and Research

Accessing Supports for Students

by Lisa Brownstone

Recently Saskatchewan Learning (SL) made changes to the method of providing funding to boards of education for special education. Accessing educational supports for a child is not always easy. It takes collaboration between the teachers, principals and parents. This article will explore the funding supports available to students and the role of parental advocacy.

Funding

While it is important for parents to know about funding, it is critical to remember that we are looking for appropriate educational programming for our children. When discussing your child with teachers and principals, it is important to keep the focus on programming, and away from the dollars involved. Your child has the right to appropriate programming, the dollars are secondary.

In the past, School Divisions (Divisions) would apply to SL for funding recognition on an individual student basis. There were a series of categories based on diagnosis which included intellectual disability and/or chronic health problems. Children with FAS were recognized in the student based funding, but children with ARND, pFAS or ARBD were recognized in a per pupil rate funding called Diversity Factor. Access to that funding took knowledge and persistence on the part of parents and Divisions. Sometimes parents needed to educate teachers and Divisions regarding their child's funding rights. This was true for my daughter, as the local Division was apparently unaware that a student with ARND also had rights to an appropriate education. Successful advocacy led to in-school tutoring through-out high school.

Currently, each Division receives a base rate and diversity factor funding for each student registered in the division. Diversity funding includes students with exceptional learning and behavioural needs and students living in vulnerable circumstances. The types of supports and services provided by this funding could include classroom supports; assessment; resource/learning assistance programs; speech/ language services; consultative supports; social skills programming; counselling; interagency collaboration; and planning and evaluation at the individual, school and community levels.

SL estimates that 15 – 20% of all students require access to additional supports. Decisions are left to the discretion of each Division regarding which students receive funding, and the type and frequency of those supports.

Each Division should have developed policies around programming for students with intensive needs. Parents have access to the policy, and can become knowledgeable about the supports available. According to the Education Act, the school system is responsible for providing the appropriate education for each student. Each child has the right to an appropriate education and school divisions and parents should determine the supports needed to be successful.

Advocacy

When you believe your child's educational needs are unmet, advocacy should start with the teacher. The first step is to develop a relationship built on respect. Where there is disagreement regarding programming supports, try asking questions about the school's policy on providing programs and supports (ask for a written copy), whether this decision is in the best interest of the child, how your child can be better included and more successful. You can ask for other staff involvement in meetings, including the vice-principal and principal, the educational psychologist, special education staff, the regional superintendent and the director of special education. Bring your own supports to these meetings to assist in your advocacy. It may help you to assert your ideas when you feel you have someone there for you.

If this process is not successful you will need to ask about the Division's policy regarding disputes with parents. You may need to involve elected board officials and/or your local MLA. As a last resort, the Office of the Minister of SL encourages parents to call or write with concerns.

One of the keys to successful advocacy is a non-confrontational approach, where everyone's focus is on meeting the educational needs of the child. Another key is parental persistence: keep looking and keep trying. Try not to get into a discussion of whether your child should receive services instead of another child. Each and every child has the right to an education that respects capabilities and leads to success.

Another source of funding may be the Cognitive Disabilities Strategy (CDS). Apparently a number of applications have been initiated through some Divisions. Discussions are underway regarding whether CDS funding can be used to provide further supports in schools.

In closing, parental advocacy is essential for children to receive appropriate educational supports. Successful advocacy takes dedication and is time consuming, but can make a real difference. Testing indicated that my daughter had limited ability to succeed in completing grade 10. With appropriate supports she graduated with a full academic grade 12. Seeing her receive her diploma made every moment spent advocating worthwhile.

For more information contact the Network. See contact details on page 12.

Community News and Activities

Upcoming FASD Training Events

The FASD Support Network of Saskatchewan has received funding through the Saskatchewan Government Cognitive Disability Strategy for the purpose of delivering FASD training events in six communities throughout the province. The locations for the training will be:

- Ile a la Crosse
- La Ronge
- Prince Albert
- North Battleford
- Yorkton
- Swift Current

An events coordinator has been hired to work with each community to plan and implement the trainings. An effort will be made to seek input and deliver training specific to the needs of the communities. The events will be promoted and available at no cost to parents, caregivers, individuals with FASD, family members, professionals and the general public.

By bringing together a diverse group of community members, the level of knowledge and understanding of FASD greatly increase. This will aid communities in the quest to better meet the needs of those persons who are living with FASD.

The events will be widely promoted in the near future. For more information contact the Network. See contact information on page 12.

Parent Support Information

Parent Support Groups were held over the fall and winter of 2005-2006. Thanks to funding from the Regional Intersectorial Committees in Regina and Saskatoon parents of children and adults affected by FASD were able to attend the groups at no cost. The FASD Support Network partnered with Ehrlo Services in Regina and Family Support Centre in Saskatoon in order to hold the weekly group meetings.

The group in **Regina** continues to meet every second week at the Regina Community Clinic, 1106 Winnipeg St.. Meetings are held on the 2nd and 4th Tuesday of each month from 6:30-8:30. New group members are welcome to attend. Feel free to call Marion Tudor at 731-2768 or email mtudor@sasktel.net for more information.

Parents and caregivers in **Fort Qu'Appelle** also meet for support and friendship on the 4th Thursday of each month. For more information call Karen at 332-2639. New group members are welcome to join in.

In addition, the **Adoption Support Centre of Saskatchewan** offers support groups for adoptive families. They also have excellent resources available through membership. Contact 665-7272 in Saskatoon or Toll Free in SK 1-866-869-2727 to find out more or become a member.

Community Health Services Association of Regina Receives 2006 Enterprise Award

On October 16th the Community Health Services Association Of Regina will receive the 2006 Enterprise Award through the Saskatchewan Co-operative Merit Awards Program.

The program honours individuals and organizations for outstanding contributions, innovation, achievement and initiative by cooperatives. Of particular importance has been the establishment of the South Saskatchewan FASD Diagnostic and Intervention Centre. Through the centre, individuals and families in Regina and area are able to access FASD diagnosis and intervention services.

The FASD Support Network of Saskatchewan wishes to congratulate the Regina Community Health Services for the creative approach they have utilized in addressing the health needs of the community. They are worthy recipients of this award and deserving of recognition for the commitment to health care services for those living with FASD.

National FASD
News, Research and Stories

Moving Toward a Holistic Approach to FASD

by Beverly Palibroda

Participants of the Canada Northwest FASD Conference, held this past May in Regina, Saskatchewan, had the opportunity to witness the growing body of knowledge around FASD. Dr. Sterling Clarren, a well known expert in FASD, described the current level and sophistication of knowledge as "stunning." According to Dr. Clarren, there are approximately 150 active projects related to FASD in the Canada Northwest FASD Partnership Region. The partnership includes: Alberta, British Columbia, Northwest Territiories, Manitoba, Nunavut, Saskatchewan, and Yukon. This alliance of seven jurisdictions works toward the development and promotion of an interprovincial/territorial approach to prevention, intervention, care and support of individuals affected by Fetal Alcohol Spectrum Disorder.

Dr. Clarren was in attendance at the conference to speak about the Canada Northwest FASD Research Network. The Research Network evolved out of the Canada Northwest FASD Partnership and was established in January 2005. Dr. Clarren, CEO and Scientific Director for the Research Network, provided an overview of the organizational structure and goals of the Research Network. The aim of the Research Network is to engage in a collaborative approach to research intended to advance the the field of understanding of diagnosis, prevalence, prevention, intervention and treatment of FASD. Communities and those affected by FASD will benefit from the existence of the Research Network. The benefits will become apparent as the Research Network links the expertise of researchers, service providers, families, and policy makers from throughout the region. A coordinated effort, receiving leadership, guidance, direction, and sharing of knowledge across the region is the best option for improving approaches to FASD. Such an approach will allow groups to learn from others, will minimize duplication of research efforts, and will promote a holistic approach to understanding FASD.

While there remain significant challenges, barriers to service delivery, and gaps in understanding, the establishment of the Research Network, when combined with current knowledge and activities in the area of FASD, certainly provides reason for feelings of hope and optimism for the future.

Source: Canada Northwest FASD Partnership Conference, May 2006. Plenary Session Notes and Handout

For more information about the Canada Northwest FASD Partnership or the Canada Northwest FASD Research Network visit the websites at:

www.cnfasdpartnership.ca

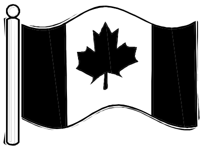
www.fasdnetwork.ca.

Meconium Testing in Yukon

A recent research project in Yukon exemplifies the fascinating research that is taking place across Canada. The Yukon Medical Association and Whitehorse General Hospital was involved in a year long meconium screening project. Meconium is the first stool of an infant and contains the materials built up in the infant's system during pregnancy. The project tested meconium as a means of identifying possible cases of FASD. It is important to note that the anonymous screening program was intended to be a means of determining the number of Yukon infants prenatally exposed to alcohol. Diagnosis was not the aim of the project.

Over a 12 month period, the meconium of all Yukon newborns was tested. Meconium testing was 100 per cent anonymous and samples were randomly coded, making it impossible to link the results to an individual mother and baby. The results of the project will provide important information on the number of infants who may be at risk for FASD in the Yukon. The meconium screening program began in January 2005 and was completed in January of 2006. Results have not yet become available to the public.

Source: Yukon Health and Social Services Website: www.hss.gov.yk.ca/programs/family_children/early_childhood/fasd/



National
FASD News, Research and Stories

Rights, Responsibilities and Persons with FASD

by Beverly Palibroda

There is an interesting tug and pull between human rights and human responsibilities. Along with individual human rights we each have certain responsibilities to ourselves, our families and communities; in turn our families and communities have responsibilities to us. Throughout Canada there has been an increasing sense that persons with FASD must recognize and embrace their human rights and that communities and the social systems must acknowledge their responsibilities. Many of us hold our rights near and dear to our hearts while some of us may not actually appreciate our human and legal rights until they are threatened and we fear the loss of our rights. It might come as a surprise to some people to know that individuals and families of persons affected by prenatal alcohol exposure are continuously required to advocate and struggle for recognition of basic human rights. In these cases it would seem that the communities and others are not taking on the responsibility to accommodate the human rights of those affected by FASD.

Currently in Canada persons affected by FASD are often unable to access the services necessary for them to lead successful and healthy lives. In many cases individuals and families find that the services do not exist or are so limited that needs go unmet. Families are left to their own resources, which over time, diminish. Individuals are left to cope; unfortunately many lives are destroyed due to lack of or inadequate services and support.

Researchers have clearly established that alcohol injures the developing fetus. The injury to the fetus includes physical, cognitive, and psycho-social disabilities that most often result in a need for life-long support. Even though Fetal Alcohol Spectrum Disorder is a known medical condition it is shrouded in shame, stigma and diagnosis remains difficult to obtain. In some regions of Canada individuals are required to pay for a diagnosis.

A result of the lack of diagnosis throughout Canada is that individuals often receive ineffective and insufficient services from multiple sectors. The ineffective services negatively impact an individual's:

- health and safety
- educational experiences
- employment opportunities
- access to social and community services
- social interactions
- experience with policing and justice system
- access to and support to ensure suitable and affordable housing.

Individuals affected by FASD have a right to receive services that meet their unique and specific needs arising from their disability. The communities, service providers, and policy makers have a responsibility to become informed and knowledgeable about FASD and provide the services and support needed so that individuals can live safe and healthy lives and be a valued and contributing member of their community.

Charter of Rights
(In Plain Language)

- The Right to Life
- The Right to Freedom
- The Right to control what happens to your body
- The Right to equal protection and equal benefit of the law
- The Right of choice
- The Right to informed consent (to know your choices)
- The Right to have things explained to you
- The Right to be heard
- The Right to see a lawyer or other advisor
- The Right to have enough money to buy food, have a place to live, and decent clothes
- The Right to proper medical care
- The Right to charge someone if they hurt you or take something of yours
- The Right to be educated
- The Right to apply for a job and be taken seriously
- The Right to safe working and living conditions

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www.peoplefirstofcanada.ca
For further information please visit the following websites:
Canadian Charter of Rights and Freedoms http://laws.justice.gc.ca/en/charter/index.html#libertes
Canadian Human Rights Act http://laws.justice.gc.ca/en/H-6/243963.html
Saskatchewan Human Rights Commission http://www.gov.sk.ca/shrc/

PEOPLE FIRST OF CANADA
PERSONNES D'ABORD DU CANADA

International FASD News, Research and Events

The 2nd International Conference on Fetal Alcohol Spectrum Disorder: Research, Policy, and Practice Around the World

March 7th - 10th, 2007
Victoria Conference Centre
Victoria, BC

Fetal Alcohol Spectrum Disorder (FASD) has a profound impact on individuals, families and all aspects of society around the world. The international conference being held in Victoria from March 7-10th, 2007 will provide a forum to discuss and examine current research, policy and practice that will assist parents, caregivers, service systems and governments as they strive to prevent FASD and provide a range of supports for people living with FASD worldwide.

An international conference is an excellent opportunity to come to understand how FASD research and intervention impacts every "system" of our society. This conference will explore ways to educate others about FASD, with an emphasis on the dissemination of accurate information by accredited speakers. Legal capacity and equality before the law remain very active areas in the face of FASD research and intervention. The conference will share evidence-informed lessons in a way that can foster improved policy and practice; healthy communities and social inclusion; and local, national and international collaboration on FASD.

Of great importance, the voices of those with FASD, birth mothers and other families will be heard throughout the event.

The combination of practical lived experiences along with the latest in theory and research will achieve the conference goal of providing participants with the means to engage in more effective decision making and planning in their own communities, wherever that may be in the world.

Participants can expect to:
- hear about current research from around the world
- establish links and international networks with those working in similar fields
- develop a framework to gauge where their own community is in the process of understanding FASD
- learn about the principles by which effective interventions can be designed and implemented
- have an opportunity to form international partnerships to develop research questions and agendas in areas currently under- or unexamined
- learn effective methods of educating others about FASD
- learn more about the area of legal capacity and equality before the law

As this event draws nearer the Network will distribute registration information.

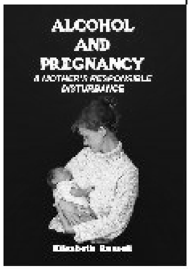
FASWORLD

FASworld is an international alliance of parents and professionals who do not want to see any more children, teenagers and adults struggle with birth defects caused when their mothers drank alcohol in pregnancy.
Co-founded by volunteers in Toronto, Canada, and Tucson, Arizona, it has resulted in the new Canadian organization, FASworld Canada, which continues to work with Fetal Alcohol Community Resource Center in Tucson.

RUSSIA

According to the World Health Organization, alcohol use in Russia is among the highest in the world. Despite the high rates of alcohol use, the prevalence of fetal alcohol spectrum disorders (FASD) among Russian children is not well known. It is hoped that Russia and other Nations less advanced in their understanding of FASD will learn from others and begin to address the complex issues around FASD.

NEW ZEALAND



ALCOHOL AND PREGNANCY
A MOTHER'S RESPONSIBLE DISTURBANCE
Elizabeth Russell

Alcohol & Pregnancy - A Mother's Responsible Disturbance is a must-read for both parents and health professionals. Elizabeth Russell, author, and birth mother of two children with FASD, provides a personal account of her family's journey. She discusses the dramatic affects of prenatal alcohol exposure on a her children's health and wellbeing, her own addiction, and the lack of services and support available.

FASD: Questions and Answers

By Marilyn Macdonald

Marilyn Macdonald is a Registered Psychologist who has worked in education for over 25 years in a variety of settings. Marilyn serves as the consultant on the board of directors of the FASD Support Network of SK. She is currently working as a school psychologist with the Saskatoon Public Schools. She is available to discuss educational issues or concerns.
Thank you Marilyn for your response to the following question.

Q. After a diagnosis of FASD, what do I tell my child's teacher?

A. Depending on the age of the child and previous school experiences, parents have valuable information that educators require to formulate appropriate programming and behavioral strategies that will ensure your child's progress —both academically and socially.

Contact the teacher to meet about your child. Be prepared to talk about and share information—about your child's health, i.e. allergies, sensitivities (textures, sounds, etc.), physical limitations, strengths, likes/dislikes, rewards that "work", best ways to calm or alleviate frustration, and ways that you can support your child's learning at home. Ensure that the teacher is familiar with the characteristics and educational implications of FASD. You are the expert when it comes to your child—share your expertise.

It is crucial to establish a good working relationship with your child's teacher, the resource teacher, the school Principal as well as your child's teacher assistant, if they have one. Children with FASD often have an individualized personal program plan established to meet their special learning needs and to address their behavioral/social issues. As a parent, you will be asked to review and contribute to this learning plan at least twice annually in most schools. Parental suggestions and input should be ongoing; don't wait for the program meetings if things are not working for your child.

Remember to report to the school any changes or inconsistencies that may upset your child's routine. Family changes (health problems, moving to a different residence, or a new baby) will precipitate behavior changes in the child with FASD. Extra patience and understanding will be necessary to accommodate for reactions to those changes.

Teachers should be aware of the need for extra supervision required for your child. Clear and specific directions are helpful with visual support (gestures, pictures, role play) to ensure understanding. Opportunities for relevant, hands-on learning with repetition and consistent routine is necessary for your child in order to gain learning through various modalities and help with memory retention.

Redirection of behaviours and changing the environment to accommodate your child's needs are ways to deal with behavioural issues. For example, anticipating this student will react negatively to a noisy assembly or unstructured time may require that he or she have a choice to leave when feeling "overloaded" or to be provided with extra supervision. Reduce clutter in the school environment to lessen the possibility of sensory overload. Do one thing at a time, allow time to clear away papers and other materials, and to take out the new work. Children with FASD need an allotted time to organize their desk and locker area.

Increase the "wait-response" time for children with FASD. They may need some extra time to process the vocabulary words, the sequence of instructions, and to do the action required. Remember, these children have a degree of brain injury and require more time to respond. Patience, consistency, knowledge about FASD, and knowing the child as an individual are keys to successful adjustment at school.

Above all, it is necessary for teachers and parents to collaborate and set up consistent strategies and routines that are realistic and "do-able" at school and home. There should be welcome and goodbye routines and ways to organize for "easy" transitions to home and school. Adherence to these routines will help everyone – especially the child with FASD – in order to know what to expect and be familiar with the way things are done.

Download a free resource in PDF format, Let's Talk FASD. This book provides an overview of successful parenting approaches with "real" parent comments.

See the review on page 5.

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. If you have a question, concerns, or would like more information on this topic, contact the Network office. See contact information on page 12.

FASD Support Network of Saskatchewan Inc.

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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

Upcoming Events And Learning Opportunities

For further event information contact the Network

6th National Aboriginal FASD Conference: Promising Intervention Strategies for Parents, Teachers and Caregivers of Children and Adults with FASD

October 19-20, 2006
Winnipeg, Manitoba
For more information, or to register, contact 1-888-683-7711 or wzarchikoff@msn.com

Ehrlo Community Services is Hosting Training Sessions with Diane Malbin

Oct. 31, 2006 Regina, SK
Understanding FASD as a Brain-based Physical Disability
For more information, contact Dave Wiebe, Ehrlo Community Services (306) 751-2730 or (306) 751- 2467

End Exclusion

November 2, 2006
A ceremony will be held on Parliament Hill in Ottawa. Various disability groups have joined to campaign for inclusion and accessibility for persons with disabilities.
For more information, please contact: People First of Canada [info@peoplefirstofcanada.ca]

8th annual Capital Region Fall Forum on FASD: Putting the Pieces Together

November 16, 2006
Edmonton, AB
$40.00 per person
For more information call Lisa 477-1999 ext 234
Lisa.Rogozinsky@catholicsocialservices.ab.ca

FASD Awareness: Community Training Events Throughout Saskatchewan

Fall 2006 Winter 2007
Swift Current, Yorkton, La Ronge, Prince Albert, North Battleford, and Ile a la Crosse

Funding from the Cognitive Disability Strategy has created the opportunity for the FASD Support Network of Saskatchewan to hold a number of FASD training events throughout the province. Details available in upcoming issues of *Network News* and through email.

Attachment & Healing with a Special Focus on Child Welfare Trends facing Aboriginal Children & Families

January 31 - February 1, 2007
Regina, SK
Contact: Ranch Ehrlo Society
Website: www.ehrlo.com
Email: conference@ehrlomail.com
Phone: (306) 781-1255

The 2nd International Conference on Fetal Alcohol Spectrum Disorder: Research, Policy, and Practice Around the World

March 7th - 10th, 2007
Victoria, BC
For more information, contact:
University of British Columbia Interprofessional Continuing Education
Room 105 – 2194 Health Sciences Mall
Vancouver, BC V6T 1Z3
Tel: (604) 822-0054
Fax: (604) 822-4835
http://www.interprofessional.ubc.ca