Spring 2005

Celebrating the Diversity of Living with FASD

Saskatchewan Fetal Alcohol Support Network Inc.

Living With FASD

Highlights of this Issue:

Saskatchewan Fetal Alcohol Support Network

A Fond Farewell

Shirley Hellquist joined the Board of the Network in 1999 and for the past six years has served as secretary. As an invaluable member of the Board, she has helped to promote awareness and understanding of FASD in Saskatchewan.

Perhaps her most important contribution, though, has been her willingness to provide a listening ear and support to parents. Shirley, we will miss you. We know that even though you are not on the board your support will still be there for others.

2004—2005 Board Members

President: Marion Tudor, *Secretary:* Shirley Hellquist, *Treasurer:* Terry Hellquist, *Past President:*Jonina Male, *Members at Large:* Kim Skidmore, Sylvia Nagy, Shelley Kolisnek, Marilyn Macdonald, Sarah Guenther, Rae Mitten, Heather Sinclair, Sandy Overs.

Kim Fast has been the coordinator for the SFASN office since September of 2002. Her responsibilities include providing information, support and links to services for families and agencies. She has been involved in a number of projects on behalf of the Network and has established links with Interagency Committees across the province.

Kim attended the University of Saskatchewan and the University of Regina and has degrees in psychology, sociology and social work. She has two children and enjoys reading, gardening and music.

Eunice Bergstrom: *Program Developer for the SFASN Supported Housing Project*, is a graduate of the University of Saskatchewan, with a background in social research and writing in various disciplines. Recently, Eunice has been employed with the Commission on First Nations and Métis Peoples and Justice Reform, and with the Saskatchewan Children's Advocate Office, *Children in Care Review.* She, with her husband Bruce, has lived in Saskatoon most of her life and has been involved in a number of community organizations, often through the activities of her three children.

Beverly Palibroda joined the SFASN in November of 2004. Her responsibilities include acting as the Project Coordinator for the Community Awareness and Action Workshops, developing the latest editions of the Network News and *Living with FASD* publication, as well as other written materials for the Network.

Her background includes a Rehabilitation Worker Diploma and a BA in Sociology and Women's and Gender Studies from the University of Saskatchewan. Beverly enjoys time outdoors.

Presidents Message

Marion Tudor

Changes, Changes and more Changes...

Changes, changes and more changes. You will see changes in this publication, at our office, and very soon in our name too. The Network is a fast growing organization with dedicated volunteers and staff who see so much to be done and just wade in and do it. It is exciting, and sometimes hard to keep up! But that is a good thing, I believe.

Saskatchewan is a province that is large in a geographical sense, but small enough in population for us to be able to work together and move things forward more quickly than in some other provinces.

Thanks to the Speakers Bureau, (a partnership between the Network and the Prevention Institute), and workshops being conducted by the Network through a Community Mobilization grant from the National Crime Prevention Strategy, people all over this province are learning more about FASD and how to support those living with the disability. This is making a real difference in the lives of many families.

We would like to be doing the best possible job of supporting parents across the province. Meeting more of you will help us to find out how we can do that. This winter we are holding three ‘parent days’. The ‘parent days’ are small gatherings of parents who will learn some new strategies to try with their families, find out more about the Network, and help us to evaluate what we are doing. We are really looking forward to these. We also invite parents and caregivers to contact us at any time for information, support, and to share ideas…..we love to hear about what works for you.

At our Annual General Meeting in May we will be proposing a small name change for the organization. The name change will bring us up to date with terminology. We have also revised our Vision and Mission statements, a good thing to do periodically as it creates an opportunity for us to look at what we are doing and why. We will bring these changes to our members at our AGM, and share them with you in our next newsletter, when they have been approved by the membership.

I hope you will enjoy this redesigned publication and find the articles and information useful and interesting. We would like your input at any time, so please write, phone or e-mail with your comments. You will find contact information on page 12.

> ***No person is your friend who demands your silence, or denies your right to grow.***
>
> ***Alice Walker***

The Saskatchewan Fetal Alcohol Support Network would like to express our gratitude to SaskTel for providing assistance with the funding of our publication *Living with FASD*. It is through such arrangements that we are able to continue to provide news and information to our readers. Thank you SaskTel.

SaskTel

A Proud Sponsor

SFASN Material Development

Introducing New FASD Tips

The FASD Tips, created by the Saskatchewan Fetal Alcohol Support Network, are handy information sheets that provide real life examples of some of the day-to-day challenges that may be experienced by parents, caregivers, and individuals living with FASD. Along with the examples, ways of addressing the challenges are suggested. The strategies are important because parents and caregivers can often feel that they have tried everything and do not have anywhere to turn. It is our hope that the Tips can prove to be useful in meeting the daily challenges faced by those whose lives are touched by FASD.

This spring we will introduce new FASD Tips reflecting a variety of day-to-day concerns. Topics include: Success at Camp, Dealing with Emotions, and Community Youth Groups. As with the previous FASD Tips, parents and caregivers who have experience, knowledge, and insight regarding the lives of people with FASD, have written the new FASD Tips. The authors offer ideas and strategies that have proven to be effective.

The newest FASD Tips will add to the existing 11 and reflect the variety of issues and concerns that parents and caregivers are facing. The FASD Tip on Success at Camp could prove useful in the near future as summer approaches.

FASD Tips in Both Official Languages

Other exciting news is the translation of the FASD Tips into French. At this time, translation is complete on the existing 11 Tips.

By providing information in both official languages, we are able to reach a greater audience as well as reflect the diversity of our nation. We will continue to work toward the goal of creating resources to meet the needs of our members throughout the province.

The new Tips will be distributed to SFASN members in the near future. Watch the website as the French Language Tips will soon be available online. www.skfasnetwork@sasktel.net. Feel free to copy and share the FASD Tips with others.

Pictorial Materials

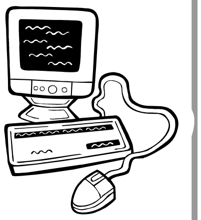
Much research has been done on the value of visual cues for readers and learners of all abilities. The SFASN has recognized the need for resource materials that are accessible to those individuals with lower reading levels. As a result, the FASD Tips are being created in a pictorial format. Three FASD Tips are currently being shared with schools, community agencies, parent groups, and individuals across Canada.

Work is in progress to further develop this project. We will keep you updated.

Virtually Speaking

We hear so often how the World Wide Web can provide a wealth of information. It can also be a very confusing place simply because of the vast number of websites on such a range of topics.

The following websites were chosen because they offer access to valuable materials and resources, as well as up to date information that may be of interest to SFASN members.



FASD Connections

http:\\fasdconnections.ca/index.html
According to the mission statement, this website is specifically dedicated to information related to adolescents and adults with FASD. The site includes articles grouped into categories such as: Aboriginal Issues, Community, Education, Homelessness, Mental Health, Supported Parenting and more. A section titled "In Their Own Words" includes the poetry and writing of individuals with FASD.

Saskatchewan Learning Website

http://www.sasked.gov.sk.ca/branches/children_services/special_ed/sepub.shtml.
The Saskatchewan Learning website offers a number of resources, but most relevant is the publication *Planning for Students with Fetal Alcohol Spectrum Disorder: A Guide for Educators.* This publication includes a The link provided will also allow you to access other publications of interest.

This publication is downloadable or available for purchase by calling 787-5987.

FASD Reviews and Resources

A Little R & R

By Sonja Polz Children's Services Coordinator
On behalf of: South Central FASD—Contact: Laurie Crosbie (403) 820-7986

The article to follow is an overview of a unique day camp for children with FASD.

The Project began as a Pilot Program initiated by the 'South Central FASD' in Alberta. The need was identified for recreational and respite services for children and families affected by Fetal Alcohol. Initially the possibility was being explored to incorporate individual goals: developmental, social, and/or behavioural. Further direction came directly from parents who identified they ultimately wanted a fun and safe environment for their child and a break from program planning and case conferencing. As a result, in 2004, Accredited Supports to the Community developed a day camp: ***"A Little R & R"***- "**Rest** for parents and **Recreation** for kids."

Children affected by Fetal Alcohol between the ages 6 and 16 are eligible for the day camp. Eligibility does not depend on medical diagnosis but suspected FASD. The day camp currently runs one Saturday per month between 10am and 4pm. There is no cost to parents but children are requested to bring their own lunches and snacks. We have organized theme days to include physical activity, crafts, indoor/outdoor activities, games and social gatherings.

Depending on activity, children are grouped according to developmental age and skill levels. We offer a low child to staff service ratio of 3:1. Experienced and knowledgeable employees use many strategies to ensure a fun and safe environment: structure/routine, picture schedules, body breaks, sensory integration, positive reinforcement, and social stories.

Parents and children explain the benefits:
"*It will give the girls a fun activity to do outside of the house together.*"
"It will provide opportunities to develop social skills."
"It will give us the opportunity to take time for ourselves without the hassle and cost of arranging childcare."
"It will give me a chance to catch up on house work and I can rest assured that she will be safe."
"It will give him an opportunity to be a part of a group out in the community."
"It will be fun to hang out with my friends from school, and do fun things."

The success of the program is largely due to listening to the needs and desires of both families and children. Accredited Supports to the Community is a 'not for profit', charitable organization diversified in its services including various supports to families with children with special needs. The success of "***A Little R & R"*** is due to the agency's ability to support the program through employee development, administrative support, use of resources, and community connections.

Our hope is that more communities, families and children will be able to access such needed resources. We hope to have more opportunities in the future to connect children/youth to their communities and build on the strengths of communities.

Planning for a Summer Camp Experience??

Saskatchewan Camping Guide
Saskatchewan Camping Association
Reviewed by Beverly Palibroda

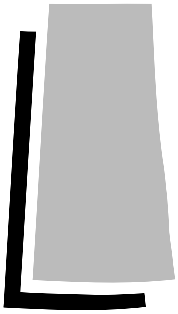
With the days lengthening and the sun's rays warming, perhaps your thoughts have turned to summer fun. There are a variety of summer camps throughout the province that provide recreational experiences for children and youth.

While there is not a camp that specifically meets the needs of children and youth living with FASD, several strive to meet the needs of children with diverse interests and abilities.

The Saskatchewan Camping Association publishes the *Saskatchewan Camping Guide*, as a resource to assist families and support people in planning for summer camp experiences. One of the objectives of the Saskatchewan Camping Association is to "promote camping as an educational, character building, therapeutic, and recreational experience" (2).

The guide provides information on selecting a camp, an overview of each camp, contact information, as well as a map with camp locations. The guide can be accessed on the web at: www.saskcamping.ca or you can contact the SCA office at 586-4026 to order a copy.

Another Valuable Resource:
Your Victory: A Happy Child Supportive Strategies for the Staff of Children's Summer Camps and Recreation Programs
Available to order at FAS Bookshelf (604) 942-2024 $4.00.



Provincial FASD News and Research

Saskatoon Supported Housing Project

by Eunice Bergstrom

In Saskatoon, Saskatchewan Fetal Alcohol Support Network is heading up the project, with Eunice Bergstrom as the project developer, supported by a steering committee of stakeholders from within the community. Funded by Human Resources and Skills Development Canada through the National Homelessness Initiative, the first phase of the project began in the fall of 2004.

This project was undertaken to address the difficulties many adults with Fetal Alcohol Spectrum Disorder experience with daily living.

While a definite model for a pilot project has not yet been finalized, ongoing support is recognized as the key to stable living situations. This in turn allows individuals to use their strengths and abilities to gain a sense of belonging in their community.

The required ongoing support may include assistance with household and money management, making and keeping appointments, supported employment and job placements, and mentoring in peer relationships. The needs and abilities of each individual vary substantially, and the types of support required must be individually assessed. Secondly, accommodation of special needs within the community is recognized as the preferred approach in developing housing options. There is also recognition of the resources that already exist in Saskatoon. The model will strive to expand and/or support these resources to appropriately assist those with Fetal Alcohol Spectrum Disorder.

Upon successful completion of Phase 1, the project will be eligible to be granted additional funding from the Homelessness Initiative to implement the developed model as a pilot project.

Watch the upcoming issues of Network News for updates on the Supported Housing Project.

Funded by the National Homelessness Initiative. For further information contact Eunice at 975-0896.

The Housing Feasibility Study for People with FASD

by Lisa Brownstone, Consultant

Recently "The Housing Feasibility Study for People with FASD" was completed. Focusing on Regina, the study provides rich detail regarding people with FASD, housing and supports. The lives of the 14 people living with FASD were explored through interviews:

- average age was 24.2 years old, range was 16 – 38
- 7% were involved in long-term relationships
- 100% of the women had been battered
- 100% of the women had stayed in a battered women's shelter
- 86% were parents
- 21% had their children living with them
- 25% had completed grade 12
- 86% were unemployed
- 100% had substance abuse issues
- 60% had been incarcerated
- 60% had a formal diagnosis

<u>Homelessness:</u>

- 93% had experienced absolute homelessness
- they moved an average of 3.6 times per year

The study also involved a literature review, interviews with those working with community, municipal, provincial, federal, First Nations and Métis organizations, and with supported housing options outside of Regina. Recommendations included development of a 3-pronged approach, including:

1. Education of the community. This includes training of front-line staff working with people with FASD.
2. Development of a continuum of supports that addresses all the functional areas affected by FASD.
3. Development of physical housing options, so that the continuum of housing is available for people with FASD.

Funded by the National Homelessness Initiative. For copies of the report contact the SFASN Office, or email Lisa Brownstone :lbrownstone@sasktel.net.

Provincial Interagency and Community Activities

Making Changes: Community Awareness and Action Workshops

By Mavis Olesen

"Treat youth with respect
who I suspect may have FASD
by using some of the techniques
we learned-…………"

"work for community action"

"go back and share the info
with my co-workers and colleagues"

"work differently with young people
with FASD by making
accommodations"

Such are comments following education about people with FASD for frontline workers in corrections, health, education and a variety of social services agencies serving our communities.

The education sessions of one day or two, are sponsored by the SFASN through a Community Mobilization National Crime Prevention Strategy grant. This grant is meant to address Crime Prevention through social development action in various communities across Canada.

Thus as part of each session, specific action is planned by participants grouped by community. Examples of action planned are: providing a transition plan for youth moving into adult services in corrections, making environmental changes to accommodate those with FASD in a regular classroom while maintaining a vital alive class for children who need that, and creating an intake process to screen all clients for FASD and then interviewing to reflect the results.

These plans are supported and followed up after six months in order to determine if the communities were able to make those changes necessary.

In order to assist each participant with their actions the SFASN provides a folder of materials and a reference book *Living in Limbo* by the facilitator, Mavis Olesen and her son Dallas Williams. Booking these sessions occurs through the SFASN Office. For more information call 975-0806 or email: skfasnetwork@sasktel.net.

Ile-a-la Crosse Interagency Report

The Keewatin Yatthe' Regional Health Authority committee on FASD has been in place now for about two years. Most committee members have done presentations in the communities along with some prevention in the area of FASD. In January 2005 we had a workshop in Ile-a-la Crosse which brought in about 22 participants from the district. The presenter was Mavis Olesen, and the workshop provided the participants with some upfront information on crime prevention and intervention strategies.

Speaker's Bureau Workshop

Members of the FASD Speaker's Bureau met recently to share information and knowledge about FASD. The afternoon session of resource sharing was both entertaining and informative.

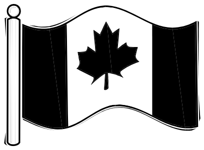
Whether it was a visual display of neuron activity, a discussion of publications, or a demonstration with the fetal doll, what was most striking was the passion, motivation, and creativity exhibited by the diverse group of presenters. Each presenter shared resources and strategies used in their individual presentations made throughout the province. Members of the speaker's bureau are available to speak at a variety of events.

For further information contact Laurie Brand at the Prevention Institute: 655-2312 or the Network office. See contact information on page 12.

Saskatoon Interagency Report

The Saskatoon group has been in existence for one year. Members have decided to establish three subcommittees to address specific issues: the Adult Committee, the Youth and Justice Committee, and the Family and Children Committee. Each committee has been focusing on specific aspects of FASD. All groups have identified a need for new services, but also a need to catalogue the existing services in Saskatoon.

The interagency group meets every two months and there is an educational component to every second meeting.



National FASD News and Research

The following article has been reprinted with permission from the Centre of Excellence for Early Childhood Development (CEECD) online encyclopedia. Please see reference information at the end of the article.

VOICES FROM THE FIELD—An Aboriginal View on FAS/FAE

Della Maguire, Executive Director and Founder Mi’kmaq First Nation Healing Society

“In the Aboriginal community, FAS/FAE is a partner, a family and even a community issue, because we are a collective society,” says Della Maguire, Executive Director and founder of the Mi'kmaq First Nation Healing Society in Hantsport, Nova Scotia. The Mi’kmaq First Nation Healing Society is a non-profit organization serving Aboriginal communities. Della Maguire educates and provides training and support on a number of issues, including Fetal Alcohol Syndrome (FAS).

What are the implications of the research findings in the CEECD papers for your work?

Maguire’s main concerns about the CEECD papers are that:

- the research is mostly American; and
- there is a lack of Aboriginal content within this research.1-9 [reference ed. note]

When we read the CEECD papers, FAS/FAE comes across as a women’s problem. “There is a need for more sensitivity and it should be stressed that FAS/FAE is not only a women’s issue,” Maguire states.1-9 The Aboriginal people look at a community holistically and therefore they talk about the partner, family and community as well.

All problems are considered collectively. According to Maguire, Aboriginal communities lack this type of research information. There is a strong need to go beyond what already exists. Aboriginal people should be more involved in the research in order to make it relevant to their communities. “The CEECD papers are a good starting point.1-9 For the time being, I need to rely on the Centre’s experts and add a cultural component and a cultural sensitivity when I present them in my workshops,” adds Maguire.

Della Maguire believes that a lot of Aboriginal communities are farther ahead than non-native communities in education on FAS/FAE and moving beyond the denial stage. “We are accepting the fact that FAS is in our communities even if we are all on different levels in terms of accepting the problem,” says Maguire. Travelling across Canada has allowed her to notice these differences in each province. For instance, at one of her workshops in Ontario, she asked how many participants had attended this kind of workshop before. Out of 50 participants, only half had been to such an event in the past. Her approach in each workshop is regularly changed and adapted to meet the needs of the participants because even though the research has been out there a long time, people are not hearing the right message. They know the basic facts (alcohol consumption during pregnancy causes birth defects), but do not realize the extent of the impact. It is Maguire’s role to further educate Aboriginal communities and provide them with advice, strategies and additional information.

She knows some of the communities have problems with alcohol, but because Aboriginal people live in a collective society, it is a challenge to get them to speak up. They fear the entire community will find out about their problem. Because of this sensitivity, Maguire has designed her workshops “according to the basic principles of respect, understanding, caring, forgiveness and hope.” Different communities throughout the country keep inviting her back and each time she visits, the workshops attract bigger crowds than when she first started 10 years ago. “Now, people want to know. They want this information. They are very curious about everything and ask very good questions.”

Where are the main gaps between research, practice and policy and how might they be overcome?

Maguire identifies trust as one of the main gaps in practice. It is especially noticeable when non-Aboriginal people are doing the research or coming into communities to conduct prevention or screening programs. “There is a lot of fear around the trust issue. In the past, Aboriginal communities have been scrutinized and surveyed. It will take time to rebuild that trust,” adds Maguire. Timing is also important and the communities need to feel safe. Researchers, service-providers and policy-makers need to be culturally aware. FAS/FAE is still a sensitive issue and should be “community-based at a community pace.”

When a non-native society looks at health, they look at the disease or the illness and its treatment, while the Aboriginal concept of health focuses on physical, emotional, mental and spiritual wellness. “It is a whole different mind-set. In a sense, this difference reflects strongly on people who try to have their children diagnosed. They do not want to be labelled, but instead want to know what could help,” says Maguire.

Through her travels, Maguire has noticed that organizations are still not educated enough and do not recognize the links between what they do and FAS. Practitioners and service-providers need to be better informed and educated. Maguire has the challenge to make sure they understand these links. “FAS/FAE is a lifetime disorder, and practitioners and service-providers need to look further ahead in the future.”

Another issue that should be addressed is the use of screening tools and the way they relate to Aboriginal people. It is important to take into account the different cultural aspects, and screening tools need to be adapted accordingly in order to prevent misdiagnosis. “Researchers are not adapting the measuring scales. The tools used most of the time will not work because we have different cultural norms,” says Maguire. Some physical features, such as eye slants and sometimes head size, can be part of the culture in some communities. Standardized psychological testing for Central Nervous System (CNS) dysfunctions may also be inappropriate for Aboriginal people, especially for those who speak their own language. Maguire states that we should have “culturally appropriate” screening tools. She also has concerns about the community-based screening mentioned in the CEECD papers.1-9 “How could this work in our communities if even our own native doctors cannot do it because of the lack of trust, confidentiality or just the difficulty of obtaining parents’ permission?” According to Maguire, Aboriginal people are not there yet.

Many Aboriginal communities have their own health clinics or health centres that provide parenting and family programs. For instance, in Nova Scotia, the Mi'kmaq Family and Children Services, a self governing program, is responsible for the 13 Aboriginal communities in the province. This would be the equivalent of Family and Children’s Services in non-native communities. However, sometimes the services needed are only offered outside the communities, and this implies travelling, accommodation problems, language barriers, lack of support and racism. As a result of these numerous barriers, the individuals concerned do not receive the proper services.
FAS/FAE needs to be addressed on a national level because each province has its own criteria governing what can be considered a disability. “We need to look at FAS/FAE as a disability and have an agreement across the borders so the government can start developing some services around it,” Maguire says. “FAS is a lifetime disability,” she concludes.

Reference

Maguire D. Voices from the Field-An aboriginal view on FAS/FAE. In: Tremblay RE, Barr RG, Peters RDeV, eds. *Encyclopedia on Early Childhood Development* [online]. Montreal, Quebec: Centre of Excellence for Early Childhood Development; 2004: 1-5. Available at: http//www.excellence-earlychildhood.ca/documents/MaguireANG.pdf.
Accessed January 6, 2005.

New Legislation in Ontario

A new law has come into effect in Ontario requiring establishments that are licensed to serve or sell alcohol to post warnings about the risks associated with alcohol use during pregnancy. The law came into effect on February 1, 2005.

Establishments have been provided with signage in both official languages and must post the signage according to specific guidelines. The warning signs can be viewed at www.cbs.gov.on.ca/mcbs/english/pdf/warningsign.pdf. This law is important as it will increase awareness and understanding not just for pregnant women but others around them.

It may also be deemed controversial as it highlights the question of human rights and discrimination. According to the Ontario Human Rights Commission, it is discriminatory to refuse to serve alcohol to a pregnant woman, as it is discrimination based on gender (http://wwwbeststart.org/apcampaign/warning_signs.html)

Ontario is leading the way by implementing such legislation. Other provinces will certainly be watching this initiative.

Saskatchewan does not have similar legislation but, according to Lois Crossman with the Saskatchewan Prevention Institute, since 1998 there has been an agreement with the Saskatchewan Liquor and Gaming Authority to implement a strategy of informing the public. Warning posters are displayed in liquor outlets and all liquor bags carry a warning message: Drinking Alcohol Can Harm the Baby. We Have FAS in our Community…Let’s Find a Solution.

Image reprinted with permission.

International News and Research

FASD Around the World

New Study Finds Babies Born To Mothers Who Drink Alcohol Heavily May Suffer Permanent Nerve Damage

Newborns whose mothers drank alcohol heavily during pregnancy had damage to the nerves in the arms and legs, according to a study by researchers at the National Institute of Child Health and Human Development, one of the National Institutes of Health. The study was conducted in collaboration with researchers at the University of Chile.

The nerve damage was still present when the children were reexamined at one year of age.

The study is the first to examine whether exposure to alcohol before birth affects the developing peripheral nervous system-the nerves in the arms and legs, rather than in the brain or spinal cord. The study appears in the March issue of the *Journal of Pediatrics*.

"Infants born to mothers who drink heavily during pregnancy are known to be at risk for mental retardation and birth defects, said Duane Alexander, M.D., director of the NICHD. "This is the first study to show that these infants may suffer peripheral nerve damage as well."

Adults who drink excessive amounts of alcohol can experience peripheral neuropathy, a condition that occurs when nerves involved in communication between the central nervous system (the brain and spinal cord) and the rest of the body are damaged. This can lead to tingling sensations, numbness, pain or weakness.

The NICHD-University of Chile Alcohol and Pregnancy Study compared 17 full-term, newborn infants whose mothers drank heavily during pregnancy to 13 newborns not exposed to alcohol in the womb. "Heavy drinking" is defined as having four standard drinks per day (one standard drink is equal to one can of beer, one glass of wine or one mixed drink). All women identified as heavy drinkers were advised that their drinking habits were potentially dangerous to their fetus and were offered help from an alcohol counselling clinic to stop drinking alcohol or to cut down on their drinking.

All of the children underwent a complete neurological exam followed by testing of the nerves in their upper and lower limbs. The researchers stimulated the nerves using a machine that passed a very mild electric current through the skin and then recorded the electrical activity of the nerves to determine if they were normal or damaged. (The procedure uses a current mild enough not to cause pain.) The nerve studies were performed when the children were about one month old and again when they were 12 to 14 months old.

The children exposed to alcohol before they were born experienced significant problems in conducting a message through the nerves--both at one month and one year of age.

The alcohol-exposed children did not experience any catch up or improvement in nerve function by the time they reached their first birthday.

"The finding that the nerve damage persisted when the children were a year old suggests that alcohol may cause permanent damage to developing nerves," said James L. Mills, MD, MS, director of the study and chief of the Pediatric Epidemiology Section in the Division of Epidemiology, Statistics and Prevention Research at the NICHD. "Because the children were evaluated before they could talk, they were unable to tell us if they had symptoms such as pain or numbness. We are continuing to follow these children to determine what effect this nerve damage will have on normal nerve function and whether it will lead to weakness or problems with touch sensation or fine motor skills later in life."

The National Institute on Alcohol Abuse and Alcoholism recommends that pregnant women not consume any alcohol. Information on the hazards of alcohol use during pregnancy is available at http://www.niaaa.nih.gov/publications/brochure.htm . March 8, 2004

Article available at: http://www.nichd..nih.gov/new/realeases/mothers-alcohol.cfm.

Reprinted under public information disclaimer. Article accessed January 6, 2005.

FASD: Questions and Answers

How do I explain to my other children, the behaviour of a sibling who has FASD and the challenges the whole family will experience?

by Anita Grosse

What we now know about FASD includes the basic facts that it is a form of brain damage, and the child will not grow out of it. The challenging behaviours we sometimes see are in large part due to the differences in how the FASD brain works. Mom and Dad are not to blame. The school is not to blame. The child is not to blame.

The question of how to interpret such complex issues to the rest of the family is anything but simple. It is also very important. We as parents and caregivers are the ones who do the actual teaching of the most important skills in life: how to care about each other, how to love, and how to recognize and accept in each other our own unique differences. It is in this context that teaching about FASD can most easily be accomplished.

While there is no right or wrong age to begin this teaching, it is important to realize that if other family members, however young or old, are being affected by behaviours, **that** is the time to start.

Teaching such important concepts requires two steps:

1. We need to think about what it actually is that we want our children to know.
2. We need to find ways to teach appropriately to the age and comprehension level of our kids.

1. What does our family need to know?

That everyone is special in different ways.
That some of us are really good at certain things like sports, music…
That some of us have things that are harder for us like sports, music…
That your brother or sister has some special problems with…
That we are a family and we care about each other.
That keeping everyone safe is important.
That keeping you and your sibling safe is mommy and daddy's job. You can help by telling your sibling when something isn't safe, telling mommy or daddy…
That it is no one's fault that your brother or sister has these problems.
That any problem we have we can solve together.
That sometimes it will be hard, we can talk about that and help each other.
That sometimes you might feel like we let your brother or sister "get away with" more than you. We can talk about that. We don't love her or him more than you, but we do sometimes have to do things differently so she or he can understand.

2. Teach according to the comprehension level of your children.

For example, a preschool child can understand: "your brother has special problems" "his brain does not work like yours" "we love him" "we need to help him" "we all want to be safe."

As children get older they will better understand difference, and will question "Why?" Beginning answers can be simple: "your brother's problems happened to him when growing in mother's tummy. It is not his fault. No one is to blame."

By the time siblings are in their teens, children can understand more complete explanations of FASD.

> *"Any problem we have we can solve together."*

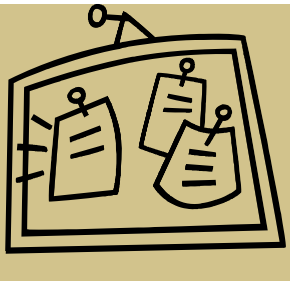
In giving such a short answer to such an important question I don't want to give the impression that I think this is simple or easy. It isn't. Every family is unique and asking this question is the first step in finding the answers you need. Thanks for listening.

Anita Grosse is a social worker with the Kinsmen Children's Centre. We thank her for sharing her wisdom and expertise.

Thank you to SFASN Board members Shelley Kolisnek, Kim Skidmore, and Jo Male for your response to the call for questions. If other readers are interested in posing a question for response in the fall edition of *Living with FASD*, please contact us using the contact information on page 12.

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. The responses, when not reprinted from acknowledged sources, are provided by members of the Saskatchewan Fetal Alcohol Support Network and are the opinions of those members based on their experiences as parents and caregivers of people with FASD. If you have a question, contact the Network office; see contact information on page 12.

Upcoming Events



Saskatchewan Fetal Alcohol Support Network Inc.
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Toll Free:1-866-673-FASN (3276)
In Saskatoon: 975-0884

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www.skfasnetwork.ca

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

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

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

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

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

FASD Training Sessions

April 14, 2005
Neurological Implications of FASD
10:00-11:00am
White Buffalo Youth Lodge
Spring 2005 Addictions, Recovery, and Treatment For Persons with FASD
For further information call Eunice Bergstrom.

Health and Wellness Event

Saskatoon Field House
April 2 & 3, 2005

International FASD Awareness Day

September 9, 2005
Watch for news about community events.

The next edition of **Network News FASD Hope** will be available in May 2005.

The next edition of **Living with FASD,** will be available in Fall 2005.

If you are interested in contributing to either publication, or have a story idea, please contact Beverly Palibroda 975-0806.

Saskatchewan Fetal Alcohol Support Network Annual General Meeting

May 27, 2005

Addictions Interagency Conference

Mind, Body, and Spirit
Saskatoon, Saskatchewan
May 25-26, 2005

Adults with Fetal Alcohol Spectrum Disorder Conference

May 4 - 6, 2006
Vancouver, B. C.
Participants can expect to:
Understand the effect of prenatal brain injury on late adolescent and adult functioning.
Learn about effective techniques for responding to the needs of late adolescents and adults with FASD within multiple settings.
Gain knowledge about existing models that could be replicated within your community.
Hear the voices of adults with FASD and others most affected by substance use.
Sponsors:
UBC Interprofessional Continuing Education
Connections: Serving Adolescents and Adults with FASD
www.interprofessional.ubc.ca