

Lifeguard Strategies For Supporting Adolescents and Adults Affected by FASD



**Developed in partnership by
Saskatoon Supported Housing Project and
FASD Support Network of Saskatchewan Inc.**

Project Developer, Eunice Bergstrom
510 Cynthia Street
Saskatoon, SK S7L 7K7
Phone toll-free: 1-866-673-FASN (3276)
In Saskatoon phone: 975-0884
E-mail: fasdnetwork@sasktel.net
Website: www.skfasnetwork.ca

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Pauline Aubichon	Wes Isbister	Melanie Pederson
Orest Baron	Connie Jones	Craig Podgursky
Ron M. Bear	Cynthia Kay	Stuart Prosper
Eunice Bergstrom	Charda Kirsch	Heather Ramsden
Myrna Bighetty	Corinna Kuntz	Darlene Rediron
Vicki Bird	Valerie Kvale	Jeff Richards
Lisa Brownstone	Angela Ledoux	Donna
Sheryl Buffalo	Virginia Loewen	Rothenburger
Marlene Campeau	Jonina Male	Christin Sayers
John Henry Charles	Sarah MacFadden	Carolyn Shields
Cathy Deneiko	Marguerite McIntyre	Robert St. Pierre
Betty Fiddler	Doreen McKay	Nicole Stainbrook
Jessica Fink	Dolores Miller	Norma Stephenson
Roxanne Greyeyes	Crystal Munroe	Marion Tudor
Anita Grosse	Joy Newberry	Corrine Walls
Debbie Hagel	Beverly Palibroda	Vern Wheeler
Karen Isbister	Kelly Patrick	Joanne Yacowec

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Developed as part of a workshop *Strategies for Supporting Youth and Adults with FASD within Community Social Services*
Presented by: Brenda Bennett
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About this booklet...

This booklet is the result of a workshop exercise designed by Brenda Bennett, founding director of FASD Life's Journey Inc. in Winnipeg, Manitoba. As the presenter at a workshop entitled Strategies for Supporting Youth and Adults with FASD Within Community Social Services, Brenda first read *Hard Issues for Parents of Adolescents and Adults with FASD, Issue #1, Playing Lifeguard*, written by ©Jan Lutke of FASD Connections (www.fasdconnections.ca). Brenda shared this analogy in an effort to assist the audience to appreciate the magnitude of the difficulties encountered by an affected adult simply to keep their head above water on a day to day basis.

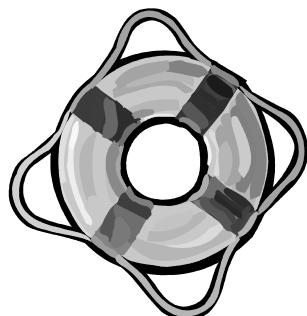
Brenda's workshop focused on understanding the primary disabilities as articulated in three areas:

1. Difficulty translating information from one sense into appropriate behaviour. "Talk the talk, but can't walk the walk". This area resulted in slow cognitive processing and flow through memory difficulties.

2. Difficulties generalizing behaviour – transferring learning from one situation into a similar situation. Results in the inability to abstract which affects the ability to understand the value of money and to internalize time. Social skills are also impacted as are poor predictive skills which compromises ability to link cause and effect.
3. Difficulties perceiving similarities and differences – inability to compare and contrast, perseveration, difficulties with transition/change, difficulty understanding safety and danger, fantasy from reality, sensory system dysfunction (difficulty filtering redundant and extraneous stimuli) etc.

Brenda highlighted disability based behaviours that demonstrated the organicity, or connection between the behaviour and the organic brain damage. Brenda then led the audience members, armed with an improved understanding, through participatory activities designed to identify their own ideas about what it takes to provide supportive “**lifeguard strategies**” to youth and adults affected by FASD. This method of active participation generated the collective wisdom contained in this booklet. The participant contributions, organized into the following categories, form the substance of this booklet:

Essential Beliefs...
Required Attitudes...
Successful Approaches...
Communication Strategies...
Environmental Adaptations...
Other Strategies...



Preface

The *Strategies for Supporting Youth and Adults with FASD within Community Social Services* workshop was presented by the Supported Housing Project for Persons with FASD through the FASD Network of Saskatchewan on February 7-10, 2006 at the Heritage Inn, Saskatoon, Saskatchewan.

The Supported Housing Project began in the fall of 2004 as a study to determine the most feasible model for implementing supportive housing for persons with FASD in Saskatoon. The project endeavoured to interact with the community by developing partnerships and providing training workshops about FASD. The training offered was intended to increase the knowledge base and build capacity in the community to better serve those affected by FASD. The Supported Housing Project was funded by the National Homelessness Initiative through Services Canada. The FASD Support Network of Saskatchewan, in collaboration with the Saskatoon FASD Interagency Committee, was the sponsoring agency.

The FASD Support Network of Saskatchewan is a parent-led provincial organization. The vision of the Network 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, support is provided to individuals with FASD, their families and circles of support by providing information & education; promoting early assessment, diagnosis & intervention; advocating for the development of life-long support services for individuals with FASD; establishing partnerships; and working to increase awareness of FASD.



Hard Issues for Parents of Adolescents and Adults with FASD: Playing Lifeguard

© Jan Lutke

One of the things, if you let it, that parenting adolescents and adults with FASD makes you face is your core values. That can work for you, or against you. It depends on how honest you are with your own personal circumstances, how willing or able you are to grow and change, and how able you may be to adapt. One thing is for sure, refusing to at least consider the possibility that some of our core beliefs may be part of the problems we encounter removes any likelihood that we can structure change in areas we control.

Most of us have not really even thought about what our beliefs are. We simply espouse to the *idea* of values, without ever having elucidated them in a clear, orchestrated manner. You have to do that before you can either defend and retain, or let go of them. And yet we, and the rest of society's systems in which our children are forced to interact, expect our children to be able to follow those values – social rules – which are, at best, small raindrops in a huge pond rippling every which way as the wind blows.



The pond is the value. The accumulating raindrops are the myriad of small things that continue to build and *change* the value over time. The waves are the events and the winds are the circumstances. The rock that then gets thrown into this mixture is the place where that value needs to be used. *Never are things the same twice.*

Those of us who have the ultimate luxury of a brain hard-wired to accommodate being perpetually sea-sick, have at our disposal a boat, a motor, fuel, a set of oars, a bailing bucket, lifejackets, a map, a radio, not to mention boots, a raincoat and an umbrella. We also know how to understand the captain's orders. We know how to follow them. We know how to work the radio and send a mayday if need be.

This is not true for the adolescent or adult with FASD. He has fallen overboard in that pond. He is alone and adrift without a lifejacket, unable to see the shore, trying desperately to keep his head above water. What must it feel like to be so perpetually close to drowning all the time?



If I am dissatisfied with his behaviour, why is it that I feel this way? Are my expectations realistic? Am I asking (demanding?) he do something he is unable to do? And if I am not pleased with his behaviour, then what about mine? How do I handle the situation? Do I throw him a life ring, or a rope, or do I let him flounder for the shore he cannot see and hope he does not drown? Just because he can sail on a sunny day does not mean he can sail on a stormy day. I know that, but why doesn't *he* know that? How many times do I have to tell him about storms, anyways?? And why is he out in that boat without permission – again? He is always in trouble. I am always on the edge, waiting for something to go wrong, because it always does. He never seems to care that I might be worried. He always does "it" again, no matter what he says. And there is *always* a next time.

At the heart of the question for the parent who experiences this behaviour is the struggle with the strong core belief that "you don't treat people you care about that way". And the adult child does not – not on purpose. But he does if he does not understand he can't swim.

Once you understand that you are living with someone who does not know he cannot swim (and remember, you can't know what you do not know), you begin to grasp the significance of lifeguards. A lifeguard does not ask the drowning man if he wants

help, or wait to see if the drowning man does drown before going to his rescue. He does not refuse to rescue him a second time, and a third time. He does not pass judgment on the person's performance. Rather, he ensures that his own is up to the task by continually changing how it is that he plans his job. The lifeguard does not place the person on the "no more service" list because he failed to learn to swim in the allotted



teaching time. Instead, he waits and watches, and whenever he is needed, goes to the aid of the non-swimmer using tools that will make the rescue easier on both of them. And then he waits – until the next time.

Lifeguards are found everywhere in society. Beaches and pools are only the most obvious places. Job sites have first aid attendants. Mechanics inspect public transportation. Weigh scales check trucks. Ski patrols monitors ski hills. Group home staff care for the mentally handicapped. School playgrounds have noon-hour supervisors. Vehicle insurance is mandatory.



Apartments, hotels and all public buildings have fire alarms. Immunization is free. Teachers, social workers, doctors, etc. must have criminal record checks. Police are subject to public complaint processes. Defibrillators are placed in malls. Legal Aid lawyers are provided to those who cannot pay. Hospitals treat first. Airport security staff check bags. Social workers remove at-risk children. Public health agencies monitor disease. Hospitals have ethics committees. Food handlers wear gloves. Red lights and speed limits control traffic.

Anyone who says he does not personally use lifeguards is fooling himself. The idea of an *individual* lifeguard is merely an extension of what is already available to the rest of society deemed worthy of such services.

The issue, and where it can conflict with their own personal beliefs and definitely with that of society, is *who exactly should have a lifeguard?* Why should they have a lifeguard? What is the role of the life guard? How do you lifeguard effectively? How much life guarding should be done? Where and under what circumstances? How does one decide? Who decides? Who should the lifeguard be? Who pays? Who has ultimate responsibility? What happens when the lifeguard goes home? Does providing a lifeguard take away the rights of the individual? And finally, what happens when there are no lifeguards for those the very most in need? And the answer to that, I think, is obvious. Look around you.

DANGER!

Lifeguard Strategies for Working with Adolescents and Adults Affected by FASD

Essential Beliefs...

- *Everyone* has gifts
- FASD is a permanent disability
- Behaviour is a symptom of a disability
 - FASD
- IQ is not an indicator of functionality
- We can't cure or reverse the brain damage
- FASD needs to be recognized as a central nervous system dysfunction; therefore, behaviours should not be viewed as intentional
- Brain not blame
- There is ignorance about FASD – we must promote awareness
- FASD can be a symptom of loss of culture
- Don't make presumptions and assumptions about behaviours (i.e.: the individual is uncooperative, defiant, difficult, lazy, dishonest)
- Logical and natural consequences don't work with those affected
- It's not that the person *won't* – it's that they *can't*
- *Chronological age* doesn't reflect *developmental* level
- What you see is not what you get – FASD is often an invisible disability
- The actions of persons with FASD doesn't reflect their intent
- We must see the person, not the label
- FASD is a social disability – not a cultural issue
- Affected individuals need advocates
- When we fail to accommodate, we create disability
- The affected individual is the teacher
- Expect challenges and know they aren't insurmountable
- Affected individuals are performing to the best of their abilities
- Individuals affected by FASD can and do succeed
- People with FASD can contribute to society with supports
- Individuals need support to manage day to day
- There are two people who need support – the birth mom and the affected individual



Required Attitudes...

- Optimistic
- Inquisitive – what are the behaviours communicating?
- Accepting – for who they are
- Caring not curing
- Open minded
- Creative
- Without presumption and assumption
- Nurturing
- Compassionate
- Non-judgmental
- Non-blaming
- Accepting of the realities of FASD and understanding that behaviour is the result of damage to the central nervous system
- Empathetic – put yourself in their shoes
- Recognize that positive outcomes should not result in withdrawal of services as the services are likely essential to continuing positive outcomes
- Open minded enough to try to think like the person we are supporting
- Always depersonalize behaviours
- Look for behavioural indicators of secondary disabilities
- Look beyond the behaviours that you see in order to understand what the behaviour is communicating
- Learn from our mistakes – we will make many mistakes as we learn
- Be a good role model of conflict resolution, anger management
- Be kind
- Accept a slow pace of involvement and progress
- Accept that you may need to re-teach a concept in a new or different setting



Successful Approaches...

- Slow down – allow lots of time
- Provide breaks and snacks as individuals can easily be fatigued
- Allow the individual's needs be the guide for the services provided
- Provide structure not control
- Utilize a strength based approach – build on strengths and interests
- Have realistic expectations that are based on actual abilities and not the presumption of competence
- Be empathetic
- Be respectful
- Provide services in a culturally appropriate manner
- Listen with your heart
- Think accommodation – how can I adapt the environment to support this person to succeed?
- Be non reactive
- Allow time for the person to respond to verbal communication
- Observe
- Be understanding
- Ask permission to hug or to make any kind of body contact
- Think outside the box
- Be genuine, caring and empathetic
- Try differently, not harder
- Think younger; develop developmentally appropriate expectations
- Focus on positives and strengths
- Create opportunities for inclusion in communities
- Meet the needs of the person, not the needs of the program
- Avoid using abstract concepts to teach
- Ensure that the approach is individualized – each person is unique
- Celebrate successes
- Provide unconditional acceptance
- Utilize harm reduction philosophy instead of expecting abstinence
- Provide trained mentors
- Think without boundaries



Successful Approaches...

- Every day needs to be viewed as a new day – don't expect generalizations
- Introduce information using a number of different methods
- Include the person in identifying & developing supports they require
- Develop a meaningful relationship with the individual based on trust
- Deal with crisis as they occur and provide a proactive focus in order to prevent incidents from reoccurring
- Plan ahead to prevent problems
- Understand and expect behaviours to occur
- Educate those around the person about FASD
- Teach links to help with the inability to generalize; prepare for new experiences by linking the new experience to familiar experiences
- Use simple language and activities to articulate/demonstrate similarities and differences
- Address behaviours when they happen – don't wait
- Re-teach, re-teach, re-teach; build in redundancy
- Assess environment to predict where they may have difficulties related to adaptive functioning deficits and inability to abstract
- Ensure that team supports are on the same page
- Through your eyes, predict and interpret the environment for them
- Utilize role playing
- Identify substance abuse triggers, i.e.: cash, twenty dollar bills, certain areas of the city
- Develop/obtain a genogram to track abuse and neglect in early life – assists in determining occurrence of secondary disabilities
- Reduce triggers in their environment – i.e.: move to area where they don't have a use history, stay away from areas where there are crack houses, peers of negative influence
- Develop an environmental map – identify who they are connected to
- Build in strategies to keep workers safe – panic buttons, buddy approach, cell phones
- Attempt to prevent or address anxiety
- Recognize memory problems and allow for variability in memory
- Work towards preventing post-traumatic stress disorder (PTSD) for those involved with the individual like family members, support providers and mentors



Communication Strategies...

- Use few words to give simple directions
- Listen with your heart
- Repetitive reminders
- Appropriately paced conversation
- Use a soft voice
- Bilingual communication is important, i.e.: Cree, French, Dene
- Use verbal cues
- Role playing
- Wait for response – receptive communication is slower than expressive
- Use pictures to teach or explain
- Check for understanding – but do not ask “do you understand?”
- Use concrete language – don’t use analogies or stories
- Provide fiddle devices when attempting to engage in a conversation
- Ask yourself ‘Would Amelia Bedelia understand this?’
- Avoid abstract language, i.e.: later, wait, soon, remember, etc.
- Talk the way the individual does – street slang/terminology, etc.
- Don’t take for granted that the person will understand what you have said
- Probe for understanding, i.e.: What did you hear me say?
- Take responsibility for adapting how we communicate so it is in ways they understand



Environmental Adaptations...

- Evaluate the environment and adjust accordingly
- Sensory recognition – clothing, environment, noise, etc.
- Consider room temperature
- Utilize soothing colors in the environment
- Limit distractions e.g. pictures, noise, movement, etc
- Provide structured daily routine
- Provide 1:1 support
- Provide low stimuli in environment e.g. low clutter on the walls, low activity/distractions
- Provide hands-on, one-on-one options for learning
- Use backward sequencing – a series of small steps, start with the last step first
- Model appropriate behaviour and conflict resolution
- Labelling instructions, i.e.: label the spaghetti pot, weather appropriate clothing
- Utilize calendars, visual prompts and post it notes to accommodate memory deficits and abstract thinking deficits
- Assist with organizing the environment
- Forewarn and prepare for transitions – provide adequate time
- Use memory aides, i.e.: pictures, calendars, etc.
- Teach links to help with inability to generalize learning
- Make video tapes to assist with transitions
- Telephone reminder calls
- Provide visual multi-modality cues
- Use yoga balls instead of chairs for those with attention difficulties
 - Use digital clocks with alarms
 - Be the reminder nag – remind again of tomorrow's activity prior to leaving the shift



Other Strategies...

- Take knowledge about FASD to the community
- Work with Elders to increase awareness of FASD
- Create drama or utilize videos to promote awareness and prevention of FASD
- Change others' frame of mind – address the misconceptions about FASD
- Use traditional approaches with Elders, i.e.: sharing and talking circles
- It's O.K. to have conversations with birth mothers through talking circles
- Change how we think – we can't have a preconceived notion that a person will learn in the same way as others
- Provide family supports
- Provide stable homes
- Address frustration and grief issues
- Advocacy across systems
- Peer community support networks
- Building communities and changing attitudes through community awareness and development
- Primary caregivers need time for themselves
- Share your knowledge and experience about FASD
- Provide supports to avoid the "black hole" at age of majority instead of expecting that young adults with FASD will become completely independent



Diagnostic Terms and Criteria

In 2005, a team of professionals developed the document, ***Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis***. This was a major accomplishment that will aid many families and individuals in the journey to access diagnosis.

Diagnosis and assessment of prenatal exposure is a complex process best completed by a multi-disciplinarian team of professionals. The team **must include a physician** specially trained in diagnosis and assessment. Diagnostic and assessment services are available throughout the province but families continue to face barriers to these services. Barriers include long wait lists, services that are more widely available to children and youth rather than all age groups, lack of trained professionals, difficulty for families in remote and rural regions to access diagnostic and assessment services due cost of travel and long distances to services and lack of understanding or knowledge of the reasons and benefits for diagnosis.

Despite the problems accessing diagnostic and assessment services, this is an important process that can improve outcomes for individuals and families. A common area of confusion for families and professionals is the language used around diagnosis. The term Fetal Alcohol Spectrum Disorder (FASD) is not a diagnostic term. FASD is an umbrella term used to describe the range of disabilities caused by drinking alcohol during pregnancy. The following are the most commonly used terms associated with diagnosis within the spectrum of FASD. The criteria for diagnosis are those used across Canada.

Fetal Alcohol Syndrome (FAS)

1. Information showing the birth mother drank during pregnancy.
2. Characteristic facial features.
3. Below normal weight, height and small head size.
4. Problems with learning and /or problems with behaviour.

Fetal Alcohol Syndrome (FAS) without Confirmed Maternal Exposure

Sometimes the fact that the mother drank during the pregnancy cannot be proven but there is good reason to believe she did. If the other 3 characteristics for FAS are present then the diagnosis of FAS without confirmed maternal exposure can be made.

Partial Fetal Alcohol Syndrome (pFAS)

Information showing the birth mother drank during pregnancy and two out of three of the following characteristics:

1. Some of the characteristic facial features found in FAS are present.
2. 'Much' below normal weight, height and small head.
3. Problems with learning and/or problems with behaviour.

Alcohol Related Neurodevelopmental Disorder (ARND)

1. Information showing the birth mother drank during Pregnancy.
2. Problems with learning and/or problems with behaviour.

A term used in the past that is no longer used as a diagnostic term is **Fetal Alcohol Effects (FAE)**. This is a term has been replaced by the diagnostic terms **pFAS** and **ARND**.

Information Sheet Developed by FASD Support Network of Saskatchewan (2003, Revised 2005).

Reference: Chudley, A.E., Conry, J., Cook, J., Loock, C., Rosales, T., Leblanc, N. Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. Canadian Medical Association Journal (March 2005).

Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis is available online at http://www.cmaj.ca/cgi/content/full/172/5_suppl/S1



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Developed in partnership by
Saskatoon FASD Supported Housing Project and
FASD Support Network of Saskatchewan Inc.
510 Cynthia Street
Saskatoon, SK S7L 7K7