ABORIGINAL APPROACHES
Fetal Alcohol Spectrum Disorder
How do Aboriginal cultures and practices help with the development and day to day lives of our community members living with FASD?

Aboriginal communities are known for their rich body of knowledge in the areas of healing and wellness. As we enter the thirtieth anniversary of the discovery of Fetal Alcohol Syndrome, what do we know? What types of strategies have evolved, and how are Aboriginal people applying their distinct cultural approaches towards assisting children, youth and adults with fetal alcohol syndrome?

This report has been commissioned by the Ontario Federation of Indian Friendship Centres as a way of documenting and celebrating some of the good work that is being done around FASD in our communities. You will find information and inspiration about parenting children and youth with FASD, fetal alcohol syndrome in the schools, community-based programming, prevention work, and alternative justice for alcohol affected offenders. We are happy to present the stories of birth and adoptive parents, as well as the story of Francis Perry, a young Mi’kmaq man with FAS, as told in his own words.

Our primary purpose in writing this report was to explore how Aboriginal cultures and practices help with the development and day to day lives of our community members living with FASD. This theme runs throughout all of the articles. As such, we have demonstrated the unique way in which Aboriginal people promote wellness for everyone in the community.

We hope you enjoy this resource!

Kim Anderson
Editor

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Aboriginal Approaches to Fetal Alcohol Syndrome/ Fetal Alcohol Effects
A Special Report by the Ontario Federation of Indian Friendship Centres

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ABORIGINAL APPROACHES TO FASD  A Special Report by the Ontario Federation Of Indian Friendship Centres

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Cover inset: “Brenda’s graduation”. Story on Brenda’s family page 15.
On the back: John Barnes of the Ktuxana Nation illustrates shifts in thinking for working with children with FASD. Story page 6.
What is FASD?

Fetal Alcohol Syndrome and Fetal Alcohol Effects are the result of a mother drinking alcohol while she is pregnant. There is no known “safe” amount of alcohol consumption during a pregnancy. Babies can suffer permanent damage if they are exposed to alcohol at any point during their time in the womb.

The effect on the baby varies from individual to individual, and not everyone with Fetal Alcohol Syndrome (FAS) is the same. The common characteristics of FAS are:

- growth retardation; children, youth and adults with FAS are often smaller than average;
- distinct facial appearance; shortened eye slits, flattened mid-face, flattened midline ridge between nose and lip; thin upper lip;
- permanent damage to the brain and central nervous system; developmental delay, intellectual impairment, behavioural disorder, learning disabilities, attention deficit disorder and hyperactivity.

Fetal Alcohol Effects (FAE) refers to an individual who has been exposed to maternal drinking, and who has one or two FAS characteristics. A person living with FAE may not look any different, but may still suffer from damage to the brain and nervous system.

Fetal Alcohol Syndrome is the leading cause of developmental disability in North America.

A child does not grow out of FAS or FAE. Exposure to alcohol during pregnancy can have the following lifelong outcomes:

Physical
- lower than average weight and height
- small brain and head
- shortened eye slits; flattened mid-face; flattened midline ridge between nose and lip; thin upper lip
- problems eating
- disturbed sleeping patterns
- difficulty seeing and hearing

Mental
- learning difficulties and developmental delays
- difficulty with abstract concepts (math, time, money)
- a short attention span and or memory deficits
- hyperactivity
- poor or delayed speech
- difficulties with problem solving

Emotional
- babies can be irritable, restless and colicky
- difficulty getting along with others, including an inability to manage anger
- impulsive behaviour
- poor self-image, depression, withdrawal and passivity

Spiritual
- the baby’s spiritual connection to his/her mother can be disconnected when she uses alcohol during the pregnancy
- the baby is not able to grow in an environment of peace and security – the development of a healthy, calm baby is thus interrupted
- alcohol and drug use in any family relationship around the mother and baby can affect the child’s ability to bond with the mother, father and the extended family

Children, youth and adults living with FAS or FAE can benefit greatly if they have access to proper services and support. For this reason, it is important that children who may have FAS or FAE receive a proper medical diagnosis. A qualified doctor and/or a team of professionals, which may include psychologists, occupational therapists, and speech and language therapists, usually do this. Unfortunately, diagnostic and support services are not in place and/or are difficult to access in many communities.

The study of Fetal Alcohol Syndrome is new, as a team of U.S. doctors first identified it in 1973. Since that time, parents and professionals have developed many effective strategies for improving the quality of life for those living with FASD. Aboriginal people have developed their own culture-based methods involving healing, support and education, as described in this document.

Information adapted from the FAS Prevention and Support Program of the Aboriginal Health and Wellness Centre of Winnipeg, Inc., Tel: (204) 925-3700

### DRUGS AND THE UNBORN

<table>
<thead>
<tr>
<th>Drug Type</th>
<th>Effect</th>
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<tbody>
<tr>
<td>Amphetamines</td>
<td>Can increase the risk of miscarriage, premature delivery, low birth weight. DO NOT USE</td>
</tr>
<tr>
<td>Caffeine (coffee, tea, cola)</td>
<td>Suspected of harming the fetus if taken in large amounts. Use any product containing caffeine in moderation.</td>
</tr>
<tr>
<td>Cannabis (marijuana, hashish)</td>
<td>Risk of abnormalities in development of fetus, undervalue of baby, and later behavioural problems (addiction, withdrawal). DO NOT USE</td>
</tr>
<tr>
<td>Cocaine, Crack</td>
<td>Risk of miscarriage, premature delivery, and malformations of the fetus. DO NOT USE</td>
</tr>
<tr>
<td>Opiates (heroin or prescription drugs like Percocet, Talwin, Darvon)</td>
<td>Risk of miscarriage, premature delivery, complication during delivery, baby born with breathing problems or withdrawal symptoms, slow mental and physical development. DO NOT USE</td>
</tr>
<tr>
<td>Tobacco (cigarettes)</td>
<td>The more you smoke, the greater the risk of miscarriage, premature delivery, undervalue baby, stillbirth, and crib death. Babies are also affected by continued smoking in the home. DO NOT USE</td>
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From Nova Scotia Department of Health
Tips on Parenting Children with FASD

**Sleeping**
- problems with sleeping
- babies with FAS have a difficult time calming themselves, so will cry longer and harder

**Tips:**
- put infants in their cribs when drowsy
- put a white noise in the child’s room (i.e. fan, quiet radio)
- provide a bean bag chair, hammock or rocking chair to help soothe the child.

**Developmental Milestones**
- may take the FAS children longer to do things
- small size may affect her skills
- remember that no two children are alike

**Tips:**
- seek evaluation by a developmental specialist
- ask a doctor to evaluate physical status such as muscle tone or hearing
- access Head Start and other appropriate programs
- establish a home to school continuum
- use preventative parenting techniques rather than control
- identify strengths and encourage successes

**Eating**
- failure to thrive is a function of being affected by pre-natal alcohol exposure, not a function of not eating
- weak suck in babies. It takes a long time to feed. Coordinating sucking and swallowing is difficult
- tire easily
- may continue to eat slowly because poor muscle control or sensitivity to the texture of foods

**Tips:**
- reduce distractions – have a calm and quiet mealtime
- allow plenty of time for meals
- small servings
- avoid using mealtimes to discuss stressful topics

**Sensory**
- sensitive to touch, light and sound (tactile defensiveness – for example a child who has been gently bumped may feel as though he has been hit or shoved)
- poor bonding – body may be hypersensitive to touch
- bright lights and sound overload the brain

**Tips:**
- avoid crowding
- choose loose, unrestricted clothing
- remove tags from clothing and turn socks inside out (so the seam does not rub the skin)

**Speech and Language**
- ear infections are common among children with FAS
- FAS children may talk at a later age
- slower to form sentences
- hearing should be tested
- may need more time to process information

**Tips:**
- speak slower to the child
- make sure she or he is looking at you
- encourage language use by talking, reading books out loud, singing songs, playing tapes

**Learning Problems**
- range from mild learning disabilities to more challenging developmental disabilities
- child’s skill may be gifted in some areas and poor in others
- some will catch up
- some have periods of learning followed by periods of delay
- some adapt to their disabilities
- some have uneven patterns
- auditory processing problems
- behavioural problems seem to start when they go to school
- processing and integrating information is very difficult
- may have short term memory
- may have poor memory
- may be poor in math
- low frustration level is very common

**Behavioural Concerns**
- friendly and fearless
- poor judgement
- may lack impulse control
- at 10 years old, may still act out (i.e. temper tantrums – related to frustration with changes)
- difficulty in making and keeping friends
- lying is common (will tell people what they think they want to hear).

**Tips:**
- share information with other parents (support groups)
- prepare the child for challenges
- arrange time for yourself
- keep structure in their lives

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Material from Patricia Tanner, adapted from *Empowering our Communities on FASD: Training Manual*, Della Maguire, Mi’kmak First Nation Healing Society. See page 14 for more information on obtaining this resource.
In the early 1990’s, the Ktunaxa Nation and Kinbasket people of BC took a courageous step. After a survey identified factors suggesting high rates of FAS and FAE among Ktunaxa/Kinbasket people, they decided to address the situation. The result was the Community Healing and Intervention Program (CHIP), administered through the Ktunaxa Independent School Society. CHIP is designed around a Medicine Wheel with the cardinal points of Wisdom, Beginning, Acceptance and Courage.

Healing with a Deep Heart

by Doug Anderson & Jennifer Wemigwans

FASD IS HARD FOR even one person to deal with. For a people to face it collectively is admirable, given the stigma and denial we all share around difficult social issues. This is why “gathering and sharing our collective wisdom” is the foundation for CHIP. The sharing of wisdom relies on relationships that tap into the heart of the nation, as well as being open to knowledge from any direction that is useful. CHIP’s philosophy is to develop services through a “participatory action research framework” that looks at how people experience FAS and FAE at the community level. The idea is to have a flexible and fluid program that learns from and responds to the realities of human society. This approach differs remarkably from the institutionalized practices we are accustomed to in dealing with mainstream health, education and social systems.

The workers
WHILE THE WHOLE CHIP team does FASD prevention, education and consultation work, John Barnes and Jason Louie are the CHIP workers who are most focused on directly helping kids who are already affected. John is the Youth Worker. Jason is the Community Support Worker, and works with kids aged six to thirteen. In addition to their jobs, both men live with FASD, each in his own way. John has partial FAS himself, and Jason’s oldest daughter is alcohol affected.
CHIP's mandate is to provide a culturally sensitive, holistic approach to intervention, prevention and service delivery for children, families and communities impeded by FAS and FAE. It serves Aboriginal people who live in the East Kootenay portion of the Ktunaxa Nation's traditional territory.

Left Youth Worker John Barnes believes that art allows people with FAS to express themselves without using all the complicated phrases they may find difficult. A bulletin board in the CHIP office displays drawings and photos by children and teens with FASD. For some of John’s drawings, see the back cover.

Right Community Support Worker Jason Louie frequently brings nature into the classroom. He has found that petting furs has a calming effect on his students, something he believes is related to the strong cultural connection his community has with animals.

John has a BA and a BSW, but found it hard to cope in university, and eventually found out that he had learning disabilities. Later on, he began to learn about the symptoms of FAE and realized that many of the symptoms fit him – such as memory glitches, difficulty understanding consequences and time, and an abnormally high pain threshold. Learning about it helped him to see what worked for both him and his clients. Just the fact that he has FAE helps his clients.

*They see that I’m an intelligent person. I have my own life. I work around my disabilities; I don’t deny them. It’s important for [the clients to see]. A lot of people won’t talk about it, ‘cause they think it means that you’re stupid, but it has nothing to do with that. Everyone that knows me knows that I’m not.*

Both Jason and John work as integral members of the community, not just as “social workers” imposed from an outside society. Jason’s role extends from his home to his work with the school, and into the homes of others. In addition to his work as a caregiver, he is an integral part of his nation, serving on council and actively participating in the preservation of his Native language. Likewise, John can be seen in various settings, depending on the needs of his clients.

Jason and John are knowledgeable about many different strategies for working with FASD, and they use them on a daily basis. We focused in our discussions on the unique ways in which they find Aboriginal cultural approaches to be useful.

A caring and open referral and assessment process

IT’S ONE THING FOR an individual to move through denial and acceptance; CHIP works at helping a whole community through these stages. This community-wide focus has led to an education, referral and assessment process that is “user-friendly.” People tend to refer themselves or their kids rather than being referred through formal channels. The CHIP workers never seek an up-front FASD assessment from clients, since it’s such a sensitive area. A lot of parents won’t say that they suspect FASD - but they come to the program with their kids, and it’s known throughout the nation that the CHIP mandate is working with alcohol-affected children, families and adults. Jason supports an approach that meets the family’s emotional needs as they come to terms with FASD.
If they come to me and say ‘My child needs some help with this or that,’ and they don’t say anything about [drinking] during pregnancy or there’s a chance their child could be affected, I don’t push the issue. I leave it up to the parents. With one family, it took 2 years before she said ‘Yes I did drink – what happened, how do you diagnose, what are some of the effects?’ If they’re coming forward and saying ‘My child needs some help’, that’s a huge step, not just for the family but the community.

Jason isn’t sure how prevalent FASD is in the community, since no detailed formal studies have been done, but it’s safe to say it’s significant. A lot of the kids he works with have not been diagnosed, and many don’t seek out diagnosis, although CHIP does make referrals for FAS diagnostic assessments. However, CHIP staff can see the patterns with clients in the community. Sometimes the birth mom shares that she consumed alcohol during her pregnancy. Because CHIP is community based, the workers may also know or hear through the grapevine that a mother drank during pregnancy. They also know that if a child was adopted there’s also a good chance that alcohol was involved.

John stresses the importance of not judging, and of treating people with respect in order to be able to offer them support. Otherwise, why would they come? The CHIP program emphasizes “hope and potential,” not just disability:

You don’t treat people like they’re dumb. A lot of people, if you tell them that they have [FAS], they think you’re telling them that they’re stupid, but it’s not like that. You totally respect and affirm that person’s intelligence; you’re just working with that area of difficulty so they can have good self-esteem.

John points out that it’s the traditional Native way to respect those who are different and consider how they are gifted in other ways. He thinks it helps the youth to look at their condition from this perspective; to see that their life as a gift, and that they are sacred because the part of them that isn’t there is with the Creator. Looking at it that way respects the person for who they are, and respects their gifts and what they have to share.

Each person is a teacher and we need to encourage that person in their gifts so they can teach us what they have to offer. I read that

Dene people believe that every child is born with a drum in his hand and that person needs to be affirmed and his gifts need to be affirmed so that his drum beat will be heard – otherwise their drum just becomes weak and you can’t hear it…

The approach of both program workers reflects Native values of respect and acceptance. They don’t interrogate their clients, but allow them to come to their own understanding and disclosure in their own time, through a process that is natural, supportive and healing. And they treat the clients as people first rather than defining them by their condition.

The value of Drumming and Dancing
JASON SEES GREAT value in traditional drumming and dancing for kids with FASD.

[Kids with FASD] can be very accident prone. One boy I worked with was very interested in learning to dance. So I helped him with his regalia, and he had no practice at dancing. He attended pow wows, and he just watched. When he went out on the dance floor for the first time, he danced so beautifully you would never know that this boy was accident prone.

CHIP: A CASE FOR ABORIGINAL STRUCTURE

Strategies for working with FASD revolve around two key themes: the need for structure, and the need to develop relationship (to people, things or subject matter), which implies emotional as well as mental understanding. This is because FASD impairs our ability to interpret and organize the world around us and to relate to that world – to feel it and react appropriately. There is a strong message from the experience of CHIP: the best way to develop structure and relationship for people with FASD is not a box or pyramid or straight line. It’s a circle.

This may seem like a contradiction, but only from an institutionalized mind, which tells us that structure must be linear. But what if there is another kind of structure? What if what we learn in school is wrong, and a linear structure is only a partial truth?

The structure of a box is rigid and inflexible. People need to be streamlined or shaped against their nature to fit into it. The box inhibits emotional understanding and relationships because we have to change who we are before we even make our first move. Worst of all, the box is artificial, and therefore has no heart. A linear approach is loaded with too many words and can’t get far beyond scientific analysis. None of this means scientists and professionals and boxes and lines aren’t useful. We need them more than ever in this
prone… His movements were perfect. The look on his face! You know, I can still see it today, how proud he was.”

It’s the same for the drum. It actually has a physical effect, stimulating the sense of balance. Some of the most awkward people with FASD are some of the best dancers. You would never think they could be so good; but they are, and it’s such an important thing. And the drum, the music, acts as a regulator for the brain. So listening to Native music actually stimulates your brain. It helps structure your brain in a sense, I guess… It works, and I can only assume why. A lot of the kids that I work with have all these different problems. But when they come to the drum, they drum, they sing, they’re coordinated with the drum stick, they’re coordinated with the beats… and to me… that’s a connection to their past, a connection to the animals. The drum is constructed from an animal hide. The frame is wood. Every aspect to the drum is from nature. To me that has a very healing effect.

John also believes that traditional dancing has therapeutic value for people with FASD. He points out that the dancing stimulates the vestibular system (in the inner ear, which is where we have our sense of balance). He has noticed that traditional and pow wow dancing make people feel grounded, that the movement somehow helps people to feel whole.

Connecting with Nature
JASON AND JOHN both see great value in bringing children and youth with FAS and FAE to natural settings. They have taken kids on outings like nature hikes, kayaking, and rock climbing.

Jason points out that when alcohol-affected kids have to sit still in an assembly or play, it can be “a big disaster.” In these settings, the kids very quickly lose interest and inappropriate behaviours escalate. But when he takes the same kids on trips to the mountains or the bush looking for traditional plants or just to be in nature, he says you would never know that the kids were hyperactive.

Jason brings nature into the classroom as well. Once, when he was working with some boys that had ADD and things were escalating, he placed furs on their desk, and found that they were able to sit.

Their hands were in motion.
They’d just pet whatever it was.

And some of them preferred the same one every time, the coyote or the beaver or the otter. It was interesting because… there’s different textures, different feels to these furs. Some are soft, some are coarse. And one boy in particular preferred the inside to the outside and the inside is much more rough, a different feeling. So he always had his hand on the inside.

Jason brought up this discovery at a conference, and the medical professionals gave him a complex explanation. Jason can’t remember exactly what they said, but he does have his own explanation:

A lot of our traditional names within our nation have to do with animals, and we’ve always lived off the different animals from the land. When I was a child I remember eating beaver and muskrat. So not only were these our names, we also used these animals to survive. And to me… it’s the presence of these animals that are helping these children, helping… to have a calming effect, or whatever it might be. I strongly believe it’s the connection to the animals.

Spirituality
BOTH JASON AND JOHN see the value of spiritual practices. John spoke about how an Aboriginal age. But they need to be placed within a more natural structure. The best way to get to linear skills is by moving in a circle.

A circle provides flexible and fluid structure. In a circle, people come when they are ready, to the extent that they are able, and take what they need. It provides a framework for all possible approaches, and for all of us to work together. There is no top or bottom, beginning or end. No one needs to fit a rigid program mold. People can take two years to seek a formal diagnosis of FASD, or they may never seek it, if they don’t feel ready. There’s still a place for them. The valuable cultural strategies expressed by Jason and John are best supported through a circle: flexibility around time, holistic learning, heartfelt expression, belonging to a wider community, breaking the “social worker” mold, connecting with nature, and so on. These ways of being move in many different directions as needed – not along a line in one direction.

We can be loose and relaxed in a circle because it has life, and life has a heart that holds everything together. The CHIP workers keep coming back to the need for “heart.” To speak and listen from the heart, to have an intuitive sense about the people you work with, not just an analytical one, and to see them as relations rather than “clients.” Maybe this is why powwows, drumming and dancing are so valuable for kids with FASD. At the powwow everyone belongs, everyone is consoled, and we are all related and part of one great circle. It’s where people of all kinds come and go, each according to their own ability and sense of time. It’s where all that diverse life revolves around that drum representing the deepest of hearts and source of all life. And that circle and it’s potential for healing never end, no matter how damaged we may be as individuals.
perspective on dreams and visions helps us to interpret our world without relying on too much information.

Say an issue comes up, and [you’re] trying to figure out what the problem is, and suddenly you have this dream and it’s all explained in this dream. To me, that’s a Native cultural thing.

I think finding a place of calm is also a Native thing, and that helps me a lot. I smudge, I pray, I braid my hair, I think about dreams, have visions. I think prayer would be a really big, big, part of that. I believe in the world that you can’t see.

The drum is constructed from an animal hide. The frame is wood. Every aspect to the drum is from nature. To me that has a very healing effect.

Jason feels that the spiritual side of things is necessary for the caregiver as well:

On a spiritual side I sweat, I pray every day, I dance at pow wows, and through those things, I (gain strength)… I think it’s prayer, a lot of prayer that helps me to cope…”

A Holistic Approach to Learning and Expression
IN ADDITION TO a strong spiritual base, emotional (affective) and physical (kinesthetic) learning styles are emphasized in holistic Aboriginal learning environments. This is a way of balancing an over-emphasis by modern education on cognitive learning, and reflects the Medicine Wheel by addressing the spirit, heart, mind and body. Much of Jason’s work with the children builds in tactile, kinesthetic experience as essential aids to learning. For example, Jason uses a lot of visuals and games, especially with the younger kids. He is also on a first name basis with the kids in the school, which is one of the ways he establishes a level of trust and emotional safety for the children. He sees calling somebody “Mister” as being a reference to somebody you don’t know, someone who’s not at the same level.

John believes that he and many people with FASD are kinesthetic learners, and that a tactile experience is vital in order to integrate knowledge.

If I touch it and smell it I’ll never forget it… I draw a lot. Certain things I try to draw. It’s a struggle unless I touch it. Then I know where everything is. For me, being there makes all the difference. That’s how our ancestors learned things. We didn’t write things.

John has noticed a strong level of creativity in his clients. He sees art as a way to express what you have to say without using all the complicated phrases that people with FAS may find difficult. He believes that many Native cultural activities such as carving and painting help his clients. “The emotion of it acts as a calming influence. It can be very grounding to do those physical activities.”

Support in the Justice System
JOHN PROVIDES INSIGHT to court workers and probation officers, talking to them about how FAS and FAE work, and how the kids think. It often explains some bizarre behaviour, such as breaking into someone’s house at 9 am rather than waiting until the middle of the night. John supports clients who end up in court and is frequently seen in the courtroom. Often the judge will ask his advice.

The judge will ask me what I think the problem is, and I’ll say there’s a learning disability. I don’t like to say FA because it’s still a loaded term, and if I say there’s a learning disability, the judge will usually know what I’m talking about without me saying it. Because there are people who I know drank during their pregnancies, or their parents have told me, and they’ll stand in front of the judge and say they didn’t… just because of embarrassment.

Basically, John does what it takes to make the justice system a safer place for his clients. For example, because alcohol-affected people have trouble with time and appointments, John will sometimes remind the youth of their court dates by actually going to where they live and waking them up.

Mentors
IN JOHN’S EXPERIENCE, regular employment agencies don’t work at all for people with FASD. He stresses the importance of mentors the kids can trust in helping prepare for life and possible work. Youth with FASD can’t just be thrown into a job and left to sink or swim. With a mentor, there is a person they can trust to help them through it.

Mentoring can be very informal and is probably more effective that way. The program took some youth on a kayaking trip, and one of the youth went out of his way to help out and do things because he was enjoying it so much. The guide was so impressed that he offered this youth a job. This reinforces the value and common sense of an informal apprenticeship model, without all the paperwork and pressure. John sees it as a traditional Native way of learning.
The way a person would teach someone is you would follow your grandpa around and you would go hunting with him, and he would just motion to you what to do; or your auntie, or whatever. You would just observe, and you would learn how to do those things because you wanted to do it.

Language and Communication

WHEN ASKED HOW he sees his approach as culture-based or different from the mainstream, John talks about how Aboriginal people communicate:

We don’t dance around it, we just tell it like it is. I don’t pretend anything. I guess I’ve proven myself by my actions, and a lot of mainstream workers, they use too many words. They talk too much, they say things that they don’t mean, and kids don’t listen to their words, they just watch what they do. And to me, it’s how do I treat people, how do I treat myself?”

John’s advice for professionals, school employees, and social workers working with FASD is simple: “Listen more and talk less.”

Native Language

THERE ARE NOT many speakers of the Ktunaxa language left, but Jason Louie is one of them. Jason uses the language as the basis for a different approach to working with FASD children. From what he’s seen, it benefits the kids. He feels there’s more meaning and communication in Native languages than in English, which is confusing and has many aspects to it that make it hard to grasp.

So with Ktunaxa, one example is there’s no word for ‘I love you’ because love is something you would show the person. Again, that’s a teaching: how would you show your mom that you loved her? What could you do for your mom? There’s no word for ‘thank you.’ In working with the kids, how do you show somebody that you’re grateful? What can you do in your actions to be thankful to this person or persons?

Many of the children have had very little exposure to language and traditional ways. Jason thinks they’re very hungry for this knowledge, and that it shows in their efforts. Some of the children do well in the Ktunaxa language circle (it’s called a circle rather than a class), which is a way of working on the child’s strengths. “If they’re getting Ds in everything but language, the language class is a big boost to their self-esteem.” He can’t say why they’re doing well, but they enjoy it, they do well with it, and he’s just happy that they’re where they’re at with their knowledge.

John also believes that Native languages show us a distinct approach to working with FASD. He points out that we speak from the heart when using Native languages, and that it’s more difficult to lie.

If I ask ‘how are you’ in Kootenay, it’s more like saying ‘What is in your heart’ – not just breezily ‘How are you?’ ‘Oh, fine, how are you?’ ‘Great!’ It’s not like that because you speak truthfully. And your emotions and your heart and soul goes into what you say. The word for ‘listen’ in Tsimshian doesn’t mean to listen with your ear but to listen with your heart. Take it into your heart. And to me, that’s a very common thing with our languages, that your heart is a very major part of how you see the world. And if you see people with FASD with your heart you see them differently – it’s harder to judge people when you’re seeing people truthfully.

Using Ktunaxa Legends

JASON USES A LOT of legends in his work with the kids. In Ktunaxa culture a lot of legends involve Coyote, also known as the trickster. Coyote’s always getting himself into trouble. Jason tries to apply the Coyote character to what might be happening in the kids’ lives. One girl he worked with was constantly bullying another kid, but Jason found that just telling her how her behaviour was not acceptable was getting him nowhere. She could sit there and give all the indications that she understood, nodding her head and saying all the right things, but at lunch hour or the next day she could be doing the same thing. So he used the Coyote story, with furs as a visual and tactile prop.

The way a person would teach someone is you would follow your grandpa around and you would go hunting with him, and he would just motion to you what to do.

A lot of FA children are visual learners. It’s hard for them to write out things or explain so I use different legends to teach; it’s so open in what you can use. In our legends the coyote talks, does different things. They can see the lesson that’s being taught, especially with the Elders. When they do it they’ll change their voice and so I try and change my voice for coyote.

There’s a legend about Coyote bullying the grizzly bear, teasing him. That’s what this girl was doing. And then she seen what

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Different things happen to coyote in the story: he ended up getting hit by grizzly. So that’s this teaching about consequences. And consequences are a hard concept for a lot of these children to comprehend. There’s a lot of impulsive behaviour.

A Different Sense of Community

Because they are a part of the community, Jason and John have often known their “clients” since they were little, in some cases since they were newborns. This establishes a strong sense of trust, allowing them to break the mainstream “social worker” mold – the “professional” who maintains a detached air from his clients.

Jason moves through the community. He works with families to help them cope at home, teaching them about visual cues like pictures of actions in different rooms to help the children with routines. He also makes drop-in visits if he’s invited to the home, and welcomes drop-ins to his office.

Sometimes it’s just very informal, where we’re having coffee or tea or juice. Sometimes it’s not even mentioned about their children. A lot of these children’s parents are single and maybe that day all they need is just another adult to visit with. That’s another way of working with them.

At one time there were family meetings and informal circles with different topics, or just to debrief on what was happening with family members, which seemed useful. Many of the parents are single, and just appreciate a time to share. The meetings were “owned” by the parents, that is, they decided on how they would proceed and what to talk about.

John sees his work as culture-based in the sense that it provides a kind of extended family rather than simply a professional relationship. The sense of community helps John as well as his clients. He shared that his boss is sort of like a sister, and the boss before her was kind of like a mom. She helped him with ideas while encouraging him to come up with his own solutions. He believes that the consistency that comes with a sense of community – and having workers who are a part of the community – is very important.

One of the key things is that sense of trust, that I’m trusted. The workers in the mainstream community are not trusted. One of the kids said to me, ‘you’re just like my brother, I’ve known you my whole life… You’re the only one that never gave up on us.’… That makes a difference, not just checking in and checking out and ignoring everyone when it’s off-hours… I think it’s more like the traditional role; like if you took responsibility for someone, you took responsibility for them for your life.

Jason also stresses the importance of knowing that once you do start working with kids with FASD, you do become a very important person in their life. Many kids with FASD have had a difficult time with feelings of abandonment over the years.

A lot of times we’ve had workers that come in, establish a working relationship with their client and they’re gone in a year, 2 years. When these workers leave these individuals’ lives it causes a lot of chaos. So… if you say you’re going to do something with them, it’s important to follow through, whether it’s a meeting or an outing or whatever. But that’s tough where in today’s society, everyone does have their own life, their own choice to move on.

It isn’t easy. Jason has worked with many of the kids for a long period of time. As a support worker he tries to strike a balance between maintaining a level of professionalism and respecting the fact that he has become a key male figure in their life.

In it for the Long Haul

John and Jason work and live with FASD, and they will probably live the rest of their lives with it in some way. They’ve seen and learned and endured a lot. Sometimes it’s been very difficult. Jason shared that he has come to understand that he cares very deeply for the kids he works with. There are days when he has actually closed his office door and cried for them because of what’s happening in their lives. At the same time, there have been a lot of successes.

I’ve learned that they can learn. Society labels them stupid or learning disabled, whatever terms they use. They can learn, they just learn in different ways. They can succeed. Their success might not be what society views as success. If they can get employment as somebody that mows the grass or cuts the weeds and they’re getting a wage, to me that’s a success. Or they’ve made it through the school year and passed – that’s another success. It’s just looking at it in a different way. I’ve learned to change my expectations of people in general, to come to accept that [FASD] is in our community, our nation, and it’s going to be here for a long time. All I can really do is work with it. All we can do as a community, as a society, is work with it.”

CHIP has a manual based on the Medicine Wheel, The Story of CHIP: A Community Healing and Intervention Program. It describes the history and philosophy of the program, and has many suggestions, tips, activities and inspiring thoughts. The manual is available from CHIP for $25 plus postage. Contact CHIP at 7443 Mission Road, Cranbrook, British Columbia, Canada, V1C 7E5. Phone: 1-250-489-3373.
Support, Education & Healing

A VISIT WITH DELLA MAGUIRE AND HER TEAM

by Kim Anderson

IN THIS RELATIVELY new field of FASD education, Della Maguire brings over ten years of experience in facilitating workshops on FASD for Aboriginal communities.

Her interest began in 1992, when, as a drug and alcohol counsellor, she attended a presentation on FASD at a “Healing Our Spirits” conference.

“I was devastated by what I had learned. I came home and decided I needed to learn more,” says Della.

From that point on, she began to dig up all the information she could find on Fetal Alcohol Syndrome. The news of her interest got around, and it wasn’t long before she was asked to present on the subject.

Della’s first workshop was only an hour long. “I was scared to death, shaking and holding on to a piece of paper,” she remembers, adding that she had wondered how she was going to fill up the time. Now she has enough material to do a three-day course – and she points out that could make her sessions longer yet.

Della operates her own organization, the Mi’kmaq First Nation Healing Society out of Halifax Nova Scotia. They specialize in training, education and support on a number of issues, including Fetal Alcohol Syndrome, residential school syndrome, youth crime and addictions and diabetes.

FASD is a sensitive topic, and Della emphasizes that one must be culturally aware in order to deal with the many issues that can come up. Nora MacDonald-Plourde, an advisor to the project, notes that people may not want to talk about FASD because of their own past. Because of this sensitivity, Della has designed her workshops according to the basic principles of respect, understanding, caring, forgiveness and hope. She finds these principles are useful in workshops as well as in the community when interacting with people living with FASD and their families.

The workshops typically make use of videos which feature Aboriginal people. This brings the familiarity and wisdom of Aboriginal culture to the setting. Della also likes to call upon storytelling as a teaching tool, and so she invites Elders who can talk about FASD in their community as well as Aboriginal people with FASD as guest speakers. (See Coming out of the Box: Listening to Francis Perry on page 20).

In talking about FASD, Della stresses the root causes of the syndrome, such as the loss of land, culture and language as well as the interference and trauma caused by the residential school years. Talking circles and circle checks can be very effective to deal with these difficult subjects. Workshop participants are always reminded to speak from the heart as well as the mind, and to value, respect and listen to all members of the circle.

Della uses the medicine wheel to demonstrate the need for the wholistic development of the individual (mental, emotional, physical and spiritual).

After 100 years of alcoholism in Aboriginal communities, affecting three generations, we are just now demanding that the physical, mental, spiritual and emotional needs of the unborn children be protected. It is not enough to preserve our land, our water and our trees – by far our most natural resource is our children and our unborn.

These children are our ancestors – each birth is the spirit of our Grandmothers and Grandfathers. They walk in spirituality and they are our teachers. Respect and protect them.

Della Maguire
Mi’kmaq First Nation Healing Society
Respect  Respect is emphasized as part of Native culture. Participants are reminded to always respect each other.

Understanding  The workshops stress that in order for healing, one must have understanding for the person who is dependent on alcohol.

Caring  All information provided in the presentations should be shared in a respectful way with the intention of helping others.

Forgiveness  One must have forgiveness for oneself and others for what has happened in the past so that we can go forward.

Hope  Education can help everyone to understand the invisible disability of FASD and reduce the incidence in all communities.

Advisory Board members can be particularly helpful in terms of accessing and developing relationships with communities. Jane Abram talks about using her own community contacts and key resource people in the community to organize a workshop at Millbrook First Nation:

“One of the ways of passing down the message [about FASD] is with the grandmothers. When I was making my list up for people to come to [this] workshop, I tried to get people who are the grandmothers to spread the news. Those who have been down that road before, [who know] how it has affected them. That have recovered since, and feel good about themselves, and they are able to talk about it. Then they can pass it on to their children and grandchildren.

The enthusiasm of the advisory board helps to keep the team going. “We have to be consistent. Keep going, even when the going gets rough,” says Nora MacDonald-Plourde. She points out that individuals may not come around the first time, but the information eventually filters through. “Every time Della comes or [they] hear about her, it’s in [their] head. Finally, [an individual] will get strong enough to come up and say “I think one of my children has FAS.”

Della adds that when she first started, no one would even ask questions at the end of a workshop. Now she has people talking about FASD in their families, and sometimes requesting to speak to her in private at the end of a workshop.

Timing is everything. “There is a great understanding of going forward at the pace of the community. The community needs to feel safe,” says Della. “The level of awareness and being ready to hear about FASD is the same across Canada. Some communities are talking about it openly. They are looking for information, looking for strategies. Other people are still listening, and not ready yet. You need to be approachable so that people don’t feel threatened; that they feel comfortable in coming to you.”

For Della, there is a great deal of satisfaction in the response she gets from communities. “People appreciate the information. They are just as astonished as I was that they never heard of FASD before. They appreciate it, and they relate to it, and they start thinking about the bigger picture.”

“What I believe is that FAS is here to teach us something,” she says. “And sometimes we may not want to look at what that is teaching. So people living with FAS are very important to us. I think they are gifts to our communities; to help us look at what is and is not working.”

This work will hopefully see a generation that is more aware of FASD. The children’s workshops are already making a difference. Della laughs as she recalls a recent presentation she did for children in Quebec. “After we did the workshop, some children had a toll booth where they were fundraising. As we were driving up, this little boy came running out [happily shouting] “It’s the FAS people!”

Empowering our Communities on FASD: A Training Manual offers Aboriginal educators and communities a thorough look at the causes and effects of FASD. The 60 page book is filled with training exercises that can be done to facilitate community awareness, prevention of FASD and health promotion for people living with FASD. Copies of the this manual may be obtained through Della Maguire, Mi’kmaq First Nation Healing Society, 2158 Gottingen St., Halifax, Nova Scotia, Canada, B3K 3B4. Phone: 902-420-1576. Fax: 902-423-6130. Email: della@ns.sympatico.ca
KIM MEAWASIGE AND GREG FLYNN are raising seven children in Scarborough, Ontario – four of them with FAS. We spoke with Kim, who is Anishaabeque (an Ojibwe woman) from Kenabojing, north of Manitoulin Island, and works as the FASD Policy Analyst for the Ontario Federation of Indian Friendship Centres. Kim’s father is traditional, and was protected from the residential school system by his parents, who hid him in the bush when Indian Affairs came to take the children away. As a result, Kim had the benefit of growing up with traditional teachings and ceremonies, and she and Greg are raising their own family with Native cultural values.

Kim worked with Native Child and Family Services in Toronto for 10 years. It was while working there that she and Greg brought the kids with FAS into the family through the customary care program – although the affected children were not diagnosed until after they had been with the family for some time. Kim and Greg knew very little about FAS when they took in the kids, and experienced all of the traumas related to having children with FAS before any of them were diagnosed. When diagnoses finally came, the discovery was hard, but also a relief, as it is for so many families who have coped unknowingly with FAS. Kim says that if someone had educated them earlier they wouldn’t have had to go through so much. She adds that the whole family has been impacted by the presence of FAS.

When CAS was dissecting us, it affected us all. When our family is treated differently we are all treated differently. When we avoided amusement parks, crowds, and other over-stimulating activities our whole family avoided them. Even though the other children were not born with FAS they feel the same negativity and stereotyping. It is our family living with FAS, not us living with four children who have FAS.

The affected children suffer from many of the typical symptoms. Kim describes two of the younger kids as being very impulsive, easily led and unable to see danger. They have a hard time dealing with stimulation in their environment; as Kim says, “they can’t handle recess – there’s 400 kids on the playground!”

Not surprisingly, problems often arise at school. There have been many stressful times over the years. The youngest child, Brenda, can’t feel temperature in her hands, has a heart murmur, and was having seizures when she was only seven months old. At the age of two, Brenda lost consciousness and was saved at the last minute by firemen with a respirator. The kids have a lot of birth defects that aren’t visible, such as hearing problems and, of course, behavioural and learning problems.

The family’s son Christopher was so emotionally flat when he came into the home at age six that he didn’t cry for two years. It was an incredibly emotional moment when he finally broke down. This led to his first hug. Today Christopher is a friendly, cheerful boy who can’t wait to show you his drawings, or give you a tour of the family home.

**Coping**

**IN SPITE OF THE** difficulties, Kim can attest to the value of Native culture in raising children with FAS and in trying to create a special, safe place that is the

**HOW NATIVE CULTURAL VALUES HELP ONE FAMILY LIVE WITH FASD**

*by Doug Anderson*
foundation for their healthy development. She shared with us how cultural practices and values help approach the challenges faced by her family. Some basic principles can be gleaned from her experience:

- strong extended family and community support;
- we all belong - nobody’s “adopted”;
- strong identity – know who you are and where you’re from;
- maintain traditional cultural practices and ceremonies;
- take advantage of nature as a healing force;
- use Native medicine, not just medication.

None of these principles stand alone; they all support each other in a holistic way. Many of them seem like common sense until you realize that they represent practices that are largely missing from the world today. In many ways they stand in opposition to the values promoted through mainstream society.

**Extended family – not bureaucracy – as a support network**

ANYONE WHO HAS worked with children with FASD knows that both caregivers and children need as much support as possible. A small nuclear family situation just isn’t enough, and may be too much stress for the family to bear. Unfortunately, the institutions mandated to help create a safe and healthy environment for children often end up creating barriers to such an environment.

Kim feels that the mainstream social services systems don’t work well, and that they may even be detrimental to children’s health, especially those with FASD. At one point, there were three workers from several different agencies coming to the home for each of the four kids – which amounted to twelve home visits per week. On top of this, there were appointments with doctors (the kids still see a doctor every six months), psychologists, and other specialists. Ultimately, it ended up feeling like the family was being dissected rather than supported.

Over the last few years, Children’s Aid has pulled away – which Kim sees as a good thing. As she says, “they were just causing turmoil in the house.” The reduced frequency of visits from CAS workers has made a big difference in helping get the kids to settle down.

Another problem with the mainstream approach to service provision is a style of direct and sometimes “formalized” questioning that can cause discomfort for Native people, and which just doesn’t work well, especially with kids who have FASD. The effect is even worse when the people coming in are “professionals,” which is sometimes just another word for an alienating stranger. One exasperated worker once asked one of the kids what she thought of her, and was given a long and blunt list – “You’re fat, you’re ugly,” and so on. This probably wasn’t the most warm or constructive relationship, to say the least.

In contrast to the bureaucratic side of child welfare is the Indian extended family and community. Greg and Kim’s family is an Aboriginal model of an extended family, with a large, strong network of people who are “aunties, uncles, and grandmothers” to the kids, whether by blood or friendship. For example, one friend of the family, an ex-colleague of Kim’s, is like an uncle to the kids, and makes himself available to drive them places on short notice. Kim’s dad visits the family from up north when he can, and there are a number of other elders who have become a part of the family circle. For Kim and Greg, the spiritual and emotional support that has come from this circle is priceless.

Extended family means people you know and trust as family, not as professionals. Even when the family was under enormous strain, Kim turned down the assistance offered through an officially sanctioned Respite Care program that gives relief to parents through paid respite workers. Kim feels such programs don’t work well, and would rather turn for assistance to her own family – in her case, it was her sister, who offered respite care for six years at no cost, until she was finally approved through formal channels.

The broader Native community adds to the sense of extended family. The feeling that one gets at Native gatherings can provide a sense of security, even peacefulness. In Native social environments there is less pressure to talk and people sit comfortably together in silence. All of this reduces the stimulation levels for the children. As Kim says, the kids like Native organizations, partially because they’re “not so busy.”

**Nobody’s “adopted” – we all belong**

PERHAPS THE MOST healing thing of all is a distinct Aboriginal concept of family and what it means to be related. After all, from an Indian point of view, we are all related. Kim is often asked the inevitable question when confronted with social workers or other people with an interest in her family: “Which ones are adopted?” For Kim, this question is part of the problem; it classifies the children and works against Aboriginal spiritual values that are healing for the kids.

Kim refuses to classify the kids to the world and tries to avoid the topic of “adoption.” This isn’t easy, because if you are open about FASD and don’t clarify the adopted status of the child, people assume you are the person responsible for the child’s condition and behaviour. This is especially true is you are obviously Aboriginal and the children resemble you, as they do in Kim’s case. Kim has too often met with the judgmental attitudes of professionals who consider her a neglectful mother. More than once, she’s had workers ask her how long she has been in recovery. But for the kids’ sake, she refrains from explanations that diminish the children’s status in the family or assign them a different
definition as a son or daughter. Sometimes Kim will send Greg to get help because he’ll get better service than Kim, since he can “pass” for a non-Native person.

As Kim says, “foster kids feel different, and they just want to be normal.” They need to know that they’re all equally loved, all from the same place, and that “they are all a part of this large extended family.” Since alcohol is estimated to account for nearly 70% of children taken from their parents, and kids with FASD are most likely to have behavioural problems, they are also the most likely to be moved around and to lack a sense of belonging. Some of Kim’s kids were moved twelve or fifteen times before they came to the home. Kim knows one youth with FAS that was moved 56 times as a child. From his point of view, he had lost fifty-six parents, and had to grieve each time.

Such children need to find and draw on strength of spirit in ways that most of us will never know. What helps them and feeds that spirit is the knowledge that they do belong, regardless of their birth situation. While most adoptive parents try to cultivate this feeling for their child, what makes a Native approach unique is that the sensibility is built right into the culture and spirituality. We are all responsible for all of the children, and all children “belong” to us as sacred beings who have recently come from a sacred place.

Identity – know who you are and where you’re from

A TRADITIONAL NATIVE view teaches us that we are always connected to our ancestors. Kim knows that the kids all still feel the connection with their birth parents. She describes one of her daughters as “so in touch with what was going on with her birth mom.” Kim and Greg make sure that all the kids have a chance to visit their ancestral territories. Greg is making plans to take one of the children to her birth mother’s home, even though it’s across the country in British Columbia. “It’s important for the kids to know what reserve they’re from, what nation and language and heritage they have.”

There is a negative aspect to knowing where you come from, especially for these kids. Kim and Greg protect the children from unhealthy contact with their birth parents. For example, while the kids get calls from their birth moms, there is a strict rule that the mothers not phone under the influence of alcohol. But even the negative side provides opportunities for learning and healing, if only because the kids see their birth moms and know they don’t want to fall into the same patterns. This is important, because many birth parents of children with FASD are alcohol-affected themselves, and we need to stop the cycle.

Maintaining a connection with their origins actually helps the kids to detach from the negative side, and allows them to see what it’s like on both sides – the “haves and have-nots.” No matter how painful some of the knowledge may be, in the end Kim sees it as a part of the healing process.

Another aspect of knowing who you are is letting the child know about FASD as much as possible. This relates to the Traditional Anishnaabe teaching of honesty. Kim and Greg have made a point of explaining FAS to the kids. The kids know it’s not their fault, and that it’s a disability. In some ways, the children in the family are experts on FAS. Kim has noted that even her 10-year-old can see FAS in other kids where many professionals can not.

Part of being honest means grieving and healing for the children, along with prayers of healing for other relations.

Christopher’s birth mother was a troubled woman from a remote northern reserve. When he began to deal with who his mother was, he and Kim put down tobacco for his mom and prayed for her, and cried together. In this way, the connection is acknowledged rather than denied, and provides an opportunity for developing respect rather than anger.

Traditional cultural practices and ceremonies

NATIVE CEREMONIAL LIFE and practice point to a positive direction for raising and working with kids with FASD. Kim believes that Aboriginal cultures already have the best cultural tools and practices which children with FASD need.

After the children were diagnosed, the family went through a grieving process, and the traditional ceremonies and values were a great help to the kids and the whole family. The kids are secure in their culture, and know who they are and where they come from. They all drum, go to powwows, have their traditional names, and have grown up with the traditional Anishnaabe ceremonies like the sweat lodges and Spirit Night, or Feast of the Dead, which is conducted by Kim’s father. This all reinforces a positive sense of identity. The sense of spiritual strength and support has helped the family through trying times, such as when a number of people in the extended community passed away all at around the same time.

Talking circle

KIM BELIEVES THAT the practice of the talking circle, if conducted properly, can be of great benefit. The kids can handle it better than a classroom because the stimulation level is much lower, which is appropriate for kids with FASD. The passing of the feather is a visual cue that helps them to focus on listening, and with visual sequencing. The practice in the talking circle is equalizing, giving the children a chance to express themselves how they see fit. It also gives them a chance to both speak and focus on what others are saying with no interruptions. For many kids with FASD, when somebody interrupts them, they have to start again from the
beginning, which relates to the trouble many of them have with sequencing. Also, in the circle, the Creator takes our “garbage”. Perhaps most importantly, the kids just enjoy the talking circle.

Sweat lodge
FAMILY MEMBERS USUALLY go to a sweat lodge three or four times in a year. Early on, when Kim took one of the kids to see an Elder, the Elder made an interesting comment: “Her spirit is still drunk.” It seems like children with FAS have a need to address the abuse that they suffered in the womb—just as those who have suffered abuse at an earlier time in their life may benefit from revisiting and healing from that time, through grieving and forgiveness. The sweat lodge is an ideal place for anyone to do this work, but perhaps especially for those who suffered in the womb. The most interesting thing about kids with FASD and the sweat lodge is that the sweat lodge is designed to take us back into a womb, which is where the damage was done to children with FASD. Kim notes that the sweat lodge provides healing from anger, which kids must deal with when considering their birth mother’s drinking. Another reason why kids with FASD like the lodge is that it’s calm and peaceful, with minimal stimulation. It could also be that the lodge provides the safe womb they never had, and which some part of them must still yearn for.

The healing force of nature
BEING OUT IN NATURE also reduces stimulation, which the kids really appreciate. Kim says they always look forward to camp. They have gone every year, sometimes for the whole summer. The kids also like going to the reserve because there’s “not so much noise.” Kim believes her son Christopher could be happy as an adult if he could work out in the bush somehow.

Kim and Greg’s kids love the FASD camp run through Native Child and Family Services of Toronto. This camp is a highly structured parent-child retreat. The one-on-one ratio of adults to children, the escape from urban stimulation, and the exposure to Native culture all work wonders for kids with FASD. Greg is in his seventh year of running the camp, and the demand for it shows no signs of slowing down.

Medicine versus medication
THE FAMILY USES THE mainstream medical system a lot, with all the medical problems the kids have had. Luckily, the doctors have generally been co-operative in working with Native Elders. Kim and Greg have taken the kids to see various Elders over the years.

Kim would like to know more about traditional and natural medicines and treatments. When her daughter Brenda was having seizures, an Elder gave Brenda some medicine in the form of a tea that she drank three times a day, which helped calm her down. The reduced hyperactivity made Kim wonder about alternatives to Ritalin. Brenda has benefited from other treatments such as addressing the imbalances and damage done in pregnancy, spiritual alignment and helping clear out the toxins in the bloodstream.

Christopher, who is now 12, has been put on Ritalin as a mechanism to help him (and his teachers) cope in school. Kim knows this can be a challenge for the child’s whole family. As Kim says: “If they screw up, we’ll be there—and they know it. We always make sure to say ‘I love you’ every night, last thing before they go to bed.”

If you know there’s such a thing as unconditional love, and if you know that it spreads out like ripples in a pond, what can be more healing than that?

Looking to the Future
IT IS HARD ENOUGH to raise one child with FAS. It is a testament to the power and beauty inherent in Native cultures that this family is raising four, along with three other kids.

Of course, not all families coping with FASD will be lucky enough to have the benefit of these cultural practices and conditions. But the principles behind them point in a direction that should prove fruitful in developing programs and support for FASD children where families are not so lucky. These cultural principles could also inspire parents who are avidly looking for new ways to cope. New avenues for Aboriginal-directed research done in partnership with universities and sympathetic medical professionals are also necessary.

Kim wonders about how the kids will cope when they finally spread their wings and move into the wider community. The world outside is increasingly fragmented, with no grounding in traditional values, and where the sense of family is usually limited to those people who are under your roof. Aboriginal family and community systems, along with all traditional family systems, have undergone a sustained and vigorous attack.

For now, there is a lot of spiritual and emotional support from the family and community. And if things do go wrong, it’s good to know that the support comes from a deep well. As Kim says: “If they screw up, we’ll be there—and they know it. We always make sure to say ‘I love you’ every night, last thing before they go to bed.”

If you know there’s such a thing as unconditional love, and if you know that it spreads out like ripples in a pond, what can be more healing than that?

Kim Meawasige can be reached at OFIC at (416) 956-7575.
Cultural Awareness Camps

In Vancouver, a camp designed specifically for FASD children has them participating in traditional activities like berry picking, medicine gathering and drying, fishing, crafts, and talking and healing circles.

by Kim Anderson

FOR THE PAST THREE YEARS, the FASD Program of the Vancouver Aboriginal Friendship Centre and the Hey Way Noqu Healing Circle have jointly run FASD Cultural Awareness Camps for Children.

Coordinator Jenelle McMillan says she came up with the idea because many of the children she was working with were not having good camping experiences. “Like school, many of the children were being asked to leave the camps they were attending due to unruly behavior” says Jenelle. She wanted to find out why:

I did a bit of research and found that many of the counsellors at regular camps are not trained to meet the special needs of children with FAS. They also do not recognize FAS when they see it. It is often described as a behavior problem, and behavior modification is attempted instead of behavior management.

The agencies usually run two camps a year for children aged 8 to 12. Camps run Monday to Friday with a high camp staff/child ratio at seven staff to ten children. Children are constantly supervised “including during the sleeping hours,” adds Jenelle. Structure, routine and supervision are key to the success of the camp: “Staff are trained to anticipate, predict and prevent – which is the key component of behavior management.”

Jenelle talks about how these camps work well for children with FASD:

The camps address the needs of the children because they provide high energy activities balanced with low key activities. They offer simplicity and limited time to remain seated. We also serve nutritional food which does not include a lot of food additives, dyes, chemicals or preservatives.

Because the environment is structured to prevent incidents, children are able to feel successful and proud of what they are accomplishing in camp. Jenelle notes that this is necessary for children to feel successful and to foster the development of their self-esteem:

This camp honors each child and supports and encourages their abilities rather than focusing on their disabilities. Children learn how to express themselves and to develop friendship skills. It is experiential learning and it is fun and enjoyable for the staff and the children.

Cultural activities at the camp include berry picking, learning the traditional plants and medicines of the area, traditional games, making paints, traditional crafts and fishing. Children are divided into groups based on their talents and things they liked to do (artists with artists, hunter/gathers, sports minded, etc.). Many staff have extra talents and knowledge in particular areas which they can share with the children.

The cultural approach is not limited to certain times – it guides the entire day. Each day begins with a smudge and a talking circle to help ground the children. Meal preparation and rest time are honoured, and tobacco is offered for everything the children and staff take from the earth. The campers dry medicines and use them traditionally whenever possible. The children especially enjoy finding ways to connect with all of nature.

At the end of the day, everyone gathers around the fire to tell stories of the day’s events. At this time, the group might also have a healing circle if an incident has occurred during the day. All consequences are immediate and short term.

Jenelle concludes, “It has been a great experience for all staff and campers over the past three years. We plan to continue with this event.”

You can reach Jenelle McMillan at following:

Train the Trainers
Box 63047 6020 Steveston Hwy
Richmond, BC Canada V7E 2K0
Tel: (604) 818-5258

Hey Way Noqu Healing Circle
#206 – 33 East Broadway
Vancouver, BC Canada
Tel: (604) 874-1831
I WAS ADOPTED INTO A WHITE FAMILY when I was three. In those days, there weren’t any introductions or anything. I was dropped off at a motel with a garbage bag.

The first day, I initiated my mom by grabbing on to her leg and biting her bum! It went on from there.

I used to like to take all the cushions off the couch. I would stack them up on the floor and then I would run circles around them all day. That’s all I would do is just run, run, run. How many children do you know that are 2 or 3 years old that sweat? I was literally soaked in sweat. My parents couldn’t believe it. They thought, Holy smokes, what have we got? We have a monster here.

I would literally run around the house like a Tasmanian devil, destroying everything that I touched. My mom was thinking, Okay, I have to do something about this. Maybe I need to have a nap to recover… She would call my aunt up and say “I have a plan: Take him to the beach. There is all kinds of sand to run. Let him run.”

So they had the ordeal of trying to get me to the beach. Back then, we never had child safety car seats or child safety locks on windows. So they had to try and keep me in the car without me trying to jump out because I could just grab the doorknob and jump out of the car with me being so hyper. It was just a never-ending process. My aunt would be driving the car holding on to me, trying to drive.

I don’t even know how we ever made it to the beach. My mom would lie down for an hour and take a nap while I was running around the beach. So that was those years.

School came along and this was a nightmare. I can’t even describe the hell that I went through, let alone what my teachers went through. Just trying to sit in the classroom with thirty other children, with lights buzzing and humming or making noises.

Things like learning time were a major problem. I couldn’t tell time until I was nineteen years old. On a regular clock, I found it hard to keep track of hands, where they’re at, what the big hand means, etc. It was really hard for me to learn time.

The teachers knew that there was something wrong. This kid is just a classroom distraction! They thought about what they could do about this. They thought about it and they put me in a box, a little cubicle. They thought that would keep me from distracting the rest of the class.

Eventually, I outgrew the box. As time went on, people asked me what my parents thought about sticking me in a box. I would tell them that my parents made the box! My father was a teacher so it kind of put things into perspective.

In school, I was teased a lot because I was in that box. As soon as I got out of that box, I had to socialize with my other peers. When you’re stuck in a box and then you have to come out and go out in the playground and play with your friends, it becomes quite obvious that you are a walking target to be picked on. Not only was I the only Native person in my community, I had FAS – trying to keep up with the classroom and being sick a lot when I was younger.

I spent a lot of time in hospital on and off. Pretty much every month I was going for ear problems, chest problems, and hernia – everything that you could name. They had me hooked up to everything, EEG’s, everything.

The school was a nightmare. I would get out in the playground and get picked on. Then I would get in trouble and I didn’t know why. Why am I getting in trouble? They’re the ones who are picking on me. Of course, I would react and respond without thinking and that’s what would get me in trouble. I would just attack a person that said something about me instead of walking away.

It eventually came to Ritalin. The teacher said that this might help and it did. It kept me calm in the classroom and that was, at that time, my saving grace. But it didn’t help me as far as trying to catch up with my work. Here I am trying to write down something from the chalkboard and I’m trying to follow what she’s doing and I would do one letter at a time for a word. By the time I got the first five words down, she’d already done the whole chalkboard and she was wiping it all off. She would say that I wasn’t paying attention and that I was just fooling around.

I couldn’t keep up. I kept falling behind more and more. Finally they said, “What are we going to do?”

Eventually high school came and the teachers all knew that I was not ready for high school. There was no way I was going to fit into a high school atmosphere where I can’t even do grade five.
Francis Perry is a twenty-nine year old Mi’kmaq man living with FAS. Originally from Afton First Nation, he now lives in Truro, Nova Scotia. Francis was adopted in 1975 at age three, and has been on his own for about 12 years.

At present, Francis is a guest speaker for the Mi’maq First Nation Healing Society. This text is taken from a speech he made at Millbrook First Nation on July 9, 2002.
The following words of wisdom are taken from an interview with Francis Perry at Millbrook First Nation on July 9, 2002.

On Alternative Education
The high school at the Friendship Centre helped me because it opened my eyes to my own culture.

I was brought up watching cowboys and Indians on TV. That’s the ideas that I got about my own culture. When I first came to the Friendship Centre [in Halifax], I was very intimidated by the fact that I was walking into a different world – and I was, because I was [living] in a white community.

The Friendship Centre classes were different – like it was Native studies instead of social studies. We never learned anything in school about Native culture, other than the fact that this land was once owned by Indians. That’s as far as it went.

The classrooms were smaller. There were about 10-12 people in the class whereas you have 35-40 kids in a [regular high-school] class. It’s totally different. You’re not as pressured. I never felt that at all. If I didn’t get something, I didn’t feel intimidated to go up to the teachers and ask them to stay and help me.

When I was younger, if you raised your hand in class, you were considered an idiot or stupid, so I never raised my hand.

I learned that in order to get somewhere, you have to ask. If you don’t ask, then you won’t receive.

On Coming Home
Once I went to my own reserve, I got to see for myself how [Native people] live. I thought they still lived in tipis! I had no idea what it was like to live on a reserve. To see doors unlocked and people just coming in and helping themselves with whatever they needed – that was totally different. Everyone shared everything and whenever someone need help, there was help. That’s what I sensed and that’s what I saw.

I was scared to go back at first. I got ridiculed a lot for not being able to speak my language. I just ignored it though.

I don’t go home often now. There’s nothing to do up there really. I went up to see it and met some relatives and family and they told me that they really didn’t want to see me.

At this time, my parents had adopted another child. Where they got the nerve to do that, I don’t know! They adopted another child and he’s ten years younger than me, and then another two years later they had a biological child. It quickly became obvious that these two children who are eight and ten years younger than me, quickly passed me in every subject. Then my parents said, “Oh my gosh, this is a bigger problem than we thought.” They thought that the professionals, the doctors, the psychologists, the psychiatrists, all of these people that were saying that we were bad parents and didn’t know how to raise a child or what to do, and then they had two other children who were a breeze. They wondered what happened with me.

They started looking into the papers, the adoption papers. On the top of the adoption paper was written “FAS”. But back in 1972, FAS was just that. It was just a phrase, a little logo. They didn’t do much research on it. They didn’t know what it was or how it affected people.

With school, my parents thought it would be best that I go to a private school in the Valley. I spent about a month and a half to two months there before I got kicked out. It was their bright idea to say, “Okay we don’t need any children here on medication. We just don’t need it. They do fine without it.” They weren’t prepared for me.

I was there for about two months, and within the first month they phoned my parents begging for the medication! A month later, I got kicked out. My parents came up, packed all of my stuff and off I went.

I went back into high school. High school wasn’t that bad. If my father weren’t the teacher, it would have made things a little easier. Whenever I got in trouble in high school, I got sent to my father. Then I would have to sit in the car all the way home and listen to my father lecture me.

I wasn’t ready for high school at all. The first year they knew. The changing of the classrooms, going to the locker, grabbing your books, etc. Trying to figure out where to go, the constant movement and stuff really threw me off. I didn’t have any clue as to what I was doing. I just walked around the halls aimlessly sometimes until a teacher would come along and grab me.

One day I was on my way to school and I missed the bus. I started a fire by accident. Well... on purpose. Anyway, I was fooling around with fire and it just got out of control and I ran down the road and told the guy who lived down the road that there was a fire going on. I took off. I hid inside my grandmother’s barn while I watched through a peephole and watched the firemen come and put out the fire. My parents were frantic.

Suppertime came and I got hungry so I had to go home. I went home and walked in nonchalantly and my mom asked where I had been and why I had started the fire. I told her that I didn’t start the fire. My brand new shoes were covered in soot and black and burnt and melted. My coat was all covered in soot from trying to put out the fire. I’m just covered in soot. I think I was grounded for about a year. The fire incident wasn’t the best.

High school turned to community college. Back then, you didn’t have to have grade twelve to go to community college. You went and picked whatever course you wanted to take and took it. I took all kinds: carpentry, engine repair, auto body, welding, etc.

Things at home were getting a little stressful so my parents decided to take a vacation. They went to PEI and left me with the house and said that they would be back in two or three weeks.
I had a blast. Me and my friends went out and decided one day – we looked at this canteen and thought that we could get some candy and pop and chips, etc. if we could only get in. We managed to break our way into the canteen and steal all the pop and chips and a cigarettes and off we went thinking nothing else of it. We did it at 3:00 in the morning.

Off I went and then the cops were investigating this break-in. I’m not the brightest criminal. They followed a smartie trail; all of these wrappers were left behind me all the way to my house. They just kept following the trail and they found me.

I figured Okay, the cops came, they gave me this little pink slip saying that I had to show up in court on such and such a date. I’m thinking, Oh great, my parents are going to come home and freak! They’re going to kill me. I thought, Well, I’d get a step ahead of them. So I took all of the pills, all the Ritalin that I had. I took them out of the cupboard. I don’t know how many were there but enough to put me to sleep for three days and paralyze me for a while.

I had dropped my laundry off at my aunt’s house the day before and I told her I would be back the next day to pick it up. I never did, for three days. My aunt was kind of concerned. At that time, I was eating at my aunt’s because I didn’t know how to cook. She thought that this was the third day and I hadn’t been there so she came over and came in and she found me on the couch.

I was lying there and my first instinct was to jump up and hide the pill bottle and the pink slip from the cop shop. I couldn’t move, run, speak or hardly see. I was lying there and totally paralyzed. I realized that something was wrong. My aunt thought I was drinking or on drugs or something and she phoned the police and they came. My mom knows me so well, she gave the police the keys to my house. They came and found me. Anyway, I’m a lot better. That was a part of my life that really scared me.

I ended up going to Toronto to “Teen Challenge”, which is a Christian group home. I was there for about nine or ten months before I got kicked out of this place. It seemed that every place I went I burnt my bridge. After nine months they said that I was too much and couldn’t handle me, and this was for troubled teens! Toronto couldn’t handle me – that’s bad.

My criminal career went down hill. I spent six months in the Waterville Youth Centre because of the two break and enters and the shoplifting. Before I went there, I had a job at Sobey’s and on my payday, I stole a carton of cigarettes. Two-hundred and seventy-three dollars – I could have bought ten cartons of cigarettes, or twenty. I couldn’t believe it. My parents were just dumbfounded. Here I am sitting in the back room at Sobey’s with a police officer and my father and the manager of Sobey’s at the time and they were all dumbfounded. I couldn’t figure it out. I don’t know, I just did it. There was an impulse. Never thought about getting caught or the consequences.

After I got out of Waterville, I had a lot of time to think about my life and everything that I had done: all the schools, group homes, everything. I had been kicked out of five schools, private schools, Teen Challenge – everything – and I thought, My God, this is what my life is going to be like? Everything I have ever done was a mistake and I got thinking. What’s the sense? What’s the purpose of me continuing? This is ridiculous; I’m just going to repeat the same thing over and over.

After I got out of jail, I went down to the basement and I took my father’s shotgun down out of the rack and sat on the chopping block and cried. I didn’t know what to do. I had no clue as to where, who, what, why; all these questions were just hitting me.

Going back to the community and asking questions about the past is hard because you’re bringing up something that they really don’t want to talk about or discuss. My mother was murdered when I was a baby, so I never knew her. I would ask who she was and what was she like and if she smiled a lot. They don’t want to hear that because it’s just bringing up stuff that they don’t want to remember.

I think it’s important to remember because if we don’t, then history will repeat itself.

On Fasting
Years ago, when I was drinking and stuff – when I quit – I took off and went to the woods for three days. I really was never much of a meditator, but at that time, I went into the woods for about three days. My mother went nuts because she didn’t know where I was. I would specifically go into the woods with a purpose of getting lost. I never got lost, no matter how hard I tried, and trust me, I tried.

One day, I was sitting there and leaning up against a tree at my wits end. I closed my eyes and just tried to relax. I was at total peace. I don’t know how you get there, but I was at total peace. I opened my eyes and smack dab in front of me was a deer looking me right in the face. There was another deer right behind him by the brook, drinking water. I reached my hand out and touched his nose and he didn’t move until later on when I sat up. They sensed that there was no evil or bad intentions in me at all. Then I got thinking about meditation and stuff, and how that affects your spirit and everything.

Growing up, I spent more time in the woods than anything else. I would come home from school and throw my book bag down the stairs and run out the door and right in the woods and explore. There isn’t any part of the woods down home that I don’t know. The woods are a good spot to be.

On Breaking the Cycle
Everything goes around in a circle, and everything happens for a reason. I know with the mistakes I made in life – I know now that I would never make them again.

What made me quit drinking was like I was saying; history will repeat itself. I knew that my mother drank and my father drank, and their fathers drank. Somewhere it has to stop.
I quit smoking cigarettes because I learned that they’re selling me a disease. If you think about it, who in their right mind would go out and buy a package of AIDS? So why would somebody want to go and buy a package of cancer? That’s exactly how I looked at it. People would tell me that smoking was bad for me and it didn’t phase me until someone told me that I was paying the government to kill myself.

No one in my family drinks anymore. My sisters don’t drink and none of us smoke. We all learned. Life is a lesson to be taught.

On Talking Circles
[In the Canada World Youth program] they had smudging, sweating. We went to pow wows and talking circles – which was the first time I actually sat with a group of people and cried. I felt totally safe. It was weird. It was the first time I had ever spoken in front of people.

That’s the first time I ever smudged, and they showed us how to do it. I was quite intimidated. I wouldn’t take part the first couple of times. Then I got thinking this was part of my culture and my history.

On Guest Speaking at FAS Workshops
There’s a sense of fulfillment in helping people. It’s like being a child again. I’m learning about my own culture and at the same time, I’m learning about myself and helping other people.

Public speaking helps me, not only other people. It helps my spirit because it lifts me up.

On Community
We put so much emphasis on vehicles and our possessions. I have lived on the streets and have lost everything, so I learned that what has been given can be taken, and materials don’t mean that much.

I’m a people person. You learn so much from meeting different people. You hear so many stories and learn so much.

On the Tasks of Daily Living
My watch tells time, it has phone numbers, it’s my memory. I can’t remember things as well, so I have phone numbers in here of everyone. I have a schedule too. If Della [Maguire] wants to meet me at a certain time on a certain day, she’ll write down where to meet her and when. I need to have this to help me remember things that I would normally forget. [My watch] is also a

and I was wondering why I was even alive. Is there a purpose for my existence? This is ridiculous. I can’t continue this. I was going to kill myself. I figured that was the only way out.

At that point, my father had come down and I had put the gun away and I was just sitting there crying. He asked me what was wrong. Of course I said nothing. He said “Why don’t you come down to the high school and help me photocopy some stuff?”

I used to love going to the high school with my dad when the school wasn’t open because I could run up and down the halls and do whatever I wanted.

On the way there, there was a religious commune, like a kibbutz-style where they all live together and share everything in common. I said something sarcastic like, “Look at that beehive,” and my father said “You don’t judge someone by what you think or what you see. You have to judge them by what you know.” So he stopped the car, turned it around and took me back into this restaurant. They all had beards and ponytails and they all believe in the bible and live a very secluded life among themselves. They don’t really deal with society as most people.

It was there that I found hope because they showed me something that I had never seen, and that was unconditional love. They really cared about me. One guy hugged me and I almost stabbed him. I freaked. I didn’t know what to do.

After a while, I brought my defenses down and I became quite open to them and I lived there for a good four years. I studied Hebrew, I taught dancing. Israeli dancing and followed the Grateful Dead. It was an interesting part of my life because at that point, I had come to my wits end as far as what to do with myself. I didn’t know what to do. They helped me a lot.

They put me in the dish room. I washed dishes for the restaurant. I was the hydro ceramic technician (dishwasher – gotta sound important!)

In one incident, I was making bread. They had this big mixer and I was mixing the bread up and my hands were all oily and I picked up this glass pyrex bowl and was dumping the ingredients in. Then the bowl fell into the mixer and shattered. I was thinking, Oh no, 150 loaves gone! I thought that they were really going to freak. The guy that was teaching how to bake bread comes in and I told him what happened and I was waiting for him to hit me. He said “That’s all right. Just take it out back and dump it and start with another batch.” Then he left!

As time went on, they moved to Winnipeg and I decided that I would stay in Nova Scotia to try and track down my family. That led me to Halifax.

I walked into the Mi’kmaq Native Friendship Centre. I walked into this lady’s office and I sat down and asked if she knew who my mom was. I had no clue where I was, who I was, where my mom was. I had no idea at all of my own Native culture or anything. All I knew is that when I was adopted, I couldn’t speak a word of English. Now I can’t speak any Mi’kmaq.

I met Marie Francis [a worker at the Centre] and she helped me locate my reserve. That led to tracking down my sisters. One lives here [on Millbrook First Nation] and the other lives in town. It took a good many years to track them down because the government would tell me that it was none of my business.

At this time, when I was at the Friendship Centre, I met Della [Maguire]. Ten years ago. I went in there and met Della and two years later I started working with her doing what I’m doing now [speaking engagements on Fetal Alcohol Syndrome/Effects].
I decided to go to school at the Friendship Centre and this led to going to Ecuador – a chance of a lifetime. They said to fill out a form and send it in. I just wrote down what I like in life, etc. and I sent this form in and a week later I was approved to go to Ecuador. Nothing had happened like this before in my life.

Going to another country was quite an experience because my [Ecuadorian] counter part, one of the houses that we were in, you would clap your hands and the lights come on. I had this guy cooking my meals for two weeks!

When I lived in Halifax, I lived on the street. I’ve been in Truro for the last seven years. I’ve worked at the Daily News in town and I have also worked at Frank and Gino’s restaurant. I’ve done a lot of things.

At Frank and Gino’s, I lost my job because they kept changing the shifts and my environment changed. I don’t know about you guys, but when my environment changes, it turns my life upside down, totally. On Saturday, I was supposed to be at work at 1:00 until 7:00 and then Sunday from 7:00 till closing, but they changed everything around and then the management changed. Then all the people changed. Along with that, come different chores. They started putting me on preps and dishes and I was trying to do both and it became quite frustrating and I couldn’t remember the times.

I lost the job which led to living back on the streets of Halifax. I walked into Della’s office and she’s like my city mom. Whenever I’m in trouble, I go running to her.

I figured that if I lost my job, my apartment and everything else, the city was the only thing that I knew, living on the streets and panhandling. It was the only thing I knew of how to get by without having an apartment, my own place. Della helped me. There was a place next door called “The Soul” which is the shelter of learning and employment and they took me in for the summer until I could get back on my feet again. Thanks to Della, I’m back on my feet again.

There’s another incident about a bank. One day, I didn’t know that the little envelopes that you stick in the machine to get money, you have to put money into those envelopes in order to get money back. I just thought you stick those envelopes in and you get money. I got in trouble so I went to Della and explained my situation to her that I didn’t know. She said that I would go to jail so I went to the bank. I had $50.00 and I walked to the bank and sat down with the manager and I told him what had happened and explained that I did not know. Of course he thought I was crazy. I gave him the $50.00. Thanks to Della, I didn’t go to jail.

Things like that, I never thought about how it works.

Growing up and coming out of that little wooden box, I got ridiculed, mocked, teased, etc. It was always my fault, and when I would react it was an overreaction and I would always get in trouble.

Life is a lesson to be taught. There’s right and wrong and then there’s just living. You have to learn from your mistakes. That’s how babies learn. Everything is learned by just living and that’s pretty much what I do. You just have to take your own pace.

Francis Perry speaks on his experiences as a person with FAS for the Mi’kmaq First Nation Healing Society. You can reach the Mi’kmaq First Nation Healing Society at 902-420-1576.

calculator, and it helps. That is what I use when I go shopping. It helps me understand money as far as what it is worth and how much I’m spending.

I like to go shopping late at night, or early in the morning when there are no people. When there are a lot of people around, I can’t think at all. I’ll go out at 10:00 at night when everyone is at home, and I feel safe.

On Learning
What helps me most with learning is one-on-one hands-on teaching. My principal used to take me grocery shopping in gym class or in art class. When he told the school board they said that he couldn’t do that because [something] might happen and he would be liable. He got in trouble for that, but he had a heart and took the time to help me. He would pick up something and say “Look this is 97 cents, and that’s 32 cents, and you only have a certain amount. How much are you going to get back?” etc. He would show me by digging in his pockets. He took money out for me to count. It helped a lot.

My mom used to sit me down every day and drill spelling into me. I pretty much passed spelling with all 90s because I had my mother twisting my arm – but I learned after awhile. Now I can spell and I’m good at reading, and I like writing.

On Managing Anger
[The community] helped me a lot because they really showed me there’s hope and they instilled in me patience in the meditating. When ever I got angry or frustrated, I would listen to heavy music and that just sort of stirred up the evil spirit. I found I could turn on something a little mellow and close my eyes and take deep breaths and relax to let that spirit go. That’s what it is. When you get angry, it’s a spirit that’s coming to you, trying to upset your life.

On Patience with the Journey
Have patience. The train of thinking has to be different – because I used to look at myself as a mistake. Everything I ever did was a mistake – and now, I’m looking at life not as right and wrong, but that there are lessons to be taught. Sometimes people have to learn those lessons the hard way, and sometimes it’s easier. Jail, for example. I’ll never go to jail again because I value my freedom far too much to have that taken away from me.
Teachers Among Us

by Rebecca Martell

IN 1975, WHILE TRAINING in Native addictions at Nechi Institute, I saw an advertisement for foster parents in our Native paper. I had always wanted to work with children and so I applied. After endless interviews with social workers, I gained foster parent status. Two weeks later, the doorbell rang. Opening the door, I was struck by the elegant features of the seven-year-old Native boy before me. A matronly social worker was behind him, delivering my first foster child. Little did I know that this moment would begin a lifelong journey of learning from many new teachers; a journey I could never have predicted.

The caseworker left. With dark eyes following me, my new foster child never uttered a word. When I touched his shoulder gently to instruct him where to put his small bag, he jerked away. Over the next month my foster son did not speak. The child would willingly attempt whatever I would ask of him, but he could also grow frustrated and angry. He would strike out at objects when he could not accomplish simple tasks. Not wanting to be touched, he kept his distance. I began to realize that I had a fantasy about child rearing, one that was not my reality with this small boy.

School was a challenge. When I registered my foster son, I discovered that he had never attended school for more than a few months at a time. His new clothes and lunch pail seemed to soften the blow of having to begin school with Grade 1 children, but a note about his anger on the playground told a different story. His teacher sent weekly reports of a child who was sullen and unresponsive in class. Our first parent-teacher interview found us in agreement that my foster son had problems fitting into the school system. His school counselor informed me this child’s problems could all be fixed with more parental control. I left the meeting defeated.

In the second month I overheard my foster son talking in the closet. Speaking softly through the closed door, I encouraged him to come out and tell me the story he was sharing with our kitty. I tried gently drawing him out over the next few days. He soon began to talk, keeping me busy trying to piece together the threads of his life from what appeared to be fanciful stories. He would say, “I’m not scared of the dark because my mother used to make me wait outside ‘til she came out at night,” or “I got all our food and cooked for my sisters.” The shreds and remnants of his previous life told the story of a fearless child. It did not make sense. This brave sounding boy was the same one who had me up repeatedly in the night. I would sit beside him, one hand resting on his heart, the other stroking his hair to soothe nightmares. Too many times I would have to change his wet sheets and dispose of food squirreled away under his pillow before finding my way back to my own bed.

Despite the fact that he was doing better at home, the school emergencies continued. A policeman pulled me over after I ran a stop sign, and was kind

“ If you are alert a teacher will come to you. It’s up to you to embrace the learning.”

Elder Edward Bellerose
Driftpile First Nation

I sat alone in the waiting room, trying to concentrate on magazines, all the while berating myself for my inability to care for this child.
enough to escort me to my foster son’s school, offering his strength until the crisis was settled. It had been three months of my first foster child rejecting motherly attention or affection, of bed-wetting, inappropriate social behavior and an inability to cope in school. I was a young woman and I believed my ignorance thwarted his daily care and development. Feeling poorly trained to fulfill the role of a foster parent, I made the difficult decision to contact Social Services and ask them to find someone who could better provide for this beautiful child.

I wanted to spend some time together before making the call, so that weekend I buckled my foster son into the truck and drove out to the Stony Plain First Nation Pow Wow. He followed me through the crowd all afternoon, clinging to my long skirt, seemingly unaffected by the swirling colour around him. We returned to the truck at the end of a long, hot day, where we found my Uncle Ed Bellerose, leaning up against the tailgate and sharing in the laughter of Elders.

As I approached the old men to shake hands, Uncle turned and crouched down, drawing the boy out from behind my skirt. Looking gently into his fearful eyes, he asked, “Who is this small man?” When I introduced the Elders to the boy, I felt badly about presenting a child who, in all likelihood, they would never see again. Rising to his feet, Uncle placed his hand on my foster son’s silky black hair. He looked off into the distance and said simply, “Whoever takes care of widows and orphans shall be rewarded ten times in their life.”

Shame and embarrassment followed me home, and stayed with me the rest of the weekend. With the Elder’s words still ringing in my mind on Monday morning, I called Social Services. Instead of asking them to take the child away, I asked for help.

Within hours we found ourselves in front of Dr. Jane Silvius, a Child Psychologist, Founder and Director of the Child Development Centre in Edmonton. She briskly shook hands, and then escorted my foster son into her office. I sat alone in the waiting room, trying to concentrate on magazines, all the while berating myself for my inability to care for this child.

Some time later, Dr. Silvius emerged with my foster son tucked protectively under her arm. She asked a staff member to take him to the playroom, and called me into her office. It was 1975 and Dr. Silvius proceeded to change my life. She became my teacher, offering me a wealth of information about Fetal Alcohol Syndrome.

When I asked her how to interpret his stories, she directed Social Services to open his case file. At that point, Dr. Silvius and I began to explore five years of my foster son’s life while in care. As the mystery of his life began to unravel, we saw how the particles of a wounded child’s memories had grown into exaggerated truths and an idealized family.

The file told us about his mother, a Native woman battling alcoholism, struggling to raise three small children alone in the inner city. My foster son was her first-born, and long before he was ready he was thrust into the role of protector of and provider for his two small sisters, the youngest of whom was developmentally disabled. Losing her children then getting them back three different times, his mother valiantly fought her addiction, only to lose them to the ‘the system’ when alcoholism consumed her once again.

Dr. Silvius helped me to see that my foster son was too young to have a clear picture of what really happened. She showed me how his wild tales held clues that could help us piece together the picture of a child’s fight for survival. His comment about not being scared of the dark spoke of the time Social Services found him waiting outside the doorway of a bar at midnight, and had taken him into care.

His remark about cooking for his siblings referred to the time an anonymous caller contacted Social Services and a caseworker was sent to an inner-city apartment where he found a boy trying to fry rice for his two little sisters. The children had been left alone for three days and were out of food.

Under Dr. Silvius’s tutelage, I began to understand how children of trauma are affected in their developmental years. We looked at how these effects are magnified in a child affected with FASD. She helped me to see that my foster child’s behaviors were not a result of my failed parenting, and offered me the new tools of repetition and patience. I learned how to work with my foster son’s strengths in order to maximize his abilities, including the childhood experiences captured in his stories. Dr. Silvius taught me how these
could be used as building blocks to develop his role as a protector and provider. A dedicated professional, over the next 10 years she would help me raise a boy into a man.

By 1978, as Native counselors trained in the field of addictions, we were taught that FASD was a totally preventable birth defect. However, we soon discovered that prevention was not that straightforward. Discussions about FASD inevitably led us to explore the many factors woven into the fabric of a historical heritage that brought many Native people into the 21st century in pain. For those drinking to deal with the generational pain of societal oppression, alcohol was a guaranteed painkiller. We began to realize that women who had learned to use alcohol as an effective way to deal with their unhappiness brought these same complex issues with substance abuse to pregnancy.

Pressing his back up against mine, tucking a small head into my waist, he moulded himself into the safe warmth of mother.

At home, I knew my foster son did not yet have the ability to comprehend generational pain. I had to find much more than counselling theories to assist him. I needed a Native woman who would be willing to share from the heart, one who could teach me more of what I needed to know as a woman in order to mother this special child. With tobacco, I asked the Creator for help.

Eva Cardinal was a counselor at Poundmaker Lodge Native Treatment Centre who doctored people with her caring and laughter. She wove the Cree language into all her conversations and possessed a dignity and pride in being a Native woman that I did not have. I longed to ask her a thousand questions about being a mother, but lacked the courage. Intimidated by the power of her presence, I offered my tobacco to Mother Earth and prayed for direction.

A week later my phone rang in the Nechi office. Upon answering, I heard a very dignified voice saying, “Mrs. Martell, this is the Charles Camsell Hospital calling. We would like to let you know your prosthesis is ready to be picked up.” Stammering, I said I didn’t have one, need one, had no limbs missing! Suddenly Eva’s rich warm laughter broke out and I could hear the roar of the counsellors behind her. The Creator had heard my cry for help.

Eva agreed to meet with me, and over lunch she shared my tears as a mother. Only ten years older than me, her life experiences as a young girl, a wife and a mother gave me a glimpse into a compassion and kindness I had never before witnessed. She painted a picture that allowed me to understand how multi-generational pain can make individuals, families and whole communities turn to alcohol and drugs for relief. She taught me how to be non-judgmental in the face of such knowledge. Above all, she taught me the lesson of unconditional love. These were the answers I desperately needed, not just for my son, but also for myself as a woman.

My mind was reeling as I went back to the office. Suddenly my work in Native addictions took on a new meaning. More importantly, as I sat across the table from my foster son that evening, watching him hide a banana from a fruit-laden basket in his shirt, I began to see him in a new light. In that moment, I began to understand Fetal Alcohol Syndrome from the heart.

**Teachings from the Source**

1980 LED ME TO NEW teachers in the northwest. I travelled to Tsimshian Territory to facilitate workshops on Native addictions and met Vera Henry, a Community Health Representative in Lax Kw’alaams. Already a grandmother, Vera was intent on learning the new skills she needed in order to become an addiction counsellor and to help her community with the information we had on Fetal Alcohol Syndrome.

She welcomed me home to share a meal of fresh oolichans with her family. I listened that evening as Vera spoke of her hopes for the people, and of her fierce commitment to find answers for the damage caused by addictions. We left Lax Kw’alaams and travelled together for six weeks into northwest coastal Native communities. In quiet moments, sitting in the back of the ferry or walking on the beach, Vera would speak about the need for First Nations to have special schools, trained Native teachers and their own community-based programs for children affected by FASD. She also spoke to me of a future when each Nation would offer a lifetime of love and support for our adult people affected by Fetal Alcohol Syndrome. My tobacco had brought a teacher with vision.

Through her teachings, Vera created a desire in me to develop a cultural foundation for my work in FASD. Upon returning home, I asked my mother to share the legacy of knowledge passed down through the women in our bloodline.

My mother responded by talking about a spiritual source of strength and goodness that comes simply from being born a woman. She told me that a woman’s greatest power, her ability to give life,
teaches a mother’s unconditional love. She had revealed her own power as a woman to me through her lifetime of selfless care for others. Her teachings echoed in me at a spiritual level and served to become an integral part of my life.

What I learned from my mother became woven into daily life with my foster son. Standing on a stool, stirring whatever was in the bowl; he learned the value of shared labour when we ventured into lessons on cooking. I taught him how traditional foods nourish our bodies, and how reverence to the animal that sacrificed its life nourishes our spirit. He enjoyed the sense of completing a task and gained a newfound sense of achievement by washing dishes. Reading labels in the grocery store brought him the teaching of making good choices. Our laughter over spills taught the lesson that it’s okay to make mistakes and that no one is perfect. With each new skill acquired I saw the fear of not being able to succeed begin to fade from his eyes.

We had successes, but it was not always easy. Seeing this, my mother handed me a grandmother’s gift of eternal patience. Patience is essential in child rearing, but it became even more important when teaching my son. This was especially true when teaching what I thought to be simple things. Each day, I had to re-teach him how to wash with a face cloth and brush his teeth. The constant repetition required during hours of homework each evening often found us frustrated and took incredible patience on both our parts. I discovered a brand-new opportunity to practice my patience when I had to make repeated visits to my foster son’s school to educate the educators on the special learning needs of a FASD affected child. Our patience was often stretched thin as time passed in a blur of constant challenges.

I was washing dishes at the sink one evening when I felt my foster son touch me for the first time. Pressing his back up against mine, tucking a small head into my waist, he moulded himself into the safe warmth of mother. I forgot the dishes as we stood silently back-to-back. It had been almost a year of waiting.

**It Takes A Community**

*IN 1985, I WAS GIVING A presentation on Native Addictions & Fetal Alcohol Syndrome at the Prince Rupert Friendship Centre when I met Sandra Dan, a woman from the Stolo Nation who had married into the Haida community in Old Massett. She brought her education as social worker with a background in addictions to Haida Gwaii and was already actively involving her community to address FASD.*

A number of years later, Old Massett Chief and Council directed Sandra to assist in an assessment of the village schoolchildren that was being done by Simon Fraser University. She invited me to be involved in developing a community plan of action for any children who might be identified with special needs.

Sharon Brintnell and Sylvia Wilson from the University of Alberta agreed to work with us. Together, we developed a model that would combine the sophistication of Haida civilization and modern techniques offered by the University. We built on what Sandra Dan and the community had already developed while exploring new solutions for children and adults affected by Fetal Alcohol Syndrome/Effects.

The University team designed workshop materials to provide a foundation of information about FASD. They also worked on a blueprint for problem solving and program planning for three sectors of the community: health practitioners, teachers and families. Participants exchanged stories, asked questions and became involved in a process of experimenting with the blueprint in order to develop their own community plan of action to deal with FASD.

In that first visit, Sharon and Sylvia were already busy creating solutions for the school children that were affected by FASD. We spent an afternoon watching children interact with counsellors at the Family Centre. During playtime, young boys were

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**ABOUT BASIC NEEDS**

**The FASD Affected Person**

- The person affected with FASD needs nurturing, understanding and support. A stable home, responsive school system, supporting friends and caring community are important aspects of nurturing the child with FASD.
- The person with FASD needs to feel that he or she is part of the community. Self-esteem and acceptance are critically important.

**The Family**

- Parents of children with FASD need connections with the community, other parents and services that provide family-centered and culturally sensitive supports.
- Parents may need help dealing with addictions, poverty, low self-esteem, limited work skills and parenting skills.
- Caregivers should be respectful and non-judgmental toward families living with FASD and acknowledge that the parents of FASD affected children perform a demanding job.
- The community social safety net should meet the basic needs of family members and provide early assistance to the child’s family. Families should have access to appropriate assessments and diagnoses and be empowered to contribute to all discussions about their children.
- Family members and friends need a good understanding of the FASD child’s behaviour, limitations and potential. Knowing that behaviour can be changed for the better gives hope and is the basis for coping and growing.

When voices and energies of FASD children would rise in the course of the day, the teacher could pick up the drum and quiet the children with a call back to the Heartbeat of the Mother.

Sylvia’s clapping hands, the rhythm of Mother’s heartbeat in the womb, became the foundation for ‘Haida classroom management’ in the school. She proposed that Haida men make hand drums and give them to each classroom. When voices and energies of FASD children would rise in the course of the day, the teacher could pick up the drum and quiet the children with a call back to the Heartbeat of the Mother. It seemed simple enough, but it was a tool we had not known before.

The University team eventually included two students who were supervised by Sylvia Wilson and worked in the community under Sandra Dan’s direction. They provided education and awareness workshops on FASD for community members, reviewed school dynamics, trained staff at the Family Centre, and met with the Band Manager and Economic Development Coordinator to address immediate and long-term planning needs for FASD affected individuals. They also presented their work to the Haida Council.

FASD videos with aboriginal content

The following extract, spoken by a birth mother, is taken from A Mother’s Choice, a video which examines the root causes of FASD from the perspective of Native mothers:

You know, maybe it started when I was three years old, when my cousin was kissing me. Or when another cousin began to fondle me, or when I was being sexually abused by an Elder. Or maybe it happened when I was fourteen, when I got raped. What that man took from me was not just my virginity, my innocence, but he took my spirit. He took my Indian spirit away from me. My spirit to want to be a woman. To want to be a person. There was no self-respect left there for me. So what went into and came out of my body after that was irrelevant. I didn’t give a -. I drank, I drugged, I went out and just did a lot of horrible and crazy things. When I was pregnant, on my eighteenth birthday party, I remember thinking “Oh my God, I’m probably pregnant.” And it took me about five months before I could actually say that I had stopped drinking. I was really stunned and felt in shock a lot of the time. Because of the sexual abuse that I had already survived, my body didn’t feel like it was my own anymore. This wasn’t mine. And this thing was growing on me. I had been objectified. I had been an object when I was three and four years old, and when I was eighteen and pregnant, I felt like an object creating an object. It didn’t feel like this was my baby growing inside me. I did not have those kind of maternal feelings. But at night, when I was scared, and crying and lonely,
order to live healthy, productive lives. From this, came a recommendation for a community action plan to address the long-term needs of individuals affected with FASD.

We left Haida Gwaii with the realization that Haidas teach a cultural form of community development that comes from their established sense of identity and collective self-worth. Willing to embrace strangers and new information, the people of Old Masset taught me a generosity of spirit that can only come from being secure within your own cultural foundations. The collective power of their Community Spirit came alive for me the night I watched the people of Old Massett adopt the University team into Haida Clans and families at a community feast.

**Taking the Challenge Home**

**THAT DAY I HEARD** the Elder say “Whoever cares for widows and orphans will be rewarded ten times in their life.” I did not realize the rewards would be stretched out over the course of a lifetime, and that they would come wrapped in the knowledge of many teachers. The boy who came to my door as a foster child was my first FAS teacher. In becoming my son, he forced me to look ruthlessly within, where I found the need for lessons on self and motherhood. Instructing me through his own daily struggles, he taught me the value of being alert to the teachers among us, while committing me to a lifetime of being a student.

My foster son left to find his birth mother when he was eighteen. We had learned of her origins in the far north and had contacted his relatives. I remember how anxiously he prepared to meet an extended family that had just learned of his existence. The day he left to find a new identity and sense of belonging, my foster child gave me another gift – courage. He taught me courage in making yourself belong, courage in meeting new challenges and courage in creating a new life for yourself. My son’s bravery was rewarded when he was welcomed and cherished by the family of his blood. His courage taught me the far-reaching possibilities of a person affected with Fetal Alcohol Syndrome and the wisdom of never setting limits on oneself or others.

Many teachers have come to me over the years. More children affected by FASD have come to live under my skirts, intent on teaching me new lessons about motherhood. Strong Native women have taught me to stand in my power as a woman, while Grandmothers have taught me unending patience and sacrifice-of-self for family and community.

Through my work in First Nations across Canada I have learned the importance of honoring each community’s unique culture and community spirit in finding their own answers for FASD. I have learned the value of being non-judgmental while watching the willingness of the People to learn from many sources. The commitment of countless individuals and dedication of caring professionals have taught me the synthesis of the deep truths of many different cultures. These teachings, revealed through the creative insights of compassionate people whose courage is consistent with their most valued ideals, have served to motivate me to become a greater part of the solution.

I am grateful to be rewarded with the knowledge of many teachers. Yet this journey is not over. Now halfway through my life, with sacred tobacco guaranteeing the prophecy of the Elder, I am eager to meet the new teachers of FASD and their lessons that await me.

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**1. Guarding the Unborn Spirit: It takes all Nations**
Kem Murch Productions
Tel: (519) 673-3342

**2. Fifth Estate:**
An Avoidable Tragedy
#4402

**3. Something to Celebrate**
Health Canada

**4. What’s Wrong With My Child?**
Tel: (905) 827-1155

**5. David with FAS**
National Film Board of Canada
Tel: (800) 267-7710 order # 9196039

**6. Precious Gift**
Divisions of Audio Visual Services
University of Saskatchewan
Education Building
28 Campus Drive
Saskatoon SK
S7N 0X1

**7. Remembering What We Know and Faces Yet ToCome**
The American Indian Institute
College of Continuing Education
University of Oklahoma
555 Constitution St., Suite 237
Norman, OK 73072-7820
website: http://www.occe.ou.edu/aai

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**I would hang on to that object and tell you “I love you. I need you.” And this was what kept me alive.**

**People look at us sometimes, and say “How could you? How could you, if you really loved your child, how could you drink? How could you drug? It goes way back before the pregnancy. It goes way back into our childhood.”**

**A Mother’s Choice** is available from Gryphon Videos, (604) 921-7627 or gryphon@telus.net. Other FASD videos with Aboriginal content include:

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Feathering the Eagle’s Nest:
Becoming an FASD Friendly School

One Northern elementary and secondary school has adjusted its school environment and its academic programming to improve the learning experience of its FASD students – and everyone is benefiting.

by Kim Anderson

CHILDREN WITH FAS OR FAE often run into difficulty when they enter the school system. The school environment can be overwhelming, with too much noise, too much stimulation, and too many demands to produce at the rate of one’s peers. “The Eagle’s Nest” [a fictional name as the school has asked to remain anonymous], a northern Native elementary and secondary school has recently been making changes to better the learning environment for their alcohol affected children. These changes are proving to be beneficial to all.

The Eagle’s Nest School began their journey to address FASD three years ago when one of their teachers attended a workshop with Della Maguire (see Support, Education and Healing: A Visit with Della Maguire and Her Team on page 13). This teacher brought the knowledge home, setting the entire staff on a learning journey about FASD that continues today. Many staff have now been out for training about FASD, and the school has sponsored a number of workshops in which they bring trainers and professionals on site.

Because of poor accessibility to diagnostic services, only a few of the Eagle’s Nest children have been diagnosed with FAS. Staff members feel that many more could be alcohol affected, and so have begun to make changes to the school environment. Teachers, students and parents alike feel that these changes have been advantageous to all 200 students who attend the Eagle’s Nest.

One of the major changes has involved restructuring the classes. In an effort to accommodate learning levels and styles, children with similar abilities have been placed together. This allows children who need more advanced material to be together, and those who are not reading to be in a class where the teacher does not focus so much on reading skills. Teachers are therefore no longer required to teach four different levels at the same time, which reduces stress and frustration and increases the learning opportunities for everyone.

The hands-on learners, including children with FAS or FAE have been thriving in an environment where the teachers can cater to their learning style. They are happy to explore more kinesthetic and creative means of learning. One class even developed their own mosquito repellent!

The school schedule had been a problem in the past. “We found that our afternoons were horrible” explains the Principal. “Children did not seem to be able to concentrate or absorb anything after the afternoon recess. It was a total waste, as kids couldn’t get anything done.” After checking the education act, the staff decided to simply remove the afternoon recess and make the school day shorter. They also made the last hour of the day a time to do something fun and creative. Teachers and children now choose appropriate end of the day activities such as cross country skiing, arts and crafts or music.

Changing the school environment also meant having to minimize the distractions. One very simple change was taking all the pictures off the hallway walls. Bare hallways may seem boring, but they eliminate the problem of children going out to the washroom and not showing up for an hour and a half. “Kids were always missing, and were following the displays up and down the hallways,” says the Principal. To eliminate distractions in the classroom, teachers put up drapes over the cupboards and limited classroom interruptions such as visitors, phone calls or announcements.

When children with FASD become overstimulated, they may seek refuge. At the Eagle’s Nest, some young children used to regularly crawl under desks or barricade themselves behind building blocks. Some would go the Principal’s office and hide under the pillows on her couch. The staff decided to meet this need for retreat by placing beanbag chairs and small tents right in the classroom. Now children have somewhere quiet to go if
they are getting overwhelmed or hyperactive in class.

The Principal also put a number of Teddy Bears and pillows under the end tables in her office. Children who are sent to the office are welcome to spend time resting among the pillows. They stay until they are ready to come out, and are allowed to sleep if that is what they need.

There had been many problems with ownership at the Eagle’s Nest in the past, with children picking up and using each other’s school supplies. The staff devised a symbol system to address this problem. Everyone has been assigned a symbol – red triangle, blue circle, etc. – and these symbols are stuck to all of their belongings. Teachers in the younger grades were delighted when one teacher found some large floor carpets with the same coloured symbols. This helps the children to sit in an orderly way on the floor, and to avoid becoming distracted or disruptive.

The staff has now applied a colour coding system to all the books in the school, with red books for math, blue for English, and so on. This is uniform throughout the grades so that students who are alcohol affected do not become confused and offset by transitions.

Sign language seems to be an effective technique for children with FAS or FAE. The teachers discovered this because one of the children in the school was deaf, and needed to learn how to sign. The Principal notes “All of the kids learned, but the kids who really took to it were those who were [alcohol] affected.” She does not know why, but supposes “This could be because of the hands-on learning.” The teachers have now developed their own uniform signs for managing the hallways. Beforehand, everyone had a different verbal way of giving directions: “Please walk,” “Don’t run,” and so on. Now all of the teachers use common phrases along with common hand signals to remind children of their responsibilities while in school.

The Eagle’s Nest has a cultural program which is very well received by children with FASD. Children have the opportunity to attend a school camp, which usually coincides with the hunting and fishing camps of traditional families in the community. In addition to hunting and fishing, children can work with hides, do pond studies and orienteering. Alcohol affected children are evidently much more at ease when at these camps in the bush. “The kids with FAS are the ones that will skin rabbits or get the geese. They have those hands on skills of building things and so on” reports the Principal. She has noticed that they learn well in “the old way”, where they have to sit back and watch someone work at a fish or a hide.

As the school values community input and participation, they have shared what they have learned about FASD with the greater community. They developed an awareness campaign, hosting information sessions and disseminating health promotion material by way of posters and coffee mugs. These sessions have been well attended, and many parents have responded positively to the changes that have been made in the school. Parent participation in the school is higher than it has ever been, with 85% of the parents coming in to discuss report cards at least three times last year.

The school shuts down every morning at 10 am so that all classes can run their own talking circles. The purpose of this is to allow children to clear what is on their minds from the day before, and to focus on the day ahead of them. Children coming from environments of addiction are thus given the opportunity to address issues that may be more pressing than reading, writing and arithmetic.

As part of their addictions awareness program, high school students at the Eagle’s Nest have been required to do a 28-day (non-residential) treatment program in the past. The Principal notes that both elementary and high school students are surprisingly candid and open about issues such as addictions and suicide. In time, this type of programming may ensure that there are fewer alcohol-affected children in the Eagle’s Nest.

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**FOUR TOP POINTS TO REMEMBER WHEN LIVING AND WORKING WITH AN FASD CHILD:**

1. **Structure, structure,**
   - reduce choices
   - prearrange environments
   - prepare kids for changes

2. **Less talk, more visual/kinesthetic learning opportunities**
   - visual clues
   - asking questions

3. **Be concrete – don’t assume anything**
   - difficulty generalizing
   - poor problem solving skills

4. **Be Aware of the “Time Bombs”**
   - stimulation levels
   - difficult periods

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*from Empowering our Communities on FASD: Training Manual, Della Maguire, Mi’kmaq First Nation Healing Society*
Annette & Daniel’s Story

by Annette Cutknife

Annette Cutknife is a Cree Woman from Hobbema, Alberta. She was born on July 6, 1959 to Hazel Cutknife and George Mackinaw. Hazel was seventeen at the time and George was sixteen. They were closely related, and for years George’s existence was hidden from Annette. She did not locate her paternal roots until she was thirty-nine.

Annette is a recovering alcoholic. She started drinking when she was thirteen and stopped at thirty-six years old. Annette was sexually abused at the age of five by her cousin, a male caregiver at the time, and then again by her step-father from the ages of twelve to sixteen. She spent two years at a boarding school when she was eight and nine.

The consequences of Annette’s drinking career included two impaired driving charges and one for dangerous driving. The most significant consequence of all was giving birth to a child with Fetal Alcohol Syndrome. This article is her account of her involvement with FAS.

Daniel Allan Lloyd Cutknife was born at 6:04 am on October 31, 1988. He was eleven days overdue, and weighed 7 pounds, 7 ounces. I was twenty-nine years old.

When Daniel was born, he did not even cry. He was delivered by forceps, and I knew something was wrong because he did not make a sound. When I tried feeding him for the first time, I knew something was wrong again because he could not coordinate his sucking and he made a funny squeaking noise. I tried breast feeding him, but this only lasted three weeks. I had to immediately return to work because I was (and still am) a single parent. I gave up breastfeeding him and put him on a bottle.

I lived in Edmonton at the time of Daniel’s birth. I was employed with a lawyer, and worked right up until my due date of October 20. We stayed with my parents in Hobbema for the first eight weeks after he was born. I felt that I needed that extra help from my mom then. However, she was working fulltime and was away at work all day, and in the evenings she was at Bingo from 7:00 pm to 11:00 pm.

I soon discovered Daniel was colicky and had a hard time burping. I would have to carry him around the house from about 6:00 pm to 10:00 pm. I would be so exhausted that I literally had no energy by the time mom came home from Bingo.

We encountered constant medical problems when Daniel was two and a half months old. In mid-January of 1989, Daniel and I went with my sister (who was my live-in babysitter at the time) to visit my friend Vivian, who lived on the 12th floor of a high rise apartment. Daniel was fussing as we rode the elevator up to Vivian’s place. When we got off the elevator, he had stopped crying. I didn’t think anything of it. Once we were in her apartment, I set him down on the couch. He was in his blue car-seat carrier. When I looked at him he was blue in the face, and I thought I was seeing things. I looked again and asked my sister if, in fact, I was seeing things. She immediately panicked. I grabbed him and literally threw him across the room to my girlfriend, who luckily caught him and threw him sideways. Then she called 911.

The paramedics arrived in less than 10 minutes. They revived him and transported him to the Misercordia Hospital. While they were working on him in the ambulance, I was sitting in front with the driver. I was praying for the first time in fifteen years. I had turned my back on my higher power at the age of fourteen, when I was the most unhappy in my life. But while I was talking to God that evening, I remember saying something like this:

Please, please, God. Do not take Daniel away from me yet. Let me raise him for you. Do not take him away just yet. He is only two months old. It’s too soon. Please, please, God, give me another chance. I will change my life around. I will leave drugs and alcohol alone. Spare him and I will do anything. Don’t take him!

I repeated this prayer over and over. I really thought I was going to lose my son that evening. He ended up in the hospital for a few days, with respiratory problems, and was introduced to the nebulizer (ventolin treatments for asthma).

Two months later, when he was four months old, he ended up in ICU for ten days. He had a very bad flu virus. Once again, I thought he was going to die, especially when I first looked at him hooked up to all kinds of machines.

During both times, I felt so helpless. I actually felt that God was punishing me for being such a bad
person and a bad mother. I hated myself for I knew that I had damaged my child while I was carrying him.

When I look back, I can see that I was dealing with a significant and recent loss while pregnant. The man I was to marry had been tragically killed in a car accident a year earlier, and I was having difficulty putting closure to his death. At that time, I was also still trying hard to gain my mother’s love and approval with whatever I did (for example, through education and various contests).

My feelings regarding my mother have changed drastically since my recovery. I now understand that her upbringing was not the best. She had been raised in residential school, which meant that she lost her mother when she was only 8 years old. But I did not see any of this while I was still drinking. The feelings of guilt were at times unbearable, and the more guilt I felt, the more I punished myself with drug and alcohol abuse.

The first major operation Daniel went through was to repair his stomach valve. He had a G-tube insertion and was hospitalized for six weeks. This had to be done because he was aspirating his formula into his lungs. He was fourteen months old at the time, and he had the tube on for seven months.

This was the first time I turned to the sweat, and my uncle as a helper. I was desperate to get any kind of help for Daniel, and then I remembered about the healing that can take place in a sweat lodge. In the past, I had always depended on my mother to assist in speaking for me when it came
to protocol with an Elder. This time, I made all the necessary arrangements for Daniel and me. We went to see my uncle in Saskatchewan and had three nights of healing sweats for Daniel. My uncle instructed us to keep the G-tube off the next time it came off, as we would not have to re-insert it like the other times. I believe Daniel had it on for another two months or so. By then he was two years old and his aspirating problems had ceased.

On father’s day, I was half-way home from Calgary when he called me on my cell phone and yelled out “Happy Father’s Day, mom!”

By the time he was five, Daniel had been hospitalized at least thirty to forty times – for respiratory problems, ear infections and the flu. He was fragile and his immune system was very weak. He has stigmatisms in both eyes, and started wearing glasses when he was seven. He recently had an operation where they tightened the outer muscles of each eye, to correct his wandering eye problem. When he was eight, he started wearing hearing aids on both ears, and he used an FM system to assist him in the classroom. This has been extremely helpful. We also had his pointed, elf-shaped outer ears repaired through plastic surgery when he was eight. I believe I did this more for myself than for him, because I did not want him to be ridiculed and laughed at when he got older. At present, we are waiting to be called in for surgery in order to correct his left ear, which is deteriorating.

When Daniel was a pre-schooler, I always had a live-in sitter for him. I denied or chose not to acknowledge that he was affected and I decided to keep him out of day cares for fear of being lectured. I worried that he would be labeled and I would be forced to do something about it.

In 1992 we moved to the Red Deer College campus so I could complete my para-legal program. Daniel was four years-old and this would be his first time in day care. He was still in pampers, but was toilet trained by the time the school term was over. His milestones were delayed in every area. He could not sit up on his own until he was at least eighteen months old. He didn’t walk until he was at least three years old, and he didn’t talk until he was about five years old.

When Daniel started school in 1994, I could not hide anymore. I had to acknowledge his condition and face it. I had gone in one day as a parent helper. When I arrived, his teacher automatically took me aside and had a talk with me. She said “There was something wrong with Daniel.” She told me that his attention span was very limited, that he could not follow simple instructions and that he had wandered off twice, causing a search party to go out looking for him.

At first I was stunned. But deep down I knew I could not deny this fact any longer – I had been caught. It was time I admitted he was alcohol affected.

I now see that admitting your child is alcohol affected is similar to admitting alcoholism. You keep denying it, yet you know that the only way things can improve is if you admit defeat. Only then can everything else get better, because you get the help you need in order to see clearly and get more focused.

I had put off acknowledging Daniel’s condition as long as I possibly could. I always sensed that once he started school my denying game would be over, and it was. I made an appointment with one of his specialists, and then we had him assessed. It was official; he was diagnosed with Fetal Alcohol Syndrome. Once that was done, we were able to get Daniel his own aid from his ECS school year. He has had an aide to assist him to some degree in all his grades.

Daniel was on his way, but my drinking problem still remained. It had gotten out of control in 1992 and stress did not help. During Daniel’s early ages, I would be with him constantly at the hospitals. I would leave him a lot of times with my mother when he was six and seven. I was dealing with a lot of unresolved grief, and desperately searching for my father.

Finally, in April of 1996, I reached out and asked for help. Daniel was seven and a half when I made the journey once again to see my uncle in Saskatchewan. The first night I arrived, I had the most deadly alcoholic nightmare. It was mainly seeing dead people – I believe that I had DTs, or something close to it. This scared me straight.

The following night, we started the sweats. We sweated three days in a row. The first session was very exhausting. I actually felt the after taste of beer coming out of my mouth. I guess that it was the alcoholic spirit being sucked right out of me. It was a very powerful experience.

Once I completed the sweats, my uncle instructed me to read the Big Book (AA). He advised that I start attending meetings, read self-help books, and keep sweating regularly, not just when I was in dire need. It has been six years and four months since I’ve been in recovery and I have not looked back. I maintain sobriety through the help of AA and regular sweats.

I started advocating for Daniel in the school system in 1997 and I’ve been speaking at various conferences and workshops since 1998. I met Dr. Lindsay Crowshoe in 1999, and I often do
presentations on FASD with him as a case study. In my presentations, I use a flip chart that was developed by Nechi Institute. When I get to the section on the developing fetus, I incorporate Daniel’s condition along with the organ that is affected. I know this information because I had recorded my drug and alcohol intake during my pregnancy. (I got into the habit of recording this because while I was in the para-legal program we had to diarize and record everything!) I now find that this information is really valuable, because it shows how the damage is being done during crucial times of each trimester. I have noticed that this is the part of the presentation that people find most interesting.

Daniel will be turning fourteen years old in October. Physically, he can pass for a ten or eleven year-old. Mentally he would be at an eight or nine year-old, and emotionally, he would be at a six or seven year-old.

Daniel tends to get very emotional when his cousins do not treat him with respect; when they belittle him and pick on him. I constantly get accused of being overprotective, and he gets called a baby. The majority of family members do not understand the extent of his condition. My heart aches whenever I see my son crying each and every time he gets his feelings hurt. I have to be strong for him and wipe away his tears of anger and frustration.

We enjoy attending cultural events. When Daniel was two years old, his uncle gave him a drum. He’s only used it once, at a round dance. He enjoys watching pow wow, and did grass dancing in 1999. He likes to listen to round dance songs and go to tea dances. Daniel wants to learn how to serve the food, but he does not have the patience to learn. He thinks that you can just serve and that’s it! – he doesn’t realize the protocol aspect of it. So he is determined to hold off on it until he is sixteen.

Since the fall of 2001, we have participated in the Catholic Social Services Respite care and the FAS mentorship programs. We have joined the Special Olympics Bowling League. It was Daniel’s first year of bowling, and at the year-end banquet he won the Happy Bowler Award, which goes out to the athlete who still has a smile at the end of the day, even though he’s having a bad day. I was so proud of him for that accomplishment.

Daniel will be going into grade seven this fall. I kept him back a grade last year in order to get his medical needs looked after (eye and ear operations and orthodontic treatments), but most importantly to work on his speech therapy.

This year he made me a father’s day craft at school. On father’s day, I was half-way home from Calgary when he called me on my cell phone and yelled out “Happy Father’s Day, mom!” I was filled with mixed emotions. I had tears of love and joy. But I also thought of him not having his father or even a step-father figure in the picture. I often feel bad for him because he is missing this in his life. To Daniel I am both is mother and father.

Since I have been advocating about my son’s condition, I feel that one service is missing. At this time, I could use a parent support group within my community. I did attend one meeting in Wetaskiwin, but I felt very singled out. I was the only birth mother and the only Native there. All I heard at that meeting was the sheer frustration these foster and step parents feel regarding their much older (17+) alcohol affected children. Perhaps I will feel differently about the meeting formats as time goes on.

I find it healing to volunteer my time and energy to a personal development retreat program, called “Choices”. I attend NA meetings and chair my AA home group meetings on Sunday mornings. This year I was nominated to chair our 20th annual AA Round-Up, which will take place in November. My hope in my message is to protect the unborn babies. My purpose in life is that I’m a wonderful woman, determined to make a difference in others by giving and receiving unconditional love.

Daniel and I have gone through a lot – especially in the early years of his life. I worry sometimes about the obstacles we may encounter in the future, but I do know that we can overcome our fears. We have faith and we are so lucky to have each other. I love my son with all my heart, and I know he feels the same. We say our prayers every night; we are grateful that we are part of this universe so we can make a difference in whatever way we can.

Hai, hai! God bless.

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Traditional Aboriginal Justice

A Toronto agency helps offenders with FASD through its Community Council Program

by Doug Anderson

IN THE COURSE OF THEIR WORK, the staff at Aboriginal Legal Services of Toronto (ALST) come into contact with many offenders whom they suspect are alcohol affected. Patti McDonald, an Odawa woman whose family is from Wikwemikong First Nation, coordinates the Community Council Program at ALST. She also works closely with other programs at the agency, which includes a legal clinic, a legal services unit, and the Aboriginal Court Worker program.

Patti has developed a keen interest in how FASD affects her clients. She sits on a community committee on FASD and has increasingly found links between the work she does and techniques for addressing the needs of people who are alcohol affected.

A lot of the ALST clients are either undiagnosed or misdiagnosed – and those who have been diagnosed with FASD often go without supportive programming. Patti notes that it’s really hard to get a diagnosis for adults, since the priorities for assessment are kids up to age 16. As she says, “It will be a while before a 35-year old adult male gets a diagnosis.”

Symptoms of FASD are hard to separate from other issues common to ALST clients. As Patti points out, the lives of offenders with FASD are very often in crisis, and relate to a variety of serious problems:

People with FAS don’t just have FAS. There’s often a whole list of things, like sexual abuse, adoption breakdown, psychiatric disorders, homelessness, abusive partners, kids taken away, and health problems like hepatitis and AIDS.

Even without a diagnosis, Patti and her colleagues and council members are sensitive to the signs of FASD. She always asks the client if they understand the charges against them, and in many cases, they don’t. This confusion exists even though defense counsel and others have already spoken to the accused, and have the impression that the accused knows what’s happening. This is not surprising, since people with FASD often give the appearance of understanding while being confused internally. It gives Patti one clue about the possibility of FASD in the client.

Patti has noted other patterns to look for that may imply FASD in offenders:

- They tend to be followers, not leaders, in criminal activity;
- They often take the rap after getting involved with others who initiate the crime;
- Their behaviour often guarantees they will be caught – for example, they may go back to a store they robbed only 2 days earlier, or use their own ID to cash a stolen check or deal stolen goods at a pawn shop.

While Patti knows that formal assessment is needed to identify FASD, she still finds it useful to be aware of the possibility of FASD in her clients. When she notices signs of FASD, it can be helpful in developing an understanding of the client’s history and behaviour, which can inform how the Community Council might proceed in its work.

The Community Council Program

THE COMMUNITY COUNCIL is based on a traditional Aboriginal system of justice. Patti believes the Council is a valuable cultural approach to working with fetal alcohol-affected offenders. Even though the program was not developed specifically with FASD in mind, its unique cultural approach mirrors many of the principles developed for helping people with FASD.

The Community Council Program diverts Aboriginal offenders from the criminal justice system and brings them before their own community. The Council will work with any kind of offender, although the crown has never diverted a murder charge. Commonly diverted types of offences include administration of justice (fail to appear or comply, obstructing police or justice); property offences (break and enter, theft, mischief); victimless crimes (possession, prostitution); and offences against a person (robberies, assault).

Council members have a strong understanding of the problems faced by offenders. Many of those who sit on councils have themselves had direct or indirect experience with substance abuse, residential school, adoption breakdown and other issues arising from colonization. Council volunteers are drawn from the Toronto Aboriginal community. They bring Aboriginal
languages, cultures and teachings from many different places, as do the clients.

The program focuses on the offender rather than the offence. The idea is that the community knows best how to reach Aboriginal offenders, and help avoid the “revolving door” of the dominant justice system, which takes most people from the street to jail and back again. The Council is not a “sentencing circle” because it removes the whole process from the court system. The program is designed to be more relevant and meaningful to offenders than the mainstream justice system. Patti believes that this is reflected in a high rate of compliance with Council decisions.

A philosophy that relates to people with FASD

IN 1991, ALST HELD AN Elders/traditional teachers gathering to develop the philosophy for the Community Council. The Elders stressed kindness and respect:

At the heart of the Community Council must be a real, conscious feeling of kindness and respect for both the offender and the victim. When the offender and victim realize that the Council members actually care about them and respect them, then the message of the Council has a better chance of getting through.

The emphasis on kindness and respect means an ability to look beyond the behaviour of the offender to what actually causes it, and to seek out creative strategies for addressing the cause. This approach is crucial as a way of supporting people with FASD, since their behaviour is best understood and addressed when seen in relation to their condition.

The philosophy at ALST means that people on staff need to excel in common sense and oral and communication skills, and that policies and procedures take a back seat. Patti laughs, “We have to ‘untrain’ the social workers.” If things aren’t working, people don’t refer to a manual, but try to look at and discuss the situation on a human level.

The program is based on the Seven Grandfather Teachings of the Anishnaabek (Ojibwe people): Caring, Sharing, Kindness, Honesty, Respect, Bravery, and Courage. The teachings are applied to everyone in the program, each in their own individual way. The Council has no hard and fast rules beyond these teachings. As Patti says, “We make them up as we go. If one approach doesn’t work for a client, we change our approach and find the right one. If it’s not getting done it’s probably that I’m doing something wrong.”

The Council assumes that changing one’s lifestyle can’t be imposed from the outside, and can only be effectively done by that person. It is about helping the offender to develop internal understanding and motivations that are more appropriate, in their own time and process. It is not about punishing the offense (i.e. behaviour modification aimed at preventing external activity without touching the person inside).

Patti notes that the Community Council philosophy is totally in keeping with the approach recommended for FASD caregivers. Consider just a few of the slogans for working with FASD that could just as easily be describing the Community Council philosophy:
- Work with rather than at;
- Try differently, not harder;
- Invite the person into solution finding;
- Move from seeing them as “not trying to get the obvious” to “needing many re-teachings.”

Diversion from an institutional to a community based process

WHEN A POTENTIAL CASE is identified, ALST approaches the Crown to divert charges to the Council. Referrals come from many sources, including defense lawyers and the community. The process is open to anyone, regardless of the offence. Patti says, “No matter how badly a client screws up, the door is still open. Some of the clients are banned from every agency in town.” If the Crown agrees to a diversion, the offender is asked if they wish to go before the Council. The Council cannot decide guilt or innocence, so the accused must first accept some degree of responsibility for their charge. The accused must also consult with a lawyer, who explains the Council process and stresses that if the accused is not guilty they should try for an acquittal in court. If the person agrees to go before the Council, charges against them are stayed or withdrawn.

If one approach doesn’t work for a client, we change our approach and find the right one. If it’s not getting done it’s probably that I’m doing something wrong.

The Community Council is much more flexible and accessible than the court system in the scheduling of hearings. This flexibility is helpful for people with FASD, who usually have trouble with dates, times, and appointments. ALST always gives less than a month’s notice for council hearings, while the mainstream system often takes
much longer in setting court dates. Even with shorter notice, Patti has found that clients are often early or late by a week or so. Patti believes that many people with FASD get into trouble for missing court appearances because the courts don’t consider their very real confusion. With ALST, missed hearings can be rescheduled. Patti has even had people miss seven or eight appointments, but they are still welcomed back nonetheless.

Sometimes the biggest success is with clients who have been diverted four or five times, even if they’ve been re-arrested. One client had over 70 previous convictions. People working for the Crown sometimes don’t appreciate the alternative approach for repeat offenders, but Patti’s argument is irrefutable: “The dominant system obviously hasn’t worked for these people, so why not try us?”

The hearing process

The Hearings are designed to engage offenders emotionally, physically, spiritually and intellectually. Building trust is essential to the process. Sometimes ALST staff members take the client out for a coffee just to get to know them and set them at ease before the hearing. Patti says that sometimes these talks are about everything but the charges, although these can also be discussed as well.

Hearings include three council members, one ALST staff, and the client. There is no “cookie cutter” approach to the process; the hearing is adapted to meet the needs of each client. The hearing usually starts with a smudge and introductions. Initially, the group may talk a bit or not at all about the offense. The council can even meet out doors or out of town on occasion. If the offence involves a victim, victim participation is strongly encouraged. Offenders and victims are made to feel welcome and to know that the Council members care about their situation.

Council members adjust how they talk if they know or suspect the client has FASD. The main principles are to keep the talk simple and to avoid abstract concepts. Council can sometimes be blunt and brutally honest, although this is only to be done out of kindness. The environment is a quiet, calm room with not too many things on the walls – not too stimulating or overwhelming.

Staff and volunteers are encouraged to listen and learn from the client. As Patti says, “You can’t listen if you’re talking.” She stresses the importance of a friendly, caring process, and says that in the relationships with clients: “We also have fun.” Patti points out that “the clients teach us” and that they have knowledge to share that needs to be valued.

The program is also open to constructive feedback from clients. The process aims to “make people feel like a person again.” Council meetings often have both crying and laughter. But the Councils are not soft on crime. Patti says the Council can really hold clients accountable and has been known to “rip clients apart” – although when this does happen it needs to come from a place of relationship, understanding and emotional authority, as opposed to the institutionalized and remote authority of the mainstream system. And any harsh words are balanced by a truly supportive dynamic. Respect is an essential part of the hearing process.

Because the Council tries to get to the root causes of behaviour, they consider many factors that may have contributed to the client’s actions, such as sexual abuse, adoption and the possibility of FASD, to name just a few. The clients themselves often identify what they need. Once the Council has reached an understanding (usually non-verbal), they take a short break. When they come back, they talk about the decision. There is flexibility around the timing of the decision-making process. Sometimes the Council may want to consider the case for a while or bring in other resources, and the hearing may continue to another date before a final decision is reached. Often the Council will give the client a rock to take with them at the end of the hearing. They may offer tobacco, depending on what has happened in the hearing.

Council decisions: supportive, practical and flexible

The Community Council hearing and decision-making process reflects what the literature tells us about effective techniques for people with FASD: that they respond well to a counselor or advocate who provides clear feedback on the consequences of their behaviour, followed by helpful suggestions.

It is significant that the Council makes “decisions” rather than “sentences.” This move away from judgement, sentences and punishment is compatible with strategies for FASD. A “sentence” assumes that misbehaviour is intentional; and while people with FASD may seem aware of their actions, their misbehaviour can also reflect an honest inability to interpret and react appropriately to the world. Also, sentences are really a form of behaviour modification – an approach that has been shown to create a feeling of being “stuck” or “cornered” in people with FASD.

The Community Council develops a plan by consensus that allows offenders to take responsibility for their actions, address the root causes of the problem, and reintegrate into the community in a good way. The plans also aim to help build self-esteem and self-respect. Any option except jail is available in making a decision. Options include counseling (traditional and western), restitution, community service, participation in ceremonies and other Native community...
events, treatment suggestions or a combination of the above. The plan often involves Aboriginal social service agencies. If the person doesn’t follow through on the decision they have to reappear before the Council to explain why. About seventy per cent of decisions are complied with, a very high success rate for this population.

Decisions are realistic and practical. One client with FAS and ADHD was diverted three times before the council. He had money problems, so the council decided to have another agency worker manage his money for him, a strategy that proved successful. Failures as well as successes are acknowledged and addressed. If a plan is not working, the council will change the decision. For example, if there’s a decision to get an abused woman out of the house to do volunteer work in the community, the council will reconsider the decision if the woman is offered a job, rather than holding to a rigid interpretation of the decision.

People with FASD struggle to learn and need to be given time to digest new things and change their behaviour. The Council approach accommodates the fact that it may take time, even months or years, for important messages to reach an offender. Success in degrees and small steps give confidence and allow offenders to come back to the Council feeling they have some control over their lives, which tends to leave them more willing to consider other suggestions.

**Community orientation**

**MAYBE THE MOST** significant underlying characteristic of Aboriginal justice that makes it effective for people with FASD is community orientation. The Community Council Program removes people from an institutional approach that has failed and brings them to a place where they belong. In the mainstream justice system the Aboriginal offender (not to mention other offenders) is an outsider. In an Aboriginal system, they are part of something. For example, there’s an annual ALST traditional feast – with a giveaway and drumming – for clients, council members, staff, funders, agencies, and crown and defense attorneys. People are given name tags with the first name only. Patti says, “We don’t distinguish the clients at these events. It’s a true Native community event.”

This overall move away from institutionalization toward an alternative community-based model couldn’t be more appropriate as a strategy for working with offenders who have FASD. Why? Because the literature tells us that people of all ages with FASD tend to be suggestible and easily influenced by peers. Because we know that one of the main characteristics of FAS is the mimicking of maladaptive behaviours. And because we know that the most effective techniques for reducing these behaviours are based on positive (supportive) rather than negative modes of behaviour change (judgement and punishment).

Obviously, there needs to be more study on the relationship between FASD and the justice system. Aboriginal models hold a great deal of promise in this direction.

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### WHEN A FATHER DRINKS

From a cultural perspective, fathers have an emotional and spiritual responsibility to their children, including the unborn. The Haudenosaunee people consider both partners to be pregnant when a baby is conceived. Tom Porter (Mohawk) advises on the father’s behaviour:

> It must be understood that when a woman is pregnant, her husband is also pregnant. Whatever health and mental precautions are observed by pregnant women, the father is also obligated to observe as well. This is the traditional Mohawk or Iroquois understanding.

From this culture-based understanding, it goes without saying that the father should abstain from alcohol, drugs, and other unhealthy behaviours during a pregnancy. What either parent takes in will have an impact on the baby.

In her work with young parents, Sylvia Maracle (Mohawk) advises mothers and fathers to abstain from watching violent movies and to avoid engaging in any violent behaviour. They are warned against staying out late, drinking, or engaging in any other type of behaviour that would be difficult or unfruitful for either the father or his pregnant partner.

Women usually drink with their partners and/or friends, and so the social impacts of a father’s drinking are profound. If the father drinks, the mother will have a much harder time abstaining.

It is very important that fathers and community members accept their responsibility to make way for a healthy newborn.

“WHEN YOU LOOK AFTER children, it has got to be in your blood, in your spirit. The spirit within.” With these words, Cree Elder Maria Linklater captures what is apparent to anyone who spends a few days watching her interact with the large community to whom she is known as kokum, auntie or simply mom. Linklater has fostered more than 350 children over the years, including many with FASD. And although she has a natural ability to work with children and youth, she has also learned a lot through her experiences. She uses a distinct cultural approach in her work, which has proven to be enormously successful.

Maria’s first encounter with FAS came through her niece, Tracy who she adopted in 1973. She was living in Thunder Bay with her husband Walter and their six children when she learned that her sister would never fully recover from a coma, and that her niece was therefore in need of care. “When I applied for her they told me that I couldn’t because she was a special needs child and that I had no training to take care of her,” says Maria. “But when I was told that I couldn’t get her because I wasn’t trained, that did it! I decided to fight for her.”

After collecting several letters attesting to her skill as a caregiver, Maria was awarded the child just before Christmas in 1973. At 11 months old, Tracy weighed only 13 pounds. She had a lot of hair on her forehead and body, her earlobes were not developed and she had a hole in her back that was always leaking. She had trouble sleeping and eating and was often sick. This could have been overwhelming to many adoptive parents. “But me, I’m a bullheaded
woman,” says Maria. “I said [to myself]: Now that I fought so hard for her, I can not give up.”

The first day she was at the Linklater family home, Tracy rolled down the stairs and bumped her head. When Maria took her to the hospital she was accused of child neglect because of Tracy’s small stature and generally poor state of health. Maria finally located her family doctor, who cleared up the story with the hospital staff. Tracy was diagnosed with FAS soon after this incident.

Raising her first FAS child was what Maria calls “a really good lesson.” She started out with the most fundamental gifts a mother can offer: unlimited contact and infinite love. “I had common sense,” says Maria. “I knew I had to touch her and hold her a lot.” Maria talks about this contact as a process of “waking up her spirit”:

There were many nights when I cried, because she was crying in pain. I had to put her on my chest for her to hear my heartbeat. It was like rebirthing her. I would rock her, and sing her so many songs. I would tell her that I loved her. I promised that I was going to give her a world to live in, and that I would be there for her.

I kept her on my body for one whole year. I put her in a moss bag wrapped her up and kept her safe. Even when I was mopping the floor, doing dishes, doing laundry in the basement, she was on my back. When I got to rest to watch TV, she would be on my chest. I was like a kangaroo. All I could hear was great big eyes, blinking. The only time she wouldn’t be on my body was when she was sleeping. And we always slept with her. I didn’t put her in a crib.

Maria spent a lot of time going back and forth to the hospital the first few years, to deal with Tracy’s many illnesses and to learn as much as she could about FAS. She came up with some ingenious ways of her own along the way. When Tracy’s head and hands began to shake as an infant, Maria sewed some white sand from Lake Superior into a bonnet and bracelets for her. She would stand the toddler in a corner and get her to practice sounds in Cree and English in an effort to get her talking. But the biggest component of her success with Tracy, Maria maintains, is Native culture: “Sweats, feasts, teaching her Indian life skills.”

**Coming Home to the Culture**

**IN THE EARLY EIGHTIES,** Maria’s husband Walter began to rediscover his Anishnaabe culture through a teacher he had connected with in Thunder Bay. The family began to attend sweat lodges, and to learn cultural teachings and practices from the Elders in the area. Walter and Maria were then able to build on the knowledge that they had from their own parents and grandparents, an education that had been interrupted by residential school. They shared this with their children and with the numerous foster and adoptive children that lived with them.

Many of the children that came to the Linklater’s had been neglected or abused. Many had been adopted out to white homes, and many were alcohol affected. Maria’s solution to all of these needs was to help them heal through culture. “The minute we accept who we are in our identity, we can heal from any kind of obstacle,” she says. “If I didn’t find my culture twenty years ago, I think I’d be a miserable old bat,” she adds, chuckling. “… always blaming. Now I don’t have time to blame.”

Maria took the children in her care to pow wows. She got them making traditional outfits, singing and dancing, smudging and going to sweats. Through cultural practices and the strength of her spirit, love and generosity, she offered them a sense of belonging that they had been missing. This is evident in the way she tells the story of one child with FAS who “broke [her] heart”:

He had gone into care when he was a just a baby, and when he was twelve years old his foster care broke down. I took him from there. I used to take him to the pow wow. I make him a ribbon shirt and he got an Indian name and his colours from an Elder. But he was a runner.

I used to tell him if he ran away from my house, the back door would always be open [for him to] come in and shower and eat and sleep. “Eventually you’re going to get into trouble and they’re going to get fed up with you,” I said. “So come home. The back door will always be open.”

When I woke up in the morning, my prayer would be for him to not run away. I needed time to work with him. I used to ask his permission if I could hug him. He
would say “Just touch my hand.” He didn’t like being touched. After I had kept him for awhile he finally let me hug him, and he would let me kiss his forehead.

When he came into my care, I looked for his mom, only to find out that she had died. I took him to the place where he remembered he used to live and he used to have orange crush in his bottle. We went into that building where he remembered. He said he was only two. He would try to reach his mom and she would be still drinking.

One Christmas morning I was cooking, and he was so sad. When I looked at him I asked “If I could give you a gift, what would it be? If I was a magic person and I could give you anything…” “To see my dad,” he said. “Good enough,” I said. “I’ll make a phone call and do my best.”

I asked my friend if he knew his father, and he said that he knew him. I picked him up and we went looking for him and found [the boy’s father]. At least he saw his dad about four times.

Maria concludes “It’s the families that keep our circles a strong foundation. It is so sacred that any family can heal, even after a child has been missing for so long.”

This boy used to come and go from the Linklater home, but one time when he ran away, he was picked up by the police and taken to a receiving home, where he was stabbed in the heart. Maria still feels tremendous sadness about this boy, and regrets that they had so little time with him:

I was so sad and devastated at that time; there was no help for children like this. We were just learning our way of life; how it feels to be a First Nation’s person, to take charge of your life. [With him], we only went to two sweats – we had such a short while.

Among the sad and painful things she has witnessed, Maria has been able to see the positive results of the many children that she has touched. Several of her former foster children keep in contact, and are doing well. Many are engaged with their own cultures: “In the end, these are the kids that are doing alright” says Maria.

Her remarkable success with FASD children is linked to the strength of her conviction that what is natural and cultural is best. She tells the story of one child who came to her suicidal, 100 pounds overweight, chronically bedwetting and too lethargic to play because of the high doses of Ritalin he was taking. Maria told the child welfare officials that she would take this child, with the condition that “the Ritalin has to go.” At this time, she was told that she couldn’t take him off Ritalin because she was not a doctor – to which she replied “We have herbs to replace Ritalin.”

She took the child home and explained to him beforehand what she was going to do. She immediately took him off the drug and put him on a regime that included two sweats a week, regular walking, sage baths to pull out the toxins, plenty of water to flush his system, three cups of valerian tea a day and lots of blueberries for his nervous system. She kept him on a strict diet of no sugar, and attempted to feed him as much wild, traditional or natural food as possible. “His spirit was gone,” says Maria. “So I made a bed for him out of a futon and put a purple sheet on it. Purple is a very powerful medicine colour for spirit, and that is where I would tell him to go to sleep. We would smudge and we’d pray, and I’d tell him, ‘You have control over your body’. “ The teaching about self-discipline and control allowed her to help him control his habit of rocking.

FASD PREVENTION STRATEGIES INVOLVING TRADITIONAL PRACTICES & TEACHINGS

Strategies for School Children and Youth
- participate in ceremonies
- go out on the land
- engage in cultural activities like drumming, stick gambling or canoe pulling
- visit with elders
- go to cultural camps
- learn the medicine wheel or other traditional teachings

Strategies for Community Leaders
- sober leadership
- bring back traditional laws and practices
- support alcohol free activities

Strategies for the Community
- organize cultural activities and events (camps, games, gatherings)
- develop a community plan and coordinated community approach

Strategies for Women of Childbearing Age
- research the role of women
- look into laws and practices surrounding conduct of women before and during pregnancies

Strategies for Men
- learn about men’s responsibilities and roles in the family and community
- open grandfather’s trails in traditional territories and learn the stories and laws of the land
- practice the role of men in ensuring a healthy pregnancy (e.g. no drinking, as women usually drink with their partners).

From It Takes a Community: A Resource Manual for Community-based Prevention of Fetal Alcohol Syndrome and Fetal Alcohol Effects. Published by Medical Services Branch, Health Canada, 1997
He used to rock. Rock and rock, and people allowed him to do that! Me, I didn’t let him. “I’ll give you rocking time,” I said. “I’ll put a blanket on the floor, you snuggle, and then you sit like this [cross-legged]. Empty your brain. Hold yourself like this, and you rock. Rock for as long as you want to, and when you are finished, you tell me.

She laughs as she admits, “See I love to rock – I find that rocking is nurturing yourself. It feels so good to pray to yourself. It’s good medicine. Instead of Ritalin.” Yet she demands a discipline to self-nurturing and healing, telling the child “I’m in charge, but your job is to heal yourself.”

This child lost seventy ponds in his first year with Maria, and soon regained his playful and friendly nature. He no longer throws tantrums. Maria has been successful in teaching him “Indian life skills” such as cooking and sewing – hands on skills that he uses to help out around the house. And although she had to call him to task regularly, in the end he is a different person today. He continues to be off Ritalin, and is able to sit through four rounds of a sweat, attend lengthy ceremonies, do his chores, and help out with the younger children.

There are four FASD teenagers living with Maria at this time. When it comes to alcohol, Maria tells them:

Most of the time, you were probably passed out in your mother’s tummy. If you use alcohol, you’ll just pick up where you left off. There’s nothing happy about drugs or alcohol.

As a result, none of the alcohol-affected youth in the Linklater home are into drugs or alcohol, and all of them help out the household and at ceremonies. Maria proudly states that her niece Tracy, now 29, “... has never gone drinking once in her life and has never tasted a cigarette.” Tracy has grown into a thoughtful and responsible young adult. “She is so loving and smart,” says Maria. “She’s one of the greatest gifts the Great Spirit has ever given me.”

Sweats and ceremonies go a long way towards keeping these young people on the right path. For youth with FASD, they can have a calming affect. “Sweats are a good way to relax and calm yourself down,” says Tracy. “They help you get away from the problems in the city that you carry throughout the day.”

Maria says that Tracy has started to attend more sweats lately, adding “She says she feels so good in a sweat, and that she prays to her mother to help us. She told me she felt so close to her mother one time, and she prayed and prayed. She said it was so nice when she could hear the singing. It made her spirit happy.”

Maria notes that the sweat lodge can help one to recover from all the disruptions that can happen in a person’s lifetime. She has come to the point where she doesn’t look upon children with FASD as different than any one else who needs healing. She notes that many people lead troubled lives. Whether it starts in utero or afterwards, they can all benefit from attention to help them with consequences like stunned emotions or hurt spirits. “I try to give them spirituality as a foundation in their life,” she says.

This type of healing is invaluable for people who have been through alcohol abuse, either as drinkers themselves, or while in their mother’s womb.

You can heal in the sweat because you are back in your mother’s womb. The only thing is, you have some control when you come out.

When we look at FASD we need to get at the root. It’s not enough to look at the alcohol – as though it created the interruption.

When we are born, we have no control – we have got to be looked after: fed, diapered, things like that. But when we come out of a sweat, the first thing that we do is look after ourselves and then we look after all the people around us. The key is wellness.

Maria has noticed that the sweat helps children with FASD because it gives them a ceremony in which they have to exert self-control.

They have a choice in there whether they are going to pull through this round. They hear people singing, praying, and they develop a way to survive. That’s a choice they make.

They learn to control their emotions: to cry and when to stop crying. There’s nobody to tell them to shut up in a sweat lodge. They just cry and when they are finished they stop. They hold and feel themselves because they are all alone in there. Each person is on his own, and they do what they can to get something out of a round.

When you sweat, all the toxins come out of your body. You just sweat it out and then you drink fresh water when the door opens. The problems that you went in with are left in there, and you come back again to a clean and safe place that is your creation. Rarely do I see a person come out of the sweat so depressed and hurt. All of them come out and say they feel so light and good.
Maria’s friend Bev Scott points out that FASD is “just a sliver of the problem” of a colonized people. She talks about it as part of “all the major interruptions that happened,” including residential school abuses, suicide epidemics, lateral and domestic violence, family breakdown and substance abuse. Bev concludes:

When we look at FASD, we need to get to the root. It’s not enough to look at the alcohol – as though it created the interruption. It happened long before that.

The talking circle is Maria’s version of restorative justice, kiddie style, and she uses it all the time.

For Bev, the sweat is a tool that “seems to validate something in a really interrupted life.” For kids with FAS or FAE, it offers the chance to cleanse and purify and start again.

Restorative Justice
Maria’s Sense of Humour and fun has likely kept her and everyone else going over the years. Her time as a foster parent has provided her with many amusing stories – particularly around her “detective work” – trying to find out who is responsible for certain kiddie criminal behaviour in the house. She has developed creative approaches to dealing with the stealing and lying that can occur among alcohol affected children.

One time, someone had written the “F” word on the bathroom wall. Maria called all the children together and told them “Okay, now we are going to have a spelling test.” She sat them down, and proceeded to dictate several words, like “Fun”, “Up”, “Cat” and so on. She then took their spelling dictées to the washroom, where she was able to compare the handwriting, and ultimately name the culprit (who spent the afternoon washing off the walls).

On another occasion, the Linklater family was preparing to have a feast, and put out several boxes of apples. Maria noticed that one of the boxes had been opened – but when she checked, all of the apples looked intact. She couldn’t believe that someone would open the box and not take an apple.

On further examination, she discovered that someone had taken one bite out of every apple on the top row, but had replaced them in such a way that the bites would not be noticeable. She immediately gathered the children and sat them in a circle, telling them they were going to have a snack. She gave each child a piece of apple and asked them to take one bite. Then she produced the star witness material (the original bitten apple) and made her way around the circle, comparing bite marks. “Does this look like your teeth marks?” she asked each child. When she got to the child who had done the crime, he happily replied “Yes! Those are mine!”

The talking circle is Maria’s version of restorative justice, kiddie style, and she uses it all the time. “You would be surprised, kids are really affected by their peer group” says Maria. Her experience has shown that children who have FASD also respond well to talking about their behaviour in a group. When they are not able to tell the truth, Maria has some playful ways of making them come around. At one point, someone had eaten blueberries that were on their way to a feast. Maria asked the children to sit in a circle. She told them she was prepared to spend the morning talking with them, until the blueberry eater confessed. It was obvious who it was, as the child who had eaten blueberries had them all over his face and fingers.

Yet Maria spent the morning sitting with the children, listening patiently to the repeated denials of the blueberry eater. Finally, she announced mysteriously that she had two key witnesses. After drawing out the suspense, she asked the blueberry-covered child to go into the bathroom, hold up two of his stained fingers, and point at his face.

Whether in talking circles or alone, Maria sees the value in spending time with FASD children, and in talking with them about their condition. She approaches FASD from a point of wellness, focusing on what the child is capable of doing or learning.

“I don’t look at fetal alcohol syndrome as an excuse that they can’t learn. All the more reason to work harder. It’s just lots of endless hours.”

Straight Talk and Boot Camp
Maria’s Parenting Style is fun, but is backed by a strictness and discipline that helps to keep the children in line. She knows the value of hard work, and children that come into her care are expected to do household chores, help look after younger children, and answer to her simple, direct orders. “Maria is going to come back in the next life as an order form,” jokes her friend Maggie, “because she is always giving orders.”

“I call it straight talk” Maria says. “Just straight talk, that’s all it is. “She has no time for fancy excuses when it comes to discipline. “Just get to the point. No nuisance talk, I tell them.” Maria adds that she can be “really rank and rough” with kids who refuse to listen. “But you have got to do it without getting angry,” she says. “You tell them that this discipline is because somebody loves them.”

Maria is so accomplished at disciplining children that she has become a resource to exasperated
parents, who drop their kids off at her “boot camp” when they become unmanageable. The children typically spend a few days with Maria, during which time she makes them work, talk and learn about culture. “That’s what I do,” she says, “I straighten people out. I give them a tune-up.”

Children who stay with Maria are required to attend ceremonies. They must learn to sit quietly and listen to Elders, and Maria checks up on them to make sure they are paying attention. She remembers one young teen that she took to a ten-day culture/boot camp:

After the ceremonies and the lectures I would spend time with her. I would be resting in the tent. “Tell me,” I would say, “tell me what you learned this morning when the Elder was talking.” Then I would ask if she was listening, eh? And if she didn’t hear it then, I would do the lecture over. “So you have to listen, and then we won’t do the lecture over,” I would tell her. “Then you can have play time.”

The strict nature of her home has worked well for FASD kids. “They need lots of structure and consistency: going to bed on time, eating at a certain time – just like a residential school,” she quips, “only loaded with culture, and with lots of love.”

Even kids who are distracted, hyperactive, or unmanageable seem to find a way to settle down and listen in these environments. “The kids listen because it is about honouring the child,” says Maria’s friend Bev. “The respect is earned by the children when they know they are loved, but they also know that they can’t get away with anything. Even just the hugs, the touching is important.” At Maria’s, children get lots of attention and lots of time to think about their behaviours. And boot camp is free, because, as Maria points out “I get rewarded by the Great Spirit.”

**Culture Camp**

MARIA STILL DOES boot camps but has slowed down on fostering young children. She leads a very active life in Saskatoon, working as an Elder for the Saskatchewan Indian Federated College and for several penitentiaries in the area. She travels regularly to do speaking engagements and keeps busy with the cultural camps and weekly community sweats that she runs with her husband, Walter.

A visit with Maria at one of her cultural camps is a chance to see all her skills and years of experience put into action. One such camp is the “Cody Bear Memorial Culture Camp,” a five-day program held on a reserve 20 minutes south of Saskatoon. This camp provides inner-city families a chance to spend some time together; to get away from the distractions of the city and rediscover parts of their cultures that may have been lost.

Each day begins with a pipe ceremony, followed by teachings with various Elders. Afternoons are for crafts, and there is a sweat every evening.

It is really a blessing to be sentenced to spend time with Maria. For a child whose life has been interrupted by fetal alcohol exposure, the child welfare system, violence, abuse or neglect, it is justice in the truest sense. Indeed, anyone can benefit from the care of someone so strict and rigorous, while at the same time so incredibly loving, caring and humorous. Maria is someone who will pay attention to you, will ask you to take an honest look at yourself, and then help you sort it through. She will teach you something about yourself and your culture as you move along the path to healing and wellness.

Maria Linklater acknowledges the love and generosity of her husband Walter, whose support has made the work she does possible.
MORE INFORMATION ON FASD AND RELATED ISSUES

Alcohol and Substance Abuse in Pregnancy Helpline
Motherisk, The Hospital for Sick Children
555 University Avenue
Toronto, Ont.
MSG 1X8
1(877) 327-4636
www.motherisk.org

FASD Information Service
Canadian Centre on Substance Abuse (CCSA)
300 – 75 Albert St.
Ottawa, Ont.
K1P 5E7
1-800-559-4514 or (613) 235-4048
Ext. 223
www.ccsa.ca/fasgen.htm

FASLink (Fetal Alcohol Syndrome Information, Support and Communications Link)
2445 Old Lakeshore Road
Bright’s Grove, Ont.
N0N 1C0
(519) 869-8026
www.acbr.com/fas

FASAT (Ontario)
c/o Homewood Health Centre,
CADS
100 – 49 Emma St.
Guelph, Ont.
N1E 6X1
(519) 822-2476
www.home.golden.net/~fasat

NOFAS – National Organization on Fetal Alcohol Syndrome (US)
216 G Street, North East
Washington, DC 20002
(202) 785-4585
www.nofas.org

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