

**FETAL ALCOHOL SYNDROME: WHOSE CHILD?
SHARED RESPONSIBILITY**

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Abstract

This multigenre, multivocal project is narrated from the point of view of a teacher, and portrays a child living with FAS. A composite child has been created from the stories of several real children. The perspective shifts back and forth between the subjective and objective, emotional and rational, impersonal and intimate. It includes confidential school documents and communications, narrative reflection, songs and poetry, and juxtaposes these with political, historical, and research data. Awareness of the characteristics of FAS is growing in medical and educational communities, and in the community at large. Diagnosis of FAS requires specialized experience, and is a source of controversy, yet seeking diagnosis the first step towards intervention to reduce secondary disabilities. Educators are learning how children with FAS are cognitively, socially and behaviourally different, and what can help them in school and in society. Community service providers are combining efforts to promote awareness, prevention, and support for children and their families who live with FAS. Substance abuse and addiction play an important role in creating FAS, and the social conditions that create addictions must be addressed in order to prevent FAS. Prevention is ultimately dependent on the will of people and their governments to change the conditions of life for those who live with meager resources.

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Introduction: At the Beginning

Imagination carries us only so far; our own sensations are invariably more real to us than the experience of others. We live at the centre of concentric circles of decreasing impingement: first ourselves, then those we love, and only much later, and much more imperfectly, our fellow creatures. But the imperfect moral impingement that others make upon us is as much a fact about us as our selfishness. It is on these facts--and our capacity to imagine them--that we build such community as we can. (Ignatieff, 2001, p. 139)

Teachers are an optimistic group. We see children as needing only the right program, a better approach, more time, more patience, and then they will overcome whatever is standing in their way. We devise plans, study examples, and adopt new methods of teaching nearly everything: Reading Recovery, Project Read, hands-on math, applied academics, process writing, etc. Our intuition allied with our training instills the belief that there is something that will help every child. This is a "fixit" approach to what we see as problem children, born of the wish or the need to be effective.

Many children do learn to read a bit better with our help, or find other ways to cope with math, perhaps with a calculator or a crib chart. We teach the use of spellcheckers and hone the skills of proofreading. We see the literacy and numeracy emerge, and we believe in our efforts. But, some children don't seem to make enough progress (we say they don't try), and they apparently forget most of what we thought they had learned. They don't tolerate what is difficult for them, don't persist, and we have to herd them and hound them every step of the way. They are in conflict with other children, and take up much of the teacher's and principal's time. It is as if they make the same mistakes over and over, and after a while, we see them as "defiant", "lazy", "unmotivated", "socially inept", and altogether frustrating. When none of the usual

ways of motivating and correcting children work, we don't want them back in our class next year.

As teachers' understanding of the nature of FAS slowly grows, frustration and anger at these children is redirected to frustration at persistent ignorance of the effects of alcohol during pregnancy, and anger at their mothers for abusing them before birth, and even more towards brewery and distillery corporations that profit by making alcohol the social lubricant that cannot be denied, not only a right, but a necessity, albeit the one that wreaks havoc equitably across economic and social boundaries.

After the initial anger, and the sinking feeling whenever the picture fits together again of another child who is a likely sufferer from alcohol-related damage, I find myself paying attention again, connecting again with this child. S/he is fighting for survival in school, at home, on the street, fighting for friendship, love, and comfort. I look farther, beyond the individuals and even beyond the power of corporate distilleries, and see how this child came to be.

Preventing the not-yet-conceived from being afflicted is part of the solution. This goal seems so enormous that it overwhelms even the most avid optimist. Even so, there is much more to be done for those who are already among us. They are not recognized, understood, or given enough care and protection. Not enough of anything.

This project is the story of a child with FAS. It is told to demonstrate the challenges that this person faces, especially at school. It follows this child's life at school in a rural Canadian community near his mother's reserve. It starts when Jamie is six, loses him for a while when his family moves on, then picks up contact again when he is eleven. Jamie's own story is told in the writings of school teachers, psychologists, and his mother. His

own words and actions are reported by other people, and are recorded here. This story cannot be told without also placing it within the context of this child's society, with the historical undertext of dislocation and victimization. The choice for each person and for governments is to either respond with compassion and the will to make changes, or to place distance between the victims of this disability and those fortunate enough to be undamaged.

Voices that Speak About the Children of FAS

1. *I am the observer. I reflect on the children, and here narrate my private thoughts. My work is to assess the children's academic skills and abilities at school, and to support them and their teachers. This means helping to find ways to make school a better place for them. Teachers come to me when their questions exceed their confidence to answer them. They need to decide whether a child can't, or won't, do what is asked, and what will help. I don't have any ready-made answers, but I systematically gather information, ask questions, and help to marshal resources.*

2. ARMAND: HE IS THE NEGOTIATOR, THE GO-BETWEEN, THE FIXER, ANOTHER NON-ENROLLING TEACHER FOR THE SCHOOL DISTRICT. HE WORKS AS THE LIAISON BETWEEN THE FIRST NATIONS STUDENTS AND THEIR PARENTS AND THE SCHOOL SYSTEM. THEY GO TO ARMAND WHEN THEY WANT SOMETHING, WHEN THEY WANT TO PROTEST AND COMPLAIN, AND WHEN THEY NEED HELP. IT WORKS THE OTHER WAY TOO, AND ARMAND GOES OUT AND FINDS PEOPLE WHEN TALKING AND MEETING NEED TO HAPPEN. HE FEEDS CHILDREN, BUYS THEM SKATES OR SHOES, DRIVES THEM SOMETIMES WHEN THEY GET SENT HOME, FINDS THEIR RELATIVES, AND ON THE

OTHER SIDE, ASKS QUESTIONS THAT PEOPLE DON'T WANT TO ANSWER.

3. Karen: she was Jamie's Grade 1 teacher, five years ago. It was her first class, and she truly loved all her children. It nearly finished her teaching career, because she felt she could not provide what they needed, and this shook her faith in herself. She saw the enormity of their need, and knew that what she offered was not enough to fill it.
4. The educational experts: these are psychologists, usually, who assess difficult children like Jamie and advise schools what went wrong and what might help.
5. *Jamie's Mother: she does not speak much, but we hear a lot about her.*
6. The poets: Jann Arden and Raffi; their voices relay feelings that Jamie does not articulate for himself.
7. The writers: philosophers, historians, anthropologists, journalists, social workers, physicians, and all the other researchers and scientists who have something to tell us that helps to understand FAS.
8. Finally, there is Jamie. He is several children: a composite, but no less real for that. You cannot point to one single child and say, "That one, only that one, is Jamie." He does not speak directly. He is reflected by others, and it takes imagination to penetrate his world.

Chapter 1: FAS--The Disability

Who is the FAS Child?

I met Jamie again today. I have not seen him for nearly five years, when he was in first grade; he has been living somewhere else since then. He has grown, but not so much that I don't immediately recognize him. He is dark, and has a nice smile, when you can raise it; there is something off kilter about one eye. He speaks only one or two words at a time, and I can barely hear him. He speaks to the side and down, doesn't look me in the eye--it's safer? He quickly looks at me afterward--checking?

Notes from school district staff observation of Jamie when he was in Grade 1

9 Feb., Karen's Gr. K/1/2 class

- . before I arrived in a.m., Jamie had major incident with his teacher
- . she asked him to do something, and he started hitting her
- . it took her 1/2 hour of talking to get him to agree that he shouldn't hit her because he is angry with her
- . for first part of class, Jamie sat in his place and did as he was supposed to--complied with routine, listened
- . when Ks went to their table to do some pencil and paper work, he did not do the work
- . he is academically okay, in terms of knowing things orally--doesn't like to write/print
- . he watched the dental video; after this he began to stand out from the others
- . called out--to dental technician, to child across the class, to give

instructions ('turn off the light!')

. got up and went...to get floss stick himself (teacher was passing these out), to examine the dental puppets in technician's bag--and actually put his hand in to explore!--by the end of class he was wandering almost constantly

. from teacher: .egocentric (does what he wants--no empathy)

.difficulty staying in his desk or place--gets up to look at things

.other kids, and older kids on playground, know they can get Jamie to explode, so they work on him often

.he typically will do no printing or writing work unless teacher is right beside him, and prompts him letter at a time

.has fine motor and gross motor awkwardness compared to other children his age e.g. doesn't like to print or colour, had a really hard time when they went cross-country skiing--kept crossing them, didn't get the hang of it

. does dangerous (to self) things e.g. when skiing, headed down to the lake when others went along the trail.

Excerpt from the first formal report, by the school psychologist, when Jamie was six years old, near the end of his Grade 1 year:

CLINICAL OBSERVATIONS DURING ASSESSMENT:

Jamie presented as a quiet child. He was cooperative, but even in this one-on-one situation he was highly distractible and I frequently had to

get him back on track. He has many of the characteristics of a student with an Attention Deficit Hyperactivity Disorder (and possibly FAS).

Students with even a mild Attention Deficit Disorder tend to have difficulty attending to task and sustaining their concentration. This usually leads to poor work habits, poor listening skills and restless, inappropriate behaviour.

Jamie seemed to like individual attention and he enjoyed many of the activities. He appreciated the frequent changes of task, but he was inconsistent. At times he would try hard, but at other times he gave up easily or attempted to divert me.

syn·drome (sndrm)

n.

1. A group of symptoms that collectively indicate or characterize a disease, psychological disorder, or other abnormal condition.
2.
 - a. A complex of symptoms indicating the existence of an undesirable condition or quality.
 - b. A distinctive or characteristic pattern of behavior: *the syndrome of conspicuous consumption in wealthy suburbs.* (2001, Dictionary.com)

The word *syndrome* indicates or characterizes “a disease, psychological disorder, or other abnormal condition” or “the existence of an undesirable condition or quality.” Seldom do people infer a neutral meaning for syndrome, simply distinctive or identifying.

The diagnosis of fetal alcohol syndrome suddenly confers a new construction upon the person receiving it. A moment ago, this was a child who could not be trusted, who did not keep his or her word, who repeatedly replayed the same dangerous and frequently hurtful actions regardless of the discipline meted out. Some people, perhaps

teachers or family, would call this child *bad*--and now this becomes a different child.

This new child does not merely have bad behaviour, but shows a group of symptoms that collectively indicate an abnormal condition. The condition is not only abnormal, but to possess it is also undesirable, in keeping with the idea of syndrome. Suddenly we realize that this child has a damaged brain that lacks neural connections and brain functioning, and can't shift into reflection, and cannot easily control impulses by thinking. S/he lives in the moment, and does not easily master the concept of time. S/he doesn't imagine tomorrow as something that depends upon today. To this child, effects are not caused by his or her own actions; things just happen. S/he does not think about the possible results of what s/he does right now. S/he interprets the world as a continually unfolding mystery, not connected to personal power or volition. This child's power is an immediate physical, personal force, not the abstract mover of the not-to-be-believed future. S/he does not readily learn language; personal reality is not shaped by language, at least not until s/he belatedly learns to use it. The future, the role of *now* in *later*, in fact, the reality of *later*, exists because of language.

This reconstruction takes the responsibility for harmful actions, insult, and anti-social behaviour away from the child and places it somewhere else. It also used to be firmly believed by many people that such a badly behaving child was the result of poor parenting and a home life that did not provide enough teaching of pro-social behaviour. Or, possibly, the child's teacher was not applying adequate classroom management skills and techniques. The naming of FAS also relieves the teachers and parents of this child of the implied responsibility for bad management and bad parenting skills. Children with

FAS may be raised with all due care and attention, and still have similar outcomes and behaviour as affected children who do not have this benefit.

Once the term FAS is uttered, the fault has shifted. Now it is assault on a growing fetus. The quick and easy (and superficial) implication is of deliberate and repeated selfish and uncaring actions on the part of a weak woman, who lacks the strength of character to put the welfare of her child above her desire for good times. This has been the common conclusion of many people when they regard a woman who bears a FAS baby, and women have consequently denied drug and alcohol use to escape this condemnation. In studies by Gillogley, Evans, Hansen, Samuels, and Batra (1990) of drug use by pregnant women, almost half the women who tested positive said they had not used drugs during pregnancy. Society does not look compassionately at women who harm their children, especially through drugs or alcohol. This judgement overlooks the reasons that men and women live with alcohol and drugs, and the generational nature of FAS, and of poverty.

Last week at the school meeting we talked about Jamie, who has just arrived back from Saskatchewan with his mother, and his brother and sister, who are really little, still babies. He is eleven now; he and his mom used to live here, when he was just starting school, left part way through Grade 1. He showed up at school this year on October 5, at 11 in the morning. His mom was either drunk or stoned when she brought him to school, according to his teacher. We talked about one of us getting his mother to take the kids to the doctor to have them checked out. They seem very listless, and dirty. Jamie won't go out to play at recess. He has no lunch. The Friendship Centre and the school are supplying lunches. The social worker said that if mom wouldn't take the kids to the

doctor, she would go to the court. She also said that they couldn't remove children for plain neglect any more: Gordon Campbell [Premier of B.C.] said that the province has to reduce the number of children in care by 40%, immediately. So, no longer can neglect be an issue, unless there is endangerment to physical or emotional well-being, and, a psychiatrist has to state that there is emotional damage. Is there a trick to these words that I'm missing?

Just today the Mental Health clinician gave me the staggering information that soon there will be no more mentally handicapped people in the province. So, of course there will be no need for Community Support programs or workers--another sleight of hand by this government. I countered, and told him that the school system requires an I.Q. of 55 or lower in order to provide extra support for a student; there is no support for children who are FAS, and the Ministry of Education refuses to create new categories, according to its recent Review of Special Education document. "The number crunchers are at it," he shrugged as he left. I can't decide who won that round.

Difficulties with Diagnosis

Fetal Alcohol Syndrome (FAS) refers to a "constellation of physical and mental birth defects that may develop in individuals whose mothers consumed alcohol during pregnancy. It is an organic brain disorder which is characterized by **central nervous system involvement, growth retardation, and characteristic facial features**" [original emphasis] (Stratton, Howe, & Battaglia, 1996 as cited in Graefe, 1999, p. 1). New diagnostic procedures for FAS were published in 1996 by the U.S. Institute of Medicine based on recommendations by a panel of U.S. and Canadian experts. For full diagnostic criteria, see Appendix. Clinicians may now make a diagnosis of FAS in one of three

categories, and it is not necessary to confirm maternal alcohol exposure when the characteristics are clear. The use of the older term FAE (Fetal Alcohol Effect) is discouraged by clinicians and no longer used in formal diagnosis, because this is misinterpreted as meaning a condition less severe than FAS. Similar lifetime challenges are faced.

Payne (2001) writes that poverty is “the extent to which an individual does without resources,” (p. 16) which includes economic, emotional, support system, spiritual, and mental resources. Many characteristics of the culture of poverty that she describes are those of the FAS individual: living in the moment, not saving or managing money, lacking conceptual thinking and language... there could be some confusion about which condition we are looking at, poverty or FAS.

Children with the outward signs of the syndrome may represent only the most severe example of a spectrum of detrimental effects. Alcohol-exposed children who lack the characteristic facial features of fetal alcohol syndrome may still suffer from attention problems, hyperactivity, aggression, and psychiatric illnesses. Some...may have trouble functioning independently, though they have normal intelligence as measured by IQ tests. (Christensen, 2001, p. 3)

Some people are concerned that individuals with behavioural difficulties and learning disorders, such as hyperactivity and conduct disorder, for example, are suspected of fetal alcohol damage because such behaviours form part of FAS, even when maternal drinking cannot be confirmed. This is a concern because

presupposition that alcohol is the major (or only) cause of the child’s problems may end the search for other possible causes such as psychosocial deprivation and

abuse...[and] educators and care providers may base their expectations for the child's performance on that of children with FAS... [and] women are stigmatised for having damaged their children when it is by no means certain that they have done so.... [and] clinicians become frustrated by the imprecision of the 'diagnosis' of FAE and thus disregard any possible contribution of alcohol exposure. (Aase, Jones & Clarren, 1995, p. 430)

Most clinicians have adopted a conservative approach to diagnosis, and describe exposure status and non-specific symptoms but defer definitive diagnosis of FAS (Aase, Jones & Clarren, 1995, p. 430).

Biochemical markers would help to solve the current problem of diagnosis that relies solely on external signs and maternal reporting. Technology is making advances in this direction; for example, alcohol metabolites in meconium can distinguish women who drank alcohol late in pregnancy. Researchers are learning more about how alcohol specifically affects the fetus. Magnetic resonance imaging (MRI) of brain structure shows that the frontal cortex and corpus callosum are especially vulnerable to alcohol. More precisely, "alcohol targets particular biochemical pathways vital to the development, function, migration, and survival of certain nerve cells" (Christensen, 2001, p. 3). We now know that alcohol damages some parts of the developing brain more than others, and proteins that alcohol might interact with directly are now being identified. It prevents nerve cells guided by a cell-adhesion molecule (called L1) from adhering to each other. L1 also triggers nerve cells to grow toward each other and form connections; alcohol can slow the growth of such connections. Mutations in L1 result in damage to the corpus callosum, which connects the two sides of the brain. Alcohol also blocks receptors for

glutamate, which stimulates nerve cell signalling, and it interferes with serotonin, which is also important in nerve signalling. Signalling is important to nerve cells, because if they do not receive enough input from other cells, neurons get the message they are abnormal, and a program is activated that instructs the neuron to self-destruct.

Some things about FAS are becoming clear, such as the tragic outcomes on children and their families, but there is a great deal that is not yet understood. Biochemical mechanisms are being studied, and some light is being shed on just what happens at the cellular level to the fetus in the presence of alcohol. Pediatricians and other clinicians are also learning the art of diagnosing the FAS infant. Dr. Lemoine, the French pediatrician who in 1968 first published the description of these children, said that diagnosis is not a matter of a “list of lab results. It is necessary to handle and think about each infant individually and to have seen other children with FAS” (Streissguth in Hay, 2001, p. 26). The better-known cranio-facial defects are specifically related to very early prenatal alcohol exposure, whereas it is the tally of all anomalies that becomes clinically significant (Hay, 2001, p. 33).

There is acknowledgement that the rate of alcohol-affected children is sometimes as much as 20-30% in some areas and communities (Warner, 2001, p. 18). Although one estimate of the incidence of FAS in North America is 1-3 per 1,000 births, “it is abundantly clear in some communities, especially those in isolated and remote regions, that the prevalence rate is much higher and has to be considered a major health and education issue” (Turpin & Schmidt, 2001, p. 10). Physicians on the front lines of the FAS war, in remote and northern regions, hesitate to diagnose imperfectly, but the

clinical expertise of such front-line physicians is at least adequate, and they can help their patients by a “good-enough” diagnosis based on valuable experience (Hay, 2001, p. 26).

Teachers and other service providers in the front-line regions also have resorted to good-enough unofficial best guesses when presented with children whose characteristics are consistent with FAS. When teachers know numbers of children who have been officially diagnosed by medical clinicians, comparisons are made with those children who do not have the benefit of formal diagnosis. It would be a disservice to misdiagnose and pathologize children, motivated solely by the wish to name and label. It is often, again, left to the teacher or caregiver to develop the art of thinking about and interacting with each child individually and to draw on personal knowledge of other children with FAS, not to make a diagnosis, but to adapt teaching and parenting adequately.

Diagnostic clinics such as Vancouver’s Sunny Hill Centre for Children, or one of its Outreach Clinics, rarely see FAS children who live with their birth mothers, although in B.C., Children’s Mental Health workers and school intervention support teams are now making some headway persuading parents to take advantage of such services. The encounter that results in such a referral is delicate, and there is no certainty that a parent will take the child to the appointment, once made. To follow through, not only must a parent believe that things are not going well with her child, but she must also be prepared to submit to the judgement of the experts, and finally, believe that this may help her child. It is an act of courage and unselfishness on the part of a birth parent to take the steps of submitting to formal diagnosis.

A few parents then wish to hide the doctors’ words, keep them secret from other agencies, such as schools, although most do not. A corner is turned when a parent agrees

A few parents then wish to hide the doctors' words, keep them secret from other agencies, such as schools, although most do not. A corner is turned when a parent agrees to, and helps carry through, a diagnostic appointment. Once the diagnosis is made, there really is no turning back.

When teachers in these same communities (remote, northern, and aboriginal) read that the rate of FAS is 1-3 per 1000, they are confused and incredulous. The more believable number in many of these communities is 20-30%, as suggested by Warner (2001). The diagnosis of FAS is not easy to make or to obtain, because evidence of prenatal alcohol exposure is not easy to confirm when a child has been living in foster care for most of his/her life. When a child still lives with his/her birth mother, many are unwilling to admit that they did damage to their own children. Also, many mothers of FAS/FAE children are living in poverty, and are vulnerable to the system that is constantly judging them and wields power over them and their children. Keeping their children is at risk if such admissions are granted. "I didn't drink when I was pregnant with him." This is the stolid and flat-eyed statement made by mothers. They know what is being sought.

Not all physicians spend time admonishing women about drinking during pregnancy, or soliciting information about problem drinking; subsequent referrals to addictions counselling, or social services, take up the physician's valuable time, and many believe that this is not an effective use of their time and training. Many do not believe that their words make any difference. Neither are all physicians and clinicians interested in making the diagnosis of FAS with an infant who clearly has many of the characteristics; some are insecure about the diagnostic criteria, "when the complete

pattern of abnormalities cannot be substantiated, often because of the patient's age, racial background, or familial characteristics...[while others] may be reluctant to make the diagnosis because they fear stigmatizing both the mother and the child" (Aase, 1994, p. 8).

Teachers also find such a label to be shocking and shameful, and half whisper when speaking of FAS.

Unwillingness, discretion, delicacy, burnout, denial, shame.

Related Conditions

What if the stigma of FAS were on a par with that of the label ADHD, or Learning Disability? Would the numbers of those diagnosed then rise drastically? Since 1975, the percentage of identified children with learning disabilities in the entire U.S. has increased nearly 300 percent, from 1.8 percent in 1976-77 to 5.2 percent in 1993-94 (Speece & Harry, 1997, p. 65). Several explanations have been proposed. Janet Lerner (1993, p. 16) suggests a combination of reasons: more awareness of learning disabilities, improved procedures for identification, social acceptance and preference of the category (to *mental retardation* or *behaviour disorder*), cutbacks to regular education funding (and thus the desire to access special education funding), and judicial decisions to re-evaluate minority children's classification. If children with the diagnosis of FAS were given special education support, would this increase the willingness to identify?

There is evidence that ADHD and Learning Disability are often aliases for alcohol-related birth defects. There are many other names for these defects: language impairment, eye and visual impairments, ear anomalies, otitis media, auditory impairments including hearing loss, cleft lip/palate/chin, dental problems, oppositional

defiant disorder, conduct disorder, depression, anxiety disorder, sleep disorder, Tourette's syndrome, heart defects, scoliosis, kidney defects, umbilical and other hernias, undescended testicles, joint anomalies, dislocated hips, allergies, and poor immune system especially with respiratory problems. This is only a partial list of characteristics occurring in children diagnosed as FAS/E (Hay, 2001, p. 27). "If we are only able to identify the tiny minority of 'classic FAS' children, we miss the vast majority of those who are more subtly affected" (Hay, 2001, p. 27). This means that these children "will not benefit from early intervention services [that will help in] coping with the physical, neurodevelopmental, neurobehavioural and psychiatric symptoms of this chronic, lifelong disabling condition" (Hay, 2001, p. 27).

Now that awareness of FAS has increased, and the willingness to name it has begun to emerge, this medical diagnosis of FAS may replace the psychoeducational diagnosis of learning disabilities, or psychiatric diagnosis of ADHD, with many children for whom the syndrome is more inclusive of a wider array of difficulties.

The issue of what to call the problem may be seen to break down to either naming the specific symptom that is perceived, such as ADHD or Oppositional Defiant Disorder, or else naming the cause of the symptom, FAS/ARBD/ARND. If we choose to limit the naming to the immediate symptom, then we suggest that everything else is fine that we have not mentioned. If we extend the naming to the root cause, that is, alcohol-related birth defects, then we imply that there may indeed be a spectrum of symptoms that are potentially included, and that might be expected to appear sooner or later. If we are anticipating the difficulties, then interventions and special ways of helping the child to cope with life may be put in place. Support programs that are needed for individuals and

families with FAS include infant development programs and early intervention, alcohol and drug counselling and treatment, speech therapy, family planning counselling, educational upgrading, job training, education and behaviour support.

Who Has FAS Babies?

Women who have babies born with Fetal Alcohol Syndrome are from all social and economic classes. The simple fact is that most women in our society drink alcohol, and most pregnancies are unplanned. Women who drink “socially” before they know they are pregnant, as well as women who are addicted to alcohol, drink in the early weeks of pregnancy. Mothers who binge drink (five drinks on a single occasion) are especially at-risk of damaging their infants, since high blood-alcohol levels are clearly shown to disrupt fetal development. Many, if not most, women know that there is danger to the baby from drinking while pregnant. There is confusion and differing scientific and folkloric opinion about how much drinking is harmful. Often “social” drinkers stop (or cut down) after the pregnancy is confirmed, but the damage to the developing fetus can often be extensive by this time. Pregnant women who are physically addicted to alcohol do not stop. Occasionally circumstances such as involuntarily going to jail or hospital, for example, intervene in the consumption pattern. The cells (particularly brain cells in the latter stages of gestation) of the developing fetus are vulnerable to damage right to the day of delivery, and beyond if the drinking mother breastfeeds her child.

Although women from any socio-economic class can and do have FAS babies, good general health and good nutrition mitigate alcohol’s effects on the fetus. The Canadian Centre on Substance Abuse confirms that binge drinking and alcoholism are strongly associated with FAS, and it

appears to depend on a number of factors in addition to alcohol, including parental health, drug use and other socioeconomic factors. The undernourished body passes along the teratogenic properties of alcohol via the placenta more readily than a body that is healthy. (Mitchell, 2001, p. 12)

According to Caroline Tait, a researcher who studied the service needs of pregnant addicted women in Manitoba, alcohol addiction is a social and health issue. The majority of at-risk women (77%) interviewed for her study were of aboriginal descent. Substance abuse during pregnancy, she notes, "is related to being part of the most impoverished group of people in Manitoba," as well as a history of abuse (Tait as cited in Mitchell, 2001, p. 12).

The day after the school meeting, Armand went to Jamie's house to have mom sign a paper so that the school counsellor could talk to Jamie.

I received this email from Armand:

I HAVE THE FORM SIGNED AT 10:00 HRS ON 09-12: EXTREME SMELL IN THE HOUSE-I STARTED TO CHOKE AND GAG UPON ENTERING THE APARTMENT. THE MOTHER WAS PARTIALLY UNDRESSED, A YEAR OLD WAS WALKING AROUND AND THE OVEN WAS OPEN ON HIGH. MOM SAID, "NO HEAT DOWNSTAIRS." SHE SLURRED WORDS AND PULLED KID FROM HOT OVEN AND SAID OKAY TO THE SIGNING. I GAGGED AND LEFT-HOUSEHOLD GARBAGE IS ON THE FLOOR, AN OPEN DIAPER UNDER THE TABLE AND CLOTHES EVERYWHERE. JAMIE WAS IN SCHOOL WHEN I VISITED AND I PROVIDED A LUNCH. ARMAND.

A good predictor of whether a woman will drink during pregnancy is whether her male partner drinks. “When a pregnant woman consumes alcohol, she does not drink alone” (Graefe, 1999, p. 1). This statement is intended to make it clear that drinking alcohol may produce the teratogenic effects of alcohol damage and disrupt the developing embryo and fetus. However, it ironically conveys the reality of life for many women. You drink to party with your man. To have a baby by a man of some status in the eyes of your friends is a symbol, for some young women, of adulthood and sexual desirability. It can also be the means to obtain government welfare support and achieve some independence. This situation is common in some communities, and comes early; the baby represents all these gains: sexual maturity, desirability, and independence. These are certain and immediate outcomes, whereas fetal alcohol syndrome is like a lottery. Maybe it will happen, maybe it won't. Perhaps you will see it, perhaps you won't.

Characteristics of FAS: Physical, Social, Behavioural, Academic

This child is sometimes born with outward telltale signs of the damage done to him or her by alcohol. S/he may have a bad heart or kidney, or specific facial or structural deformities. His/her head may be small, or s/he has an undersized body. S/he is not an easy baby to care for: s/he cries and cries, and apparently cannot be comforted. Often s/he does not have a strong sucking reflex, and it is not easy to feed, or to bond with, this baby.

But, depending on just when his or her mother knew she was pregnant, and when and if she stopped drinking, or just when her binges occurred, s/he may have few or none of this visible and more easily measurable evidence of fetal alcohol damage. It may take years for the other kinds of damage to become obvious. S/he might look unremarkable,

even handsome, be loveable and affectionate, and be capable at some things, but the way s/he acts and interacts with others reveals the damage. S/he may rock and twirl for comfort. S/he might not speak until age four or five, and then imperfectly and inarticulately, and communication with others is poor. S/he can seldom fall asleep easily when put to bed, and rarely sleeps through the night. His or her teeth, when they emerge, are rotten and weak, as if s/he ate nothing but sugar. The child's eyesight may be poor, and sometimes there is a cast eye. *Optic nerve hypoplasia* is the most frequent anomaly found in FAS, and was observed in 76% of the children in one study (Stromland & Hellstrom, 1996, p. 851). Often the child's hearing is impaired; but almost certainly s/he has difficulty discriminating sounds accurately and easily. S/he frequently has problems moving with good control and balance, and is underweight for his or her height.

This child does not seem to feel cold, or pain. S/he runs around outside in winter with no coat, and doesn't seem to notice the cold. S/he will be cut or be hit and not react much. S/he may forget to eat, or may eat until all the food is gone, without seeming to be satisfied. S/he gets a lot of colds and can be frequently ill. His or her immune system is impaired, as is the awareness of temperature, sleep, hunger, and other homeostatic biological controls.

Once s/he goes to school, life is often hell. When teachers see this child wandering around the class instead of sitting in his or her desk, they are exasperated. S/he seldom starts on work without repeated nagging; and finishing is even more difficult. S/he has trouble with abstract thinking, and has limited problem-solving skills. S/he often stays in at recess for hitting other children, for not listening to the teacher, or for not doing work. S/he appears to be defiant, because s/he does not do as s/he is repeatedly

told. Other children get fed up with the amount of negative attention and time spent by the teacher with this child, and they soon learn how to amuse themselves. S/he is their target. They goad him or her until s/he does forbidden things and gets into trouble. They make fun of or call him or her a name, and s/he explodes in a temper, and gets into trouble. S/he learns to run away from the class or the school when the bad times come. This brings more trouble. Every time s/he is corrected, disciplined, or punished for something, his or her sense of isolation and misery increases. S/he doesn't connect the humiliation to the actions, and s/he doesn't remember it when s/he acts again, the next time, with impulsive anger or impulsive desire.

If s/he has someone to associate with at school, it is usually someone similar. Often they misbehave either together or more often serially. If it's not one, it's the other. They don't seem to know how to play with other children without someone ending up crying. Negotiating and maintaining interpersonal relationships seems an impenetrable maze.

Later, this child becomes an adult, and s/he becomes intimate with the drug culture and the justice system. One estimate is that up to eighty percent of Manitoba youth in custody may be FAS (Coghill, 27 March 2001). Finding and holding a job is next to impossible when you are unreliable, can't seem to get along with others, and don't read and write well.

Not every child with FAS has all this damage. Many have quite a few of these impairments, enough so that life is difficult, at best. At worst, it is sad, full of pain and failure, and frequently short.

Jamie was taken from his mother this weekend, so he is clean and his clothes are

new. He has a really nice haircut, and with his shiny black hair he looks very good. He still has an unhealthy odour, as if his body is still exuding poison. I compliment him on the haircut, and ask where he got it. He told me--didn't miss much about this town.

Mom somehow had hooked up with the town's chief drug dealer, well known to all including the RCMP, social workers, everybody. (How does this work?) Jamie and the little kids were removed this weekend, and I met him today, right in the middle of his personal nightmare. I don't ask anybody how it was done; I'm just thinking that things had to be serious now, for it to happen at all. I believe that their mom will get them back, probably with a supervision order. That means the social workers can go in anytime to check things out. But, that won't actually happen, because as soon as she gets them back, they will all disappear. Just like they disappeared from where they lived before they popped up here. They will go wherever there is another relative, a connection. It will take a little while for people to put pressure on them again in the next place. I guess their life is pretty desperate, when we notice things this quickly.

Kendra, the child protection worker who removed the children, told me that Jamie didn't want to leave. She tried for kindness, explained to him that the little kids needed to go because their mom couldn't look after them; mom would be worried, though, she told him, and Jamie better go so he can let his mom know that they were okay. So he came, no crying. When mom visited them the next day, Jamie was the only one she paid any attention to. Very unusual, said the social worker; usually the parents make a big fuss over the kids when they visit, even if it's a show. This one was quite distracted, not involved in these kids at all, didn't even look at the little ones or speak to

them, only Jamie. I wonder if she was still stoned, or maybe she is stunned by the turns of her life.

Jamie is withdrawn, passive, unwilling to engage with people. He answers questions, attempts to do what is asked of him. He shows a lot of little flashes of capability, of pride, amid all the self-deprecation and what looks like disdain. It's probably distance, and fear. It is like he is a giant bruise, don't touch. Can't stand it.

What if he had, say three years in a home with people who would treat him with care, give him safety and respect? I can't imagine a longer period of time, not in all your dreams does a child like Jamie stay even that long in one home. I think he must have been through all this before. I wonder where he would choose to be. Mostly they choose to be with their parent, however bad things are.

And later, when he is older and out of the school system, we know how things go for Jamie. He enters the culture of welfare, at best, but probably not unless he is female and has children. Otherwise he is offered the model of drugs and crime and a woman to support him and his life style. He has no other paths that he is free to follow. Jobs are minimum wage and do not go far to support a single person in this material, free market culture. Even if he can find one. Even if he can keep one.

Jamie is free, though, free to be drunk, to be stoned, and he will, in just a few short years. He trusts nobody, believes in...anything? What do I believe in any more? I know that none of us can do much to help, when we put our effort into helping. But what else can we do?

People with a social conscience think about cultural and material oppression and

domination, about addiction, about poverty, abuse, and while doing that, almost forget to know the children that seem to be lined up in the halls in school, sent out of class, waiting in the office to see the principal, in the waiting rooms at the medical clinic, in the emergency ward, in the lockup. They are not less important because they are damaged. They are always important to someone, they are someone's children. If this is hard to see or believe, because their loved ones neglect and abuse them, don't worry, it's just hard to see; love is expressed in strange ways at times. Does someone have to be in good condition to deserve being looked after? When does someone stop having the right to that? Is it when s/he reaches a certain age, whether or not s/he is capable of independent living, or whether or not s/he is able to find or keep a job because s/he lacks skills, or physical stamina, or the ability to keep track of time, or because there are no jobs to be had that can support a person?

Can we ever say that an FAS child or adult does not need looking after? It may not be fair to expect a person who is physically and psychosocially impaired to be responsible for looking after him/herself. If we, the rest of society, don't look after them, then we condemn them to a short life of addiction and despair, taking happiness in the moment, in the brief lift of drugs and alcohol, the companionship of getting high. Many of these FAS children go on to have children like themselves. Can we blame them for this, too? Fairness and justice demand difficult answers from those who believe in them.

Chapter 2: Jamie

All I really need is a song in my heart
 food in my belly
 and love in my family...
 So that I can grow up strong and
 Take my place where I belong

“All I really need” (Raffi, 1980).

I Really Need...In School

When Jamie was six, his mother had agreed to have an assessment done by the school district. This is from that report:

VERBAL IQ	83 (13 th percentile)
PERFORMANCE IQ	95 (37 th percentile)
FULL SCALE IQ	87 (19 th percentile)

SUMMARY:

1. Results of testing on the WISC-III suggest that Jamie is functioning in the “Low Average” range of verbal cognitive skills and in the “Average” range of nonverbal cognitive skills. In spite of this, there are factors affecting his academic progress.
2. Jamie had difficulties with certain visual and auditory processing skills. Students who experience these difficulties are usually delayed in their academic skills, particularly during their primary years.
3. Jamie has the characteristics of a student with ADHD. His distractibility is interfering with his learning (and possibly the learning of others).
4. Jamie is achieving well below his measured potential and there are indicators that he has a severe learning disability particularly affecting his reading and spelling skills. He is seen as an “at risk” student who is still

functioning at an early Grade 1 level in basic reading readiness skills. His difficulties would appear to be related to the following factors.

- a) Jamie has difficulty attending to task and sustaining his concentration. He frequently “tunes out” and this is not conducive to learning.
- b) He has some visual and auditory processing difficulties. He is approximately two years delayed in skills important for success in reading and spelling.
- c) He has difficulties with auditory memory and sequencing skills. This can also affect his rate of learning.
- d) He continues to have difficulties with associating sounds with symbols.
- e) A referral to the district Speech/Language Pathologist for assessment and possible therapy is recommended.

RECOMMENDATIONS:

1. It is recommended that Jamie’s mother discuss with their family doctor the possibility of medical intervention for his attention deficit disorder. Medication can often help children such as Jamie to focus their attention better and become more receptive and attentive. This in turn helps improve their academic skills. At the present time he is missing out on much of the learning that is taking place in the classroom and his behaviour is affecting his social interaction with his peers.

2. Jamie is likely to benefit from working with a classroom support person. He does not learn well incidentally and will need direct teaching techniques and plenty of “over learning” if he is to become successful.
3. He likes discussion activities, with the class or small group, but he doesn't work well independently and rarely completes his assignments when left alone. He will need monitoring and extra attention when in class.

Shaughnessy Park Elementary School in Winnipeg, Manitoba has up a special program to help FAS children learn. This school is near a housing development where most of the children live. These families are mostly low-income, aboriginal, on social assistance, and transient. More and more children are attending Shaughnessy Park who are FAS (Coghill, 27 March 2001). The school's program is called the Right Program (as in, all you need is the right program), and was started because the typical approaches to FAS in a regular classroom do little to help these children. The environment is very structured with predictable daily routines. The daily agenda is presented in words and pictures in the same clearly visible place. Making transitions (going to gym, in and out for recess, home time, etc.) involves consistent routines. The class size is small (about eight students), with lots of special equipment and extra help. A Right Program classroom is bland and under-stimulating. The walls are grey; there are no posters, no artwork on the walls. The sound is muffled with grey upholstered partitions between each desk. Covering equipment when it is not in use reduces the number of distractions further. Sensory overstimulation and distraction interferes with the learning of FAS children. Calming techniques (brushing, swaddling, quiet, low stimulus area for a calming time) are in place. The teacher attempts to reduce her talking--staying on topic,

focussing on one problem at a time--and to repeat things frequently. She also exaggerates her emotion when she's talking, so that these children will more easily interpret emotion. Remembering is a huge problem. Patience is most certainly required. What has been learned one day may well be gone the next. The teacher slows the pace of learning and draws out a task by having short sessions and then going back over previous steps; it takes a lot longer to accomplish the simplest activity. Abstract concepts and generalizing are a problem for FAS children, so everything must be concrete. The school music program (dance, choir, acting, composing) starts from the beginning of Grade 1. Preventing frustration is important, because these children can become angry or violent when they become frustrated.

If we choose not to name, to pretend that what we see is within the range of normal, then we expect this child to be on time, to listen and remember what you tell him, to learn from his mistakes, to stay calm, to do it right next time, to organize his time and his belongings, to remember what he vowed to do this morning.

Nobody knows me, no one will ever see
 the distance between what is and what will never be
 A bird will break his wings
 Like a heart will cut her strings
 And there isn't anything to comfort me
 "Gasoline" (Jann Arden Richards, 1994).

Karen's Journal

Karen was Jamie's teacher in Grade 1. What follows is from her confidential journal:

This is a record of my observations of Jamie through the year. I hope this will be helpful. I did not think that others would be looking at it so I have put my own honest feelings and observations. Most of the

notes are brief and usually written in the evening when I have some time. I hope this can help Jamie who I see as a wonderful child who needs some extra help.

Sept. 23

10:32 Runs over to show me he is finished. He is very happy that he is done. I say, 'good for you, now you can get your snack.'

10:34 Mrs. Dean says, 'I told you you'd get it done if you worked hard...Good for you'

10:40 I am busy helping other students when Jamie pulls Kirsten's chair out from under her because, 'she pushed my papers on the ground.' I talk to Jamie about what else he could have done, and they say sorry to each other.

Oct. 6

Jamie has begun yelling in other students' ears. He puts his mouth to their ears and screams. Today he yelled at Kirsten and Cole, both in kindergarten, who started to cry. Jamie seemed to think it was more of a game and even laughed at Kirsten. I have talked to Jamie several times about how it feels to be yelled at. I don't think he understands. He didn't want to apologize to Cole, saying it was only a game.

Oct. 10

I have repeatedly talked to Jamie about yelling in others' ears and I have had the other students tell him how much it hurts them and that they don't like it. Brent got mad at Jamie today when he yelled in his ear and ended up yelling back. Making Jamie cry. I talked to both of them. I was disappointed in the afternoon. Sammie said Jamie yelled in her ear. Jamie is drawing a picture in the office about not yelling in others' ears.

Oct. 31

Jamie is not yelling in others' ears as much. For the last few weeks he has only done it once.

Nov. 18

Jamie frequently out of his desk today. He has started to chase other students in the class. I have talked to the whole class and Jamie privately about the dangers of running. We role-played how to walk in the classroom.

Nov. 26

Today was a difficult day for all the students. A few fell asleep in their desks. Jamie started crying when we were sitting in a circle at

carpet time. Mrs. Dean took him to the office to talk to him but said he just cried and cried.

I've got holes in my head
 Holes in my head
 I've got filthy rotten wall to wall
 I've got a couch made out of corduroy
 My cat's dying, words flying, leading
 down from the shower stall
 And that's not all...
 I can't believe the things I hear
 Falling from the atmosphere...
 And I can't sleep

“Living under June” (Jann Arden Richards, 1994).

Nov. 27

Jamie was complaining his ears were 'too loud'; he kept putting his hands over his ears and at one time looked like he was about to cry. I have made cards for him to use. If he feels it is too loud he gives me a card and he is allowed to go out into the hall or library to work...where it is quiet. He may have an earache???

I mentioned that Jamie maybe should get his ears checked to his mother. She said that it was just that he listened to his radio at night and stayed up late.

Minutes from the School-Based Team Meeting:

Red Lake Elementary School

School-Based Team Meeting

2:30 p.m. 30 Nov. CONFIDENTIAL

Jamie Youngman:

- . medical assessment?
- . videotape
- . Karen communicate with mom, get consent to video-tape
- . can get someone to take them to doctor
- . federal health - tell them
- . behaviour plan:
 - stay at desk - 'too loud' card
 - try some ear protectors - sound/touch sensitive
- . external rules - repetition
- . something tactile - soft-can't chuck it: fabric pieces
- . counsellor will lend videotape (ADHD ideas)
- . timeout consequence

Dec. 5.

The cards worked well for a while but now Jamie was running up and down the hallway sliding when he had given me his too loud card. I think without another person to be around to settle him he will keep playing and being noisy when he is left to work on his own.

Dec. 8

I have taken Jamie's too noisy card from him. Today he hid in the paper room when I had set him up in the library. We looked for him

for at least 10 minutes. We talked to him about hiding and how we were worried about him.

Dec. 15

Jamie's mother phoned to let me know that she would be away for an operation. He will be staying with his grandmother (also does not have a phone).

Letter to Joanne Youngman, Jamie's mom:

Dear Mrs. Youngman,

Thank you for spending the time to discuss Jamie's progress in school. I hope that you are feeling better soon.

As I have mentioned to you Jamie is a very sensitive child in school. He often reacts to other students in a spontaneous way. He also tends to find that he feels bothered by changes to the school routine, or when there is more movement and/or noise than usual in the classroom. As I have mentioned, I talked to the Student Support Services teacher for this area in an attempt to develop some extra support for Jamie. She suggested taking Jamie to Sunny Hill Outreach Program so that the doctors can assess him. I feel that Jamie is getting a great deal of support from home and school,

however the evaluation would allow us to give Jamie even more support.

To have the evaluation done Jamie needs to visit the doctor and first eliminate the possibility that his ears are not causing him problems. He has mentioned many times that he hears ringing in his ears. At the doctor's you need to ask for a referral to Sunny Hill Outreach Program. He may try to get you to go to Vancouver but there is a team that visits this region that would be easier for you to get to. We can set up a ride for you to the doctors and to the appointment if you need one.

Please phone me and tell me which doctor you have the appointment with and I'll make sure he understands what assessment Jamie needs (a psychoeducational and medical evaluation) OR you can have the doctor phone me at the school or at home.

Ms. Karen H. (Jamie's teacher)

Dec. 16

I sat with Jamie in the hall during math. We talked about his friends and what he liked to do: play Nintendo and play outside with his friends.

hoping that the kindness will lead us
 past the blindness and
 not another living soul will ever have to feel
 unloved...unloved...unloved...unloved

“Unloved” (Jann Arden Richards, 1994).

Dec. 18

Jamie is very excited and tired. He is looking forward to Christmas, but all the extra activities have been hard on him. Any noise or movement different from the routine tends to make him look distracted or want to hide. Calming him down is hard as well because he is even more noisy and active than the rest of the students. I have taken to have Sammie sit in the eagle room and read a book when she is showing signs of being tired or overwhelmed like Jamie becomes. But unlike Sammie, Jamie will not sit and take that quiet time unless there is an adult there talking or reading books with him. I wish there was another person to even just sit and read with him. Unfortunately all the older students I have tried to get to do this with him, end up 'bouncing' as much as Jamie just from being around him. - I need help with him - He needs a full time support worker and I need to know more on how to help him!

The salt inside my body ruins everyone I come close to
 My hands are barely holding up my head
 I am so tired of looking at my feet
 Or all the secrets that I keep

My heart is barely hangin' by a thread

"Hangin' by a thread" (Jann Arden Richards, 1997).

Jan. 6

First day back from Christmas holidays. First thing in the morning

Jamie crawled under the table and curled up in a ball. I talked to him

and he said that he did not want to do any school, just computers.

Sammie crawled under the table, but came out when I asked her to. I

told Jamie that it was OK to want to have a fun day the first day back

to school and that I would let him play on the computers for the

morning. He still stayed under the table. Mrs. Dean came over and in a

confident voice said, 'OK Jamie, which computer are we going on?

You'll have to show me because I forget where the computers are!'

Jamie came out then but still looked sad. I wish I could help him

more...

Jan. 10

Jamie has not wanted to get back into school. He is saying, 'I don't

want to', or 'I can not' frequently. I try to stay very positive and

supportive. He is allowed to go on computers frequently (which he

loves). I also try to joke with him (he's got a great sense of humour).

Jan. 12

Today I told Jamie, 'let's finish this page and then you can go on the computers.' He did not even want to go on computers. His 'I don't want to' has become more encompassing and more frequent. He has even stopped wanting to do colouring and pasting. He never did get his work done.

I sent a note home with some homework to his mom, who thinks that it is because he is not finding the schoolwork challenging enough. - I don't agree.

Jan. 15

Jamie is showing increased signs of frustration and anger. Today he pushed Brent when they were lining up. Brent hit his head very hard. Mrs. Dean asked Jamie to come and talk to her and he started screaming and crying. He started kicking the wall. Mrs. Dean had him wait in that spot until he had calmed down. I just sat on the floor beside him and waited until he calmed down. When he calmed down we talked and then went together to find Brent to say sorry. Afterwards Jamie ran off to play on the slide.

...My heart is barely hangin' by a thread

Feb. 2

Jamie got stuck on the slide today.

All the staff mentioned how frequently Jamie was hurting himself.

Feb. 10

Jamie today started yelling and banging his hands on the desk. I had Mrs. Monroe [principal] come talk to him. She very quietly asked him to come talk to her in the hall. Jamie became very frustrated and angry. I was talking to the other students at the time, but Mrs. Dean witnessed Jamie hitting Mrs. Monroe and yelling at her. They both talked to him until he quieted down and then phoned Armand to come out and talk to Jamie. Together they made the choice to have Jamie suspended for the following day.

No I will not lay down
I will not live my life like a ghost in this town
I am not lonely swear to God I'm just alone
...No I will not go back
"The sound of" (Jann Arden Richards, 1997).

Feb. 14

Jamie has returned to school. He is still showing signs of being frustrated and angry. He has been pushing other students on the playground and frequently talking about blowing up the school or destroying the school and everyone in it. We have talked to Jamie

frequently about this. Sue [support staff for Mrs. Monroe's class] has agreed to volunteer to work with Jamie in the mornings to give him some individual attention. They do a little work and then they work on the computers. Jamie enjoys this time but for the rest of the day says, 'I already did my work with Mrs. Sue. I don't want to do anything else.' When he says this he is showing signs of/facial expression of - upset and pathetic (is closest I can come to describing his expression). When he says this he does not want to do much of anything other than curl up or find a quiet place to sit.

Feb. 21

Swimming instructor (Tamer) mentioned that Jamie was having a difficult time staying with the group and mentioned he was very 'spontaneous and active'.

Feb.22

Today I sat beside Jamie on the bus to swimming. Jamie asked if he had to listen to God. I told him that, that is something he should talk to his mom about because she would be able to tell him more about God. He seemed satisfied with this but then after thinking some time asked, if he had to listen to God and Jesus because they were so loud

at night. I told him that he should always ask another if he was thinking they were telling him to do something he did not feel was right or if he needed help to decide if he should do something. He was quiet for some time and then said 'God and Jesus are just so loud at night that I can not sleep'. - what a strange conversation.

Hide your heart under the bed and lock
your secret drawer. Wash the angels
from your head won't need them anymore.
Love is a demon and you're the one he's
coming for. Oh my Lord.

"Could I be your girl" (Jann Arden Richards, 1994).

I know that you're sorry
I know you've been drunk all week
I know that you did not mean to

"I know you" (Jann Arden Richards, 1997).

good morning

please send the rest of Jamie's homework and we will

work on it this weekend

Jamie and I went hunting yesterday

Jamie is still very ~~hostile~~ upset

with his school

oh yes and he says he would like

to start his high grade one book

thank you

Joanne Youngman

March 23

Dear Mrs. Youngman,

Jamie was very sick at school today. He had a fever and was coughing quite a bit. He did not want to go and lie down, so I found a quiet spot he could work.

I will send some work home tonight so if you would like to keep him at home until he is feeling better he will not miss anything. Many of the students are away this week because of a terrible flu, and I will not be starting to teach anything new until most of them return.

Jamie has been very fragile the last few weeks but is very happy that you are home again.

Please phone if you have any questions or comments. I will try to write to you to keep you informed on how Jamie is doing.

Thank you for your support.

Ms. Karen H. (Jamie's teacher)

March 26

Jamie's mom came to observe him for a day. As usual Jamie was frequently out of his desk. Things easily distracted him. Not focused on what the rest of the class was doing. He hurt himself several times

on the playground by jumping from too high places (he tends to have little fear). She also observed Jamie playing with several other older students. Although the students were warned not to continue playing this by the supervisor, Jamie was trying to jump up onto their backs and they were throwing or flipping him off. She got very upset at this, thinking he would be hurt (which he was). From what she said she seemed to think that it was more that the school was unsafe than that Jamie was making inappropriate decisions to keep himself safe.

March 30

I have started a back and forth book for Jamie. If Jamie gets his work for the day done (at any point in the day that he is focused) he gets a happy face. I also write down for his mom how the day went. After three good days, Jamie gets to pick a prize or gets a popsicle.

April 15

Wow, the back and forth book seems to be working still. I have become accustomed to reinforcement activities to work for only a few days or weeks. But this is still working. I have to be absolutely immediate in giving him a happy face. And I have to take the time every day to write to his mother (I don't think it would work if I did

not do both of these things). Jamie seems a little happier.... I'm so happy!

April 20

Jamie and Derrek got in a fight while waiting for the bus. Derrek is a new student to the school and is just as spontaneous and explosive as Jamie. We are working hard to keep them friends...(including getting them to do extra jobs together and giving them extra time to play together). I cannot figure out why it started (I got the typical - he did, and he said, and I did nothing...)

Jamie was scared that I would suspend them for fighting. I had a talk to them both about fighting. Both seemed friendly to each other by the end and honestly sorry.

I think I know why Jamie is so sensitive to getting in trouble lately.

He mentioned that he was given a spanking for being suspended. He was also given a spanking on the weekend before returning to school

(both days) to remind him that he was to behave in school.

Can you hear me laugh dazed and scared to death?
thank God my thoughts aren't drifting
through the air

'cause you would catch me there bound so
tightly to your knees
the dirt beneath your feet is all I need
to be completely mad...

Can you see my heart? "Demolition love" (Jann Arden Richards, 1994).

April 28

I have noticed that Jamie has a very hard time with thinking things through. It's as if he has no internal self-talk. ...I spent some time with Jamie going through how he feels and how the class feels when he gets his work done. Each day when I sense he's slipping I read this story with him. I also have a happy face system to keep track of how Jamie is doing. I have relaxed on how much I push him to get his work done - focusing more on him being safe and treating others in a kind manner. I wish there were more hours in the day to spend more time with him (he can be such a caring, sensitive child).

More From the School Psychologist's Report for Jamie, Age Six:

Jamie has characteristics that are typical of a child with ADHD/FAS. It is important that this be checked out.

It is recommended that Jamie be referred to the Sunny Hill Outreach Clinic with the possibility of follow up by one of the visiting child psychiatrists from Children's Hospital, Vancouver. Such referrals can be made through the family doctor and through Mental Health.

Jamie is likely to require ongoing support to help him behave and socialize more appropriately.

Near the end of Jamie's Grade 1 year, school district staff arranged an appointment with Dr. A., a visiting child psychiatrist from Children's Hospital who sees people referred by Mental Health. The school district youth worker went to see Jamie's mother the day before the appointment, along with the band education support worker, and mom agreed to go to this doctor. When the youth worker arrived in the morning, the boyfriend told him that no one was going. Armand was phoned, went to the house, mom locked herself in the bathroom and talked through the door. No, people were just not giving them a chance, boyfriend said. The following week the boyfriend was arrested for tearing the house apart, and was ordered to stay away from them. Jamie and his mom quickly disappeared. No one knew or would say where they had moved.

Five years later, Mom and Jamie surfaced here again, with two more little ones now. When Jamie was finally registered at school, in October, we found out they were here. Jamie and the babies were taken from their mother this weekend. The social worker took them to McDonald's to eat, and Jamie cut his hamburger in half, and wolfed down the one piece. He wrapped the other in a napkin.

"Why don't you eat it?"

"I might be hungry later." Not--I'm not really hungry right now--but--What if there is no food later?

He can barely read; we wonder how much school he has attended over the last five years. We ask for the Sunny Hill assessment, now that there is no obstacle of consent.

Jamie's Diagnosis

**Sunny Hill Health Centre for Children
3644 Slocan Street
Vancouver, B.C.
V5M 3E8**

Tel: (604) 453-8300

Regional Developmental Assessment Clinic
_____ Outreach Centre

Psychoeducational Assessment

REASON FOR REFERRAL:

Jamie was referred to the Regional Developmental Assessment Clinic with regard to the possible diagnosis of fetal alcohol syndrome and its effects on learning, behaviour and adaptive functioning.

BACKGROUND INFORMATION

Information for this assessment was obtained from written referral forms, review of available records, clinical observations, and test findings. Jamie has an involved medical and developmental history, which is documented in Dr. _____'s report, so is not repeated here.

Jamie has experienced difficulties in school, both behaviourally and academically. Concerns have been expressed regarding his cognitive/intellectual development, speech and language development and speech articulation. His foster mother describes Jamie as a child who easily follows others and doesn't think about consequences. He has recently been involved with the RCMP in _____. The purpose of this evaluation then is to provide a psychoeducational assessment in order that his foster family, community team and the school team can effectively provide an appropriate educational program suited to his strengths and needs...

Jamie's Verbal IQ score (10th %ile) placed these skills within the low average range. His Performance IQ (39th %ile) was significantly higher, placing skills within the average range. A Full Scale IQ was not calculated, as there was a considerable discrepancy between Jamie's verbal and non-verbal abilities. Results indicate that Jamie is better able to demonstrate skills and abilities if language is removed from the task.

...Peabody Picture Vocabulary Test – III (Form A)...the content is reflective of vocabulary that is required in school learning and reflects the dominant cultural vocabulary in North America. Jamie obtained a standard score of 79, which is within the borderline range, further indicating difficulties with receptive vocabulary development.

Beery Picture Vocabulary Test – On this test of expressive (verbal) vocabulary, the child is asked to say the name for a series of developmentally sequenced pictures. This is a measure of Jamie's expressive vocabulary development. Jamie obtained a standard score of 89, which is more highly developed than his receptive vocabulary.

Child Behaviour Checklist – Achenbach

This checklist measures social competence in areas such as social involvement and relationships with peers. It also identifies problem behaviour along three dimensions: internalizing (social withdrawal), externalizing (aggressive), and mixed (immature). There are eight syndrome scales that can be interpreted. ...Jamie exhibits behaviours that are clinically problematic and will need to be addressed. [Foster mother]

describes Jamie as showing signs of withdrawing behaviours. Jamie is described as being a child who experiences anxiety and depression, somatic complaints, some social problems, thought problems, and attentional problems. He will need on-going support through counselling in these areas. ...It is critical that Jamie receives ongoing intensive support for his social/emotional and behavioural well-being.

Vineland Adaptive Behaviour Scales

This inventory of skills is designed to assess a person's personal and social functional developmental age level. All of the questions concern adaptive behaviour, or a person's performance of the day-to-day activities that are necessary to take care of oneself and get along with others.

...Communication: or what the person understands and says; Daily Living Skills: practical skills needed to take care of oneself; Socialization: how the person gets along with others and uses leisure time; and Motor Skills: physical movements and coordination necessary for daily activities...Jamie demonstrates significant impairment in all levels of his adaptive functioning. His scores are found to be within the 'mild mentally handicapped' range.

Connors' Rating Scales

Problem Behaviours: Conduct Disorder

Learning Problems

Psychosomatic Problems

Impulsive/Hyperactive

Anxiety

Hyperactive-Immature

[Foster mother's] ratings were within the clinical range for all areas. Jamie is beginning to show signs of delinquent and aggressive behaviours.

SUMMARY AND CONCLUSIONS:

1. Jamie is a child who has a diagnosis of Alcohol-Related Neurodevelopmental Disorder. He does display significant weaknesses in factors related to the effects of prenatal exposure. Prenatal exposure to alcohol has significant effects on learning, language, attention, memory, and affective and adaptive functioning.
2. Jamie demonstrated overall verbal abilities within the low average range. However, his expressive language and abilities to problem-solve and make good judgment is severely impaired. He presents with severe language-based learning disabilities. His basic reading, arithmetic and spelling skills are significantly deficit from his potential to learn. He will require a functional skills program, which will ensure basic literacy skills.
3. Jamie showed significant difficulties with sustained focus and concentration to a task. While his many psychosocial and emotional stressors may also explain these behaviours, his ability to attend is severely impaired. He has a further diagnosis of Attention Deficit Hyperactivity Disorder – Inattentive Subtype,

with the probable etiology being related to poor language processing.

4. Jamie is at risk for depression and for conduct disorder. He will continue to benefit from intensive counselling.
5. Jamie demonstrates significant delays in all levels of his adaptive functioning and will continue to benefit from protective settings both within his school and home environment.

RECOMMENDATIONS:

1. It is essential that Jamie continue to have access to a consistent, stable and safe home and community environment to assist him in coping with the many psychosocial stressors he has faced in his young life.
2. To support Jamie's social-emotional development, it would be of benefit for him to participate in small-group sessions or individual work with the counsellor focusing upon problem-solving skills, behaviour management and social skills training. In the future, Jamie may also require psychiatric care. Jamie is showing signs of depression.
3. Jamie's difficulty with language skills and limited reading skills will continue to make academic subjects very difficult for him. He will need additional time to process verbal cues. Areas of strength were identified in the non-verbal area or when

language is removed from a task. Hands-on experiences will be most beneficial to provide opportunities for success for Jamie.

4. Jamie will require alternatives to access new information. He will have difficulty reading to gain new information in school or in the community. Therefore, alternatives such as taped materials, videos, and the CD-ROM should be investigated.
5. Jamie's math programme will require modification. He will need to use a calculator for all math activities (shopping, banking, etc.). He does not have an understanding of many of the concepts. A curriculum that can focus on 'real life' situations or math skills that are necessary for life will be most beneficial.
6. Listed below are sets of strategies/interventions for both home and the classroom that may be used to assist Jamie in his further development of socially appropriate behaviours.
 - a. Predictability
 - b. Structure
 - c. Opportunity for choice
 - d. Shorter work periods
 - e. Learn and work best in small-group situations
 - f. Individualized instruction
 - g. Motivating and interesting learning experiences
 - h. Use of positive reinforcers.

Chapter 3: The Outer Circle

The People's Choice

Behind the shock and anger at the acts of alcohol consumption that irreparably damage a child, the question may lurk as to whether by some stroke of the pen or some civil action this may be prevented. This would amount to forceful action against women who are unwilling or unable to abstain from alcohol for the duration of pregnancy.

Whose rights are most in need of protection, or rather the question is, whose rights must prevail? It is the civil right of the woman to consume a legal substance; it may also be the human right of her child to be born without damage from her drinking. Our laws do not compel the living woman to give up her rights in favour of the rights of the unborn. Her personal life will not be interfered with in the name of the human rights of the not-yet-born. This is the controversial nature of human rights principles, which “confer the authority of argument,” not the “authority of faith” (Ignatieff, 2001, p. 52).

Prevention becomes what concerned people put their faith in, prevention of FAS. It is an entirely preventable birth defect. A non-controversial method to reach eradication is to educate all people about FAS, to support women and families for whom alcohol is part of their lifestyle, and to induce the possibility of choice for these women.

The notion that personal choice influences the events of life is a middle class belief. To not drink means believing that drinking alcohol does indeed shackle an unborn child, as if indeed one even believes that the future and impact on others can be in the hands of the individual person. Among the hidden rules of generational poverty are the driving forces for decision-making: survival, relationships and entertainment (Payne, 2001, p. 42). So, not drinking may also mean putting your not-yet-born child above your

man, who expects you to drink with him. It also means denying yourself the only freedom you have: to be drunk.

It is a notion of the middle class that “if the poor had a choice, they would live differently” (Payne, 2001, p. 148). There are arguably freedoms that come with poverty, “of verbal expression, an appreciation of individual personality, a heightened and intense emotional experience, and a sensual, kinesthetic approach to life...” (Payne, 2001, p. 148) as well as freedom of time, and many would not choose to lose these. A belief in fate and destiny, as opposed to choice and individual action, also militate against fighting the lifestyle. As she also points out, alcoholism and drug addiction “in effect make the choices for the individual.” Addiction cuts across class and culture.

Bruce Alexander argues that “dislocation is the necessary precursor of addiction...[and shows] that free markets inevitably produce widespread dislocation among the poor and the rich. As free market globalization speeds up, so does the spread of dislocation and addiction” (Alexander, 2001, p. 1). Free markets require that individuals become unencumbered by family, community or religious obligations or values.

The exchange of labour, land, currency, and consumer goods must not be encumbered by clan loyalties, village responsibilities, guild rights, charity, family obligations, social roles, or religious values. Since cultural traditions ‘distort’ the free play of the laws of supply and demand, they must be suppressed to establish a free market society [and this] requires coercion on a massive scale. (Alexander, 2001, p. 9)

It is the “rhetoric of the neo-liberal propagandists who continue to talk about the ‘free market’, free enterprise, open markets, and the exalted role of entrepreneurs,” (Dobbin, 2001, p. 36) but free markets ended with industrialisation. The “invisible hand” of the market is fantasy, and it has been replaced with corporate administration. “The world is dominated by country-size corporations whose ‘central planning’ capacity eclipses that of any country,” (Dobbin, 2001, p. 36) and whether or not an economy is planned is not even a question, but rather the question is in whose interests will control be exercised--shareholders or citizens? “Every economic sector is ‘multi-functional’-- culture, energy, finance, health, education, municipal services, transportation, etc.-- because all of them have impacts that go far beyond the simple economic” (Dobbin, 2001, p. 37). Dobbin concludes that when the interests of transnational corporations are exclusively considered by trade “treaties” (such as NAFTA, the North American Free Trade Agreement), then cultural, social, democratic, and community cohesion is destroyed.

Polanyi says that establishing a free market society “must disjoint man’s relationships and threaten his natural habitat with annihilation” (as cited in Alexander, 2001, p. 9). To be cut off from the place of your people, and to be cut off from the people of your family or group, produces not only geographical dislocation, but also psychosocial dislocation. It is best understood as a compulsive lifestyle that people adopt as a substitute when they are dislocated from ties between people and groups. Some people avoid addiction, by achieving enough psychosocial integration. Others enter non-addiction lifestyles, for example, becoming “eccentric, physically ill, depressed, hypochondriacal, violent, or suicidal instead” (Alexander, 2001, p. 13). Addiction may be

the compulsion for money, power, work, food, or material goods, as well as for drugs and alcohol. Addictions programs are inadequate at best, when fundamental political and economic changes are needed in society to address the problem. It is not so much an individual tragedy as a problem of underlying social and political dynamics. "...[T]he responsibility for these changes [in the family and the unfortunate social consequences] must be borne by the spread of market thinking into the domain of our intimate social relations" (Schwartz, 1999, p. 42).

Alexander uses the example of Vancouver, "Terminal City," Canada's most drug addicted city; British Columbia is Canada's most drug addicted province, as evidenced by per capita consumption of alcohol, death rate attributed to alcohol, prevalence of alcoholism, death rate due to drug overdose, prevalence of HIV and Hepatitis C infection among injection drug users, availability of illicit drugs, arrest rates for drug crimes, etc. This drug problem is only part of a larger addiction problem. When people experience psychosocial dislocation, they are vulnerable to addiction. Drugs, including alcohol, are not the only dependencies, but they are effective agents of enslavement.

For any people, aboriginal or not, the right to be the member of a nation, to be respected as such, is a vital condition for personal respect, honour, and dignity. When such group rights to nationhood are stripped from a people, the individuals within the group often disintegrate. The lesson that follows is true for aboriginals and non-aboriginals alike: you can't act effectively in the world and take responsibility for yourself unless you respect yourself. And you can't do that unless your identity as member of a people is honoured by the political system in which you live. (Ignatieff, 2001, p. 60-61)

The dislocation of our economic and political world makes such an honouring of identity impossible. “It was only during assimilation that alcoholism emerged as a pervasive, crippling problem for native people, along with suicide, domestic violence, sexual abuse” (Alexander, 2001, p. 15). Although assimilation nearly eliminated native languages and spiritual practices, it also failed to integrate native people into free market society.

Along with recognition of FAS people as a group within society, and society’s recognition of the individuals who belong to this group, it is first required that this group of people...recognize themselves first, to overcome their own shame or lack of self-worth and then project an image of themselves as they wish to be seen by the watching world. Once this process occurs, the struggle turns into a demand that the watching world change its view of the group, engage with its own stereotyped views and reach out to its members both as equals and as people whose differences from the mainstream are to be acknowledged and welcomed. (Ignatieff, 2001, p. 87)

Ignatieff was writing about people whose ethnicity or culture is the reason for their existence as a group, not about people whose common birth defects leave them with common challenges. Yet there is no difference to the argument for recognition, and for the rights that are sought. The idea of approval is implied by the demand for recognition of minority groups, for example gay groups; however, the FAS group is also part of the group of disabled citizens who require support from the rest of society. They demand acceptance, even approval, not shame or disdain. Individuals do not seek and are not responsible for their disabilities.

This is not to suggest that the entirely preventable disability of FAS is to be welcomed, any more than are accidents that result in spinal cord injuries. We continue to officially militate against drunk driving, for the wearing of seatbelts, for speed limits on the roads, for safety features on vehicles--all in a concerted effort to prevent spinal cord and other injuries resulting from vehicular accidents. We might militate against drinking while pregnant. Physicians could make this warning part of the universal, standard prenatal checklist. Groups might arise with names like Mothers Against Drunk Pregnancy, or Mothers Against FAS. Reminders and admonishments would appear at every turn, in every store or establishment where liquor is purchased, in every high school and college.

Young women have been encouraged to see themselves as equal to men, to put aside the role of child-bearing, self-sacrificing victims, and to seek individual autonomy. This has resulted in social changes, including rising divorce rates, the erosion of the family as an institution that depended on female self-sacrifice, and rising abortion rates (Ignatieff, 2001, p. 90). No one tells a young woman to get out of a bar today because she is a woman, or that she must be escorted to drink, or how much, or when. Women's equality demands the right to be as hard-drinking as any man. If a woman decides to continue an unexpected pregnancy, she very likely also decides to keep the child, regardless of her age, marital status, or employment. All this means that more children are being raised in single parent families, and in poverty. When non-birth parents adopt an FAS child, there is a greater willingness by them to investigate and seek diagnosis for problem behaviours than by birth parents. When a child is born with fetal alcohol

damage, whether or not the damage is acknowledged and visible, whether or not s/he has advantages of family and security, the effects compound the difficulties of life.

According to Ignatieff, “abundant societies that could actually solve the problem of poverty seem to care less about doing so than societies of scarcity that can’t” (Ignatieff, 2001, p. 92). Inequalities of race, gender and sexual orientation have become more visible with the burgeoning affluence and “rights revolution” of the last fifty years, while inequalities of class and income cease to arouse most people’s indignation. We are blinded to poverty; we assume the poor have disappeared. A flimsy welfare net has not erased poverty; the Value Village stores that cheaply sell donated clothing, the Food Banks that supplement thin welfare cheques that don’t last the month--these help to make poverty less visible on the streets and in the classrooms, less of a problem of appearance. It’s often not easy to know who is poor just by looking.

Our society has a class of poverty that runs deep, with numbers increasing yearly. In Canada, 13 % to 17% (depending on the index used) of people live below the poverty line. As Scott McKeen (2001) reported in the *Edmonton Journal*, Alberta’s child poverty rate was 17.3 per cent in 1998; the poverty rate for single-parent families headed by women is 52.9 per cent, compared with a rate of 10.7 per cent for two-parent families. Although in 1989 the parliament of Canada voted in support of working towards the elimination of child poverty by the year 2000, the number of poor children in Canada increased by more than 50 per cent, according to the United Church of Canada. During the 1980s and 1990s, successive Canadian federal governments asserted the primacy of the market and limited the scope of the state’s poverty intervention. Policies have focused on “deficit and debt control, spending restraint, less government, and a restructuring of

the Canadian welfare state” (Ternowetsky, 2001, p. 90). Most important was the Canada Health and Social Transfer (CHST) of 1996, which came along with lower federal transfers for education, health and welfare to the provinces. Not only is there now less money transferred, but also there is no stipulation as to how this money is spent. National standards for welfare programs are virtually eliminated, especially the principle of entitlement of benefits. Provincial welfare programs are “diverse...punitive, restrictive and minimalist” (Ternowetsky, 2001, p. 92). Welfare families are increasingly treated as undeserving when employed families receive the National Child Benefit, or in B.C., the Family Bonus (part of B.C. Benefits) of \$103 per child only when a parent is in the paid workforce. Neither of these is available to families whose parents are not employed.

Poverty and injustice are frequently borne by people who do not become addicted; it is poverty of the spirit (called *dislocation*) that is the precursor of addiction. Payne’s (2001) understanding of poverty centres on the lack of resources: economic, emotional, support system, spiritual, physical, mental, and knowledge of the hidden rules that make the system work. The most important resource, according to Anne C. Lewis (1994), is the understanding that there are options, and the only intervention that helps is education.

It might be convenient for some people to assume there is a genetic predisposition when viewing generational poverty and generational FAS. This idea of predisposition comes dangerously close to notions of racial inferiority, or inferiority of genetic inheritance in certain social groups, especially when these groups are seen to be in crisis.

It is a no-brainer that sociobiological research will...discover that the poorest of the poor have increased rates of alcohol and drug abuse, dysfunctional families and poor social networks, low IQ, and a high rate of ‘maternal neglect’ and that

they mostly belong to minority populations... Given the current establishment of a genetic discourse on crime and 'deviance,' these findings will be interpreted as the result and not the cause of the misery. (Rothenberg & Heinz, 1998, p. 60)

This eugenics perspective feeds the notion that people are fated to their disability and thus their suffering. In the case of FAS, nothing could be farther from the truth, since it is completely preventable. Rather than recognize the overwhelming results of being brought up in poverty and cultural oppression, those who adopt the predisposition view (of alcoholism) give themselves permission to make no effective changes in social policy. The old saying, "the poor are always with us," reflects the idea that nothing can be done.

"The welfare state is not enough" (Ignatieff, 2001, p. 96). It has a limited capacity to protect children from abuse; there are laws that allow children to be taken into care, that protect their rights. When a government demands (such as the current one in B.C. did in September of 2001) that 40% fewer children are to be in care, this shows increasing unwillingness to protect children's rights. This could be a backlash against protecting individual rights of children, or perhaps conservative limiting of the state's hand in making assertive social policy. It also could be a simplistic slashing of state expenditure, made in an accounting frenzy. If the state is not willing to protect children from abuse, including prenatal abuse, it must then be up to the rest of us to have the courage to intervene when abuse is seen. The right of the individual to drink seems to be inconsistent with the right of the child to not be poisoned. The responsibility for protecting the child's rights can also be vested in the parent, and not only in the state. The answer to the dilemma may have to lie in the community's action and response.

Communities in Crisis

Fetal alcohol syndrome and alcohol related birth defects are especially devastating for First Nations people. Zaleski's 1983 study of 173 Saskatchewan children diagnosed with FAS/E revealed that 84 percent of the FAS and 79 percent of the FAE children were of First Nations or Métis origin (Hart, 2001, p. 73). In the Yukon, the rate is 46 out of 1,000 First Nations people who are affected (Asante & Nelms-Matzke, 1985, cited in Hart, 2001, p. 73).

First Nations communities are especially vulnerable to the effects of dislocation. This dislocation is nearly complete for some, and for others, there is still personal understanding of what is being left behind. Hugh Brody (2000) reports the words of a traditional hunter-gatherer of the Innu community of Sheshashiu:

There was never any government out here, on our land. We never saw them. Now the government gives people money. Welfare allowances. The government want to own us. They behave as if we have no rights. But we have been hunters here since time immemorial. In the country everyone works together, but in the settlement people fight each other. (p. 238)

The details of culture-death are long and complex. They include religious and spiritual usurpation by Christianity, new diseases, economic replacement of traditional hunting by settlements and welfare, seizure of hunting lands for agricultural settlement, and language eradication.

Some of the women of Sheshashiu were still going out on the land, "into the country," and were teaching their families how to live there. As one of these women explained,

these houses were built to trap us...it was a trick to get our children to go to school and to make sure we stayed in one place. It was a lie, so we wouldn't see our land being destroyed...on the land we are ourselves. In the settlement we are lost. That was the way they made our minds weak. (p. 277)

An elder from this community explained about what had happened to his people:

they spread death everywhere...they make laws against everything, especially hunting. They harass us even when we have done nothing. We have to have some pleasure, so we drink. It's the one thing we're allowed to do. Our way of life seems to be illegal...so we drink...the only right we have is to be drunk. (p. 235)

Brody (2000) tells us that all hunter-gatherer societies, and many other tribal cultures, are shamanistic. A *shaman* is a person who has the power to cross from the human to the spirit world in a disembodied form, and back; this is transformation. The spiritual belief system of shamanism is not dichotomised; it refuses absolutes and is equivocal, as a way of keeping close to the truth (p. 246). Morality is ambiguous, because each place, each reality, requires different knowledge, different stories. When one's own place is changed, it is dangerous because knowledge (of the influencing spirits) of the new place is not understood. Presently, in Canada, many First Nations communities embrace Christianity, because it is needed for "going to heaven," as well as their traditional stories and practices, because they are needed for "staying alive." Being drunk is a little bit like *trancing*, a way of going out of body and mind, in the manner of a shaman. It is a release from self, more welcome in the shamanistic cultural tradition than the European one, where one should repress the outward signs of intoxication--staggering and slurring--which are shameful.

“Alcoholism in many reserves is nearly 100%, including people in stages of recovery.” (Alexander, 2001, p. 15) but it was only after assimilation that alcoholism became a ruinous problem for Canadian native people. It is not a racial problem. The dislocation of the Hudson’s Bay men produced widespread alcoholism, and often transformed the sober young men from the Orkney Islands who voluntarily exiled themselves to what is now Canada. “One is exiled from and never to, and that disinheritance and marginality are all too often the price of freedom” (Newman as cited in Alexander, 2001, p. 16).

One well-known example of a group that was subjected to forced dislocation and poverty is the Highlanders of Northwestern Scotland in the mid-18th century, when Britain systematically began to destroy highland traditional life and customs. Evictions (“clearances”), and emigration to Canada and other colonies became the lot of many. “The children of those who are removed from the hills will lose all recollection of the habits and customs of their fathers” (James Loch, as cited in Alexander, 2001, p. 11).

The modern middle class is not exempt from dislocation either. Spreading social problems are indicators of this, and include divorce, single parenthood, economic disparity, excessive television babysitting; children do not receive time and support from their parents. Corporate television networks are nurturing children. It is easy to blame social problems on drugs and alcohol, but increasing geographical and cultural dislocation is the logical precursor to many of these social changes.

Even if rights are not enshrined in judicial practice, then responsibilities might, in theory, be invoked. “If pregnant mothers so abuse themselves with drugs and alcohol that they damage their children, they should feel the penalties of the law” according to

Ignatieff (p. 101). At this time, the only consequence is that welfare agencies step in to cope with the situation, rather than somehow link the right with the responsibility. It is not clear how such penalties would work. Some might speculate that mothers who bear children damaged by drugs or alcohol should be jailed or fined, or that the children be taken away from them to be raised by others. At this time, no such penalties are used. All women are legally free to produce children with fetal alcohol damage. "Freedom is a chilly virtue: it is not justice, equality, or a quiet life; it is merely freedom" (Isaiah Berlin as quoted in Ignatieff, 2001, p. 112).

Penalties may be unpalatable, and also provoke an unsolvable legal conundrum. Legal action alone cannot answer the problem of FAS. If the psychological effects of dislocation can be healed, if identity is to be honoured, then it is the communities of people who must turn towards, not away from, the unfortunate who live among them, and act for justice and equality.

Community Response

There are FAS prevention groups springing up in communities. One of these is in Prince George, B.C. As social worker Chris Leischner (2001) writes,

FAS is a difficult community issue to address. Some communities are not ready to acknowledge FAS as a problem. Other communities prefer to blame the women, judging them as immoral and allowing them to be shamed and degraded. Because of this, birth mothers find it impossible to reach out for help or to stand up and be heard and acknowledged. Foster and adoptive parents are busy convincing service providers that these children need differential treatment. (Leischner, 2001, p. 1).

If communities view *health* as more than individual physical well being, to include the collective well being, and what people can do for and with each other, then they can begin the process of valuing and choosing healthier options.

I got a message at work that there was an FAS group that just formed in town, and did I want to go to a meeting? There was quite a mix of people there: the elementary school counsellor, the Community Health Service addictions counsellor, the Mental Health clinician, a few foster parents of FAS kids, someone from the Women's Centre, from Baby's Best Chance, two FAS adults, an FAS birth mother who also was a band councillor... This group had a grant of \$3900 to put on a conference, and at that first meeting we committed ourselves to do this.

After a lot of discussion, we decided that the goal of this first sally was to be awareness of the problem of FAS. We gathered together those who work with FAS people, or have any special interest in them, including being FAS, or a parent of an FAS person. We invited every teacher, administrator, and support staff in the school district, and over fifty of these came. That's not bad, considering each one begged and scrounged money for a sub. All together there were around a hundred people present. We had two main speakers, including a birth mother from our group, who wrote out and told her own story, most eloquently, most wonderfully, (almost like AA meetings, where there is similar confession and exposure of the self), and no eye was dry. We had invited and miraculously were accepted by a busy pediatrician who gave up a day of her practice to deliver her slides and her message: this is what the problem looks like, it's a war that we are fighting, we have to face it, only by working together will we conquer it. We also had a panel of "service providers"--social workers, teachers, and health workers--and

somehow another FAS adult appeared on that too. More tears. Oh, there were some men there, but this entire event was women cherishing each other, acknowledging each other and sharing the same obstacles. The feeling in the room was full of grief, and pain.

Sharing it starts a little bit of hope.

We see each other around town since that conference, the people who were there. We didn't know each other, still don't in the usual social sense. We talk to each other calmly, intimately, like people who share a secret at last. The secret is that we all care.

Society in Crisis, Political Responsibility

Ignatieff (2001) cautions that if society is to protect the family (in whatever form it takes) then that protection must occur as child-protection, universal health care, childcare, and excellent primary and secondary education. Otherwise to espouse family values is just cheap talk, and possibly a way for deficit-reducing conservatives to increase the gap between rich and poor.

The British Columbia Children's Commission, which looks into the death of every child that occurs in the province, chose the factor of alcohol to use in a study of children's deaths. John Greschner and Wayne Mitic of the Children's Commission presented the results of this study by Paul Pallan (2001), and the twenty-four recommendations that it produced, on February 23, 2001 in Vancouver at the *FAS and Other Related Effects: Building Hope* conference. One of these recommendations was that systemic training be given to staff and caregivers on the early recognition and service implication of FAS, and on the ongoing need for training and outreach to foster parents. It also recommended that treatment programs, addictions services, counselling services for youth and women, more timely services for youth involved with the justice system,

and post-discharge services and supports for FAS infants and their mothers be put in place. It called for research into the needs and service implications for children with FAS, and for the Ministry for Children and Family Development to develop a coordinated approach to prevention and early intervention regarding alcohol abuse. A number of research projects were funded, and the Ministry for Children and Family Development was working on a provincial strategy to address the needs of those impacted by FAS. Inter-ministerial and community-based measures were undertaken to improve coordination in alcohol abuse prevention and early intervention.

In November of 2001 a press announcement was made that the Children's Commission was facing cancellation by the provincial government. Paul Pallan, Children's Commissioner, spoke out again this cancellation publicly, reminding British Columbians what the Commission does.

In November of 2001 the British Columbia's Ministry for Children and Family Development publicly announced foster care cuts for children who are age seventeen and over (Davies, 2001). These children may be placed on an "independent living" program, which means they will all live in group homes or apartments, but not with their foster families. To keep a child in foster care costs around \$40,000 per year. Laverne MacFadden, Child, Youth and Family Advocate, joined ranks with Paul Pallan in speaking out against government reductions to services; the Ministry of Children and Families is slated to be cut in total by 30%. She went further and reminded the public that many children are not ready for this step at age seventeen, and do not have the life skills (Teens worry..., 2001). The expectation that all children age seventeen are capable of independent living is unrealistic. Most children in care have been abandoned by or taken

from their families at a much earlier age because of abuse or neglect, sometimes to the point of endangerment. They have endured dislocation and their early experiences have not equipped them to be self-reliant or independent.

Children ages seventeen, eighteen or nineteen with FAS are especially vulnerable; they cannot find or keep a part-time job without continuing support for ordinary things such as getting to work each day and being on time. They require direct instruction and modelling about appropriate workplace language and social skills, and much repetition and teaching of skills for managing household chores of shopping, cooking, cleaning. Carefully managed routines are essential to the coping and management of the basics of life. Managing money is a continual challenge.

Duimstra, Johnson, Kutsch, Wang, Zenter, Kellerman and Welty (1993) conclude that

intervention will be most effective if implemented early and provided a continuum from all aspects of society...includ[ing] the school system, family planning services, prenatal clinics, church, community, and establishments where alcohol is served. Community ownership of the problem is essential to the success of FAS prevention and surveillance.

I spoke with Jamie's grandmother one late spring morning on school awards day, and told her that I wanted to understand how we in the school could help Jamie, and other children like him, children who had a lot of problems behaving and learning in school. I wasn't ready to use the term FAS with her. She really didn't want to talk; she wanted to go sit with the other parents and not miss the awards. She looked closely at me for a long moment, then, "The problem is not the school. You should look at the family."

I wasn't expecting this, "Look at the family?" She repeated, slowing it down for me, "The problem is the family." Then she left me, to watch and celebrate the other children who received awards that day. Her grandson did not receive one.

Since that day, Jamie continues to live with his foster family, which also includes his two little siblings. "We make our own pizza," he proudly told me last week. He is learning to swim, and although he still finds it very stressful to play with other children, he has moments of fun with them. He smiles shyly when he sees me.

His mother has dropped out of sight, for now. She isn't doing anything to get the children back, yet.

In the schools here, teachers are beginning to consider whether a child's difficulties might be alcohol-related. It is no longer a notion that has to be thrust upon them. One teacher told me, "I find this little boy's behaviour is better this year, now that I know why he acts this way."

The FAS community mobilization group is planning a second conference, this time to create discussion around the importance of diagnosis. FAS is a disability, and the medical, legal and social lines need to be firmly drawn. These are children and people first, but to deny the facts about their damage is to magnify the unfairness. We have asked yet another pediatrician to attend and address our topic. We also invited a federal cabinet minister to speak, to find something to say about this. She declined, with regrets.

Chapter 4: Visions for Change

“If you could change anything at all about this school that would make it better for you, what would it be?” This is the question that a skilled counsellor often poses when a student is being asked to enter and participate in a process of change.

Here is another way to ask it: “If you could change anything at all about this world that would make addiction, poverty, and FAS disappear, what would it be?”

The social and political activist’s wish list might be to reduce poverty, and economic and social marginalization (Ternowetsky, 2001, p. 88). Alexander (2001, p. 22) would prevent transnational corporations from inducing local governments to rescind local labour, health, safety, and environmental protection, support for local schools and hospitals to prevent people being sent to far off centres when they are ill. His positive wishes would be for policing of petty crime, increasing numbers of social workers to investigate cases of child abuse and to assist some families to restore peace and to apprehend where needed, and restoration of social spending: housing, jobs in home communities, universal health care in home communities, and rebuilding welfare and UI. Finally, and back to the beginning where market capitalism went off the wagon, governments would exercise controls over markets and corporations (Schwartz, 1999, p. 34-35). “The most effective way of dealing with FAS/E is to prevent its occurrence. We know from the etiology of FAS/E that its roots lie to a large extent in poverty and the economic and social marginalization that poverty produces” (Ternowetsky, 2001, p. 88).

Teachers might dream of smaller classes, more understanding of FAS behaviour and FAS learning characteristics, more support in class, more help to work on life skills both in and outside of the school. Many of them want to know whether a child has FAS,

so they can know what to expect, how to manage. They would wish for substance abuse programs, sexual abuse and birth control counselling and support for adolescents. They would like the police and justice system to understand FAS and how to deal with FAS children who get into trouble. They would wish for more patience.

Jamie, and his mother, might have difficulty answering such a question. They don't see themselves as changing the world. But let us imagine that they tell about their reality and what would make it better.

Jamie's mother's list could include having someone reliable to look after her children when she goes out of the house, to have enough money to buy food whenever it runs out, to pay the rent when it's due, to have people leave her alone, and treat her well, let her be in peace, just because she is a person, not because of the man whose presence in her life confers temporary protection and status, no matter how he treats her. And to know that she can hope for better.

Jamie's list might be that he could read and write and be able to do what he needs to in class, and to have friends at school. To not be backed into a corner by teachers, to be given some space and time to fix things. To have things explained, and for people to stop assuming he knows and remembers everything. To slow things down and to have time to finish something before something new jumps out at him. To have somebody see what he is good at, what is loveable about him, not just what is not. To be able to live with his mom, and for her to be happy and keep their house nice so that when the social workers come to their place, nothing happens--no, that the social workers never come to their house. And not to have to hide what is in his heart.

When I imagine change, I dream of the day when prevention, diagnosis,

intervention, recognition, acceptance, and support for the individual with FAS become reality. In my dream, prevention of FAS will be an important policy concern for governments, and ministries will allocate funding to promote prevention of FAS and support for FAS people. Important policies always receive significant funding. Ministries of Health will assault public awareness with media campaigns to equal and surpass those used against drinking and driving. Ministries of Education will include FAS prevention knowledge in formal curriculum--in B.C. this can be part of Career and Personal Planning, and in other provinces this material can be inserted in whatever equivalent courses that exist. Teachers and other professionals will learn what to expect, and how best to care for and teach FAS children. When a new category of disability is created that provides extra support for FAS in schools, then not only will these children receive the educational support they need, but it will be an incentive for seeking diagnosis; shame and denial will lose out to getting and giving immediate help and intervention for the child. Physicians will routinely include verbal information in prenatal visits that directly proscribes alcohol for the duration of pregnancy and lactation, regardless of their personal assessment of the patient. Pediatricians and psychiatrists will overcome their hesitations, and proceed with responsible diagnosis. Ministries of Justice across the country will recognize that FAS offenders do not belong in Canadian jails, but rather in rehabilitation facilities and programs. The reason could easily be "decreased responsibility," or just as easily, that jails simply are not at all effective at reforming FAS offenders and preventing reoffense.

Legal rights issues will be resolved. A woman now has the right to an abortion of a non-viable unwanted fetus; moreover, the fetus has no rights until it is born. When we

are winning the war against FAS, our laws will recognize the fetus' right not to be abused by drugs and alcohol. After a woman knows she is pregnant, and she has also made the decision not to abort, then her fetus' right will prevail. The present legal impasse, between the rights of the living mother and those of the unborn, will be cleared away, and it will be the mother's responsibility to protect the health of the unborn child that she has decided to bear. The mother's community will have the responsibility to promote her well-being and to protect her, not only during her pregnancy, but also before and after. People will band together to speak and act on behalf of their FAS families and children.

This child will have the right to grow up in a family that protects and supports, and does not deliver abuse, either physically, sexually, emotionally, or mentally. School experiences will give this child confidence, skills, and a belief in his or her worth. Teachers will recognize the difference between won't and can't, and treat this child with respect, and patience born of understanding.

The social safety net of welfare and unemployment benefits will become standardized again, and the federal government will neither off-load this responsibility on to the provinces nor abdicate the job of ensuring money is spent on reducing poverty. People will not be made ineligible for benefits because of a work test, nor will they be further penalized by denial of extra child benefits.

Imagination carries us only so far; our own sensations are invariably more real to us than the experience of others. We live at the centre of concentric circles of decreasing impingement: first ourselves, then those we love, and only much later, and much more imperfectly, our fellow creatures. But the imperfect moral impingement that others make upon us is as much a fact about us as our selfishness. It is on these facts – and our capacity to imagine them – that we build such community as we can. (Ignatieff, p. 139)

If we imagine the facts of Jamie's all-too-real existence, however imperfectly, then we bring his circle a little closer in, nearly to the circle of those we love, or even, by imagination, in even closer, to share his experience. Our human community, our being together in the world, takes its nature from this mix of selfishness and moral impingement. By our capacity to shift the balance of the mix we change its character, and by imagining we start to change.

References

- Aase, J. M. (1994). Clinical recognition of FAS: Difficulties of detection and diagnosis. *Alcohol Health & Research World, 18*, 5-10.
- Aase, J. M., Jones, K. L., & Clarren, S. K. (1995). Do we need the term "FAE"? *Pediatrics, 95*, 428-431.
- Alexander, B. (2001). *The roots of addiction in free market society*. Vancouver: Canadian Centre for Policy Alternatives.
- B.C. School District #59 Confidential records and communications, by permission.
- Brody, H. (2000). *The other side of Eden: Hunters, farmers and the shaping of the world*. Vancouver: Douglas & McIntyre.
- Christensen, D. (2001, February). Sobering work (fetal alcohol syndrome research). *About FASE, Feb. 2001, 3*, 11-14.
- Coghill, K. (2001, March 27). FAS. *This morning*. Toronto: CBC-Radio.
- Cook, P., Kellie, R., Jones, K. & Goossen, L. (2000). *Tough kids and substance abuse: A drug awareness program for children and adolescents with ARND, FAS, FAE and cognitive disabilities*. Winnipeg: Addictions Foundation of Manitoba.
- Davies, J. (2001, November 28). Child welfare changes coming. *British Columbia Online News*. Retrieved December 28, 2001, from the World Wide Web: http://vancouver.cbc.ca/template/servlet/View?zone=Vancouver&filename=bc_welfare011129
- Dictionary.com (2001). Lexico LLC. Retrieved December 4, 2001, from the World Wide Web: <http://www.dictionary.com>

Dobbin, M. (2001). The corporation: The dominant institution of our time. In D. Qualman (Ed.), *The farm crisis and corporate power* (p. 30-37). Vancouver: Canadian Centre for Policy Alternatives.

Duimstra, C., Johnson, D., Kutsch, C., Wang, B., Zenter, M., Kellerman S., & Welty, T. (1993). A fetal alcohol syndrome surveillance pilot project in American Indian communities in the Northern Plains. *Public Health Reports*, 108, 225-229.

Gillogley, K. M., Evans, A. T., Hansen, R. L., Samuels, S. J., & Batra, K.K. (1990). The perinatal impact of cocaine, amphetamine, and opiate use detected by universal intrapartum screening. *American Journal of Obstetrics and Gynecology*, 163, 1535-1542.

Graefe, S. (1999). *Parenting children affected by fetal alcohol syndrome: A guide for daily living*. Vancouver: Society of Special Needs Adoptive Parents (SNAP) in cooperation with the B.C. Ministry for Children and Families Child Protection Division.

Greschner, J., & Mitic, W. (2001, February). Findings and recommendations of the Children's Commission study into alcohol-related deaths of children in British Columbia. In *FAS and Other Related Effects: Building Hope*. Conference, Vancouver, B.C.

Hart, M. A. (2001). Support for First Nations to address fetal alcohol syndrome and effects. In J. Turpin & G. Schmidt (Eds.), *Fetal alcohol syndrome/effect: Developing a community response* (pp. 73-79). Halifax: Fernwood.

Hay, M. (2001). A practical roadmap for the imperfect but practical-minded clinician. In J. Turpin & G. Schmidt (Eds.), *Fetal alcohol syndrome/effect: Developing a community response* (pp. 26-43). Halifax: Fernwood.

Ignatieff, M. (2001). *The rights revolution*. Toronto: Anansi.

Lerner, J. (1993). *Learning disabilities*. Boston: Houghton Mifflin.

Leischner, C., & Thio-Watts, M. (2001). *Community building & FAS action*. Prince George: Prince George FAS Network.

Lewis, A. C. (1994, Nov.). Washington commentary: Education is the only way out of poverty. *Phi Delta Kappan*, 180-181.

McKeen, S. (2001, December 2). Children left behind. *Edmonton Journal*, pp. D4, D8, D9.

Mitchell, P. (2001). Address poverty, reasons for addiction, health experts say. *Horizons*, 15, 12.

National Council of Welfare (1998-99). *A new poverty line: yes, no or maybe?* Ottawa: Minister of Public Works and Government Services Canada.

Pallan, P. (2001). *Fetal alcohol syndrome: A call for action in B.C.* Victoria: B.C. Children's Commission.

Payne, R. K. (2001). *A framework for understanding poverty*. Highland, TX: **aha** Process.

Raffi (1980). All I really need. On *Baby Beluga* [album]. Willowdale, Ont.: Troubadour.

A Review of Special Education in BC. B.C. Ministry of Education. Retrieved July 16, 2001, from the World Wide Web:

<http://www.bced.gov.bc.ca/specialed/review/report/>

Richards, J. A. (1994). Could I be your girl. On *Living under June* [compact disk]. Canada: Polygram.

Richards, J. A. (1994). Demolition love. On *Living under June* [compact disk]. Canada: Polygram.

Richards, J. A. (1994). Gasoline. On *Living under June* [compact disk]. Canada: Polygram.

Richards, J. A. (1994). Living under June. On *Living under June* [compact disk]. Canada: Polygram.

Richards, J. A. (1994). Unloved. On *Living under June* [compact disk]. Canada: Polygram.

Richards, J. A. (1997). Hangin' by a thread. On *Happy?* [compact disk]. Canada: Polygram.

Richards, J. A. (1997). I know you. On *Happy?* [compact disk]. Canada: Polygram.

Richards, J. A. (1997). The sound of. On *Happy?* [compact disk]. Canada: Polygram.

Rothenberg, J., & Heinz, A. (1998). Meddling with monkey metaphors-- capitalism and the threat of impulsive desires: Defending rights & just futures in the real world order. *Social Justice*, 25, 44-65.

Schwartz, B. (1999). Capitalism, the market, the "underclass", and the future.

Society, 37, 33-43.

Speece, D. L., & Harry, B. (1997). Classification for children. In J. Lloyd, E. Kameenui, & D. Chard (Eds.), *Issues in educating students with disabilities* (pp. 63-66). Mahwah, N.J.: Erlbaum.

Stromland, K., & Hellstrom, A. (1996). Fetal alcohol syndrome--an ophthalmological and socioeducational prospective study. *Pediatrics*, 97, 845-851.

Teens worry about foster care changes. (2001, December 3). *British Columbia Online News*. Retrieved December 28, 2001, from the World Wide Web:
http://vancouver.cbc.ca/template/servlet/View?zone=Vancouver&filename=bc_teens011
 203

Tehrani, M. (1998). Pancapitalism and migration in historical perspective. *International Political Science Review*, 19, 289-304.

Ternowetsky, G. (2001). Poverty, policies of disempowerment, and FAS/E. In J. Turpin and G. Schmidt (Eds.), *Fetal alcohol syndrome/effect: Developing a community response* (pp. 88-93). Halifax: Fernwood.

Turpin, J., & Schmidt, G. (2001). Introduction. In J. Turpin & G. Schmidt (Eds.), *Fetal alcohol syndrome/effect: Developing a community response* (pp. 10-13). Halifax: Fernwood.

Warner, K. (2001). Parenting children with fetal alcohol syndrome. In J. Turpin & G. Schmidt (Eds.), *Fetal alcohol syndrome/effect: Developing a community response* (pp. 14-25). Halifax: Fernwood.

Appendix

Diagnostic Criteria for Fetal Alcohol Syndrome (FAS) and Alcohol-Related Effects, as recommended by the Institute of Medicine (IOM), 1996

Fetal Alcohol Syndrome**1. FAS with confirmed maternal alcohol exposure ^a**

- A. Confirmed maternal alcohol exposure
- B. Evidence of a characteristic pattern of facial anomalies that includes features such as short palpebral fissures and abnormalities in the premaxillary zone (e.g., flat upper lip, flattened philtrum, and flat midface)
- C. Evidence of growth retardation, as in at least one of the following:
 - low birth weight for gestational age
 - decelerating weight over time not due to nutrition
 - disproportional low weight to height
 -
- D. Evidence of CNS neurodevelopmental abnormalities, as in at least one of the following:
 - decreased cranial size at birth
 - structural brain abnormalities (e.g., microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)
 - neurological hard or soft signs (as age appropriate), such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor eye-hand coordination

2. FAS without confirmed maternal alcohol exposure

B, C, and D as above

3. Partial FAS with confirmed maternal alcohol exposure

- A. Confirmed maternal alcohol exposure
- B. Evidence of some components of the pattern of characteristic facial anomalies

Either C or D or E

- C. Evidence of growth retardation, as in at least one of the following:
- Low birth weight for gestational age
 - Decelerating weight over time not due to nutrition
 - Disproportional low weight to height
- D. Evidence of CNS neurodevelopmental abnormalities, as in:
- decreased cranial size at birth
 - structural brain abnormalities (e.g., microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)
 - neurological hard or soft signs (as age appropriate) such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor eye-hand coordination
- E. Evidence of complex pattern of behaviour or cognitive abnormalities that are inconsistent with developmental level and cannot be explained by familial background or environment alone, such as learning difficulties; deficits in school performance; poor impulse control; problems in social perception; deficits in higher level receptive and expressive language; poor capacity for abstraction or metacognition; specific deficits in mathematical skills; or problems in memory, attention, or judgment

Alcohol-Related Effects

Clinical conditions in which there is a history of maternal alcohol exposure^{a,b}, and where clinical or animal research has linked maternal alcohol ingestion to an observed outcome.

There are two categories, which may co-occur. If both diagnoses are present, then both diagnoses should be rendered:

4. Alcohol-related birth defects (ARBD)

List of congenital anomalies, including malformations and dysplasias

Cardiac	Atrial septal defects Ventricular septal defects	Aberrant great vessels Tetralogy of Fallot
Skeletal	Hypoplastic nails Shortened fifth digits	Clinodactyly Pectus excavatum and carinatum

	Shortened fifth digits Radioulnar synostosis Flexion contractures Camptodactyly	Pectus excavatum and carinatum Klippel-Feil syndrome Hemivertebrae Scoliosis
Renal	Aplastic, dysplastic, Hypoplastic kidneys Horseshoe kidneys	Ureteral duplications Hydronephrosis
Ocular	Strabismus Retinal vascular anomalies	Refractive problems secondary to small globes
Auditory	Conductive hearing loss	Neurosensory hearing loss
Other	Virtually every malformation has been described in some patient with FAS. The etiologic specificity of most of these anomalies to alcohol teratogenesis remains uncertain.	

5. Alcohol-related neurodevelopmental disorder (ARND)

Presence of:

A. Evidence of CNS neurodevelopmental abnormalities, as in any one of the following:

- decreased cranial size at birth
- structural brain abnormalities (e.g., microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)
- neurological hard or soft signs (as age appropriate), such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor eye-hand coordination and/or:

B. Evidence of a complex pattern of behaviour or cognitive abnormalities that are inconsistent with developmental level and cannot be explained by familial background or environment alone, such as learning difficulties; deficits in school performance; poor impulse control; problems in social perception; deficits in higher level receptive and expressive language; poor capacity for abstraction or metacognition; specific deficits in mathematical skills; or problems in memory, attention, or judgment

^a A pattern of excessive intake characterized by substantial, regular intake of heavy episodic drinking. Evidence of this pattern may include frequent episodes of intoxication, development of tolerance or withdrawal, social problems related to drinking,

legal problems related to drinking, engaging in physically hazardous behaviour while drinking, or alcohol-related medical problems such as hepatic disease.

^b As further research is completed and as, or if, lower quantities or variable patterns of alcohol use are associated with ARBD or ARND, these patterns of alcohol use should be incorporated into the diagnostic criteria.