



Barriers to Those with Invisible Disabilities

An individual's place, and success, in society is almost entirely determined by neurological functioning. A neurologically injured child is unable to meet the expectations of parents, family, peers, school and career and can endure a lifetime of failures. The largest cause of neurological damage in children is prenatal exposure to alcohol. These children grow up to become adults. Often the neurological damage goes undiagnosed, but not unpunished.



Don't Ask My Child to Fly

Bruce Ritchie 1997

Don't ask my child to fly,
for he has not wings.

Don't ask my child to see the glint on the eagle's beak,
for his vision has been diminished.

Don't ask my child to remain calm amid the din,
for her ability to screen out the noises has been taken away.

Don't ask my child to be careful with "strangers",
for he is affectionate with everyone and prey for the
unscrupulous.

Don't ask my child to "settle down",
for the clock which works for you and I, does not exist for
her.

Don't ask my child to not play with the toys of others,
for he has no concept of property.

Don't ask my child to remember you tomorrow,
although you met today.

Don't ask my child to heal your wounds,
for her hands cannot hold a scalpel or sutures.

Don't ask my child to meet the challenges set by society,
for you have denied her the tools.

Don't ask my child to forgive you for standing idly by,
while he was being tortured in his mother's womb,

for he will,
but He may not.

Fetal Alcohol Syndrome (FAS), Fetal Alcohol Effects (FAE), Partial Fetal Alcohol Syndrome (pFAS), Alcohol Related Neurodevelopmental Disorders (ARND), Static Encephalopathy

(alcohol exposed) (SE) and Alcohol Related Birth Defects (ARBD) are all names for a **spectrum of disorders caused when a pregnant woman consumes alcohol.**

Fetal Alcohol Spectrum Disorders (FASD) is not a threshold condition. It is a continuum ranging from mild intellectual and behavioural issues to the extreme that often leads to profound disabilities or premature death.

Fetal Alcohol Spectrum Disorders are 100% preventable.

The sole cause is prenatal alcohol exposure. It is not hereditary.

A child does not grow out of it. However, early diagnosis and intensive intervention can make an enormous difference in the lifetime prognosis.

Rates of Exposure

Legally intoxicated is defined as a Blood Alcohol Level (BAL) of .08%. A 100 lb (45 kg) female consuming 5 standard drinks will reach a **BAL of .25% - three times the legal limit.** BAL reduces .01% per hour. A drink equals a 12 oz. regular beer, 1.5 oz. shot of 80 proof liquor, or 4 oz. glass of regular table wine.

The Statistics Canada, Canadian Community Health Survey, 2000/01 found that:

- 19.8% of girls age 12 to 19
26.0% ages 20 to 24
19.9% ages 20 to 34 consumed 5 or more drinks on each occasion **12** or more times per year
- 32.2% ages 15 to 34 consumed 5 or more drinks on each occasion **1 to 11** times per year.

Roughly 50% of pregnancies are unplanned.

Most girls are 2 to 3 months pregnant before they find out. It is likely that **about 20% of babies have been exposed to multiple episodes** in high levels of alcohol in the first trimester, before the girl even knew she was pregnant. It is Party Hearty Time. The vast majority of these girls are NOT alcoholics.

Even low levels of consumption, as low as 1 drink per week, are adversely related to child behaviour.

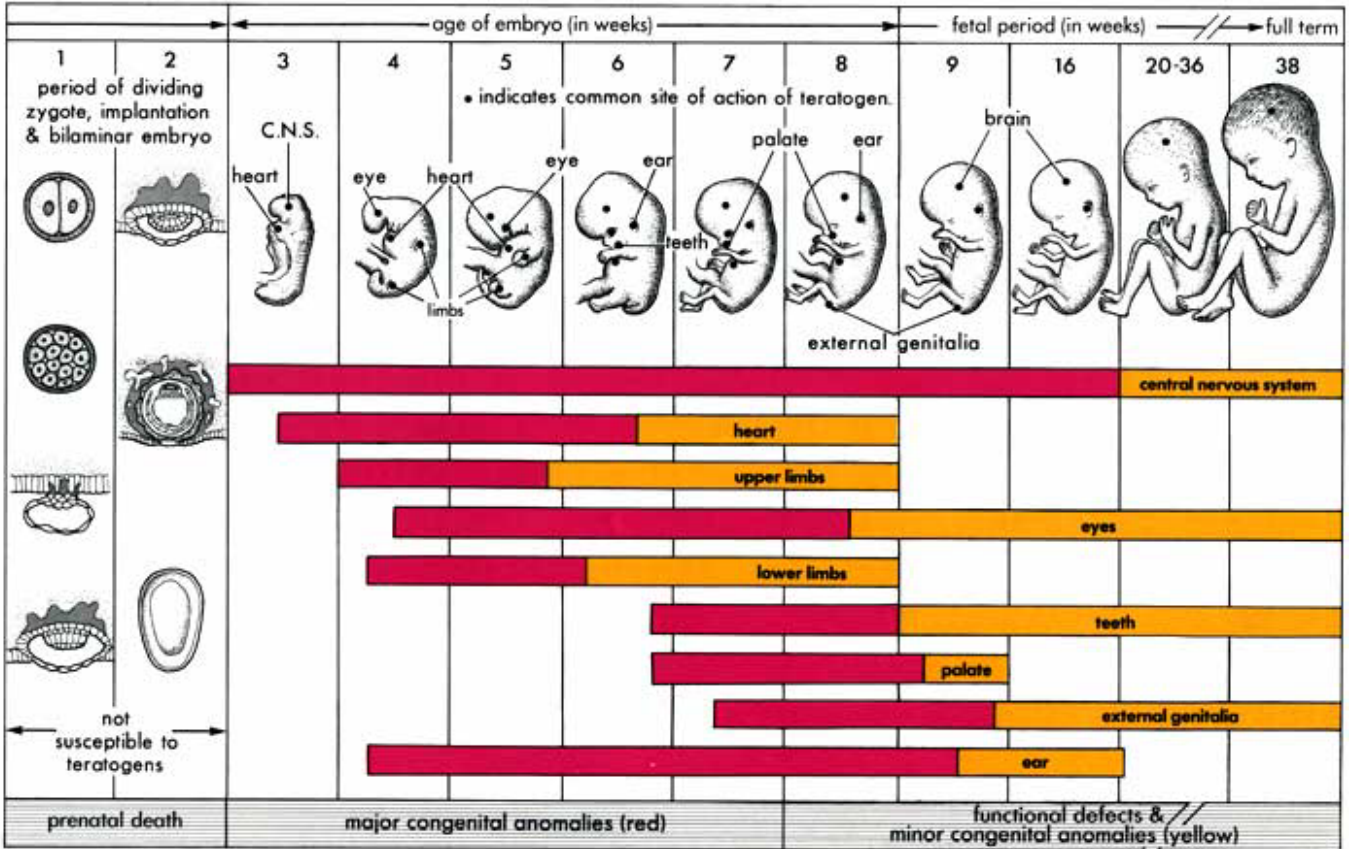
There is no known safe level of alcohol consumption during pregnancy.



Results of pre-natal alcohol exposure can include:

Attention Deficit Disorders - ADD	Attention Deficit Hyperactivity Disorder - ADHD	Mental Retardation
Developmental delay	Failure to thrive syndrome	Swallowing/Feeding disorders
Little or no retained memory	Severe loss of intellectual potential	Loss of intellectual functioning (IQ)
Poor adaptive skills transferring learning to new situations (AQ)	Severely compromised life skills development	Emotional maturity far below chronological age
Behavioural problems	Inability to predict consequences of actions	Extreme impulsiveness
Poor judgment	Little or no capacity for interpersonal empathy – social cues	Little or no capacity for moral judgment
Highly concrete. Inability to understand abstract concepts	Tourette's traits	Reactive outbursts
Autistic traits / Asperger syndrome	Cognitive perseveration	Echolalia
Bi-polar disorder / Manic Depression	Depression	Suicide
Sociopathic behaviour	Sleep disorders / Night terrors	Sensory integration problems
Higher than normal to dangerously high pain tolerance for major insults	Extreme sensitivity to touch, food and clothing texture and minor injuries	Developmental coordination disorder – Fine and gross motor skills problems
Microcephaly	Height and weight deficiencies	Cerebral palsy
Heart defects	Heart failure	Death
Deafness / Hearing problems	Central auditory processing disorder	Developmental speech and language disorder
Mild to severe vision problems	Esotropia	Dyslexia
Facial anomalies	Serious maxilo-facial deformities	Cleft palate
Dental abnormalities	Immune system malfunctioning	Asthma
Complex seizure disorder	Epilepsy	Tremors
Tight hamstrings	Rigidity	Slack muscles
Genital deformities	Hernia	Precocious puberty
Renal (liver) failure	Kidney defects	Hip deformities
Underdeveloped fingers	Shortened and bent little finger	Spinal dimple

Effects of Alcohol as a Teratogen on the Baby



6 Week-Old Baby
Normal brain

6 Week-Old Baby
Fetal Alcohol Syndrome brain

Brain Injury

The brain's **Frontal Lobes** control judgment, inhibition, concentration, self-control, conscience, personality and emotional traits as well as cognition and memory, motor speech and movement skills.

The **Left Hemisphere** deals with language based memory - **logical interpretation** of language, mathematics, abstraction and reasoning, facts and rules (such as safety and social).

The **Right Hemisphere** deals with **holistic functioning** - processing of images, sound, touch, for a "holistic" picture. Memory here is visual, auditory and spatial. So, the Left side is logic, facts, rules. The Right side is sensory input and reactive.

The **Corpus Callosum** connects right and left sides to allow communication between the hemispheres. The Right side senses input, checks with the Left side to see if there are rules to deal with this pattern of input, integrates the stored information and reacts in a modified way. Damage to any of these systems causes very poor, inappropriate response.

For example, if the Corpus Callosum cannot access the appropriate information, quickly enough (or at all), then reaction to stimulæ will be completely spontaneous, impulsive. Alcohol seriously damages the physical structures, "wiring" and brain chemistry. In many FASD individuals, the Corpus Callosum is damaged or missing.

One resulting problem can be failure to follow instructions. The individual may be able to physically hear instructions (right hemisphere) but be unable to process the meaning of the request and develop a prompt and appropriate response. The individual may then be seen as being oppositional and treated accordingly.

FASD is grossly under-reported.

The Canadian Paediatric Society states:

"Fetal alcohol syndrome (FAS) is a common yet under-recognized condition resulting from maternal consumption of alcohol during pregnancy. While preventable, FAS is also disabling."

"Health care providers play an important role in identifying babies or children with FAS. They should become familiar with the screening tools that are available to diagnose the condition in children at various ages."

"FAS diagnostic and treatment services require a multidisciplinary approach, involving physicians, psychologists, early childhood educators, teachers, social service professionals, family therapists, nurses and community support circles."

Yet medical schools in Ontario do not teach FAS screening or diagnostic procedures to undergraduate physicians. On graduation, these doctors will be the front-line family physicians. Such information is only taught to post-graduate students specializing in addictions.

There are very few Ontario doctors who have received any training to diagnose FASD. Most doctors prefer to use "non-judgmental" diagnoses such as ADD, ADHD, LD, MR, RAD, ODD, Bi-Polar, Tourette's, etc.. These "diagnoses" don't imply the mother has done something that could have affected her baby during pregnancy - no alcohol related social stigma. However, they can also lead to inappropriate treatment and a lifetime of pain. Failure to identify the real source can lead to more children being born with the same issues to the same mothers and the cycle continuing into the next generation - FASD children having FASD babies. Alcohol,

hormones, a twitch in the kilt, poor impulse control and inability to predict consequences are a deadly combination. Accidents cause people. "Denial" is not just a river in Egypt.

The Canadian Paediatric Society in their Position Statement on Fetal Alcohol Syndrome states: "Funding should not depend on a formal diagnosis of FAS. Because of waiting lists and the lack of a definitive diagnosis, the 'window of opportunity' for dealing with behavioural abnormalities and preventing secondary disabilities is often missed. Currently, only children who are labelled as 'disabled' can access funding. FAS and related developmental and physical conditions should be considered disabilities that are eligible for financial help."

The failure of the Ontario Medical Schools to provide such diagnostic training at the undergraduate level results in the denial of diagnostic services to thousands of children with FAS related congenital disabilities.

The Invisible Disability

Neurological injury is often called the invisible disability. You can't physically see it, but it is as disabling as any condition of the human body, mind and spirit. Crutches, braces, wheelchairs, white canes, missing limbs and burns are visible indicators of visible disabilities.

What does a person with FASD look like? These individuals may have apparently normal physical characteristics. Even a person with full FAS may not look unusual. The average untrained person will not recognize a person with FASD just by looking at him or her.

FAS (Fetal Alcohol Syndrome) individuals may or may not have a distinctive physical appearance and lower IQs, but have lower crime and addiction rates than FAE individuals as they get earlier diagnosis and can be better protected by society and their parents.

While FAE (Fetal Alcohol Effects) individuals may lack the outward physical appearance of alcohol damage, and generally have higher IQ's, the internal damage to the brain and other organs can be just as serious as full FAS.

The intellectual abilities of individuals with FASD can vary greatly. To-date, a wide range of IQ has been documented: 29 to 120 for FAS and 42 to 142 for FAE.

IQ measures convergent fact based thinking. Life skills require **AQ**, divergent adaptive thinking that in FAE individuals will be substantially lower than their IQ. However, because FAE individuals "look normal" they are expected to perform normally. These issues lead to secondary disabilities. Primary disabilities are those the child is born with. Secondary disabilities are those that develop as a result of failure to properly deal with the primary disabilities.

Some support programs in various jurisdictions require that an individual's IQ be below 70. Yet an individual can test at an IQ of 71 but have an AQ of 50, making them as profoundly disabled as those with a much lower IQ yet ineligible for supports. Much greater flexibility in the system is required.

"The girls get knocked up and the boys get locked up." They are followers, easily misled, with little or no appreciation of consequences. Without intervention, many ride the justice system merry-go-round or become **"homeless street people"**. They are required to compete in society but have been denied the tools to do so.

Of FAE individuals between the ages of 12 and 51:

- 95% will have mental health problems;
- 60% will have "disrupted school experience";
- 60% will experience trouble with the law;
- 55% will be confined in prison, drug or alcohol treatment centre or mental institution;
- 52% will exhibit inappropriate sexual behaviour.

Of FAE individuals between 21 and 51:

- more than 50% of males and 70% of females will have alcohol and drug problems;
- 82% will not be able to live independently;
- 70% will have problems with employment

Typically, an FASD individual emotionally functions at about ½ their chronological age.

Youth in Care

FASD children can become the forgotten kids - the children that have nearly invisible disabilities. They have their arms and legs, can see and hear, run, play, etc., but most have never been to a birthday party or a sleep-over. They are last to be chosen to play, and first to be blamed. Their illnesses aren't fatal, but a small part of their hearts and souls die with every rejection. Their behaviours may seem odd or unpredictable to themselves as much as to society.

50 years ago, the vast majority of children placed for adoption came from healthy young teens that "got into trouble" and became pregnant. The social stigma of being an unwed mother and the lack of financial supports were serious problems. Today the stigma has virtually disappeared and many babies born to unwed young mothers are raised by their mother and the grandparents in the family home. The availability of birth control has also made a difference. Today, a very large percentage of children in care have been removed from abusive homes, usually involving alcohol and other drugs. Most of these children have been prenatally exposed to high levels of alcohol and will pay the price for a lifetime. Often, these are children who are difficult to place and who grow up bouncing through many, many foster homes. They started with serious primary disabilities and become adults with a bunch of secondary disabilities added on.

Thousands of children in foster care in Ontario are denied adoption because although their birth parent(s) / birth family may not be able to care for them, the biological families do not want to permanently lose contact with them and the possibility of playing some role in their lives. Consequently, they refuse to waive their parental rights and the children remain in limbo. Ontario must adopt an Open Adoption system. Many other jurisdictions have successful systems of Open Adoption.

"I can't possibly imagine what was going through my mothers head when she was drunk. I wish I knew because if I knew I probably wouldn't be so angry with her. I'm still pretty close to her even after being adopted because luckily I had an open adoption and I'm very glad because I have gotten the chance to know her sober.

There are also times that I have a hard time with my disability and get angry with her for drinking but I also know that she didn't know as much about how dangerous it was for a baby back when I was born in 1980.

My mother started drinking when she was 13 and was an alcoholic by the time she was 16. My grandparents tried to get her treatment several times but she could never stick with it. She drank while she was pregnant with my brother, who died as a baby from Hydrocephalus. Obviously, she drank while she was pregnant with me, and she drank while she was pregnant with my sister, who has FAE.

I would never wish any of it upon anyone, but I wouldn't change it for myself for it has made me who I am today and it also gave me the ability to help others and teach others and I think that is one of the greatest gifts I could have gotten.

By the way, I forgot to mention that she has been sober for over 10 years now and I'm more proud of her than ever.” *Erica – FASlink adult with FAE.*

Adoption agencies are faced with a dilemma. If a child is diagnosed with FASD, they must disclose it to potential adoptive parents, or face lawsuits. But disclosure may reduce the chances for a particular child to be adopted. However, if they do not have a diagnosis of FASD, they do not have to disclose the fact. But the child and family will then be at high risk of secondary disabilities, inappropriate treatment and a lifetime of pain and frustration.

Some agencies have been known to threaten termination of a foster contract if the foster parents go to a non-agency doctor and obtain a diagnosis of FASD. This is nothing short of criminal behaviour in our opinion.

Every child entering an agency's care should be thoroughly screened and at any indication of FASD or prenatal alcohol exposure, should be seen by a doctor trained to diagnose FASD. Detailed records must be kept.

Education

Typical of school boards in Canada, the Lambton Kent District School Board (urban / rural mix) with 28,000 Elementary and Secondary School students has 6,000 students receiving services from the Special Education Department. Of the 6,000, only 250 are classified as "Gifted" with the balance having **significant disabilities (20.6%)**. While not all the individuals with disabilities are identified as the disabilities having been caused by prenatal exposure to alcohol, the vast majority of the disabilities are of types known to be caused by prenatal alcohol exposure. Being "Gifted" can also carry a significant burden of disabilities.

Our children have disabilities, but their biggest handicaps are the battles we have to continuously fight to get the services they need and that they have a human right to receive. Early diagnosis and intensive intervention can dramatically improve the FASD child's chances for success and the avoidance of secondary disabilities.

It is time that the Ministry of Education formally recognized FASD as a disability requiring a broad range of supports. Currently, children with FASD have to be pigeonholed into other "exceptionality" categories to obtain special needs services.

Inter-ministerial turf barriers can be a serious problem. A Special Services At Home worker may be available to the disabled child, if the parent is prepared, and skilled enough, to do battle to get the service. The Special Services at Home (SSAH) program helps children with developmental or physical disabilities and adults with a developmental disability to live at home with their families by providing funding on a time-limited basis to address individual needs. With this funding, families can purchase some supports and services which they could not

normally provide themselves and are not available elsewhere in the community. Funding is very limited and only "highest priority" families-in-crisis receive approval. More funding is needed.

From personal experience, this program can be extremely effective. However, the support worker is not permitted to enter a school. That is Ministry of Education territory. But the Ministry of Education does not have sufficient funding to provide the needed dedicated support worker, an Educational Assistant, for the child who qualifies for the Special Services at Home program. As a result, the child is denied the needed support services. We need co-operation between Ministries, not territorial barricades.

The Grade 10 Literacy Test is almost a guaranteed failure for many FASD children. Most deal with significant communications disabilities. Failure to waive the requirement for FASD kids means they may not receive a Secondary School Graduation Diploma. The "Certificate" alternative is meaningless to educational institutions and employers alike.

"Incorporating accommodation into the standard itself ensures that each person is assessed according to her or his own personal abilities, instead of being judged against presumed group characteristics." - Supreme Court of Canada in *Grismer*

World-renowned physicist and Cambridge University professor Dr. Stephen Hawking has been honoured for his continued ground-breaking research in theoretical physics and his influence on young scientists around the world. And he's done most of this work while confined to a wheelchair, brought on by the progressive neurological disease amyotrophic lateral sclerosis, or Lou Gehrig's Disease. He is unable to write or type and his verbal communication is very slow and must be translated by his support worker / assistant. Hawking is the Lucasian Professor of Mathematics at Cambridge, a post once held by Isaac Newton. Perhaps his most impressive feat was writing the international bestseller *A BRIEF HISTORY OF TIME*. The book spent more than four years on the London Sunday Times bestseller list—the longest run for any book in history.

Given the present requirements of the Grade 10 Literacy Test and the nature of Dr. Hawking's disabilities, today, with the limits on accommodations, he would not be able to pass the test or graduate in Ontario with an Ontario Secondary School Graduation Diploma. As a result he could not have been admitted to university. What an incredible loss it would have been to the world.

Failure to receive an OSSGD effectively bars entrance to university, community college, trades apprenticeship programs and most decent paying jobs. Yet many FASD kids could become terrific mechanics, trades people, construction, transport and plant workers, if they could get past the personnel department's OSSGD Grade 12 requirements. Perhaps they could be elected to political office. The Literacy Test's 25% failure rate, combined with the excessive stresses of the new curriculum is leading to a 25% drop-out rate in Grade 10. This guarantees a new slave class, fodder for the justice system (law enforcement, court and corrections are large employers) and increased stress on the social support systems of the country. It is no different than requiring a quadriplegic in a wheelchair to do the pole vault to graduate. It is access denial of the worst type - denial of access to a decent future.

My experience with the Principals and staff in the schools has been wonderful. I have been Co-Chair of my child's school councils (Elementary and High School) for many years. They are doing an incredible job with the limited resources available to them.

The fixes have to come at the government policy and funding level. The objective of the education system should be to prepare every individual to make the greatest contribution possible to society and enjoy a positive, fulfilling life.

Homelessness

Poor impulse control, failure to predict consequences and inability to plan or manage money (pay rent, utilities, etc.) often lead to eviction. No fixed address denies social assistance and therefore no money for survival. Morality begins at 2000 calories per day. Therefore, see Justice System.

Consider the majestic impartiality of the law. It makes begging and sleeping under bridges illegal for rich and poor alike.

A program of advocates for people with mental health and neurological injury issues is needed. They could assure that the rent and utilities are paid on time, appointments (medical, probation, etc) are kept, healthy food is purchased and a spending money allowance is available and makes it through the month. Inability to be able to manage money because of mental disability is a major barrier to access to decent housing.

FASD individuals will always require an "external brain" (parent, spouse, advocate, support worker).

Justice System

You cannot cure neurological damage with punishment. The Canadian Charter of Rights and Freedoms states: "Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice."

There are those people from whom the public needs protection, particularly those who use violence as an integral part of their lifestyle. And there are those who need protection from "society" and the "justice system". Too often the justice and correctional systems are used to warehouse those whose only real crime was being born with an invisible disability while governments fail to provide rational, humane alternatives. The victims of pre-natal assault continue to be victimized by a system in denial. It is fundamentally unjust to imprison an individual because he or she is disabled.

"(Human rights legislation) is often the final refuge of the disadvantaged and the disenfranchised." - Supreme Court of Canada

It costs approximately \$120,000/year to "house" a Young Offender and \$82,000 for an adult offender in the Ontario Provincial system. The average annual cost of keeping an inmate in a federal penitentiary is \$68,000 for males and about \$115,000 for females. Studies indicate that **60% to 80% of prisoners** in our jails and prisons were prenatally exposed to alcohol and should be diagnosed with FASD.

Poor impulse control, failure to predict consequences and inability to plan or manage money (pay rent, utilities, etc.) often lead to conflict with the law - no money, need money, crimes of opportunity (shoplifting, robbery, B&E) - repeated, stupid crimes with lots of evidence. FASD individuals are followers and easily misled by "planners". They get caught and do the time, not the "planners". Further, they will often admit to things they did not do in order to gain favour with others, such as police officers. Very poor short term memory may prevent them from even

remembering whether or not they did something, so if someone else says they did it, it must be true.

Poor impulse control, failure to predict consequences, poor social skills and hormones often lead to inappropriate sexual behaviour and conflict with the law. With a more sophisticated, socially skilled, intelligent individual it is called seduction. With FASD it becomes sexual assault, stalking or indecent acts.

Poor short term memory, poor impulse control, failure to predict consequences and inability to plan, almost guarantees they will violate probation or parole and be recycled into jail. The courts must stop creating conditions that guarantee failure.

Many lawyers and judges are constantly surprised to see the same clients charged with the same offences, time after time. You would think they (lawyers and judges) would suspect something is wrong. Insanity is continuing to do the same thing over and over, expecting a different result. So why do police, lawyers and judges continuously recycle the same people through the system expecting that punishment will teach them a lesson? With prisons bursting at the seams, why do politicians think zero tolerance is the solution to cure those who break the law?

How does a person with FASD feel? Individuals with FASD are overly sensitive to environmental stimulation. They have difficulty coping with sensory stimulation like noise, crowds, being pushed or shoved. When they feel overwhelmed, they may withdraw and shutdown or they may act in an aggressive manner.

A lifetime of being picked on, teased, bullied, put down, reviled and punished, leads to a terrible self-image and triggers an instinctive fight or flight reaction. The trigger incident may be minor by normal standards but seen as the straw that broke the camel's back. If the reaction is "fight", the ensuing defensive rage may not be limited to a "reasonable" level of defence but could escalate to an unpredicted level. The consequences can be serious. If the reaction is "flight", it can lead to running away or suicide.

FASD individuals, most of them undiagnosed, suffer from imbalanced brain chemistry. Those who are diagnosed and who receive proper intervention are prescribed a variety of medications, depending on their specific case. Most FASD individuals have ADD, ADHD for which they are often prescribed stimulants such as Dexedrine, Ritalin, Clonidine, etc. Many are bi-polar/manic depressive and can be helped with lithium. Many have a variety of seizures and are prescribed drugs such as Zoloft or Tegritol.

However, many are either not diagnosed or fail to receive proper medical care or simply cannot afford prescription medications. They will try to self-medicate using drugs such as alcohol, marijuana, cocaine and other street drugs. Dexedrine and Ritalin are among the more popular street drugs, for a good reason. Self-medication is rarely successful and leads to conflict with the law, time in hospital emergency wards, or the morgue.

Access to proper diagnostic services is critical, followed by proper access to and supervision of legitimate medication. Such facilities are not available to street people.

Self-medicating substance abuse, poor impulse control, failure to predict consequences and a twitch in the kilt lead to unplanned pregnancy and a new generation of FASD individuals. The cycle continues.

In the short term, prevention is expensive. But in the long term, the cost of preventing the secondary disabilities of FAS/FAE is much, much cheaper than the cost of institutionalizing through prison or hospitals.

In 1919, Dr. Frank Crane wrote:

“The criminal class is just as much of a humbug, as artificially produced, unnecessary, and maintained in ignorance, as the high-born class of Europe, the hierarchy of ancient Egypt, or the castes of India.

Any class, any exclusive group, is an enemy to democracy, whether the elect be saints or sinners. The criminal class exists simply because society creates and maintains it.

Our whole police system is built on the vicious theory that once a criminal a man must remain a criminal. We drive the weak-willed out like lepers, and handle them as snakes and not as human creatures. At first they may have sought crime of their own free wills; at last we will not allow them to follow any other business.

Call men criminals and you make them so. Our criminal law, with its prisons and gallows-trees, is the greatest source of crime. It manufactures lawbreakers. It drives men to crime as a livelihood.

There is but one sure way to treat wrongdoers, and that is to treat them as human beings, to help, cure, and strengthen them.”

Unfortunately, not much has changed since then.

Personal Supports and Income

A single disabled adult on the Ontario Disability Support Program receives Basic Needs \$516 + Shelter up to \$414 for a total of \$930.00. Many families care for permanently dependent adult children with disabilities. If they are living with their parents, \$930.00 is reduced to \$708.00 per month, a reduction of \$222.00 or 24%. Why is there a financial discriminatory penalty against the disabled individual and the parents? I know of no apartments in Ontario that rent for \$414 per month. This is discrimination in access to health care, accommodation and personal supports based on disability and blood relationship. The reduction would not occur if they were living with a non-family member. This is denial of access to care.

A single individual on ODSP can earn part-time income up to \$160 per month after tax on net earnings plus they may keep 25% of the balance up to a very low limit. If they are living at home with their parents, they cannot even earn up to the amount they would have received without working but living alone with no supports. The costs to the parents of supporting and caring for a disabled child or adult are far in excess of the maximum ODSP available.

Individuals who must rely on disability support income are severely restricted in their access to housing, personal supports, decent food, clothing, education, recreation and many of the "luxuries" those without disabilities take for granted. They are simply not allowed to earn, receive or keep sufficient income. If they do find a job, they fear leaving disability supports because if the job does not work out for any reason, they will have great difficulty getting back onto the system.

If they try to start a small business, they will be cut off supports after 30 days. The only two businesses that are profitable within 30 days are prostitution and drug pushing. They are trapped in their bodies and trapped by "the system".

Some are forced to break the law to survive. Some fail to report earned income of a few dollars and are severely punished if caught. Others in the non-disabled community can break the law for millions of dollars with impunity. Consider the majestic impartiality of the law. It makes begging and sleeping under bridges illegal for rich and poor alike.

Let's get this straight. If they live in poverty-stricken isolation on ODSP, the government will give them between \$8,500 and \$11,000 per year. If they throw a brick through a store window, the government will spend \$82,000 per year to jail them and provide shelter, food, clothing, recreation, education, medical services, companionship and the certainty they will be taken care of. Frankly, as a parent and taxpayer, I find that logic appalling, degrading and disgusting. I hope you do too.

In Ontario, Disability and Social Assistance supports are reduced by any outside income or family resources that may be provided. If a disabled child or adult inherits money, that money must first be depleted completely before government will provide financial support. The individual must become destitute before receiving assistance. This guarantees permanent dependence in poverty. If the disabled individual receives a gift of money, that must be declared as income and the government will reduce their payments accordingly. If a disabled child, adult or spouse receives court ordered support under the Family Law Act or the Divorce Act, the government payments are reduced accordingly and there is no net benefit to the recipient of the support. Poverty is mandated by law.

Poverty is a horrible destroyer of self-esteem, self-worth, confidence, ambition and the ability to positively contribute to society. Yet many individuals with both visible and invisible disabilities can make enormous contributions to this country.

Nobody chooses to become disabled. We have to stop treating people as if their disability is voluntary and they could "fix it" if they wished. **We have to stop erecting visible and invisible barriers to their success.**

Health Care

The right to decent health care is a fundamental right in Canada. In reality, it is a fundamental human right. Our system is one of the best in the world. Canadians are such a placid people that perhaps the only thing that could cause a revolution is if politicians tried to destroy our universal health care system. Contrary to popular media hype, our health care system is not broken. It works wonderfully and simply needs a bit of fine tuning.

One area that could be fixed is universal availability of prescription drugs to those with FASD and other invisible disability issues. Prescription drugs are available to those on social assistance and disability income supports. They are not available to the working poor with disabilities. They are not available to the homeless who cannot receive social assistance and who consequently self-medicate and feed the justice system.

The Canadian Paediatric Society in their Position Statement on Fetal Alcohol Syndrome states:

"Children across Canada do not have equal access to diagnostic and intervention services. For example, status Indians are funded for more comprehensive services than non-status individuals in northern Saskatchewan, despite having the same range of problems. Training of early childhood education specialists, school psychologists, occupational and physiotherapists should also be covered globally. Funding should not depend on a formal diagnosis of FAS. Because of waiting lists and the lack of a definitive diagnosis, the 'window of opportunity' for dealing with behavioural abnormalities and preventing secondary disabilities is often missed. Currently, only children who are labelled as 'disabled' can access funding. FAS and related developmental and physical conditions should be considered disabilities that are eligible for financial help. Funding for FAS must be global, with each jurisdiction contributing to a 'pot' from which all children can benefit. This would require unprecedented

cooperation between the federal government, provincial governments, social services, native bands and departments of education.”

The Canadian Paediatric Society recommends that the following measures be taken to prevent, diagnose and manage FAS.

- ❑ Primary prevention of FAS should involve school based educational programs; early recognition; treatment of at-risk women; and community sponsored, culturally-centred programs. Health care providers should ask women about their drinking habits, whether or not they are pregnant.
- ❑ Health care providers play an important role in identifying babies or children with FAS. They should become familiar with the screening tools that are available to diagnose the condition in children at various ages.
- ❑ If behavioural or physical abnormalities consistent with FAS are identified, intervention should begin without delay, even before a definitive diagnosis is made.
- ❑ Intervention programs should involve the child’s family and community.
- ❑ FAS diagnostic and treatment services require a multidisciplinary approach, involving physicians, psychologists, early childhood educators, teachers, social service professionals, family therapists, nurses and community support circles.
- ❑ Diagnostic and treatment services should be publicly funded and available to all Canadians, regardless of their ethnicity, status (e.g., status and non-status aboriginals), place of residence or income.
- ❑ Interventions should continue to be evaluated for effectiveness.
- ❑ To ensure that all children have access to the appropriate services and support, cooperation is required at various levels and across various sectors: federal government; provincial ministries of health, social services and education; and local community groups.
- ❑ Individuals and groups providing diagnostic and treatment services should take a culturally based, holistic approach.

Conclusion

<p>Where services are lacking, omitted or not available, our children, whatever their ages, die - frozen in the snow bank, through suicide, through drug overdosing and complications, by being on the street, falling prey to predators, falling prey to abusers, making high risk decisions, falling into high risk behaviours, unable to keep jobs, lack of shelter and nutrition, and on and on and on.</p>

There are serious barriers to access to almost every area of life that confront those individuals with invisible disabilities. They include obtaining diagnostic and treatment services in the health care system; surviving the education system with the skills and opportunities to build a decent life; access to employment or a decent level and flexibility of financial supports where needed; and security of the person guaranteed in the Canadian Charter of Rights and Freedoms from a justice system that tries to cure brain damage with punishment. Most of the problem areas are controlled by one or more government ministries, departments, boards or agencies. Most can

be fixed by simple policy changes as well as by education of the public service who administer the policies.

Canada spends over \$12 billion annually on the justice system alone. More than half the cost (well over \$6 billion) is related to the fall-out from alcohol consumption. The costs of alcohol consumption and the related disabilities inflicted on our children, on health care, education, social services, industry and families is astronomical. The cost in terms of human suffering is tragic and absolutely unacceptable. The beverage alcohol industry provides a mere \$3.2 billion annually in taxes and continues to produce a “legal” drug that inflicts death and disability on tens of thousand of people annually. There is something clearly wrong with the equation.

“If you want to play, you have to pay.” The beverage alcohol industry should be paying the full shot for the damages they cause and all the money should be going back to the grassroots level those they negatively affect. As it is now, none of the money gets to those who have to deal with these issues face-to-face on a daily basis.

A conservative estimate is that each FAS individual will cost the taxpayer some \$3 million in their lifetime. The direct 15 year cost of one FAS child to one family has now exceeded \$1.5 million, and still counting. The lifetime costs to affected individuals and their families are incalculable.

The Ontario Government is the sole distributor of beverage alcohol in Ontario. Both government and industry are fully aware of the massive damage to individuals and society caused by beverage alcohol. The entire manufacturing and distribution chain is jointly culpable. Government policy controls alcohol’s advertising, promotion, distribution and pricing. It is time governments went into rehab to get over their ridiculous addiction to beverage alcohol taxes. Unfortunately, about 10% of the policy makers are actually addicted to alcohol itself and another 15% to 20% drink to a level that places them at high risk. Denial is not just a river in Egypt.

Prevention of disabilities is always preferred, and in the case of prenatal alcohol exposure, that includes investing in educating our young people beginning in the early primary grades; tightening the rules and taxes on alcohol distribution to more realistically reflect the true costs financially and in human terms; provide more treatment facilities and supports for those with alcohol addictions; and deal with the root causes of alcohol addiction particularly in relation to poverty.

For those who are already affected by Fetal Alcohol Spectrum Disorders:

- Remove the barriers to health care diagnosis and treatment, including prescription medication.
- Properly fund special education support programs and staff.
- If a child qualifies for the Special Services At Home Program, permit that support to be able to carry through into the school. This calls for ministerial co-operation, not turf wars.
- Waive the Grade 10 Literacy Test requirement for the Ontario Secondary School Graduation Diploma for children diagnosed with FASD. Frankly, the entire concept of the Grade 10 Literacy Test being an absolute requirement for an OSSGD is repugnant and also discriminates against recent immigrants. It should be scrapped completely.
- Provide decent personal economic supports, flexibility and security to raise those with disabilities from economic poverty, deprivation and desperation so they can fully participate in the life of this country. Their disabilities should entitle them to a decent

basic level of support with no restrictions on additional income they might earn or inherit.

- Require government staff to focus on how to provide the needed supports and allow them the flexibility and creativity to do so,
- Stop using the justice and corrections systems to try to cure brain injury.
- Require diagnostic screening and intervention at the beginning of any legal proceeding if there is any reason to suspect an accused is suffering from a brain injury such as that caused by prenatal alcohol exposure.
- Require a massive education program for justice personnel. There really is a poisonous attitude in many areas of the system.
- Remove group homes from the urban core where FASD individuals are set up for failure.
- Build alternate programs and facilities that can provide lifetime supports and protection for FASD adults when their families are no longer able to. Parents of permanently disabled, dependent children and adults fear what will happen to them once the parent dies or can no longer provide the day to day care.
- Provide a system of advocates who can help manage the financial and other affairs for those with invisible disabilities so they do not become homeless.
- Requiring each government department to undertake a review of its facilities and policies in relation to accommodating those with FASD and other invisible disabilities.

Bruce Ritchie
Moderator & Executive Director, FASlink
Parent

FASlink is the Canadian Fetal Alcohol Spectrum Disorders Internet support, information, advocacy and discussion forum. FASlink serves parents (birth, foster, adoptive and grandparents), caregivers, adults with FASD, doctors, teachers, social workers, lawyers, students and government policy makers across Canada and worldwide. FASlink's website Home Page receives more than 400,000 visits per year in addition to on-line searches of the 90,000 FASD related documents in the FASlink Archives, the largest FASD resource in the world.

The biological and adoptive parent of a child with Fetal Alcohol Syndrome, Bruce Ritchie was a founding director of the Fetal Alcohol Support Network in 1991. He publishes the FASlink website, CD's and other educational material and is Moderator of the on-line discussion forum. He designs knowledge management systems and is a life-long advocate for children's issues. His son's birth mother, now deceased at age 45, was a brilliant and talented Family Physician.