Building Educational Success for Pupils with FASD Foetal Alcohol Spectrum Disorders

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Author/Presenter Background:

Mary Cunningham is a FASD educator/advocate and parenting education consultant from Kitchener, Ontario, Canada. She can be reached at cunninghammary@rogers.com. She is retired from 30 years of teaching in the Ontario (Canada) education system. She is the co-author of a parenting education textbook (*Parenting in Canada*, 2003) and a co-founder of OCMPE (Ontario Coalition for Mandatory Parenting Education). She is grateful to many for their contributions to her understanding of FASD and the help received to cope with FASD up close and personal in her family. Much of what she understands about FASD today is because she has had the privilege of parenting a child with it. Today she wears two hats: one, that of a teacher who firmly believes those who care, teach, and the other is that of a parent of a young adult with diagnosed FASD who 'slipped through the cracks' in the education system.

Introduction:

Educational success for pupils with an FASD is possible when educators, other school and community personnel, parents and caregivers understand FASD in the educational context and work together to meet the needs of individual pupils in their own school settings. As a major builder of the social fabric the education system must work effectively for all pupils with special needs. Success for pupils with FASD is extremely important for two reasons. Those with FASD are the most misunderstood and, since FASD is the MOST PREVALENT of ALL birth defects, with FASD, in all likelihood, outnumber **all** other pupils with special needs. Currently, FASD is rarely recognized, but it is hiding in plain sight in many disguises.

Educational success for pupils with FASD sets the stage for a positive and socially connected adulthood. Success is critical because school failure and dropout has been identified in the research as the first of a series of common negative secondary effects of FASD. At present our education systems display a limited awareness of FASD and of the thousands of pupils with FASD they are trying to serve. A lot of resources are being used ineffectively. We all have a vested interest in making our education systems effective for pupils with FASD, diagnosed or suspected. FASD, in the opinion of this author/teacher, is currently hobbling education systems in many parts of the world.

This paper introduces the topic of FASD in the education context, describes what FASD may look like in various school settings and individual pupils, explores the invisibility of FASD in most pupils and emphasizes the need for a massive shift in thinking that allows teachers and other educational professionals to see behaviour as brain damage and not wilful misbehaviour. Resources for educators will be suggested along with strategies, attitudes and interventions for pupil success.

Preparation of educators new to FASD to effectively serve pupils with FASD could be done well in a short, 4-day summer/vacation course. Such a course would allow teachers to practise and more fully understand new techniques and FASD basics. This presentation will cover some of that material, all of which is simply good Special Education designed to address the permanent brain damage of Foetal Alcohol Spectrum Disorder. However, should you apply these techniques to other pupils with other learning disabilities, particularly those involving sensory integration dysfunctions, **you will do no harm**.

Index of Topics

1. Introduction to FASD

- FASD is the spectrum of physical, cognitive &/or behavioural characteristics educators and other professionals may see in pupils with FASD**.**
- FASD is caused only by maternal drinking in a pregnancy.
- FASD is a brain-based set of disabilities. Nothing will work until this fact is understood and accepted. All people with FASD have brains that work – but differently from "normal"
- All pupils with FASD are not all the same and exhibit a wide range of disabilities.
- Fortunately all pupils with FASD have a wide range of aptitudes and abilities which must be developed if they is to be any hope of a functional adulthood
- Focusing on their aptitudes and talents rather than disabilities is one of the bases of success with children with FASD
- FASD is one of many neurobehavioural disorders – all respond similarly
- The strategies and thinking shifts in this resource will help ALL pupils with brain-based disabilities. It is important to understand that every school system has many, many pupils with FASD but most are misdiagnosed as having some other condition
- FASD-tuned strategies will NOT hurt ANY pupil but will help almost all of them
- Re-framing "dysfunctional" behaviour as a product of brain damage is a key to success.
- It is not that pupils with FASD "won't" behave properly, they "can't" behave.
- Although pupils with FASD may appear "bad", actually they are simply "hurt".
- More than anything else children with FASD just want to fit in and be accepted.
- The parents and caregivers of children diagnosed **or suspected** of having an FASD are, at present, the real experts on how to care for them and achieve success
- Using parents, grandparents and carers as "experts" will make an educator's job much easier.

This resource assumes some knowledge of Foetal Alcohol Spectrum Disorders. If this is a first introduction to FASD as an educator or other professional it is advised that you get more basic understanding of FASD. **Damaged Angels** (2004) by Bonnie Buxton is a comprehensive, riveting and easily understood resource on the subject. There are many more as well. (References)

FASD refers to the brain damage and permanent physical disabilities caused ONLY by maternal drinking during a pregnancy. It is not a diagnostic term, but an effective way to indicate the spectrum of **physical**, **cognitive** and/or **behavioural** characteristics educators may see in pupils

with FASD. Alcohol during pregnancy causes FASD because it is a potent **neurotoxin** (kills nerve cells) and **teratogen** (causes birth defects). Most people with FASD are "invisible" though, and its usual manifestation is dysfunctional behaviour. The amount of damage done varies with timing and dose of alcohol consumed, age and genetics plus maternal stress and nutrition. Although the male does not cause FASD, alcohol and drug use by the father prior to conception have been linked to sperm damage manifesting itself as impulsivity, learning disabilities, attentional problems and lower birth weight in babies. We have no names for these syndromes or disabilities yet. There is still much here that we do not know.

Diagnoses of FASD include **FAS**- Foetal Alcohol Syndrome, **pFAS**- partial Foetal Alcohol Syndrome and **ARND** – Alcohol Related Neurodevelopmental Disorder. ARND makes up 95% of all cases of FASD. Other terms you may hear are ARBD – Alcohol Related Birth Defects and Static Encephalopathy (FASD without confirmation of drinking). FAE or Foetal Alcohol Effects is an older term, the use of which is now discouraged. (FAE: is roughly equivalent to ARND + pFAS). The acronym PAE – Prenatal Alcohol Exposure – is also used when a diagnosis is not obtainable but maternal alcohol consumption during pregnancy is understood.

FASD is a new name for an old malady. Historical references to conditions roughly equivalent to modern day FASD have been found in *The Bible* (Judges 13:7) and Aristotle's writing as well as numerous other historical documents. FASD was first studied scientifically and formally identified in 1973 in *The Lancet* by Jones et al. FASD is now the subject of over 3 000 scientific inquires.

Anyone who has taught for any length of time will have already interacted with many pupils with FASD. One Canadian study (2000) found that 50% of pregnancies were unplanned and that 17-25% of women reported drinking during pregnancy. It must be remembered though that **no woman drinks to hurt her child** and that women who continue to drink in pregnancy need help, not condemnation. **Addiction is a physical illness, not a moral failure**. We will never completely conquer FASD until we all accept this last statement.

Nevertheless, the FASD rate is **conservatively** estimated at 1% of live births in developed countries. FASD is the most common birth defect in North America, bar none. Reliable United Kingdom data was not available to the author. But all teachers have seen pupils with FASD. Even at the conservative estimate of 1% of live births there are thousands and thousands of them in North American and United Kingdom education systems. We can and must fix this serious problem, as it is currently a major contributor to the ineffectiveness of taxpayer-financed education systems

The Effects of FASD

1. Brain Damage from intrauterine alcohol - causes behavioural dysfunction. (Primary)
2. Learning Disabilities– due to the brain damage which ALWAYS exists (Primary)
3. Physical Effects- Alcohol Related Birth Defects (Primary)
4. Mental Health Problems (Secondary Effects)

- **Primary FASD Behaviours** are those that are caused by underlying damage to brain structure and function (Diane Malbin, 2004)
- **Secondary FASD Effects** are defensive behaviours which develop over time in response to a non-supportive environment, the individual with FASD suffers from a chronic inability to "fit in"(Diane Malbin, 2004) It should be noted that Secondary Effects are not exclusive to

FASD.

Primary Effects caused by the brain damage are not repairable at this time. However, the person can be supported effectively and learn to live effectively thus preventing the emergence of the serious Secondary Effects of FASD. This is our best hope for FASD, the support of the Primary effects or behaviours of FASD and the prevention of the emergence of Secondary Effects.

- **Tertiary FASD Effects** - As of 2012 we now also refer to the Tertiary Effects of FASD in addition to the Secondary Effects of FASD. Tertiary Effects of FASD emerge when secondary effects are unsupported and thus worsen and harden into the more or less permanent social problems we recognize in people with FASD who have received little or no understanding or social support. These "big social problems" are common and many of them are listed in the following section.

2. Why Should I Care About FASD?

Foetal Alcohol Spectrum Disorders are lifelong conditions that negatively affect the individual, the family and the community because of the Secondary Effects found in most untreated, unsupported and unrecognized cases. FASD is considered, by most experts, to contribute to a "hemorrhage" of social spending on a long list of stubborn and usually intractable social problems. FASD is a large contributor to social spending on the provision of services in ALL following areas: (As of 2012 we now call many of these social problems The Tertiary Effects of FASD. We recognize them as Tertiary Effects when they are found in a person recognized as being affected by PAE or Prenatal Alcohol Exposure or diagnosed with a form of FASD.)

1-Special Education	2-Social Assistance	3- Child Welfare	4-Domestic Abuse Prevention
5-Unemployment	6-Assisted Housing	7- Homelessness	8-Mental Health Problems
9-Drug and Alcohol Abuse	10- Law Enforcement		11-Justice & Corrections

One American study estimated that each individual with FASD was costing $ 2 million (US) in extra social spending. These figures DID NOT include justice and corrections.

School Dropout and FASD: The 1996 research of Dr. Ann Streissguth, a leading FASD expert from Washington State showed clearly that the "first signs of a marginalized adulthood" with FASD can be seen as "early school dropout". According to the BBC on June 28, 2007 "the UK has one of the worst records on teenage school drop-outs". At that time the government was promising to sharply reduce the number of teenagers in England outside of work, education or training (NEETs). Their numbers at that time were 206,000. By November 05, 2007 the BBC was reporting that the numbers of people aged 16 to 24 not in work, education or training (NEETs) had gone up by 94,000 to 850,000 between 2003 and 2007. The secondary effects of FASD could have played a large part in school withdrawal for many of these youths.

The Secondary Effects of FASD: Secondary effects are behaviours that are normal protective reactions to frustration and an inability to 'fit in' an environment, in this case, little or no school success. These effects are very common in unsupported FASD but are preventable when one's environment is adjusted so it works and the person is supported. If a pupil has a large number of these secondary behaviours (which can be caused by problems other than FASD) he or she should definitely be assessed for a possible FASD diagnosis.

What are the Common Secondary Effects of FASD?

Irritability, Resistance	Fighting, Outbursts
Argumentative	School Failure, Expulsion, Drop-out
Isolated, has few friends	Running Away, Avoidance
Pseudo-sophisticated	Sexually Inappropriate to a dangerous level
Inappropriate humour, "class clown"	Addictions to Alcohol and Drugs
Fatigue	Trouble with the Law
Anxious, Fearful	Poor Self Esteem
Overwhelmed	Depressed, Suicidal
Bullied, Teased, Picked on	Other Mental Health Issues
Unrealistic Goals	Co-occurring Mental Illnesses – "alphabet soup"

The Common Co-occurring Mental Illnesses: Dr. Kathryn Page 2002

Page described several overlapping illnesses as an"alphabet soup of diagnoses"

- ADD/ADHD is most often diagnosed – see O'Malley following
- (Reactive) Attachment Disorder (R-AD)
- Bi-Polar Disorder/Depression
- Conduct Disorder (CD)
- Oppositional Defiant Disorder (ODD)
- Obsessive Compulsive Disorder (OCD)
- Borderline Personality Disorder (BPD)

The Triple Threat of FASD: Dr. Kieran O'Malley, Consultant Psychiatrist, Adolescent & Mental Health Service, Belfast Health & Social Care Trust indicated in 2008 (Vancouver) that a large portion of people with (1) FASD (mostly undiagnosed) will develop (2) mental health problems and of this second group a large proportion will also develop (3) drug and alcohol addiction issues. I.E. FASD creates a "Triple Threat" to society

O'Malley also noted in *ADHD and Fetal Alcohol Spectrum Disorders (FASD)* (Nova Publishing, 2007) that "FASD are the true clinical masqueraders and ADHD is their most likely disguise". So the conclusion is that FASD is a massive public health problem "hiding in plain sight" in the guise of "an alphabet soup" of other diagnoses, none of which commands the correct intervention treatment or pharmaceutical regimen.

Criminal Justice System Issues: (CJS)

Dr.Ann Streissguth reported in 1997 that "60% of individuals with FASD will encounter 'trouble with the law,' and more than 40% will be incarcerated in a penal institution at some time in their lives." She also reported that the 'most frequent crimes are theft and shoplifting but whole gamut of criminal activity is represented to some extent…' and that "intentional premeditated criminal activity is not characteristic of people with FASD, despite their high rate of trouble with the law…instead it is impulsive"

When we look at Streissguth's CJS findings above in a UK context it is possible to connect ASBO (Anti Social Behaviour Orders) and youths who have unsupported and unrecognized FASD. Traditionally young offenders with FASD will not learn from punishment or behaviour modification techniques. Is there a need to understand FASD here and try differently?

On September 30, 2000 Daniel Zakreski of the ***Saskatoon Star Phoenix*** reported that an unnamed Saskatchewan judge said, "The whole question of FAS(D) is a sleeping giant in the criminal justice system. As many as 40 per cent of all young offenders in custody are FAS(D) kids." (Note: In 2012 we would now refer to them as young offenders with FASD **not** *FASD kids*)

Judge Sheila Whalen from the Saskatchewan Provincial Court offers the following "red flags" or indicators for recognizing FASD in young offenders being seen in court.

- Poor school experiences
- Difficulty with institutions & compliance in general
- Known maternal drinking, removed from the home, have sibling(s) diagnosed with FASD
- One or more previous psychiatric diagnoses
- Disconnect between actions & consequences
- Repeated failure to comply
- Lacks empathy, remorse and insight
- Not affected by past punishment
- Risky crime behaviours for little gain

In conclusion, with regard to CJS, the results of a University of Saskatchewan Study into FASD and Young Offenders are particularly interesting. This study by Dr. Patricia Blakley ran from December 1999 to March 2006 and studied a group of 141 Young Offenders (YO) in Saskatchewan courts. The 141 YO were charged with a total of 1329 offences. This is an average of 9.43 offences for each young offender! System Offences such as breach and failure to appear made up 45% of the charges, 37.2% were property offences and 12.6% involved violence. Drug related offences were only 1.1% in this sample and other offences came in at 4%. Most tellingly though, 103 or 73% of this sample of young offenders were assessed and were found "qualified" to begin the rigorous diagnostic process for FASD. In other words almost 75% of these young offenders showed enough signs of FASD to enter the diagnostic process. FASD is alive and well and keeping our judicial systems working overtime!

3-Good News about FASD and FASD 101

The costly Secondary and Tertiary Effects of FASD can be preventing by effectively accommodating the Primary Behaviours of FASD. Even though the primary effects of FASD are serious and permanent, adaptation and success in life is possible

Schools play a major role in building this success. An effective school is the best place to build life-long success for individuals with FASD. Conversely, it can be shown clearly that schools that do not accommodate FASD effectively start young pupils with FASD on their way to a marginalized adulthood full of the secondary effects of FASD. **This is the bottom line**.
Schools must change so that they provide effective interventions for pupils with FASD.

Schools already have the strategies to address FASD well. The author of this resource is a retired educator who firmly believes that "those who care…teach" but she also the parent of a young woman with FASD who slipped through the cracks in the school system and developed secondary effects in the process. Today's teachers, in the opinion of this author, are doing the best they can and already possess the skills and teaching strategies with which to successfully teach

young people with FASD. There is no need to "reinvent the wheel" or develop new strategies.

However, it is recognized that schools today are not achieving success with pupils with FASD, witness the high drop-rate with pupils showing many of the primary behaviours of FASD. Why are schools so unsuccessful at present? According to Diane Malbin we are using the wrong road map! We are trying to get around London with a map of Madrid! We need to take the skills we have now and *Try Differently*. There is no sense in trying harder, it is not working.

We Need to "Try Differently" in schools and make change in the following areas:

- Education is about positive or progressive change – FASD is not like that
- Pedagogy is about developing independence not interdependence – **inter**dependence needed
- Schools (and justice systems) are based on Watson and Skinner and behaviour modification
- Behaviour Modification DOES NOT WORK for pupils with FASD
- Pupils with FASD DO NOT LEARN from rewards, punishments or consequences
- Parenting practices DO NOT cause FASD
- We need to try differently in all of the above areas for success

Parenting Practises

- The only parenting practice that causes FASD is alcohol use in pregnancy
- Other parenting practices after birth DO NOT cause FASD
- Most parents of children with FASD will be unable to control their behaviour with "discipline" no matter how hard they try
- Using old-fashioned "discipline" on children with FASD simply does not work!

FASD 101 Basics

If an educator does not understand FASD, it won't matter how hard they try, they will NOT be successful with pupils with FASD. (Note: Some of the following material is repeated from Section 1- Introduction above. Repetition will hopefully serve to reinforce these points)

- The most serious disability caused by alcohol in pregnancy is permanent brain damage.
- FASD is permanent and can cause life-long social, intellectual and developmental disorders
- Permanent disabilities & brain damage are caused ONLY by alcohol consumption during pregnancy
- Alcohol causes FASD because it is a potent **neurotoxin** and **teratogen** – more potent than any "street drug" according to the IOM in the United States
- Amount of damage varies with timing and dose of alcohol consumed, age and genetics of the mother plus maternal stress and nutrition
- "Invisible disability" in most persons with FASD
- Usually shows only as wide range of behavioural symptoms or abberations related to brain damage

Historical Viewpoints on FASD

- Behold, thou shalt conceive and bear a son: And now, drink no wine or strong drink. (Judges 13:7)
- Aristotle in ***Problemata*** indicated that women with drinking problems often had children who were like them
- ***Gin Lane*** by Hogarth-1697-1764 – famous picture "showing affected people"
- FAS was formally identified in 1973 in ***The Lancet*** by Jones ***et al***
- Now scientific studies on FASD number over 3 000 and this number is growing.

No Mother Ever Drinks to Hurt Her Baby!

- Avoiding mother blame is critical
- Didn't know she was pregnant (this is common)
- Didn't know alcohol was harmful or thinks a little is OK
- Her Mom or a friend or her doctor said it was OK (this causes huge problems!)
- We tend to think of alcohol as a food group
- The FASD story seems "too bad to be true"
- Partying and binge drinking are extremely common today and VERY dangerous!
- Addiction, abuse, poverty and mental illnesses are often at root of serious alcohol addictions
- We must recognize alcohol addiction as a disease (think cancer) NOT a moral failure.

What about Dad?

- Paternal alcohol consumption prior to conception has been linked to subtle neurological effects even when the mother does not drink during pregnancy. (Abel,1992, Cicero,1994, Joffe & Soyka,1982, Little & Sing, 1986, Yazigi *et al*, 1991)
- Effects include impulsivity, learning disabilities, attention problems & lower birth weights
- Paternal consumption does not cause FASD
- FASD is caused only by maternal consumption

Incidence of FASD

- FASD is the most common birth defect in developed countries & the most common cause of developmental delay (*aka* "mental retardation" – a term which we thankfully no longer use!)
- Research-based estimates show at least 1% of live births are FASD-affected in some way
- Most experts believe the rate is higher than 1% but even at this rate there would be at least 609 000 living people in the UK with FASD based on 2008 population statistics
- As the MOST common birth defect and the most common cause of developmental delay we have to realize that … Thousands of pupils have FASD
- If you are a teacher you have worked with many pupils with FASD already!
- As a minimum requirement it is critical that ALL STAFF in contact with who have or may have FASD understand the FASD 101 BASICS!
- Otherwise … "There are none as blind as those who will not see…"

- It takes only one person in the school who doesn't understand FASD well to de-rail everybody else's work and do immense damage to (a) pupil(s) with FASD
- There are people who think they understand FASD and people who genuinely do understand FASD. There are few of the latter and many of the former

4-How do I know it when I see FASD?

Most pupils with FASD will be undiagnosed and unrecognized. Instead they will **"be hiding in plain sight."** FASD is an umbrella term for several conditions. These include Foetal Alcohol Syndrome or FAS. This is very recognizable as the classic "face of FAS" but only makes up 1-2% of the population, so very few children have this form of FASD. The same applies to Partial Foetal Alcohol Syndrome or pFAS. This is somewhat recognizable from facial features but again only 1-2% of the population with FASD has pFAS. **Facial features ARE, therefore, NOT a reliable means of recognizing FASD.**

Alcohol Related Neurodevelopmental Disorder or ARND makes up 95% of the FASD population. It has NO reliable facial or other markers and is usually diagnosed as something else because these children tend to show only the dysfunctional behaviours of FASD. (children with ARND tend to be diagnosed with ADD/ADHD, Asperger's or Tourette's Syndrome or a number of mental health disorders – see *Alphabet Soup*).

There are a number of Physical Birth Defects or ARBD which may accompany an FASD. Three of them are the facial signs that accompany FAS or pFAS. All the rest of the common ARBD can be caused by factors other than alcohol in pregnancy. Some common ARBD are:

Club Foot Hearing/ear problems Dental abnormalities Small head size
Heart defects Scoliosis (skeletal) Cleft lip and palate Being overly thin or small

The Iceberg Effect – most incidence of FASD is "hiding below the waterline" like the iceberg that sunk The Titanic.

- Most pupils with FASD show no external physical characteristics
- Over 90% of pupils with FASD have ARND and one or more other mental health diagnoses!
- BUT, the brain damage related to these forms of FASD is **as or more extensive** than people with FAS/pFAS which you can see
- If you are dealing with problem behaviours that just doesn't seem to go away no matter what you try – pupil's behaviour that is very resistant to change – Think FASD First
- If you see a lot of birth defects that may or may not be associated with FASD – these are clues to FASD
- In all of the above practice TIFF – **T**hink **I**ts **F**ASD **F**irst

The Usual FASD School Story

- Nursery – unduly quiet or aggressive and unruly (ADD/ADHD-like – may have a diagnosis)
- May slip through cracks at first with moderate to weak evaluations on reports
- By age 8-11 serious learning problems are obvious: reading, maths, science
- May be an extreme safety challenge with frequent suspensions or calls to the home
- By age 12-13 is dropped by achieving friends who "see" the disabilities

- Poor transition to secondary school (UK Stage 3)
- Picks up with peers with similar problems
- School skipping, no homework, school failure
- Petty crime, drugs, alcohol use, early sexual activities
- Early school dropout or expulsion – "first sign of marginalized adulthood" – age 14-16
- Pupils with invisible FASD are rarely identified by the education system
- But their peers (and teachers) know that something is not right
- Pupils are shunned, teased, and punished for behaviour they can't control
- Continuous disappointment for themselves and for everyone they care about…
- This results in The Secondary Effects of FASD or, more seriously Tertiary Effects

Primary Behaviours Frequently Seen in Children, Adolescents and Adults with FASD

- **A**daptation- trouble getting stopped or started
- **L**anguage- great expressively, poor receptively
- **A**ttention – ADD/ADHD is frequently diagnosed
- **R**easoning – abstract concepts out of reach
- **M**emory-'sketchy, gaps, don't learn from experience (sometimes can, sometimes can't)
- **S**ensory Processing Disorders –an under and/or overreaction to environmental stimuli
- **A-L-A-R-M-S**
- **Behaviour = Brain Damage**

Executive Functioning is Always Affected – Teresa Kellerman 2003

- Inhibition→ Socially inappropriate, uninhibited
- Problem Solving → Can't figure out solutions by self
- Sexual Urges → Unable to control sexual impulses
- Planning → Doesn't learn from past consequences
- Time & Money → Does not "get" time or money concepts
- Ordering Self→ Difficulty processing information (melts down or shuts down)
- Memory → Difficulty storing & retrieving information
- Self-Monitoring → Needs frequent cues, 24/7 supervision
- Self-Regulation → Needs to talk out loud, needs feedback
- Emotions → Moody, exaggerated, roller coaster emotions
- Motivation → Doesn't show remorse, needs an external push

Schools Don't Get What They Need From with FASD

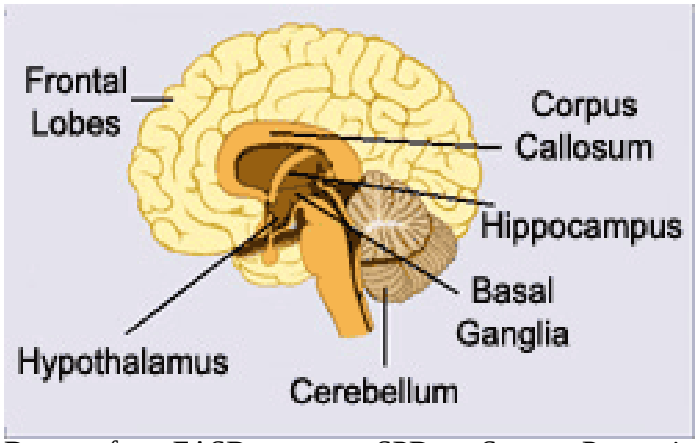
Schools need pupils who have abilities; but pupils with FASD bring disabilities that are caused by the permanent brain damage ALWAYS found with FASD.

Abilities That Schools Need …	Disabilities That Come With FASD
• Thinks quickly→	Slow cognitively, aurally
• Makes good decisions→	Poor executive functioning
• Pays attention, focused→	Distraction, Impulsivity
• Remembers well→	Widely Variable Memory
• Understands concepts→	Inability to Generalize
• Abstracts well (15+)→	May never be able to abstract or hypothesize
• Good social Skills→	Boundary and Touching Issues
• Good social conscience→	"Lack of conscience"
• Communicates well→	Confabulates, "Big Talkers"
• Reliable performance→	Performance will vary widely

5-Understanding the Permanent Brain Damage of FASD

- It is a lot easier for educators to change themselves as opposed to trying to change the child.
- FASD brain damage is considered to be permanent right now; BUT there is research into interventions in infancy that could "repair" this brain damage when the brain is "neuroplastic"

Brain Areas Often Affected By FASD



Damage from FASD can cause SPDs or Sensory Processing Disorders (a.k.a. Information Processing Disabilities)

SPDs (Sensory Processing Disorders) Simplified

- **Problem 1** – Getting Information into Brain
- **Problem 2** – Sorting the Information
- **Problem 3**- Sorting the Information
- **Problem 4** – Getting Information out of Brain

- BRAIN DAMAGE = SPDs = "BEHAVIOUR" (problem behaviours)
- "Misbehaviour" is a brain-based organic problem

What does an information processing disorder feel like?

- Imagine trying to understand something when loud music is blaring, the lights are buzzing because the ballast is gone and you are wearing a scratchy wool sweater over your bare skin
- This is how it feels for a child or adult with FASD, how would you behave under these circumstances? How would you act under these conditions?
- SPDs = Data Overload – too much stimulation (or "underload" – not enough stimulation)
- How long can you - look at a crooked picture? - tolerate sand in your bed?
  - listen to the tap drip at night? - tolerate a tag rubbing your neck?
- What did you do when the fire alarm rang at school?
- What do you do if an ambulance is screaming towards you from some unknown direction?
- Most people with FASD have some form of SPDs along with "their FASD"
- FASD produces a set of very serious Information Processing Disorders or SPDs
- These often create or help create specific learning disabilities – in addition to FASD
- Carol Kranowitz' book **The Out-of-Sync Child. Recognizing and Coping with Sensory Integration Dysfunction** is an excellent resource – it is on the Reference List

Two Common Reactions to the SPDs caused by Brain Damage

- 1- Total shut down and turn off – Often confused with or diagnosed as ADD
- 2- Hyperactive acting out – Often confused with or diagnosed as ADHD
- These pupils process information outside of the boundaries of "normal". Focusing your efforts on damping down or mediating Sensory Processing Disorders (SPDs) will make your job MUCH easier! It is definitely worth the effort!

(Please see previous references in these notes to Dr. Kieran O'Malley on ADHD and FASD and "The Triple Threat of FASD" with respect to ADHD and FASD – see Page 6)

"The Meatloaf Metaphor"

- It is easier to put a cover on the meatloaf in the microwave for 40 seconds than spend 10 minutes cleaning up the microwave after the explosion!
- Head off trouble, nip escalating stimulus (SPDs) overload before the child explodes
- E.g. Providing constant supervision, especially at eating or play times, and preventing a crisis is easier than cleaning it up! (Times where there is no routine – eating, playing, assemblies, fire drills etcetera are especially dangerous for FASD crises)

6-Reframing the "Behaviours" & Using External Brains

- The classroom teacher is probably the most important determinant of success for an individual pupil with FASD
- Reframing the "behaviours" is the most important first step
- Primary behaviours and learning problems are caused by the permanent brain damage

- **"It is not that they won't; they can't"**
- **"It is not that they are bad; they are hurt"** (from brain damage)
- Understanding this will change your life and their lives!
- Always ask yourself, could this behaviour be due to brain damage?
- **NEVER punish brain-based behaviour.** Punishment doesn't work and almost always will cause the Secondary Effects!
- Strategies for reframing are presented later in this document – *Translate Misbehaviour*

Brain Damage Also Causes *Dysmaturity* (look up Diane Malbin for more on this concept)

- Pupil will appear to be acting like (s)he is 6, 8, 11 and 12 years old all at the same time. E.g. S/he is 6 socially, 8 emotionally, 11 in reading ability but is actually age 12
- *Dysmaturity* is a classic sign of FASD
- This is VERY confusing for parents and teachers
- All modifications should be planned around where the pupil seems to be developmentally
- "Figure out where they ARE developmentally and start there, not where their age says they should be". D.Malbin
- Research shows that people with FASD tend to become "more together" and mellow out as they age. They reach this stage by about age 30, too late for the school system but still hopeful

Examples of Dysmaturity in Pupils with FASD (D. Malbin)

- Prefers to play with younger children
- Suggestible, peer-driven, easily influenced
- Needs constant supervision to be safe
- Is " in your space and in your face." – boundary issues
- Doesn't get hints, nuances or subtle suggestions
- May be dangerously impulsive
- May be unaware of danger, no "stranger danger"
- May need to touch like a 6 year old – (even at 16)

Typical Unaffected Pupils	**Pupil with FASD (D. Malbin)**
5 Year-Old	**5 Year-Old**
-goes to school all day	- needs an afternoon nap
-follows 3-part instructions	-follows one instruction at a time
- can share and take turns	- "my way or no way"
10 Year –Old	**10 Year-Old**
-answers abstract questions	-learns by doing
-gets along with others	-needs to be supervised all the time
-solves problems	-mirrors or echoes words/others
-has physical stamina	-easily tired by mental work – goes home exhausted

18 Year –Old	**18 Year-Old**
-makes most decisions on own	-needs structure and guidance
-drives a car	-plays with toys, eg. trucks
-graduating from school	-may never graduate school
-has a life plan	-lives in the "now" – no life plan
-can practise safe sex if active	-often acts out sexually
-usually acts responsibly	-acts responsible for a 10 year-old
-is almost independent	-needs to be interdependent

The Bottom Line

- Pupils with FASD can't change, their brain damage is permanent
- So… educators, carers and others have to change to accommodate this brain damage
- It is much easier to change yourself than to effect change in a person with FASD
- THE ONLY ONE WHO CAN CHANGE IS YOU – not the pupil

Starter Strategies

- Reframe all "behaviours" as brain-based
- Do not ask "why?" – They don't know now and won't know later
- If things go wrong try differently, not harder
- Make transitions as easy as possible
- Use visuals as often as possible
- Break everything into steps, do 1 at a time
- In general reduce stimulation, provide quiet places for them to de-stress as needed
- Go slowly- "These are 10 sec. children in a 1 sec. world" – Diane Malbin
- Hands-on learning, focus on their strengths
- Foster interdependence not independence – This is critical for future success
- Repeat, re-teach, repeat, re-teach, repeat… (And be prepared to do this over and over again)
- Remember that pupils with impairments teach life lessons to everybody else
- Supervise all non-routine situations ALL THE TIME – e.g. Lunch, Morning/Afternoon Breaks

Using Person-First Language

- If possible do not use FASD, FAS, or ARND as adjectives.
- Remember you would never say "a cancer pupil" or a "diabetes pupil."
- "Susan is a pupil with FASD, not, Susan is a FASD pupil."
- "The Greens are a family with FASD, not; the Greens are a FASD family."
- "Mrs. Cunningham has two pupils with FASD, not Mrs. Cunningham has two FASD pupils."
- "He has brain damage from FASD, not he has a FASD brain."
- "Middlesex School has a program for pupils affected with FASD."
- FASD IS SOMETHING YOU HAVE, NOT SOMETHING YOU ARE

- Do not refer to people with an FASD as a "victim" or "struggling with"
- These words put them down and give them excuses ("cuz it's not my fault!")
- These are individuals living with FASD or learning to live with FASD
- They can learn to adapt with constant support but not if they think they are "victims"

Use External Brains

- Friends, teachers, family members and community members should be organized to serve as "external brains" in a circle of support.
- Encourage INTERDEPENDENCE not INDEPENDENCE
- This is something teachers have to learn to do – it is not natural in the school system
- Most people with FASD will need this type of support for the rest of their lives!

External Brains (Dr.Sterling Clarren, FASD expert and researcher)

- Help the child reframe their world
- Provide crutches for an invisible disability
- Provide pro-active and intervention strategies
- Assist the child to process information and to respond more appropriately
- *If you are physically disabled you need a wheelchair.*
- *If you are blind you need a Seeing Eye dog.*
- *If you are a child with FASD you need an external brain.*

Dan Dubovsky, a FASD expert from SAMSHA prefers to use the term "anchor" in place of External Brain but the concept is similar from Clarren and Dubovsky. Anchor focuses more on developing interdependence than the external brain idea.

7-Parent and School Relationships

- "FASD parents" are the ultimate, 24 hour front-line workers and desperately need your support
- These parents only appear to be crazy; they are almost all overwhelmed and super stressed
- FASD experts such as Malbin or Debolt acknowledge that many parents of children with FASD give the impression of being 'over the top'. **They obsess to get proper service**.
- Professionals often assume that FASD is the result of ineffective parenting and family dysfunction but in many cases it is the FASD in the child which is making the family dysfunctional.
- HOWEVER, in many life-giving families FASD goes back 2, 3 and 4 generations. Generation after generation has permanent brain damage. This situation usually presents as different needs

A Little Understanding … Goes A LONG Way

- Suggest strategies for FASD to make the teacher's life easier – use carrots, no sticks
- Stay as calm as you can as a carer
- Take a "friend" as a supportive advocate – this strengthens your position

- Focus on only one change at a time
- Plan in peacetime – not after a crisis!
- Keep records of everything
- Very few parents know…that summer vacations DO NOT make up for 10 months of extremely stressful teaching. They merely allow most educators to get healthy enough to continue to teach the next September – Carers – please keep this in mind.

Talking To Parents and Carers or Pupils Themselves

- Educators should remember that every pupil has parents and/or carers who understand their individual needs better than anyone else
- An involved parent or carer for a child with FASD is generally going to know a lot about FASD and should be considered as an "expert"
- **Educators should assess and never diagnose**!
- If parents are complaining to you about suggestive problem behaviours at home suggest strategies NOT possible causes
- If the strategies you suggest work for them- then maybe you can have a frank discussion
- Adoptive vs Life-giving parental issues – adoptive parents tend to have a little less 'baggage'
- **Don't suggest causes (FASD) to teenage pupils unless they come to you**!

Psycho-educational Tests & IQ

- Average IQ - full FAS - 74
- IQ range- full FAS - 20-130
- Average IQ for FASD – whole spectrum - 90
- Most pupils with FASD cannot "live up" to their IQ scores
- Adaptive testing like Vineland or ABAS produces much more useful information than IQ tests

Examples from one Vineland/FASD Study: with thanks to Allan Mountford - Canada
The average age of students in this study was 16.6 years

* Adaptive Behaviours → Functionally 9.1
* Communication → Functionally 9.0
* Daily Living → Functionally 10.1
* Socialization Skills → Functionally 7.5
* Receptive Language → Functionally 6.8

FASD as a Learning Disability

- FASD is usually not recognized as a specific learning disability
- Many parents feel their children would be better served if FASD were treated as a specific learning disability
- FASD is unlikely to be recognized as a separate educational disability anytime soon!

Then Why Diagnose FASD?

- A pupil's educators MUST know they are dealing with FASD if at all possible
- Early diagnosis tends to prevent secondary effects
- If your child has a diagnosis be prepared to teach his/her educators about FASD
- If FASD is suspected but there is no diagnosis treat it as if it's FASD – effective strategies are just good education and will do no harm

A Word of Warning

- Being classified as Behavioural for Special Education rarely seem to lead to success for a pupil with FASD because it usually relies on Behaviour Modification strategies
- Behaviour modification rarely if ever works with these pupils (because they all have some brain damage). (Behaviour Modification for FASD wastes time and money)
- Rewards and Punishment DO NOT work with FASD or other neurobehavioural conditions and are considered to do considerable harm – read bring on Secondary Behaviours

Serving Pupils with FASD

- Most – regular classrooms with accommodations and/or modifications
- Many- regular classroom with resource room support
- Some – Self-contained classrooms to deal with severe behavioural, problems (safety issues)

Attainment Targets & Assessment

- Programming and attainment targets almost always need to be modified for pupils with an FASD.
- All the expectations in curriculum won't be met, with most pupils who have FASD. Maths, science and reading comprehension are often the most difficult areas to master
- In the most seriously affected pupil there will be a need to teach life skills and blend in academics – the focus should be on life skills which will critical to their survival

Thinking FASD First and accommodating FASD Makes Everybody's Day Better
Missing FASD is not an Option!

8-Specific Strategies for Success for Pupils with an FASD

SCORES - Changing the Classroom Environment is a Good Place to Start
The classroom learning environment has the most effect on pupils' abilities to learn within the ABAS or Vineland-tested settings which we provide. This includes its organization, its management, and its emotional components. The acronym S-C-O-R-E-S can be used to categorize changes to consider making.

S is for:

- **Supervision** - Close supervision to keep pupils safe and out of trouble- 24/7 (Playtime & lunch/dinner times and non-routine and need constant supervision most of all!)
- **Structure** -Teach pupils that every day has a consistent and routine structure to it
- **Simplicity** - Keep rules, routines and directions simple. Give directions orally and visually

C is for:

- **Communication**
  - -Regular and frequent communication between home and school – tracking book/e-mail
  - - Pupils are taught and reminded how to communicate feelings and needs to teacher, peers and others
- **Consistency**
  - -Routines, rules and consequences are consistent
  - -Steps to complete a task are given in the same way every time, usually one at a time

O is for:

- **Organization**
  - -The school helps pupils to become organized by teaching and reinforcing sequential organization strategies – repeat, repeat, repeat
  - -Classroom is organized – a place for everything and everything in its place
  - -The lessons and the day are organized and don't change from day-to-day – No surprises!

R is for:

- **Rules**
  - - Simple, concrete and easy to follow e.g.– "Don't hit" ; "Stay on sidewalk"-
  - - Abstract rules do not work – e.g. Saying be kind or stay safe.
  - - All staff use the same words for each rule and follow the same rules (*With All Due Respect*)
  - - Check to see whether pupils know and understand what the rules mean –ask simple questions
  - - Consequences applied immediately/consistently taking into consideration pupils ' disabilities

E is for:

- **Expectations**
  - -Focus on life skills/social skills vs academics
  - -Realistic, attainable, and easily understood
  - -Modified/take into consideration the special needs of
  - -Clearly specify what is to be expected and accomplished on any given assignment
  - -Limit the amount of work, including homework

S is for:

- **Self Esteem**
  - -Use Person-First Language
  - - Make pupils feel accepted, valued and safe
  - -Positive encouragement is given in a consistent way each day
  - -Pupil's strengths are explored to help them cope with the frustration of things they cannot do
  - - Pupils are reassured that they are not bad even though their behaviour is unacceptable and needs improvement

The "Reach To Teach" Resource – IS EXCELLENT!!! – Strategies that work with FASD

"Educating Elementary and Middle School Children with Foetal Alcohol Spectrum Disorders" Produced by Substance Abuse and Mental Health Services Administration, Center for Substance Abuse Prevention SAMHSA (www.samhsa.gov)

- FASD strategies will not hurt any pupil so when in doubt or waiting for diagnosis go ahead and use these strategies
- All these Special Education strategies are just good teaching
- Most of these strategies will work for most learning disabilities but are crucial for with FASD
- The presentation is an introduction only and teachers should be aware that an endless repertoire can be developed

***Reach to Teach* Strategies**

1. Restructure the Classroom
2. Caring, Consistent Environment
3. Shifting Your Attitude as an Educator
4. Translate Misbehaviour
5. Adjust Teaching Style
6. Make Whole School Efforts

1-Restructure the Classroom

- Seating arrangements that don't change – stay the same all year basically
- Desk fits – feet on floor improves focus
- Tidy room, tidy bulletin boards, calm displays
- Give pupil with FASD a place in the room with a blank or low interest view
- Teacher stands in front of clear spot to teach – few background distractions
- Cover up materials not in use
- Define pupil's physical boundaries
- Close the classroom door – sounds, smells
- Try to have a Calm Corner or "Bunny Hole" (for younger children)

2-Provide a Caring and Consistent Atmosphere

- Consistent, unwavering environment
- No surprises – Routine works!
- Think of this like a handrail on a stairs
- Make rules for learning and behaviour very clear and visible
- Point to the rule on the wall when needed
- Rules should not change from class to class

- ALL staff should understand FASD and reinforce this consistent environment
- When the timetable must change – e.g. Fire drill or a special event work with the pupil beforehand and provide an "external brain" during the event AND…
- Seriously affected pupils may need to be removed – it is not worth a "melt-down"
- A buddy or mentor to depend on or go to may be very helpful for all with FASD

3-Shifting Your Attitude as an Educator

- Make the "paradigm shift" (Diane Malbin)
  ….. FASD is a brain based disability - CRUCIAL THINKING CHANGE
  ….. Think this pupil "can't" not that they "won't" – CRUCIAL THINKING CHANGE
- Focus on strengths rather than problems
- NEVER, EVER remove a strength activity as a punishment – very destructive
- Enlist parent support to understand their child. ("All About Me" workshop & resource)
- Use the parent(s) or carer(s) as an expert resource
- Realize that FASD is usually invisible
- Foster interdependence – build bridges to success but expect them to remain forever
- Use testing to identify individual strengths and learning styles
- Tell yourself that you already have the skills to be successful with pupils with FASD

4-Translate Misbehaviour

- A melt-down means "I am overwhelmed
- Getting fidgety may mean "I don't know what to do here".
- Hitting another pupil may mean s/he was startled.
- Have pupil tested for Sensory Processing Disorders so you can predict "melt-downs"
- Being able to repeat instructions does not mean I understand what to do – give one instruction at a time – could a volunteer help here?
- Trouble with sequencing, order or taking turns may mean "I lost track of the order and don't know where to start."
- Becoming upset at a change in routine may mean that "I have no idea what is coming next and I am scared."

5-Adjust Teaching Style

- Use consistent signals, e.g. Soft bell to indicate that a transition is coming
- Show related visuals, e.g. A book for reading time
- Provide transition buddies to get them through changes in routine
- Share class schedule/rules with parents so they can be consistent at home with routines
- Consider the parents/carers to be experts!
- Tell them exactly what to do, not what NOT to do – too confusing
- Redirect most poor behaviour

- One-to-one supervision during recess and lunch – (any non-routine times)
- Ask parents what works at home-imitate
- Use social scripts to reinforce skills
- Be prepared to re-teach repeatedly
- Tape record lessons for re-use at home
- Build in frequent breaks – these pupils wear out and tire easily
- Duplicate set of texts for home – less loss
- Minimize homework- program modified
- Allow standing to learn if it works (at the back of the class)
- Be concrete and literal - ALWAYS
- Think younger – 2-3 years younger
- Go slowly – 10 sec. children in 1 sec world
- Extra time, fewer questions on worksheets
- Lots of white space on sheets
- Get pupil's attention before starting
- Check for understanding not repetition

6-Make Whole School Efforts

- EVERY staff member in contact with pupils in ANY way understands FASD well
- Pupil has an adult advocate other than the teacher on staff. A "go-to" person
- Ask parents to share with whole staff
- Share what works with other teachers
- Seek testing and assessment for the child
- Ask for classroom support, use volunteers (Volunteers will help spread the word about FASD)
- Seek support from other staff members to reduce your sense of being overwhelmed
- Stay in touch with pupil for a year, help next year's teacher with that pupil
- Advocate for styles that will work even if they are contrary to current educational theory – e.g. consistent seating for the whole year, calming rather than exciting classrooms
  You may need to negotiate/lobby/convince to get these changes to happen

The Silver Lining… Recognize ability not disability!

All pupils with FASD have innate strengths and competencies and bring their gifts to the world. Use a Strength-based approach which celebrates strengths and minimizes weaknesses. This is the good news and a reason for hope; a basis for intervention and educational success exists. Fostering innate strengths and minimizing weaknesses is the basis of success for all pupils with an FASD. Success has been shown to prevent defensive secondary behaviours in those affected. Start from a position of strength with what they do well now. Adapt programs to focus on strengths.

Common Abilities Found in People with FASD

- Art
- Music
- Poetry
- Mechanics
- Hands-On Skills
- Working With Children and Animals
- Computers and Technology in general
- Competitive Sports

More on Typical Strengths and Abilities

- Hands on learners
- Kinesthetic, energetic
- Learn by doing and repeatedly shown
- Good long term visual memory
- Value fairness and can be rigidly moral, comforted by rules and orderliness

FASD & Education Resources (→ means start here – "the best of the best" MKC)

This list of FASD and Education Resources was developed by Mary Cunningham to accompany her June 2012 FASD and Educational Success speaking tour in the United Kingdom.
This tour was organized by FASawareUK (www.fasaware.co.uk) by the founder/full time volunteer and chair Gloria Armistead of Billinge, Wigan.

Educational Success for Pupils with FASD **talks took place in**
Stockton on Tees, Huyton (Nutgrove), Wigan , Skelmersdale, Melrose Scottish Borders, Glasgow, Manchester and Rochdale between June 19 and June 29, 2012.

→ ***"A Team Approach to Supporting Students with FASD"***
http://education.alberta.ca/admin/special/resources/re-defining.aspx- download and print (Alberta Learning and Teaching Resources Branch. (2009) (NEW – Excellent – a must have)

Buxton, Bonnie. (2004) ***Damaged Angels*****.** Toronto: Knopf Canada. (FASD 101 +) (A "must read" for anyone really new to the field of FASD)

FASD Tip Sheets **–** FASD Support Network of Saskatchewan – download and print these 20 valuable tip sheets from **www.skfasnetwork.ca** - Check under "Resources"

FASD Toolkit for Aboriginal Families pp. 20-28. Download and print from website. **http://www.ofifc.org/pdf/20080415_FASD_Toolkit.pdf**

→Florida Department of Education. (2005). ***Teaching Students with Fetal Alcohol Spectrum Disorders, A Resource Guide for Florida Educators***. **http://www.fldoe.org/ese/pdf/fetalco.pdf**

Kranowitz, Carol. (1998). ***The Out-of-Sync Child. Recognizing and Coping with Sensory Integration Dysfunction****.(SPDs)* New York. Perigee Books. (Great book for teachers)

→Malbin, Diane. (2002) ***Trying Differently Rather Than Harder.*** (Purchase only) **http://www.fascets.org/market_place.html** (This is the BEST book on explaining FASD behaviours in my opinion. Every teacher should read this book.)

McFarlane. Heather. ***Fetal Alcohol Spectrum Disorder – A quick guide for schools.*** Lakelands Centre for FASD**.** **www.lcfasd.com** (Great starter resource-order from this website)

Morrish, Ron. (2000) ***With All Due Respect, Keys for building effective school discipline*** AND (1997) ***Secrets of Discipline for parents & teachers***. Woodstream Publishing. (Not about FASD but Ron's methods will help you deal with it.) PO Box 1093, Fonthill ON, Canada, L0S 1E0 905-892-2715, 905-892-8936 **www.realdiscipline.com**

→ ***POPFASD – Provincial Outreach Program For Fetal Alcohol Spectrum Disorder*** **www.fasdoutreach.ca** (On-line teacher education on FASD from BC – Excellent)

→***Reach To Teach – Educating Elementary & Middle School Children with FASD*** **www.fasdcentre.samhsa.gov/documents/Reach_To_Teach_Final_011107.pdf** (The BEST resource book I have seen yet for nursery, primary and early high school teachers)

Strategies Not Solutions Booklet **http://www.betterendings.org/strategies_not_solutions.pdf** **(**An excellent "how to" resource to understand/ deal with the SPDs commonly found in FASD

"Teaching Pupils with FASD, Building Strengths, Creating Hope" **www.education.gov.ab.ca/k_12/specialneeds/fasd.asp** (Alberta Learning and Teaching Resources Branch. (2004) (Has everything, absolutely everything on FASD and Education but will take at least one ink cartridge to print!)

→Yukon Department of Education. (2006) ***Making a Difference: Working with Students who have Fetal Alcohol Spectrum Disorders*** www.education.gov.yk.ca/pdf/fasd_manual_2007.pdf

→ means to start with these resources first – these are the best use of your time

For More Information, Questions and/or Power Point Notes
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