Fetal Alcohol Spectrum Disorders

Students and School

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Fetal Alcohol Spectrum Disorders

'Fetal Alcohol Spectrum Disorders (FASD) is an umbrella term describing the range of effects that can occur in an individual whose mother drank during pregnancy. These effects may include physical, mental, behavioural, and/or learning disabilities with possible lifelong implications. The term FASD is not intended for use as a clinical diagnosis.'
(FASD Terminology Summit Consensus Statement, April 7th, 2004).

How does prenatal exposure to alcohol affect a child?

Alcohol crosses the placenta undiluted, and within minutes, the level of alcohol in the fetus' blood reaches maternal blood alcohol level. Alcohol is a teratogen which can cause

(a) any type of physical malformation (e.g., alcohol exposure has been linked in cases of spina bifida, heart defects, kidney defects, etc.), as well as

(b) learning and behavioural challenges.
(Taken from Stratton, K., Howe, C., Battaglia, F., [eds.], 1996, p.6, Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention and Treatment).

Why teachers need to know about FASD

Since FASD are under-reported and under-diagnosed, teachers may be unaware that one or more of their students were exposed to alcohol pre-natally. These children may exhibit behavioural or learning difficulties.

"Since alcohol is consumed throughout our society, there is no doubt that all teachers have taught and will continue to teach students who have had prenatal exposure to alcohol."
(Lasser, P., [1999: p. 1], Challenges and Opportunities – A Handbook for Teachers of Students with Special Needs with a focus on Fetal Alcohol Syndrome, [FAS], and partial Fetal Alcohol Syndrome, [pFAS]).

"FAS is thought to be the leading known cause of mental retardation in the Western World,"
(Abel and Sokol, 1987).

"Children with FASD have been born to mothers from all socioeconomic groups,"
(Stratton, K., C. Howe, F. Battaglia, [eds.], 1996: Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention and Treatment. p.p. 116-117).

"Children with FASD have intellectual difficulties, but 'only 25% of 178 individuals with the full FAS were classified as having mental retardation"
(Streissguth, Barr, Kogan & Bookstein, 1996), cited in Streissguth (1997:121)

Disorders within the spectrum include

1. Fetal Alcohol Syndrome (FAS) (with confirmed maternal alcohol exposure):

(a) Confirmed maternal alcohol exposure;

(b) Evidence of a characteristic pattern of facial anomalies with features such as short eye openings, a thin upper lip, low nasal bridge, flattened philtrum and a flat midface;

(c) Evidence of low birth weight for gestational age, decelerating of weight gain over time which is not due to nutrition issues and disproportional low weight to height;

(d) Evidence of Central Nervous System neurodevelopmental abnormalities, as in at least one of the following;

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

2. FAS (without confirmed maternal alcohol exposure)
(b), **(c)** and **(d)** as above

3. Partial FAS (pFAS) (with confirmed maternal alcohol exposure)

(a) Confirmed maternal alcohol exposure

(b) Evidence of some components of the pattern of characteristic facial anomalies and any of **(c)** or **(d)** above or

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

4. Alcohol-related birth defects (ARBD)
Congenital anomalies, including malformations and dysplasias

5. Alcohol-related neurodevelopmental disorder (ARND)
Presence of **(d)** or **(e)** as above

Children with FASD may have both ARBD and ARND.
(Synopsised from Stratton, K., Howe, C., Battaglia. F., (eds.), [1996, pp.76-77], FETAL ALCOHOL SYNDROME: Diagnosis, Epidemiology, Prevention, and Treatment).

Why do we not hear about FASD?

FASD is under-recognised and under reported
Diagnosis within the spectrum is uncommon even in countries where there is knowledge of the disorders and access to comprehensive screening tools

FASD masquerades as "other disabilities"
Some of the behavioural manifestations of FASD have resulted in children with FASD being called 'masqueraders'*. For example, children with FASD have been diagnosed as having Attention Deficit Hyperactivity Disorder (ADHD), or Autistic Spectrum Disorder, or Asperger's Syndrome (to list a few examples). Misdiagnosis may be occurring because of the absence of proper screening methods.
*(O'Malley, April 29th Lecture at NISLD, TCD, 2005,)

Some may feel that a diagnosis of a disorder (related to maternal consumption of alcohol) can result in guilt and blame
It is a challenging task for a diagnostician to tell a client that their child has a FASD, just as it is difficult for parents to acknowledge the impact of alcohol consumed during pregnancy. Families often experience guilt and/or blame, and this often prevents others from hearing about FASD.

Children with FASD may be in foster care
Foster parents/carers must respect the confidentiality of the child and biological family and are not often able to refer the child for diagnosis.

How common are FASD?

There are no official statistics available for the prevalence of FASD in Ireland.
Applying the rates of FAS reported by the Substance Abuse and Mental Health Services Agency, Center for Disease Control in the United States (SAMHSA 2005)*, to the 2002 Irish birth rates (Central Statistics Office, 2002), we can estimate that 1%, i.e. 605 of the 60,503 babies born in Ireland in 2002 could have FASD. The incidence may be higher due to the high rate of binge drinking among young women in Ireland.
*(SAMHSA 2005 cited in Ryan and Ní Chionnaith, *On the Spectrum* [2005;4])

From the coalface - "Bíonn siúlach scéalach":

"Our children with FASD struggle in a world that doesn't understand their issues caused from central nervous system damage."
(Kulp, L., Kulp, J., *The best I can be: living with Fetal Alcohol Syndrome or Effects*. 2000. Minnesota; Better Endings New Beginnings.)

"Think: 'Ten-second children in a one-second world.'
(Malbin, D., 2002: *Trying Differently Rather Than Harder*, 2nd ed.)

"You cannot see my disability on the outside. I like to make myself look pretty….I just know I have to live with it"
(Liz Kulp, 2001)

"If I don't learn the way you teach me, why don't you teach me the way I learn?"
(Young woman with FAS, cited in Lasser, p.110).

"Day after day you have to keep going over and over the same issues - re safety, or which part of school uniform to wear, or, most particularly, HOW and WHEN to do WHAT in maths homework!"
(Foster-carer, Ireland, 2005)

"People with FASD live in a world that doesn't understand the link between brain differences and behaviours."
(Diane Malbin, 2002)

"*Children with FASD don't 'grow out of it'. However, with appropriate interventions, they can be greatly helped in achieving their potential."*
(Foster carer, 2005)

Why a diagnosis is important

A diagnosis may lead to intervention, treatment and supports to children with FASD and their families.
Students with FASD experience learning and behavioural challenges. With a diagnosis the student may receive the individualized and specialized services that he/she needs. Parents of children with FASD can then access the necessary supports and services. FASD has life long implications for a child and his/her family.

"A diagnosis before six years of age …. is a strong protective factor for all secondary disabilities except Mental Health Problems",
(Streissguth, Barr, Kogan and Bookstein in Streissguth and Kanter, [eds] The Challenge of Fetal Alcohol Syndrome – Overcoming Secondary Disabilities.,1997:35).

Secondary disabilities include:

- Mental Health Problems
- Disrupted school experience
- Trouble with the law
- Confinement
- Inappropriate Sexual Behaviour
- Alcohol /Drug Problems
- Dependent Living
- Problems with Employment.

(Streissguth, Barr, Kogan and Bookstein in Streissguth and Kanter, eds.,1997:pp33,34).

Some challenges affecting the day-to-day lives and the education of children with FASD.

No two children with FASD are exactly alike, either behaviourally or physically. Some of the co-occurring, behavioural, social and learning characteristics may include:

1. Attention problems or hyperactivity.
(Morse, 1991; Nanson and Hiscock, 1990).*

2. Academic problems, including specific deficits in mathematics and memory skills.
(Streissguth et al., 1993).*

3. Very specific language deficits.
(Abkarian, 1992).*

4. Problems with adaptive functioning that grows more significant with age**.**
(Lemoine and Lemoine, 1992; Streissguth and Randels, 1989).*

5. Behavioural challenges.

6. Social or relationship challenges including difficulty making or sustaining friendships.

7. Sensory impairments such as vision or hearing.

8. Sensory integration challenges including auditory, visual and tactile processing.

All of the above issues are expanded upon in Lasser, (1999, Challenges and Opportunities, p.p.19-23).

*(1-4 cited by Stratton et al., eds., 1996).

Kranowitz, cites research on Sensory Integration Dysfunction, which suggests that a "mother's drug or alcohol abuse", are, *inter alia,* possible factors*. Children with Sensory Integration Dysfunction may be hypersensitive or hyposensitive to stimuli in their environment.
(Kranowitz 1998: The Out-of-Sync Child, p.23)

How teachers can help students with FASD

By working at the developmental, as opposed to the actual age of the child – this would minimise frustration for everyone.
Malbin, (2002, p.26) gives a powerful example of the conflicting range of levels of competency which can occur in a person with a FASD.

By using clear and uncomplicated instructions.
Avoiding figures of speech or idioms. Eye contact and varied tones help the student to do what is required. Sign language can be used to endorse the spoken word in order to maximise the student's receptiveness.

By remembering 'Here Today - Gone Tomorrow'.
What a child may learn today may be a mystery to her or him at a later time. Some children with FASD may only remember information if they can recall where they learned it, or if they are once again in that place.

By understanding that children with FASD may have a memory gap which they try to fill in.
"This confabulation is not lying"
(Malbin, 2002).

By modifying the curriculum to what the child can achieve, with an individual edu*cation plan* for the child.

By remembering that appearances can be misleading.
As Liz Kulp says above, you cannot see her disability on the outside. This is a helpful reminder of the various effects of prenatal exposure. A noticeable disability is more readily accepted and accommodated. It's not that a child won't behave, or won't bother to retain information, it's that she or he can't, without appropriate interventions being in place.

"Mol an óige agus tiocfaidh sí?"
Students usually enjoy being praised for good effort, nice manners, a task well done, etc., particularly students with FASD, who often have low self-esteem. However the student with FASD may be unable to remember, recognise or internalise what the praise was related to. The student may not be able to learn to generalise from this positive experience and may not realise that this could be relevant to other areas, activities and aspects in her/his life. As a result, it is helpful for teachers to review their expectations of the student's ability to learn from, and build on, experiences.

By seating the student where eye contact can be maximised, (but not among or behind students with challenging behaviours).

By remembering that students who are hyposensitive may not feel pain even when they have injured themselves badly.

'Special needs' Assistant for student throughout the school day- in class, yard and on school outings/field trips.
Children with FASD benefit from constant one-to-one support from an assistant who is aware of and sensitive to FASD issues in helping the student

- to follow their personalised Individual Education Plan (IEP)
- to stay 'on task'
- to minimise the possibility of the student either experiencing or causing distractions in class
- to facilitate time-away-from-the-desk (either to meet IEP specifications, or for pre-empting and minimising scenes arising from sensory integration and/or behavioural issues, if necessary
- to get to the Resource Teacher's room
- to support the developmentally-delayed student in the yard where there is much scope for him/her to be overwhelmed physically, and/or psychologically, and/or emotionally, and/or socially and so minimise the possibility of bullying, and of false allegations being made by or against the student with FASD.

How school can help with homework

Pre-prepared sheets with homework tasks already written out will greatly assist students with FASD who are well past senior infants' class, as they

(a) may not be able to take down the list from the chalkboard in time, due to attention difficulties, or processing challenges, etc.
(b) may be experiencing sensory overload.

This may seem to conflict with the goal of having a student work independently, but students with FASD who continuously cannot cope with tasks may experience feelings of inadequacy or frustration, and may have a 'meltdown' behaviourally.

Some Classroom Features

- ❖ Bright and cheerful but using pastel, not bold, colours on the walls.
- ❖ Minimum of distracting features such as posters, etc.
- ❖ Lower part of class windows could be covered to minimise distractions from outside, particularly where break-times are staggered and classrooms are on the ground floor.

Resources for Teachers

'A Demonstration Classroom for Young Children with FAS.' Tanner-Halverson, (1997), in *The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities*, Streissguth and Kanter [eds], (1997).

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