Watch out for 'Jack', he's a real challenge!

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Abstract

Foetal Alcohol Syndrome Disorder (FASD) is a cluster of conditions that are the result of pre-natal exposure to alcohol. Children with FASD may have noticeable facial features as well as intellectual, social, emotional and behavioural difficulties. Providing a loving, structured and supervised learning environment has significant positive impacts on the development of a child with FASD. A teacher can assist a student with special needs in reaching their full potential, through establishing an effective individualized learning plan and building strong relationships with the child and guardian.

"FASD is a leading cause of developmental disabilities worldwide and is also the most preventable cause of learning and behavioural disabilities"

Introduction

As Sharon walked into the Year Three class that day she quickly scanned the room for 'Jack'. Called in as the relief teacher that morning, she had been warned by another teacher that he might be 'quite challenging'. Sure enough, as the day progressed, Jack displayed an inability to follow directions and remember what he had been told, impulsively leaving his seat, a sensory overload reaction to loud noises and then a meltdown when he had to finish a game he was enjoying.

Later that day, Sharon reflected on this attractive little boy with ginger curly hair and a ready smile. What was it about Jack that caused these characteristics? Before she went home, Sharon checked in at the school office and asked to read his file – and there she found the answer. With a history of cognitive and behavioural issues he had recently been diagnosed with Foetal Alcohol Spectrum Disorder, and specifically, ARND (Alcohol-related neurodevelopmental disorder).

Little boys like Jack, and little girls too, face a lifetime fraught with difficulties because their mothers consumed alcohol during pregnancy. This disorder is permanent and totally avoidable; however, research has found that 40 per cent of Australian mothers drink while pregnant. Further, ten per cent of Australian women reported binge drinking at least once during their pregnancy (O'Keeffe, et al., 2015).

Foetal Alcohol Syndrome Disorder (FASD) is a group of permanent disabilities caused by pre-natal exposure to alcohol (Horecka-Lewitowicz, Lewitowicz, Adamczyk-Gruszka, Skawiriski, & Szpringer, 2013). FASD is a leading cause of developmental disabilities worldwide (Miller et al., 2017) and is also the most preventable cause of learning and behavioural disabilities (Judd, 2012).

History

In 1973, Jones and Smith, two physicians at Washington University, who specialised in birth defects, detected a group of children who all had similar defects: small heads, distinctive facial features and cognitive delays. The common link was that their mothers all drank alcohol during their pregnancies. Jones and Smith suspected that alcohol was the teratogen that had damaged these children in utero, despite other medical opinion to the contrary. The two doctors continued to gather data and in 1973 published their first article, naming this condition 'Foetal Alcohol Syndrome' (Jones & Streissguth, 2010). A similar study had been published by Lemoine and his colleagues in France, five years earlier, but it had received little attention. However, by 1988, cautionary warnings for pregnant women became a legal standard on alcoholic beverages.

Over a period of some years following review by various organisations, a number of sub-categories have been identified within Foetal Alcohol Syndrome Disorder (FASD). These, together with their characteristics are displayed in Table1.

As can be seen from Table 1, confirmed maternal consumption of alcohol is present in each

Table 1: Classification of varying levels of Foetal Alcohol Syndrome Disorder (FASD)

Sub-Categories of FASD	Characteristics
Foetal Alcohol Syndrome (FAS)	Confirmed maternal alcohol exposure. At least two of the characteristic facial abnormalities, growth deficiency and Central Nervous System abnormalities such as cognitive or behavioural neurodevelopmental abnormalities.
Partial Foetal Alcohol Syndrome pFAS	Confirmed maternal alcohol exposure. At least two of the facial abnormalities and either growth deficiency or CNS/neurodevelopmental abnormalities.
Alcohol-related Birth Defects (ARBD)	Confirmed maternal alcohol exposure. At least two of the facial abnormalities and one or more congenital organ system abnormalities.
Alcohol-related neurodevelopmental disorder (ARND)	Confirmed maternal alcohol exposure. Normal growth and typical facial features. Some CNS/neurodevelopmental abnormalities.

Source: The National Center for Biotechnology Information, 2018.

of the different sub-categories, with additional characteristics ranging from facial, cognitive and growth abnormalities (FAS) through to normal growth and facial features, but with underling neurodevelopmental abnormalities (ARND).

Causes

Alcohol is a 'Teratogen' , terminology for any substance that causes the malfunction of an embryo (Beauchamp, 2013). Foetal Alcohol Syndrome Disorder is caused by a mother consuming alcohol while pregnant. The alcohol transfers through the placenta to the child; and due to the baby's underdeveloped liver, the blood alcohol is unable to be filtered and is stored in the foetus for extensive amounts of time (Preece & Riley, 2011). The alcohol damages the foetus' nervous system, tissues, and prenatal development by restricting pure blood supply. When alcohol exposure occurs in the early stages of development, it results in permanent brain damage in the child. There is no known "safe" dosage or time to drink alcohol during pregnancy (Beauchamp, 2013) and it is a myth that the placenta filters out harmful substances in order to protect the foetus. A recent study (Creeley, Dikranian, Johnson, Farber, & Olney, 2013, p. 1) found that exposure of a foetal brain to alcohol, on a single occasion, resulted in the acute and widespread apoptotic—genetically directed (programmed) cell self-destruction—death of both grey and white matter brain cells.

Unfortunately, some populations have a higher than average incidence of FASD, such as those children in care, with estimates of up to 50%; and further 23% of those admitted for psychiatric treatment in British Columbia had FASD (Millar et al., p.6).

Management

Identification

FASD is a completely preventable condition but still accounts for the majority of intellectual disabilities. Though approximately nine in 1000 live births are children born with FASD, current research suggests that one in 20 school children in the United States of America (5% of the total population) have undiagnosed FASD (Judd, 2012). Early diagnosis is key to the management of FASD. However, the average diagnosis age is sixyears old. Early diagnosis is uncommon for FASD as high rates of cases of adoption amongst children with FASD means that parental history is lost (Millar et al., 2017). Often known as the hidden disability, as facial characteristics frequently develop later in childhood, FASD is often mistaken for Autism Spectrum Disorder and misdiagnosed as other behavioural and intellectual conditions (Mukherjee, Layton, Yacoub & Turk, 2011). Children with FASD who are diagnosed early have a higher chance of learning social norms, developing their strengths, and making a contribution to their community.

The widespread damage to the brain caused by alcohol poisoning in utero is illustrated in Table 2 where the injury can be seen to affect many areas of the child's cognitive potential as well as most other aspects of life.

The paradigm shift adaptation

Perhaps the most important aspect of meeting the needs of a child with FASD is what Miller et al., (2017, 14) call a 'paradigm shift'. This means that rather than trying to get the child to fit in with the rules and regulations designed for typical children, the teacher identifies the child's specific needs, ensures that the Individual Education Plan

> *"some populations have a higher than average incidence of FASD, such as those children in care, with estimates of up to 50% with FASD"*

Table 2: Brain domains affected by prenatal alcohol exposure- Adapted from Millar et al., 2017, p. 4

Domain	Descriptors
Physical motor skills	Children may have poor coordination (hand/eye and total body) and sensory input (regarding needed force/pressure) and abnormal muscle tone that affects balance. They may also have an immature grasp and manipulation patterns when using pencils and scissors.
Sensory processing skills	Children may be oversensitive and feel 'bombarded' by sensory information or they may seek out intense sensory information. The sense of overstimulation affects the inner sense of calm resulting in anxiety, aggressive or defiant behaviour and inability to learn/perform.
Cognition	Problems include learning difficulties, deficits in school performance, poor impulse control, problems in social perception, deficits in higher level receptive and expressive language, poor capacity for abstract thinking; deficits in mathematical skills, and problems with memory, attention, judgment or organisation. (Children may seem above average in one area and well below average in another.)
Communication	Expressive language skills may develop at a slower rate than normal. Problems using complex language structures and problems retrieving words from memory. Receptive communication deficits may include problems with following instructions, comprehension, discrimination, generalisation, abstraction and sequencing.
Academic achievement	Deficits in comprehension, abstract thinking, comprehension and communication that can impact academic achievement in multiple areas (e.g., math, science, vocabulary, direction/temporal concepts and arts.
Memory	Children may have problems with each of these processes. They may have remembered or done something many times before and be unable to remember or do it on a given day.
Executive functioning Abstract reasoning	Children may have decreased common sense and repeat the same mistakes. They often do not recognise consequences, learn from past experiences or generalise possible outcomes from one behaviour to another.
Attention deficit/ hyperactivity	Children may be easily distracted by visual and auditory stimulation that may not even be noticed by the other students. They may have problems self-regulating when they are overstimulated or tired.
Adaptive behaviour	Children have decreased capacity to develop/acquire new social, practical and conceptual skills to help them better respond to daily demands.

> *Children with FASD have many behavioural problems including fussiness, jiittering, trouble sleeping and trouble with the law … Many of these stem from a struggle to understand social and behavioural norms*

(IEP) goals and strategies align with the domains (Table 2) that need support and adapts the learning environment as needed.

Learning strategies

Table 3 outlines some of the learning strategies that are relevant for children with FASD.

Physical implications

FASD is sometimes termed a "silent disability" (Brown & Mather, 2014) as not all affected children will display "noticeable" symptoms. Additionally, children often outgrow the significant facial characteristics of their disability. Delayed development resulting in an individual being shorter than their peers; heart, bone and kidney problems; vision and hearing problems; potential seizures and poor balance and coordination due to underdeveloped fine motor skills are also issues that these children face (Horecka-Lewitowicz et al., 2014). A child born with FASD often suffers a double-burden due to these health effects which impinge on all other aspects of their lives and may trigger other health complications as they grow older.

Social implications and strategies

Children born with FASD are often put up for adoption (Brown, 2015). In many cases, adoptive parents may struggle to understand why their child has many behavioural problems. It can take years before parents discover the underlying cause of their child's behaviour. Children with FASD have many behavioural problems including fussiness, jittering, trouble sleeping and trouble with the law (McLean, McDougall & Russell, 2014). Many of these stem from a struggle to understand social and behavioural norms. Brown (2015) notes that these behaviours are not non-compliance, they are in fact an aspect of the disability. Due to this social unawareness, which is often diagnosed as Autism Spectrum Disorder,

Table 3: Basic classroom strategies to support learning for students with FASD

Learning Strategy	Explanation
Create an Individual Education Plan (IEP) / Universal Design for Living (UDL).	Plan and Implement a collaboratively designed IEP, incorporating Universal Design for Learning principles, aligned with the individual child's specific needs.
Provide a logical, structured, consistent routine with close supervision	Hyperactivity coupled with decreased common sense and distractibility, will benefit from a closely supervised routine which will aid in the development of self-regulation.
Ensure a calm, organised, tidy classroom	A peaceful classroom environment will reduce the problem of over stimulation and may provide an antidote to anxiety.
Teach in small, segmented chunks, using scaffolding	Teaching in small steps, together with scaffolding, helps address the issue of memory impairment
Engage through multisensory teaching, including demonstrating	Using a variety of approaches: visual, tactile, auditory and kinaesthetic. Using pictures, stories and role-play. Use of assistive technology to support memory, writing, reading, and numeracy.
Provide personal space/refuge	Placing a tent at the back of the room, a bean bag, a reading nook, all can provide a place of calm for the child to re-focus and relax in. Use headphones at times to reduce distractions.
Schedule several 'brain breaks' of physical activity through the day	Breaks including physical activity will help the child to relax, improve mood and then re-focus.
Positive, affirming communication	Positive communication will encourage improved self-esteem. Teaching listening skills will ensure effective transmission of affirmation.
Visual and tactile materials	Timetables, timers, desk reminders, charts, colour coding … all support memory and organisation.
Clear, concise instructions	Teachers should: give direct, clear and concise instructions; engage in a lot of carefully selected small group work, so as to include students with FASD into the class in a supportive relational environment.

Source: McLean, McDougall & Russell, 2014

"Mental health issues can stem from their guilt from feeling continually dependent on others to integrate into society and perform everyday tasks. … they may also have to deal with … being adopted and not knowing their biological parents"

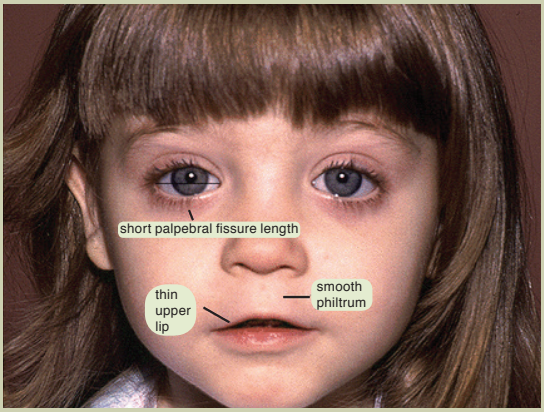
people with FASD often have inappropriate sexual behaviour, drug and alcohol problems, problems with employment and may require dependent living as they grow older (Kellerman,2003). "Individuals with FASD are significantly overrepresented but undertreated in psychiatric populations, the child welfare system, and juvenile detention and correctional settings" (Paley & Auerbach, 2010, p. 508). For individuals from rural, indigenous or low socio-economic communities, inability to access the services and support required to care for a child with FASD can place the child at an even deeper disadvantage.

Early diagnosis is crucial to a child with FASD receiving the proper social support during important early development. Organising access and eligibility for services plays a role in providing a supportive, safe and stable classroom. Setting clear, firm boundaries and repeatedly reinforcing them is crucial in the learning of social norms. Further, it is essential that consequences are logical, known and consistently applied. Setting up a buddy system can help reduce bullying and provide positive support and social interactions. Promoting problem solving strategies and careful decision-making for these students, will help them in developing appropriate behaviour. Much repetition will be needed as those with FASD find it hard to remember and to generalise across different settings.

It is essential that the teacher understands FASD. Brown (2015) states "The children suffer from sensory processing and integration disorders culminating in sensory overload that manifests as tantrums or emotional eruptions" (p. 251).

Individuals with FASD recorded high rates of mental health problems (Kellerman, 2003). Mental health issues can stem from their guilt from feeling continually dependent on others to integrate into society and perform everyday tasks. For many children with FASD, they may also have to deal with

Figure 1: Main FASD facial characteristics (Horecka-Lewitowicz et al., 2014)



Noticeable physical features that are visible on a person with FASD include:
- an underdeveloped jaw,
- thin upper lip,
- smooth philtrum (upperlip midline goove),
- small eye openings,
- a low nasal bridge,
- epicanthal folds (corner of the upper eyelid),
- a flat midface and
- a short nose

Other physical implications associated with FASD include
- low birth weight and
- later struggles to gain weight.

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the struggles that come with being adopted and not knowing their biological parents. Students with FASD also struggle with change. Order and consistency in their routine are critical for their emotional well-being and stability.

Teacher responses

When a student with FASD is made known to a teacher, he/she should follow a set of initial educational strategies to ensure the child is provided with the understanding and support needed. Firstly, the teacher must read the student's file. If the school does not have a file, contacting a previous educational institution should be an early response. Following this, the teacher should organise a transdisciplinary meeting with parents, doctor, specialist teacher, teacher aide and any others that can assist in establishing an IEP for this student (State Government of Victoria, 2017). Making sure the school has the correct access to facilities and support for this student is important in sustaining a safe learning environment. Finally, the teacher should take time to talk to this student and develop a relationship with them. Through getting to know the student, the teacher can better understand the students' needs and strengths.

Parental perspectives

Parents who have a child with FASD are often suffering from feelings of guilt, including the perceived loss of their child (Rosenbaum, 2017). A teacher of a student with FASD will need to have effective communication with the parents/carers of the child. Ensuring that empathy and inclusion are shown at all times is essential and a great way to build the relationship. Parents can provide innumerable insights into the student's behaviour. It is necessary that the teacher listens to these parents and while being an advocate for the student, is also a supportive resource for the parents (Rosenbaum, 2017). As the student is a minor, the teacher should always make decisions with the parents, as this is specifically crucial in gaining the parents' support and trust.

Back to Jack

The tragedy is that so many children with ARND, look perfectly normal but perform well below their potential because of their disability. Teachers may not realise that the learning and behaviours displayed by the child, such as described in Table 2, directly result from the alcohol-caused damage to the immature brain of the foetus, rather than any deliberate action by the child.

Conclusion

Taking the time to support a child with special needs, in this case, FASD, can be the difference between that child reaching a full potential or ending up in prison. Through a multifaceted approach, the wellbeing of this child can develop and improve as he/she acquires the skills to cope with physical, intellectual and socio-emotional impairments.

Resources and support

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