

Fetal Alcohol Spectrum Disorder, Adaptive Behaviour and Children's Development

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Prenatal alcohol exposure can result in significant cognitive deficits that impact a child's ability to successfully function in today's world [1]. Children who have been alcohol exposed and meet strict diagnostic guidelines are diagnosed with a Fetal Alcohol Spectrum Disorder (FASD) [2]. FASD has detrimental effects on a person's ability to learn, live independently, and individuals with a FASD have a propensity toward criminal behaviour and co-morbid mental health issues [3-6]. Contact with criminal justice and mental health agencies are likely to increase if the child or individual with FASD is unsupported and unable to manage their affairs independently. This paper will outline the adaptive behaviour difficulties facing children and adolescents who have a FASD and consider whether current services are meeting their needs.

Prevalence

Current worldwide FASD prevalence data agree on at least 1 per 100 [7] but some research has estimated prevalence to be between 2-5% [8]. More recently there have been reports of 13-20% prevalence in some high risk international communities [9, 10]. Although no prevalence data exists for our New Zealand population there is, however, research indicating that some mothers continue to drink alcohol whilst pregnant [11-14] and therefore there is a population who are at risk for an FASD.

Adaptive Behaviour

Adaptive behaviour is defined as the ability to care for oneself, interact in a social world, and function in the community [15]. It includes skills such as communication, self direction, maintaining health and safety and participating in leisure and social activities. An assessment of Intellectual Disability includes a measure of general intellectual functioning and adaptive behaviour [1] and in general, adaptive behaviour correlates with general intellectual functioning (IQ). Children with FASD, however, typically demonstrate lower levels of adaptive behaviour relative to their level of intellectual functioning [1, 16]. The most influential theory regarding this discrepancy between adaptive behaviour and intellectual functioning is that it may be linked to significant executive functioning deficits found in FASD [1].

Executive Functioning

Executive functioning encapsulates processes of attention, flexible thinking, goal setting, decision making and problem solving [17, 18]. Children with FASD have been noted to experience difficulties in all of the above aspects of executive functioning [18-21]. The ability to plan, organise and shift attention in a goal-directed way appears to be particularly impaired in people with FASD. There is empirical, as well as anecdotal, evidence suggesting that in FASD difficulties in these cognitive processes emerge when tasks become complex, and the environment more

challenging [21, 22]. All of these processes may directly affect an individual's ability to be independent in today's challenging world.

Adaptive development in children and adolescents with FASD

As children mature into adolescence, adaptive skills typically grow and the children are able to increase their amount of independence and responsibility within their family and school communities. However, increasing adaptive behaviour requires increased skills in planning, organising, reasoning and controlling impulses. Children with FASD consistently have significant impairment in these areas and these difficulties continue into adolescence whether or not the individual has a concurrent diagnosis of intellectual disability. Some research suggests that adaptive functioning deficits increase in adolescents with FASD even more than we would expect from children who have a specific learning disability [23] or who experience psychiatric diagnoses [24]. In a recent study adaptive social skills were noted to significantly decrease in a group of 13-20 year old adolescents with FASD when compared to a group of children 8-12 years [25]. This difference was not observed within an IQ-matched comparison group with a specific learning disability who showed an improvement in their social skills as they matured.

We know some children experience a 'double jeopardy' where parents continue to use alcohol and there can be a higher prevalence of violence, abuse and neglect in the home [26]. However not all children experience post natal adversity especially in the case of children who are adopted or where parents do not have long standing addiction or mental health issues. Those children who are neurologically compromised by prenatal alcohol exposure and experience an adverse post natal environment may be more likely to experience increased social, emotional, cognitive and adaptive difficulties. Nevertheless even without the exacerbating factors of poor post natal care children with FASD continue to experience marked difficulties in their adaptive behaviour and ability to successfully navigate their way through school, home and community environments.

Why current services may not be sufficient

Adolescents are required to adhere to a higher standard of acceptable behaviour than what is expected of younger children. This is due to the typical development of cognitive skills such as inhibiting impulses, goal directed planning, and managing emotions. These areas are described to be particularly impaired in those who have been diagnosed with an FASD [18-21] and directly relate to being able to manage increasingly more complex social situations.

In New Zealand as in many countries around the world many children with special needs are educated in mainstream schools and integrated into everyday community life. In primary school the environment is relatively consistent with one teacher and one classroom for the child to negotiate. In this environment a child with FASD can be managed relatively well by providing structure and strategies to suit a child's specific profile. Once the child enters middle childhood many of the cognitive difficulties associated with FASD become more apparent and the gap widens between the child with FASD and their typically developing peers [27].

As the child moves into adolescence and into high school the environment becomes increasingly complex and highly stimulating. Each day adolescents are required to move classrooms multiple times, experience a variety of teachers and teaching styles and cope with a change of peers with each move. For a young person with significant difficulties in attention, organisation, planning and social skills this environment is extremely challenging. Subsequently these adolescents often act out, sometimes aggressively, due to their difficulties in impulse control, social communication and sensory processing. A difficulty generalising past learnings to new situations means that everyday challenges must be re-experienced and solved once again. Learning depends on being taught by rote and integrated through repetition.

Many of these adolescents are currently in school undiagnosed. They are often in trouble due to difficult behaviour and have a number of learning needs. Without advocacy by family, education or community agencies they may leave school early, without qualifications, and fall into deviant peer groups. Unfortunately many of these youth go on to have secondary psychiatric disabilities and trouble with the law [4, 6]. For school success children and adolescents need appropriate assessment and then implementation of learning and behavioural plans that take into account the need for routine, consistency and structure[28].

Some children with FASD also meet criteria for intellectual disability. If a child has a concurrent intellectual disability diagnosis then they are accepted into disability support services and a Needs Assessment Service Co-ordination (NASC) will visit with the family to see what services they and their child may qualify for. However, children with a FASD demonstrate significant impairments in their everyday functioning despite having an IQ above the cut off for intellectual disability. For these children service needs to be based on functional disability not IQ. Measures of adaptive function better encapsulate the difficulties they experience in everyday life.

What do we need?

Many children and adolescents with FASD remain undiagnosed. For those children who are diagnosed it seems that few supports are available at a time they need it most. In adolescence the social, educational and community environment becomes increasingly complex. However at this age youth are expected to adhere to higher standards of behaviour and become increasingly independent. This is at odds with the profile of an adolescent with FASD whose adaptive and social behaviour has been shown to decrease when compared to other children with similar difficulties but have not been alcohol exposed. So what is required? In short a place to start would be:

- 1) Access to disability services should be based on level of disability rather than IQ.
- 2) More children and adolescents need to have access to quality FASD assessments that include a neuropsychological profile to help develop learning and behavioural plans.
- 3) More educational support is required to enable these children to stay in the school environment and access what is a right for all other children.

FASD is a lifelong disability and those affected need structure, support and supervision to lead productive successful lives. In other countries FASD is widely recognised as a disabling condition with high levels of risk involved for the affected individual, their family and society when not appropriately recognised and accommodated.

Andi Crawford is a Clinical Psychologist who is involved in the assessment and diagnosis of children and adolescents with developmental difficulties including FASD. She is enrolled in the Doctoral Programme at the University of Auckland and her PhD research aims to investigate executive functioning, social cognition and adaptive behaviour in children with fetal alcohol spectrum disorders.

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