

Fetal Alcohol Syndrome

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More than 25 years have passed since fetal alcohol syndrome (FAS) was first identified and named as a birth defect (Jones and Smith, 1973). Since that time, FAS has been recognized as the leading cause of mental retardation in the United States (Abel and Sokol, 1986; Clarren and Smith, 1978). The incidence rate is about 2 fully affected children for every 1,000 newborns in the United States (Abel, 1995), making it more prevalent than Down's syndrome or spina bifida. In some Native American populations, the incidence rate is considered 10 times higher. Another 10 in 1,000 babies will show many, but not all of the problems associated with FAS. FAS, and its counterpart—referred to as Fetal Alcohol Effect (FAE), Alcohol Related Birth Defect (ARBD), or Alcohol Related Neurodevelopmental Disorder (ARND) (Stratton, Howe, and Battaglia, 1996)—is a permanent, and entirely preventable birth defect, that results in lifelong disruptions in cognitive, linguistic, and social development.

FAS refers to a pattern of congenital malformations seen in children born to women who consume large amounts of alcohol during pregnancy. When a pregnant woman drinks alcohol, it crosses the placenta and circulates in the bloodstream of the fetus. When this occurs, alcohol decreases the amounts of oxygen and nutrients that the fetus receives. As a result, alcohol can have a direct effect on the cell of the fetus, disturbing or inhibiting the normal pattern of cell growth and development. Thus, alcohol is a known neurobehavioral teratogen: it can cause birth defects, central nervous system dysfunction, and mental retardation (Carmichael-Olsen, Streissguth, Bookstein, Barr and Sampson, 1994).

Diagnosis of FAS is based on the presence of features from three main areas that include growth deficiency for genetic background, specific facial appearance, and central nervous system dysfunction (Astley and Clarren, 1996; Jones and Smith, 1973; Streissguth and Kanter, 1997). It is not yet clear why one child exposed to alcohol before birth shows FAS, while another is affected but does not show the full syndrome, and yet another is apparently unaffected. Likely factors, though, include the amount, timing, and conditions of the exposure to alcohol, as well as the characteristics of the mother (e.g., her ability to metabolize alcohol and her age).

The core features of FAS along with descriptions are provided below:

Growth

The child with FAS is typically small in stature (height and especially weight) (Burgess and Streissguth, 1992). Physicians, who are trained to recognize birth defects, look for growth deficiency—low weight and/or short length at birth that continues into childhood. Generally, findings for height, weight, and head circumference less than or equal to the tenth percentile are considered a significant finding (i.e., 90 percent of the population have greater height, weight, and head circumferences) (Astley and Clarren, 1997).

Facial Features

Children with the diagnosis of FAS have a common set of facial features that set them apart from other children. As head circumference is below the tenth percentile, microcephaly (an abnormally small cranium)

is common among these children. Distinctive facial features include short palpebral fissures (the measured distance between the eye corners), an indistinct or absent philtrum (the ridge between the upper lip and bottom of the nose), and a thin upper lip. Other facial features common among these children—but less diagnostically significant—include epicanthal folds (folds in the inner corner of the eye), ptosis (drooping eyelids), midface hypoplasia (under- developed maxilla), and posteriorly rotated ears. Other common features to these children can include small teeth with faulty enamel and skeletal anomalies (i.e., cervical-vertebral, finger, and arm defects) (Jung, 1989).

Brain

The Central Nervous System manifestations of FAS include measures of general intelligence (IQ), mastery of reading, spelling, arithmetic, and general level of adaptive functioning. These are referred to as “primary disabilities” (Streissguth, Barr, Kogan, and Bookstein, 1996). As there is variability in the presentation of FAS (Astley and Clarren, 1997; Streissguth et al., 1996), there is also variability in the IQ scores that children with FAS demonstrate. While the average IQ for FAS children is in the 65 to 70 range (mild, mental retardation), scores can also range from severe retardation (below 50) to normal intelligence (above 85) (Streissguth, Clarren, and Jones, 1985). Interestingly, however, children with FAS present with considerably lower Adaptive Behavior scores relative to their respective IQ levels. An Adaptive Behavior score is composed of three skill areas—Daily Living skills, Communication skills, and Socialization skills. In fact, the relative deficit in these scores is considerably greater than their shortfalls in academic achievement.

Adaptive behavior deficits are well documented in children with FAS (Klienfeld and Wescott, 1993; Streissguth, et al, 1996; Streissguth and Kanter, 1997). Parents and caregivers have noted that individuals with FAS give little evidence of learning from personal experiences. They repeat the same inappropriate behaviors regardless of consequence and make poor social judgements on a routine basis.

Other Common Malformations:

- Congenital anomalies of the heart (Ventricular Septal Defects most common)
- Renal anomalies

Other Common Issues:

- Poor coordination
- Short attention span
- Behavioral problems
- Hyperactivity
- Poor social and play skills
- Impulsivity
- Poor cause-effect understanding
- Concrete thinking
- Limited organizational skills
- Poor language use

As a Speech and Language Pathologist, I am particularly interested in the social use of communication. In order for children to exchange information, initiate and develop social relationships, assert needs or wants, or cope with changing environmental demands, they need to develop the social-communicative

functions of language (Walker, Schwartz, Nippold, Irvin, and Noell, 1994). Through social communication, individuals can effectively influence daily occurrences in their lives. This is accomplished through activities such as social interaction and understanding, information sharing, and understanding intended meanings (Frith, Happé, and Siddons, 1994). As noted, however, children with FAS commonly demonstrate disrupted social communication skills.

This is, in my view, one of the most intriguing issues surrounding children with FAS and FAE/ARND. These youngsters are verbal but not communicative. In fact, the language form (syntax, morphology, and phonology) and language content (word knowledge and world knowledge) of school-age children with FAS is generally within the normal range of development on standardized assessment (Abkarian, 1992; Kleinfeld and Wescott, 1993), with expressive language skills being significantly higher than their auditory comprehension of language. Thus, they have a tendency for verbosity.

Interestingly, however, children with FAS do not use their strong language skills effectively. They are noted to frequently interject comments based on personal experiences that are unrelated or just remotely related to the given topic. And when confronted with social situations, children with FAS have been noted to be unable to perform appropriately (Clarren et al., 1994). They have difficulty with tasks that require them to say and understand more than one word at a time. In the language skills of children with FAS, there appears to be a discrepancy between their linguistic abilities and the social use of those abilities (Coggins, et al., 1998). This discrepancy makes it difficult for youngsters with FAS “to live and participate in social environments” (Streissguth, 1992, p. 26). And, unfortunately, this gap does not appear to lessen with age; adolescents and adults continue to demonstrate poor socialization and communication abilities despite their talkative disposition (Streissguth, Aase, Clarren, Randels, LaDue, and Smith, 1991).

A social communication deficit may also play a role in other descriptive or characteristic behaviors of FAS children noted by both parents and caregivers (Burgess and Streissguth, 1992). These behaviors include the following:

Poor social skills. Children with FAS are noted to demonstrate a limited desire to please socially significant people and have a limited social attachment. These children frequently exhibit poor social judgement.

Impulsive. Children with FAS are frequently noted to act on sudden impulse. They appear to give little evidence of forethought. This maladaptive behavior has been distressing to many families who have come through the University of Washington’s FAS Diagnostic and Prevention Network Clinic. For example, they describe their children with FAS as youngsters who dart in traffic or who touch stoves despite being told that it is on and hot.

Poor understanding of cause-effect. Children with FAS are known to repeat the same inappropriate actions despite the consequences involved. Regardless of how much structure and support is provided, these children give little evidence of learning from experience. Thus despite repeated warnings about the dangers of traffic, or being involved in an auto-pedestrian accident, these children have been known to repeat the same action (such as running out into the street), time and time again.

Concrete thinkers. Many children with FAS are capable of making reasoning-based decisions for problems that exist (are concrete). They give little evidence, however, of being able to make decisions based on critical thinking—hypothesis building and testing. For example, a child with FAS who observes a chemistry experiment is able to understand that a certain set of colorless chemical liquids can be combined to create the color yellow. As concrete thinkers, however, children with FAS only obtain the result (i.e., the

color yellow) through the process of trial and error. And once the correct combination of liquids is found, concrete thinkers cannot reproduce their success immediately without further trial and error.

Limited organizational skills. Planning and executing a series of goal-related actions is genuinely difficult for children with FAS. Thus, referring back to the chemistry example above, these children are unable to approach the problem in a systematic manner; they are unable to sort through the combinations of different variables in order to achieve the result (in this case, creating the color yellow).

Early Intervention

One of the most critical elements in determining and altering the prognosis for a child with FAS or FAE is early intervention (Burgess and Streissguth, 1992). The earlier in the child's life that educational, clinical, medical, and family support services can begin, the better the outcome (Burgess and Streissguth, 1992; Hinde, 1993; Streissguth et al., 1996). It is important to clarify here, that early intervention can by no means overcome the damage that alcohol imposes; children with FAS or FAE are not just simply learning disabled, meaning it is doubtful that they will catch up to and be indistinguishable from their peers after an educational push. Rather, early intervention can dramatically improve life skills as well as provide the groundwork for later development (Burgess and Streissguth, 1992; Hinde, 1993). To date, there is not a curriculum for teaching children with FAS or FAE; most authorities who research FAS, however, recognize the importance of early intervention and make that recommendation (Burgess and Streissguth, 1992; Hinde, 1993; Roebuck, Mattson, Riley, 1999; Streissguth and Kanter, 1997).

A common theme in the literature is that there needs to be stable environments that are both structured and nurturing (Hinde, 1993; Grant, Ernst, Streissguth, and Porter, 1997). As such, one key element to effective early intervention programs for FAS or FAE children is support in the form of advocacy for the parent. Early intervention programs with this component can lesson possible future "secondary disabilities" in children, adolescents, and young adults with FAS or FAE (i.e., mental health problems, disrupted school experience, trouble with the law, confinement, inappropriate sexual behavior, and alcohol/drug problems (Grant et al., 1997).

As an example, Grant and colleagues (1997) offered a four-step, birth-to-three, advocacy model. The steps of this model were to:

- Establish a strong advocate-client relationship
- Identify and achieve meaningful client goals
- Create links to service providers
- Role model and teach basic skills

This model could easily be established and implemented by home-based early interventionists.

As mentioned, children with FAS tend to use the language skills they have ineffectively; many have a pragmatic deficit. These children appear unable to produce relevant and related utterances to the topic at hand. In other words, they lack social-communicative competence. As such, it is critical that the social use of communication be a component of early intervention and throughout their schooling.

To do this, however, Speech-Language Pathologists, Child Developmental Specialists, Educators, and Special Educators, need to see beyond the formal test measures used to qualify children for services.

Remember, these children typically obtain low-average to average standardized test scores on expressive and receptive language measures. These scores become meaningless to parents, caregivers, and teachers when the child is exhibiting inappropriate, one-sided interactions or is continually making poor judgements in social situations.

To ameliorate this conundrum, a broad goal of developing and using socially desirable behaviors should be considered for the majority of these youngsters. This is a goal that promotes, in essence, the language skills they do have, while maintaining a focus on their need for functional, social competence.

In order to treat a child's social competence, researchers of other children with social-communication deficits (e.g., children with autism spectrum disorder or children with Asperger syndrome) suggest that clinicians, educators, and parents use a two-pronged approach (Attwood, 1998). The focus of the first prong—the external approach—is to manipulate the child's environment so that there can be in change in performance. Examples of this method range from changing the expectations of those who interact with the child to structuring the environment. These children need prompts, cues, and consistent reminders. Picture schedules and checklists are common techniques employed. Another commonsense external manipulation is to provide routines: consistent expectations and predictable steps promote success.

The other prong then, to treating social-communicative competence deficits, is to teach the child strategies that will help them compensate for their existing deficit. This is known as an internal approach. By directly targeting and teaching behaviors that are needed to be a successful communicator, one can change the child's abilities. As an example, children with FAS might need to be taught the steps involved in how to perceive a communication breakdown (e.g., the listener's facial expressions or body language). Once this is accomplished, they would need to learn what the options are for when a breakdown occurs and how to act on those options (Attwood, 1998).

Summary

Children with FAS present some unique challenges for educators, related-service personnel, and school districts. As there is variability in the presentation of this syndrome, there must also be a range of treatment and service options available. A specific curriculum that would serve all children with FAS and FAE is unlikely. There are themes, however, that professionals should be aware of: generally, these youngsters have poor adaptive skills and poor social use of language; gauging their language abilities solely through standardized testing seems unwise. Early intervention programs are important as they can lessen possible future “secondary disabilities” in children with FAS or FAE. These children need structure, consistency, and repetition. External and internal treatment approaches can and do help these children cope with social situations as well as learn new skills. And lastly, although FAS is a permanent birth defect that results in lifelong disruptions in cognitive, linguistic, and social development, the future of these youngsters with good intervention and planning is not hopeless.

A complete bibliography is available upon request from AAHBEL.

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