

School of Education

Faculty Publications and Presentations

Liberty University

Year 1999

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Educators

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Available from Eric Clearinghouse on Disabilities and Gifted Education

Abstract

Fetal alcohol syndrome has been recognized as one of the most common causes of mental retardation and has also been indicated as a cause for a variety of other learning and developmental disabilities. This paper provides a discussion of definitions, historical precursors, and prevalence figures for fetal alcohol syndrome and highlights relevant medical and behavioral characteristics. The paper also addresses the educational implications of working with children with fetal alcohol syndrome in terms of instruction and curriculum.

Fetal Alcohol Syndrome: Implications for Educators

Educators and child care providers today face a new community of children identified as one of the fastest growing populations at-risk for learning difficulties in the United States (Kinnison, Sluder, & Cates, 1996). This growing population is due to exposure to drugs and alcohol prenatally. A key contribution is prenatal exposure to alcohol. Fetal Alcohol Syndrome (FAS) is now recognized as the leading known cause of mental retardation in the Western World (Burgess & Streissguth, 1992). Some startling facts have come to light concerning the exposure of children to conditions that can negatively affect their learning and create risks of cognitive disabilities and school failure (Price & Stevens, 1992). It is imperative that school personnel understand and comprehend the concept of FAS and the implications for instruction and curriculum for students who are FAS-affected so that appropriate efforts are made to assist these children in their school and community experience.

Definitions

A teratogen is a prenatal exposure that may adversely affect the developing fetus (Bothuis, Dyke, Dyken, & McBrien, 1996). Alcohol is a teratogenic drug. Exposure to alcohol during gestation can damage an embryo or fetus (Bookstein, Barr, Sampson, & Streissguth, 1996). The term fetal alcohol syndrome was coined in the United States by Jones, Smith, Ulleland, and Streissguth in the early 1970s in a report of their study of eight unrelated offspring born to chronically alcoholic mothers. These offspring showed a pattern of abnormal growth and physical characteristics (Howard, McLaughlin, & Williams, 1994). FAS is correctly diagnosed when children meet the following three

criteria: growth deficiency; a specific pattern of minor anomalies; and central nervous system (CNS) damage (Streissguth, 1997).

Other children who are exposed heavily to alcohol before birth may have one or two of these primary features, but not all three. According to Streissguth (1997), children who have only some of the characteristic of FAS are often said to have fetal alcohol effects (FAE) or possible fetal alcohol effects (PFAE). Children with FAS are not necessarily more severely affected than those with FAE, but they most often will be. The term FAE has been criticized because it is not officially recognized as a “diagnosis”. Consequently, it is often more difficult for children with FAE to get needed services because they do not have a medical diagnosis. However, the FAE concept is widely used and recognized among parents and clinicians (Streissguth, 1997). Children with FAE may be in need of the same type of services as those with full FAS.

Historical Precursors

It has been known since Biblical times that alcohol ingestions during pregnancy resulted in fetal abnormalities. In Scripture, this is reflected in passages such as this: “Behold thou shalt conceive and bear a son: now drink no wine or strong drinks” (Judges 13:7). Centuries later, during the “Gin Epidemic” in England (1720-1750), when cheap gin was popular and widely available, a rise in the number of children who were retarded and physically malformed led to admonishments about drinking during pregnancy. The College of Physicians called for a gin tax to discourage heavy drinking. In 1736 a report warned that “unhappy mothers habituate themselves to these distilled liquors, whose children are born weak and sickly, and often look shriveled and old” (cited by Warner & Rosett, 1975, p.1395)

At the turn of the 20th century, reports began to appear on children of alcoholics in many countries. In 1899, Dr. William Sullivan, a prison physician, published a study of 120 female “drunkards”. He found that the pregnancies of these women resulted in stillbirths and infant deaths 2 ½ times more often than those of their sober female relatives. In the 1950s, a medical thesis from Paris described 100 children born to alcoholic mothers and fathers who had malformations very similar to those now recognized as constitution FAS (Streissguth, 1997). Nevertheless, it was not until 1973 that Jones and Smith first described the fetal alcohol syndrome and their work resulted in worldwide attention to the condition as a birth defect (Streissguth, 1997). This influence can be observed in the increase in research between 1973-1993 in which there were over 550 extensively researched cases of FAS (Cook & Shelton, 1993). Educators now have the foundation for a database sufficient to provide better services to this unique population.

Prevalence

Although formal prevalence studies have been conducted, data remains inconsistent on the prevalence of FAS. In the United States, prevalence estimates have been posited with a range from 3.5 in 1000 births to 1.3 in 1000 births dependent on the population (Hawks, 1993; McLaughlin & Williams, 1994). Worldwide figures place the rate of FAS at about 1.9 per 1000 live births in the general population (McCuen, 1991). However, these statistics are probably conservative in that they reflect only those children who have actually been identified, referred and diagnosed with these conditionings. It remains likely that many of the young people who are affected may remain unidentified.

FAS and FAE are problems that have a significant impact on our social and educational services. The cost to society is enormous and has been estimated at \$596,000 per child with FAS throughout his/her lifetime (Streissguth, 1991). In 1987, individuals with FAS were estimated to require residential and support services exceeding an annual total cost of \$1 billion (Bonthius, Dyke, Dyken, & McBrien, 1996). These figures adjusted for the late 1990s would reflect a much greater financial impact.

Research results demonstrate that FAS and FAE occur more frequently among some population groups in the United States (Burgess & Streissguth, 1992). For example the overall Southwestern Native American rate is 1978-1982 was 4.2 per 1000 or nearly twice the 2.2 per 1000 for the United States at the time (May, 1994). Nevertheless, FAS and FAE can occur among any women who drink during pregnancy, so these conditions should not be thought of as particular to any racial or ethnic group (Burgess & Streissguth, 1992). With approximately 35,000 newborns each year having been exposed to drugs including alcohol (Price & Stevens, 1992), it is clear that educators will need to play an important role in the lives of these children.

Characteristics

These are a series of distinctive characteristics which may describe individuals with FAS. Characteristics most often discussed in research can be categorized generally as medical and behavioral. The discussion of behavioral considerations will be more extensive due to their greater relevance for educators.

Medical Characteristics

FAS is a medical diagnosis. As mentioned above, FAS is diagnosed when children meet three criteria. The first criteria is growth deficiency which can be detected

both prenatally or postnatally. This growth deficiency can affect height, weight and/or head circumference (Piersel & Shriver, 1994). The second criterion is a specific pattern of minor structural anomalies that most notably includes facial features such as small eye openings, drooping eyelids, a receding chin, small teeth, a short ruptured nose, a smooth philtrum (i.e., the ridges between the nose and the lips), and a thin upper lip (Cook & Shelton, 1993). The third criterion is evidence of CNS damage, which may include microcephaly (i.e., small size of the brain), tremors, hyperactivity, fine or gross motor problems, attentional deficits, learning disabilities, intellectual or cognitive impairments, or seizures. Mental retardation and developmental delays also qualify as CNS criteria, but like the other single items listed here, are not necessary conditions for accurate diagnosis (Streissguth, 1997).

Other medical or physical characteristics have been discovered among individuals with FAS. Cook and Shelton (1993) highlighted heart defects as well as poor skin and muscle tone. Joint anomalies, small distal phalanges (i.e., fingers), small fingernails, and small hypoplasia (i.e., tapering finger nail) are other common medical characteristics found in individuals with FAS (Bonthius et al., 1996; Streissguth, 1997). These main characteristics of prenatal exposure to alcohol result in the diagnosis of fetal alcohol syndrome.

Behavioral Characteristics

The effects of exposure to alcohol on cognitive and behavioral development has become an important research focus in recent years (Jacobson & Jacobson, 1996). Researchers have found that although children with FAS and FAE are, of course, unique individuals, many share a common behavioral profile (Burgess & Streissguth, 1992).

They may not exhibit all the characteristics or they may have some of the characteristics to a greater or lesser extent. However, clearly there are certain common behavioral characteristics with children with FAS. Using the term broadly, the behavioral characteristics that are most frequently discussed include the domains of motor, social, language, and cognitive development (Cates, Kinnison, & Sluder, 1996).

Behavioral characteristics have the greatest implications of educators. Once a child with FAS enters school, the learning and behavioral problems typically become apparent as the normal and social academic expectations become a setup for failure and frustration (McCreight, 1997). Everyday school expectations can present extreme difficulties for these children.

Studies have suggested that children with FAS have underdeveloped muscle tone and poor reflexes (Cates, et al., 1996). This may be what underlies some of the problems in *motor development*. Children diagnosed with FAS were more likely to perform lower on measures of reaction time, finger tapping, grip strength, and motor-speed precessions compared to children not diagnosed with FAS (Piersel & Shiver, 1994). Through infancy and early childhood, they may experience delays in walking. They may be clumsy or immature with their use of tools such as crayons or small toys. Motor-performance deficits at 4 years of age have been correlated with mothers who exhibit “heavier” drinking patterns (Piersel & Shiver, 1995). This deficit may affect how well young children interact with other students because of potential inability to perform tasks at play (Cates et al., 1996).

The most discussed characteristic of individuals with FAS involve their *social development*. Small children with FAS and FAE are often very engaging and may be

extremely active. This high level of activity and distractibility most often causes parents or teachers to refer them for evaluation (Burgess & Streissguth, 1992). Some parents have reported that their children are so active and impulsive that they fear for their safety (Streissguth, 1997). In a related vein, Becker (1990) reported that 80% of children with FAS experience attention deficit disorder which can have a significant effect on their educational success. Times of transition become more difficult for these students. They tend to be more impulsive with their feelings and reactions. Without the ability to pay attention, the child cannot concentrate on, or follow through with, a given task. However, the difficulty with attention is not limited to learning situations or to school. It is a constant factor in the child's life and may interfere with the ability to play, to participate in team activities, and to comply with normal social expectations (Streissguth, 1997).

Individuals with FAS also lack a sense of personal boundaries which provide emotional protection and prevent individuals from invading the personal space of others. According to Streissguth (1997), children who lack personal space and have inappropriate and excessive curiosity are often disliked and shunned by their peer group. The manifestation of this trait often results in poor self-esteem (Price & Stevens, 1992).

Poor impulse control can be a direct result of attention deficit disorder, information processing deficit, and poor personal boundaries (Forness & Kavale, 1994). This constellation of problems frequently results in children putting themselves in dangerous or forbidden situations. Further, it has been indicted for being one of the major reasons for stealing. Sixty percent of the adolescents and adults with FAS, and 14% of the children, had documented differences with the legal system. Shoplifting/theft was the most frequent crime (Streissguth, 1997).

Another social deficit commonly found in individuals with FAS is the inability to relate behavior to consequences. It is difficult to understand a cause-and-effect relationship when the individual can not always process the information that links the cause to the effect (Streissguth, 1997). This difficulty results in students exercising poor judgment (Burgess & Streissguth, 1996) which also makes it problematic for parents and/or teachers to find a relevant consequence for a child with this condition. Because the natural or logical consequences used by most parents and/or educators often have little or no value in terms of teaching the child personal responsibility, these individuals may have no sense of connection to societal rules (Streissguth, 1997). “Societal rules” may be considered to be those that generally require little teaching past early childhood because they are self-evident. For example, most children past the age of five would see the danger in running out in front of a car. However, an individual with FAS may be just as likely to run in front of a car at age 30 as they are at age five (McCreight, 1997). They fail to realize their vulnerability and frequently place themselves in serious danger.

Because of these social characteristics, adolescence is a challenging time for individuals with FAS. They have difficulty comprehending and/or responding appropriately to others’ feelings and needs. As noted above, they may be impulsive and aggressive, demonstrate unpredictable behavior, and may have trouble with the law (e.g., lying, stealing, vandalism). These deficits often result in low self-esteem and limited motivation. Streissguth (1997) reported that the majority of adolescents had experienced a disrupted school experience with suspension being the most frequent one.

Prenatal alcohol exposure directly influences *cognitive development*. Deficits in intellectual functioning have been reported frequently in groups of children with

FAS/FAE who were given standard IQ tests (Streissguth, 1997). The average IQ of students with FAS has been reported as 65 to 70, with the range being between 30 and 105 (Burgess & Streissguth, 1996). Children with FAE are in the mentally retarded range, it is erroneous to assume that all children with FAS are mentally retarded (Streissguth, 1994). Because achievement in school appeared to be positively correlated with performance on intelligence scales, it is not surprising that children diagnosed with FAS and FAE who received low scores on the intelligence scales also demonstrated low performance in the classroom on achievement measures (Piersel & Shiver, 1994).

Children with FAS and FAE display difficulties carrying out sets of activities (Streissguth, 1997). For example, if a teacher asks a student to open a math book and do problems one through ten, the student must understand to first get out the textbook, the pencil, the paper, and clear the desk of anything that is distracting. Then the student must understand which question to begin with, what order to follow, and how much time to spend on each question. After all this, the student must begin the work, stay on task, use prior knowledge of the subject, and complete the task. For most people this process is not thought out consciously. While it is not uncommon for students with FAS and FAE to have minimal learning problems (Griffeth, 1992), the disabilities, may spread across the learning spectrum. If every aspect of learning has a problem, no matter how small, then the ability to learn is severely affected and the child can miss much of what is being taught (Burgess & Streissguth, 1992).

Information processing deficit is a common characteristic of individuals with FAS (Streissguth, 1997). Such problems include the inability to translate information into appropriate action and failure to generalize the information from one situation to another.

The child may be able to repeat everything that has been said, but the fact that the child can hear and repeat it does not mean he can figure out what to do with it. For example, a teacher may ask a student with FAS or FAE to get out their journals. If the children had never heard of a notebook referred to as a journal, they would not know what to remove from their desks.

Children with FAS or FAE may have problems with the ability to perceive patterns or common threads, and the ways in which life is presented to us everyday (Streissguth, 1997). The patterns involved in routines may be invisible to these children and therefore, every day of school is the first day.

One of the most difficult problems for students with FAS or FAE involves their short term memory (Streissguth, 1997). This may also be connected with some of their other deficits because the child's focus of attention is constantly changing, and the processing disorder prevents the brain from properly analyzing, channeling, and storing information. Consequently, it may also be quite difficult for these children to learn from their own experiences (Burgess & Streissguth, 1992), and thus, for example, they may repeat the same mistakes.

Students with FAS or FAE often experience difficulty with abstractions. The child is unable to generalize learning to new situations. This often causes problems with time and money skills as these ideas change and shift. Streissguth (1997) reported that 95% of the people she studied could not handle money regardless of their background, age or any other factor.

Children with FAS also frequently experience problems with *language development*. Individuals with a lower IQ may encounter speech problems that take the

form of perseveration (repeating a word or over and over). Those with higher IQ scores may have problems with articulations, talking too quickly, interrupting, or mumbling (Griffeth, 1992). They may also experience difficulties with opposites. For example, they may say “up” when they meant to say “down”. Children with FAS may experience consistent problems with grammatical errors. All young people tend to have these problems in language development. However, students with FAS do not always outgrow these errors (Griesbach & Polloway, 1990).

Implications for Instruction and Curriculum

Children who are exposed prenatally to alcohol may present a variety of challenges for educators. The behavioral and academic characteristics associated with individuals with FAS or FAE require that we investigate the implications for instruction and curriculum. Educators should be concerned with providing an appropriate educational program and planning for early intervention, targeting functional skills, teaching communication and social skills, managing challenging behaviors, and collaborating with parents.

Providing and Appropriate Program

It is important when considering implications for educators that we discuss the type of setting in which children with FAS will receive their services. Because children with FAS exhibit an average IQ of 70 (McLaughlin & Williams, 1994), some of these students will be educated with children who are mentally retarded. However, children with FAE or children with FAS who have a higher IQ may need programs more typical of children with learning disabilities or emotional and behavioral disorders (Kavale & Forness, 1994). Streissguth and her associates in 1991 (as cited by McLaughlin &

Williams, 1994) conducted an extensive follow up examination of 61 adolescents and adults with FAS. They found adolescents with FAS were served in various settings including regular classes (6%), self-contained classrooms (28%), outside of any school system (15%), and in sheltered workshops (9%).

When considering how to meet the needs of these unique individuals, we should first consider our goals as educators. Most educators would agree that we want students to become productive and independent members of society. This is not to say that all children will become independent, but that they should have opportunities to function in normal settings with as little support as necessary (Burgess & Streissguth, 1992). The principles guiding the design of instructional programs should be to encourage independence and productivity among students.

Early Intervention

Like children with other disabilities, children with FAE and FAS benefit from early diagnosis and intervention. It is the responsibility of school personnel to refer children who may have been prenatally exposed to alcohol for evaluation which may lead to a medical diagnosis.

It is important for educators to see early on that these students need much encouragement and support to achieve the same success as other peers. FAS is a lifelong disability that requires continuous educational programming (Burgess & Streissguth, 1992). Educators should guide the learning of appropriate, functional skills and to decrease the occurrence of inappropriate behaviors (Streissguth, 1997).

Targeting Functional Skills

Developing a prescriptive curriculum for students with FAE or FAS would be unwise because the ages and abilities of such students vary (Burgess & Streissguth, 1992). It is important that instead these students be recognized as having unique needs. The academic curriculum is important, but students also need to be taught the skills that will help them survive and function in the real world. A functional curriculum encompasses daily living skills and vocational training. A functional program is considered to be one of the most complete models for students that are mentally retarded (Saint-Laurent & Lessard, 1991). It can be as concrete as riding a bus, ordering food at a restaurant, and filling out job applications, or as abstract as interacting with peers and learning the skills for keeping a job (Burgess & Streissguth, 1992).

Teaching Communication Skills

As noted above, one of the characteristics for children with FAS or FAE was speech and language problems. In order for these students to experience success with peer relations and job skills, it is important they be taught functional communication skills (McCreight, 1997). To be functional, communication must be both purposeful and successful in the natural and daily environments experienced by the communicator (Butterfield & Arthur, 1995). Educators need to watch children's attempt to communicate and shape those attempts into appropriate words or actions (Burgess & Streissguth, 1992). When considering communication, it is important not only to focus on language, but on the verbal, gestural, and behavioral skills that allow us to live and participate in social environments (Streissguth, 1997). These skills can be added to the curriculum and can also be taught with "teachable moments." For example, a student with FAS may want

a crayon and rather than asking for it, he may impulsively grab the crayon. This instance is a great time to teach the child an appropriate communication strategy.

Teaching Social Skills

Social isolation is tragically common among students with FAS or FAE (Burgess & Streissguth, 1997). Poor communication, the inability to predict the consequences of their behavior, poor boundary skills, and impulsivity all contribute to difficulty maintaining relationships (McCreight, 1997). Teaching social skills can be a critical addition to the curriculum. Social skills can be defined as “learning behaviors that are necessary to get along successfully in a majority of social situations” (Sheridan, 1997, p.2). Teaching communication and social skills does not need to be seen as a separate curriculum, but rather a component of the functional curriculum (Burgess & Streissguth, 1992).

Managing the Child’s Behavior

There are four considerations when dealing with any student who has difficulty managing their own behavior. The first is the classroom environment (Mignana & Weinstein, 1993). The classroom should always have a positive atmosphere, and the rules, consequences and expectations should be clear. The second consideration is to conduct a functional behavioral assessment to determine why a student is not behaving appropriately. What happened before the negative behavior? What was the child trying to communicate when misbehaving? What is the function of the behavior? The third consideration is to determine what response the student is receiving from his behavior. The final consideration is teaching the child self-management skills (Swick, 1991).

When dealing with students who are FAS or FAE, it is important to remember their frequent lack of ability to communicate appropriately. An individual behaves a certain way in an effort to communicate. Educators typically see problem behaviors as malicious or attention seeking, but a student may be trying to communicate a thousand things (Burgess & Streissguth, 1992). These children need to be taught an alternative form of communication (Streissguth, 1992). For example, a student may throw a pencil because it is broken. The child should learn the appropriate thing to say is “My pencil is broken.” The teacher should also find reinforce the appropriate behavior by providing meaningful rewards and consequences (Sheridan, 1997).

It is important to allow students to grow rather than not to “control” them (Burgess & Streissguth, 1992) and thus the concept of self-management is very important. We need to teach these students to function independently or with as little support as necessary. It should be a goal for educators that a child with FAS or FAE will manage their own behavior.

Collaborating with Parents

Working together, the teacher and parents can more effectively provide the support that children with FAS/FAE need. They can help each other understand and monitor these children who are usually dependent on external support (Streissguth, 1997). Collaboration means that parents and schools work together in the best interest of the child. Not only can the school guide the parent with ideas and information, but the parent can also provide the school information on their experiences. Although school-parent collaboration is the ideal, it is not always possible. School personnel may encounter the challenge of mothers that are still abusing alcohol. Educators can provide

the parents with additional resources and support to help them overcome the disease of alcoholism. Unfortunately, the school may provide the primary support for students with FAS/FAE from troubled homes. In these situations the school can become more than an institution of learning and may serve as a haven of understanding and sound advice (Streissguth, 1997).

Discussion

Given the prevalence of students with FAS/FAE, it is important that school personnel develop an understanding and awareness of the needs of these students. History has warned us of the dangers of prenatal alcohol exposure. The last 15 years of research have confirmed history's warnings by providing sufficient information regarding the medical, and behavioral characteristics of individuals with FAS/FAE. It is now the responsibility of educators to provide these students with appropriate educational programs. The students need to be taught functional, communication, and social skills. We also need to help the students manage their behavior. It is important to collaborate with parents and provide them with sufficient support. It is our duty to maximize the potential of these students by continually educating ourselves regarding their educational needs.

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