The Need for Advocacy

Advocacy must come from both the parents and the professionals involved in the FAS/FAE child’s care. The parent must coordinate the services of the school, therapists, and doctors; they must educate the teachers to the special needs of their child; they must deal with the reactions of friends and families as they realize the child’s differences; while at the same time trying to parent a wonderful, but sometimes difficult child. The professionals that treat children prenatally exposed to alcohol need to share with their professional peers the data about these children. More doctors and therapists need a better understanding of the problems that many of our children are facing daily. The professionals need to have a better sense of the struggles that the families face in seeking out services for children that have an often invisible disability. Teachers need to be trained that our children are not troublemakers, they are learning disabled. Teachers need to know that our children did not choose to be born with a birth defect.

The challenge of caretakers and service providers is to help these children harness their potential and become the best that they can be.

Can FAS be treated?
Birth defects related to alcohol use are permanent. Surgery can repair some of the physical problems, and schools and day care centers offer programs to improve mental and physical development. However, children born with FAS remain below average in physical and mental development throughout their lives.

The Need for Support

The daily energy used to support a child with FAS/E places a strain on the whole family. The support of extended family is often missing because of denial of a problem or seeing the problem as bad parenting. The resources for respite are often hard to find or access.

The FAS/FAE family support group offers each of its members a place to voice concerns, offers suggestions, share information, and to just be with people that understand. We do not have all the answers only the commitment to work together as a group to listen to each other and look for solutions together. It is through our varied experiences and network of resources that we draw upon to help each other.

The support group meets every other month. The site of the meeting varies on which member wants to host the group in their home. Please phone Betsy Meeks at (770) 514-9606 or Renn Doyle at (404) 292-7303 for location and date of the next meeting. The families currently involved have children ranging in age from toddlers to mid-teens.
What is FAS / FAE / ARBD?
The Fetal Alcohol Syndrome Study Group of the National Council on Alcoholism outlines minimal criteria for the diagnosis of FAS as being, "evidence of abnormalities in three specific areas: growth, central nervous system functions and facial characteristics."

Fetal Alcohol Effects (FAE) is the term commonly used to describe children with fewer or less severe birth defects in the same areas. In both FAS and FAE, the birth defects are caused when a woman drinks alcohol during pregnancy. FAS and FAE are 100% preventable.

Alcohol Related Birth Defects (ARBD) is a term that is gaining in popularity to describe birth defects caused by prenatal exposure to alcohol that had previously been called FAS /FAE.

Characteristics of FAS/FAE
Children diagnosed with FAS or FAE may have any number of the following characteristics.
• Low birth weight and failure throughout their lives to catch up to their peers in physical growth. Typically these children are shorter than average and have a small build.
• Facial characteristics:
  • Small head size
  • Narrow eye slits
  • Flat midface
  • Low nasal ridge
  • Loss of groove between nose and upper lip
• Central nervous system:
  • Mental retardation
  • Poor sucking response
  • Sleep disturbances
  • Restlessness
  • Developmental delays
  • Short attention span
  • Learning disabilities
• Organs and body parts:
  • Muscular problems
  • Minor bone and joint problems
  • Dental abnormalities or high pallet
  • Vision and Hearing problems
  • Genital defects
  • Heart defects
  • Kidney defects
• Other areas of Impairment include:
  • Difficulty structuring work time
  • Impaired or sporadic learning patterns
  • Experience poor memory
  • Tend to be very outgoing and socially engaging, yet they are frequently seen by others as intrusive, overly talkative, and generally unaware of social cues
  • Have trouble generalizing behaviors and information
  • Act impulsively
  • Often labeled hyperactive
  • Display fearlessness and are unresponsive to verbal cautions
  • Over dramatize events or fear
  • Demonstrate poor social judgment
  • Due to their social immaturity, they have difficulty establishing friendships, especially with children of the same age
  • Cannot handle money appropriately
  • Have trouble internalizing modeled behaviors
  • Sensory integration issues
  • Larger vocabulary than comprehension
  • Auditory or visual processing problems
  • Poor problem solving strategies

Effective strategies for parenting an FAS /FAE child include:
• Give your child choices and encourage decision-making
• Focus on teaching daily living skills
• Have child get ready for next school day before going to bed
• Establish a few simple rules
• Be consistent
• Tell your child what behaviors are expected of him / her
• Establish routines so child can predict coming events
• Give advance warning when an activity will change or end
• Establish a firm routine
• Break tasks into small pieces so they are not overwhelming
• Use concrete examples when teaching a new concept
• Set limits and follow them
• Change rewards often to keep interest in reward getting high
• Have pre-established consequences for misbehavior
• Do not debate or argue over rules already established
• Have child repeat back their understanding of the consequences
• Notice and comment when your child is doing well or behaving appropriately
• Avoid threats
• Redirect behavior
• Intervene before behavior escalates
• Avoid situations where child will be overstimulated
• Have child repeat back directions

Keys to working successfully with FAS/FAE children are structure, consistency, creativity, patience and persistence. Because many of these children lack internal structure, care givers / parents need to provide an external structure for them. It is important to be consistent so that the child feels the world is predictable. Because these children may have problems maintaining attention, it is important to be brief in explanations and directions. These children often do better when a difficult tasks is broken down into several, smaller, more manageable jobs. Using various types of rewards may help to get and keep their attention. Finally, and most importantly, be patient. As a caregiver you must repeat what it is you want them to learn, over and over again until it becomes second nature for the child.

Remember all children are different. What works for one parent / child team may not work for another.