

Fetal Alcohol Spectrum Disorders

Competency-Based Curriculum Development Guide

for Medical and Allied Health Education and Practice



U.S. Department of Health and Human Services
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FASD Regional Training Centers

National Organization on Fetal
Alcohol Syndrome (NOFAS)



Competency VI: Treatment Across the Life Span for Persons With Fetal Alcohol Spectrum Disorders

The health care student or provider will be able to provide long-term case management for persons with FASDs.

Learning Goals

(Learning objectives for each goal can be found at the end of this section.)

- VI-A Describe developmental and functional concerns for individuals with FASDs and their families across the life span.
- VI-B Explain various treatment approaches.
- VI-C Explain family support services and resources.

Content Outline for Competency VI

- I. Concerns across the life span
 - A. Infants
 - B. Toddlers and preschoolers
 - C. School-age children
 - D. Adolescents and teens
 - E. Adults
 - F. Families and caregivers
- II. Providers and approaches to treatment for FASDs
 - A. Medical, mental health, and therapeutic considerations
 - B. Psychopharmacological considerations
 - C. Behavioral and educational interventions
 - D. Alternative approaches
- III. Family support services and resources
 - A. Parenting strategies
 - B. Disability services
 - C. Legal system
 - D. Resources

Also included in this section are:

- Suggested learning activities.
- References.
- Chart of all learning goals and objectives for this competency.

I. Concerns Across the Life Span

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Fetal alcohol spectrum disorders (FASDs) occur as a direct result of maternal alcohol use during pregnancy. Alcohol is a neurobehavioral teratogen that results in lifelong problems with learning and behavior. Disabilities that are not addressed early not only persist, but might become more severe and result in additional disabilities or problems as an individual ages. As with any family that has a child with a disability, stressors and complications should be addressed for the entire family. Families affected by FASDs often have even more complex problems than families with other disabilities (Streissguth, 1997).

To best understand the developmental disabilities associated with prenatal alcohol exposure, it is important to have a basic understanding of developmental processes and how these processes might go awry. In an infant or preschooler, typical, or normal, development is established by the accomplishment of particular milestones at particular ages in a standard sequence (Kessen, 1999; Behrman & Kliegman, 1998). For example, for motor development, infants begin to roll over at about 3 months, sit assisted at about 5 months, sit unassisted at 6 months, crawl at 7 to 8 months, cruise at 9 months, walk at 11 to 12 months, and run smoothly at around 14 months. This is considered developing on schedule. In older children and adolescents, development is said to be typical if the individual is learning at the same rate as other children of similar age and background (Kessen, 1999; Scheerenberger, 1983). The term intelligence quotient (IQ) derives from this concept: age of mastered material divided by chronological age (times 100) would equal 100 for someone who was learning at the same rate as his or her chronological peers.

Developmental disabilities arise when children (a) have a slowed rate of development but the sequence of development is within normal limits (i.e., delayed development) or (b) achieve skills in a nonroutine sequence or manner (i.e., different or scattered development). It is important to note that these two concepts are not necessarily mutually exclusive in any particular child, but on the whole characterize the general types of developmental disabilities.

In regards to delayed development, young children or infants who are not meeting milestones on time are said to have developmental delay (Kessen, 1999; Behrman & Kliegman, 1998; Scheerenberger, 1983). Older children who are learning new material at a significantly slower rate than their peers are considered to have an intellectual disability (formally referred to as mental retardation). For example, a child with a generalized intellectual disability might learn language, reading, and math skills, but mastering each of these skills might take years rather than weeks or months.

Different or scattered development proceeds in an atypical sequence, a child uses an unusual pathway to develop skills, or skills develop unevenly across domains (Kessen, 1999; Spreen, Risser, & Edgell, 1995; Zigler & Hodapp, 1986). This latter path of development often results in “peaks and valleys” of strengths and weaknesses, which very much describes individuals with FASDs (Streissguth, 1997). Overall, basic language skills (vocabulary, syntax) are considered areas of strength of individuals with FASDs. In contrast, visual spatial skills are an area of weakness that can lead to significant deficits in knowledge and math-related skills. Another

type of “scatter” demonstrated by individuals with FASDs occurs even within domains (Coles, Kable, Dent, & Lee, 2004; Kable & Coles, 2004). For example, although for early language, vocabulary and syntax are strengths, other social aspects of language might be impaired, such as understanding social boundaries, reading social cues, and relating to peers (O’Connor et al., 2007; Thomas, Kelly, Mattson, & Riley, 1998).

The core disabilities that individuals with FASDs often experience include attention problems, memory deficits, executive functioning impairments, neurocognitive delays and impairments, motor delays, and inconsistent social skills. Some disabilities associated with FASDs might be overlooked in infancy and toddlerhood. However, as a child grows older, and expectations increase, his or her disabilities usually become more apparent. Practitioners who treat or provide case management for individuals with FASDs and their families might need to make referrals to a variety of specialists throughout the individual’s life span (Behrman & Kliegman, 1998; Spreen et al, 1995).

Across the life span, several protective factors have been shown to improve functioning for individuals with prenatal alcohol exposure: stable nurturing care giving, early diagnosis, absence of violence, stable home placements, and eligibility for social and educational services (i.e., special education) (Streissguth, Barr, Kogan, & Bookstein, 1996). Conversely, risk factors for poor outcomes also have been identified, including multiple care giving placements, early or continued exposure to violence, and failure to qualify for disability services.

A. Infants

Infants with FASDs often have sensory and regulatory problems (Coles, Smith, Fernhoff, & Falek, 1985). Issues such as poor sleep-wake cycles, irritability, failure to thrive, and nursing difficulties are reported frequently. Hypotonia and fine motor problems (e.g., weak grasp) are also reported (Jones, 2006). Physical therapy or generalized early intervention can be very beneficial. Additionally, infants with FASDs often have poor immune function and experience multiple bouts of otitis media and upper respiratory infections. Because the spectrum of issues related to infants with FASDs is broad and can be relatively nonspecific, infants with known or suspected prenatal alcohol exposure should be closely monitored and evaluated regularly.

B. Toddlers and Preschoolers

Parents generally begin to suspect delays or problems at this stage of development, regardless of the developmental disabilities. For parents of children with FASDs, common areas of concern include fine and gross motor delays, failure to comply, and loss of previously learned material (Mitchell, 2002). Disabilities that were present in infancy might also continue or increase in severity during this period, including regulatory problems, poor sleep patterns, or toileting difficulties (especially mastering this skill then regressing). Children with FASDs at this age often present as fidgety, easily distracted, and unable to focus attention. Sensory issues might emerge at this time or become more pronounced, with hypersensitivity to certain food textures, sounds, and fabrics. Physically, toddlers and preschoolers with FASDs might be short for their age and be prone to infections and colds. Conditions often suspected at this age as a result of these behaviors are attention-deficit/hyperactivity disorder (ADHD), conduct disorder, and oppositional defiant disorder. Increasingly, studies are documenting psychiatric sequelae

associated with prenatal alcohol exposure (O'Connor et al., 2002; O'Malley & Huggins, 2005; Streissguth & O'Malley, 2000).

A particular concern for children with FASDs is attachment disorders or reactive attachment disorder (RAD). This social and emotional disorder is characterized by disrupted emotional bonding between child and caregiver that results in a variety of abnormal social responses, including indiscriminate approach to strangers, poor boundaries, and lack of social understanding or empathy (Olson, Morse, & Huffine, 1998). RAD can result from neglect, abuse, and multiple caregivers within a short time or early in life. These factors are very common in substance-abusing families and even in the foster care environment. Children with RAD or any attachment issues should be referred as young as possible to a mental health or abuse professional for assessment and an individual treatment plan, which could include medication, play therapy, or even intervention from Child Protective Services (CPS) (Olson et al., 1998).

C. School-Age Children

Consistent with findings from developmental studies of typical children, neurodevelopmental functioning becomes less centralized or global and more specified during the school-age years (Kable & Coles, 2004). This differentiation of skills and abilities often leads to identification of weakness and vulnerabilities for school-age children with FASDs. However, it should be noted that deficits in neurocognitive functioning for school-age children with FASDs still occur across all areas and domains of function. In addition, school-age children might continue to manifest delays in adaptive functioning and regulatory problems. Unaddressed core deficits, weakness, and vulnerabilities during this period can lead to the development of secondary disabilities, such as disruption of school, criminal activity, and mental health problems.

Attention problems are particularly common complaints during early and middle school years. Problems reported often include difficulty sitting in class, problems with focus, poor impulse control, difficulty learning, attention disorders, and often problems with sleep. By this time, many children with FASDs have been diagnosed as having attention-deficit/hyperactivity disorder (ADHD), conduct disorders, learning disabilities, or various mental health disorders. Such diagnoses might or might not be appropriate. As learning requirements become more abstract and less concrete during the school years, executive functioning deficits become more apparent. One area where such executive function problems manifest is difficulty understanding cause-and-effect relationships and difficulty learning from mistakes. This can lead to problems with behavior (temper tantrums, outbursts) as well as social difficulties (Kable & Coles, 2004).

Visual-spatial abilities and math skills are also areas of weakness for children with FASDs (Bertrand et al., 2004; Kable & Coles, 2004; Streissguth et al., 1996). In fact, weaknesses and deficits in these domains are one of the earliest and most robust findings for this population (Bertrand et al., 2004; Streissguth, 1997; Streissguth et al., 1996). These two domains are likely developmentally related, and problems in one affect the other. Studies show that individuals with FASDs on average score 5 points or more lower on tests of Performance IQ compared to their scores for tests of Verbal IQ (Mattson & Riley, 1998). Further, deficits in visual perception, visual memory, visual-motor integration (i.e., drawing and writing), and spatial memory have been reported by many investigators (see review in Kable & Coles, 2004). Early visual-spatial deficits and weaknesses have been related to poor performance on arithmetic achievement tests (Coles et al., 2004; Kable, Coles, & Taddeo, 2007).

Finally, during the school years, social skills problems are likely to be identified. Unlike their peers, children with FASDs often display difficulties understanding social boundaries, reading social cues, and relating to peers. Resulting behaviors can cause problems in developing friends and/or put the child at risk of being abused. Children with FASDs are at high risk for victimization and do not readily understand stranger safety.

D. Adolescents and Teens

All the cognitive, behavioral, and functioning problems associated with FASDs during the school-age years continue, and might be magnified, during adolescence. The onset of puberty, increased difficulty with social understanding, and other cognitive difficulties put teens with FASDs at very high risk for new or ongoing mental health issues. They can be prone to mood disorders, anxiety, depression, or a combination of these. They might struggle with developing personal or social boundaries and be easily led into dangerous situations. Some students with FASDs experience behavioral issues that might draw negative attention, and as a result become isolated. Impulsivity and poor judgment can make it difficult to achieve independence and to accomplish successes that their peers are experiencing, such as dating, obtaining a drivers license, or just “fitting in.” All of these issues create low self-esteem leading to a difficult adulthood. Adolescents with FASDs are at greater risk than adolescents without FASDs of developing substance abuse problems, possibly as a coping mechanism, as a result of peer pressure, or due to increased genetic susceptibility.

A particularly difficult aspect for older children, adolescents, and adults with an FASD is the “hidden” nature of the disorder and its specific disabilities. This is especially true for individuals without a correct FASD diagnosis or a late diagnosis. Often, because of the inconsistent nature of strengths and weaknesses, individuals with FASDs can give the impression of being more capable than they really are, understanding things they really don’t, or having mastered material only to forget the material and need to relearn it. Again, this aspect of FASDs puts affected individuals at high risk for mental illnesses and secondary disabilities.

E. Adults

Adults with FASDs might need support in many areas of their lives. Many adults with an FASD are very articulate and might present themselves as more capable than they really are. For instance, they might be a talented musician or artist but be unable to do simple math. Their difficulty with abstract thinking and concepts might make understanding time, money, or even crossing the street an impossible task. Like teens, adults are easily led into dangerous situations and are at high risk for victimization. Adults benefit from case management and need ongoing supports such as housing, vocational rehabilitation, transportation assistance, and employment coaching. A diagnosis of a condition under the umbrella of FASDs will not automatically qualify an individual for Social Security income or disability, although many adults with FASDs need these kinds of support systems.

F. Families and Caregivers

Parenting a child, or children, with an FASD can be challenging in the best of circumstances. Many children with FASDs enter the foster care system because of substance abusing parents,

difficult behaviors, and abuse or neglect issues. A study of children in foster care in King County Washington found 15% of children had evidence of an FASD, which is more than 10 times the rate reported in the general population (Astley, Stachowiak, Clarren, & Clausen, 2002). Birth families might need to be assessed for addiction problems and might need to be referred to addiction treatment centers. All families with an individual with an FASD need counseling and resources that will support their concerns and assist them in caring for the affected loved one. A stable home environment is crucial in preventing and addressing the behavior and learning problems that are associated with FASDs. Individuals with FASDs require structure and support in all aspects of their lives. Families and caregivers are essential in helping to create environments that will support successful outcomes for individuals with FASDs. Medical and allied health professionals should address the overall health of the family environment when treating individuals with FASDs.

Beyond a supportive clinical relationship, families caring for an individual with an FASD can benefit from specific instruction about FASDs (cause, issues pertaining to developmental differences), explanation of how typical parenting practices might not be effective for an alcohol-affected child, and specific techniques shown to be helpful (see next section).

II. Providers and Approaches to Treatment for FASDs

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Assisting families that are dealing with FASDs can be a complex task depending upon the number and severity of the deficits. Critical elements of referral considerations include, but are not limited to, medical, clinical, therapeutic, and educational interventions. Many families and providers are experimenting with nontraditional and alternative methods of intervention. Research is currently underway to investigate successful interventions for individuals with FASDs and their families.

A. Medical, Mental Health, and Therapeutic Considerations

Children, adolescents, and adults with FASDs have all the same health and medical concerns as the general population, such as well-baby care, vaccinations, good nutrition, exercise, hygiene, and basic medical care. However, for individuals with an FASD, additional concerns specific to the disorder must be monitored and addressed either by a current doctor or through referral and consultation with a team of specialists. Following are some issues both noted in the scientific literature and gleaned from the combined clinical wisdom of the authors. Titles of health care providers appear in bold to demonstrate the breadth of health professionals typically involved in managing care for individuals with FASDs and their families.

The **pediatrician's** role in identifying a possible FASD is crucial in the early intervention process. Some pediatricians feel confident to diagnose FAS based on the Institute of Medicine (IOM) recommendations (Institute of Medicine, 1996) or the CDC FAS Guidelines for Referral and Diagnosis (CDC, 2004). Others will refer the child to a **dysmorphologist** to rule out other genetic disorders that have characteristics similar to FAS (Aase, 1990). Poor growth (prenatal, postnatal, or both) is an area that the **pediatrician** might pay particular attention to since obtaining this information is standard for the pediatric visit. For the patient with growth problems, possible FASDs should be considered in addition to pursuing nutritional treatments. Children with FASDs, especially young children, seem to have poorly functioning immune systems that make them vulnerable to colds, flu, and especially frequent bouts of otitis media (Yuan, Sorensen, Basso, & Olsen, 2004). While each episode will require specific treatments, repeated bouts might be a clue to indicate prenatal alcohol exposure in children not yet diagnosed. Referral to or consultation with an **otolaryngologist, audiologist, or immunologist** might be warranted.

Pediatricians need to be equipped with the skills to speak to a mother about her possible alcohol and other drug use when evaluating a child who might have been exposed to alcohol in utero. In addition, a pediatrician might need to refer the mother for assessment or possible **addiction treatment services** to prevent future birth exposures. It is best to think about how to handle such a situation before it arises and be prepared with information and potential referrals (Behrman & Kliegman, 1998; Levine, Carey, & Crocker, 1999).

In older children, adolescents, and adults, the **primary care provider (PCP)** serves many of the same functions as the pediatrician for younger children and infants. In addition, a PCP's role

includes case finding, case management, and providing referrals and anticipatory guidance for the families of children with FASDs. They can be instrumental in the early recognition of an FASD when addressing parental concerns of poor growth and development. Primary care providers can also assist parents with ensuring the safety of the child. They can help the family make decisions such as whether or not to place a child in a residential or therapeutic placement. Finally, referrals from PCPs are critical in integrating people with FASDs into the greater medical system (Appelbaum, 1995).

Two other specialties often involved in the identification and care of individuals with FASDs are neurologists and psychiatrists. Undisputed is the fact that prenatal exposure to alcohol can cause lifelong brain damage resulting in structural, neurological, and functional deficits (Sowell, et al, 2008). As such, **neurologists** are often involved in the exclusionary process of diagnosis. Individuals with FASDs frequently have work-ups for attention-deficit/hyperactivity disorder (ADHD) or evaluation of motor coordination problems before proper diagnosis with an FASD. After diagnosis, monitoring and treatment for these issues by a **neurologist** might be appropriate. **Psychiatrists** also play an important role in identifying individuals before diagnosis and in providing treatment throughout the life span. The attention, attachment, abuse/neglect, and behavioral problems associated with FASDs are often evaluated by mental health professionals, especially **child psychiatrists and psychologists, school psychologists, and behavior management specialists**. Examining the possibility that the behaviors for which an individual is evaluated are a result of an FASD is an important part of the differential diagnosis process. Even if these problems are identified as being related to prenatal alcohol exposure, therapy, family treatment, and medication management by a **psychiatrist** might be effective (Lockhart, 2003).

Individuals with FASDs might require referral or consultation with a variety of other specialists as well. Research has shown that prenatal alcohol exposure affects fetal midface development (Astley & Clarren, 2001; Moore et al., 2002) resulting in several eye anomalies, most notably small palpebral fissures noted in the diagnostic criteria. Other eye anomalies include ptosis (drooping eyelid), strabismus (deviation of the eye), myopia (nearsightedness), hypoplasia (underdevelopment of the optic nerve), and tortuosity or twisting of the retinal vessels (Jones, 2006). Hearing and vision problems also have been associated with prenatal alcohol exposure (Church, Crossland, Homes, Overbeck, & Tilak, 1998). Thus, referral to an **ophthalmologist** might be appropriate. **Plastic surgeons** are often contacted when a child with an FASD has a cleft lip or palate, a rare birth defect associated with very heavy alcohol exposure (Romitti, et al., 2007). The lip and palate begin forming during the early weeks of gestation, when a woman often does not know she is pregnant. A notch or cleft is created when the tissues of the developing mouth or oropharynx do not fuse together properly. An **endocrinologist, gastroenterologist, or nutritionist** might be involved to assess for medical problems that can affect growth or lead to failure to thrive (e.g., thyroid problems, celiac disease, mental health problems) and be part of the differential diagnosis process as well as ongoing monitoring.

After referring patients with FASDs to specialists, primary care physicians should follow up with patients about the recommendations of those specialists. Specialists might not be well-educated on the neurodevelopmental issues with which clients struggle. An individual with an FASD might not fully understand the recommendations of the specialist, nor be able to organize all of the information to follow up on treatments. Thus, as the child gets older, it will be important to have a family member or other support person familiar with the history of the child accompany the individual for his or her visits.

B. Psychopharmacological Considerations

At present, no medications have been approved specifically for the treatment of FASDs. However, several classes of medications are routinely prescribed to address common symptoms, negative behaviors, or other concerns for individuals with FASDs. Because children often see many professionals before receiving an FASD diagnosis, they might present with multiple medications prescribed by multiple providers (with or without communication between providers). As a first step, it is important to evaluate the appropriateness, impact, and potential interactions of these medications. Second, monitoring of medications is essential for these individuals since they might encounter multiple caregivers, chaotic living situations, developmentally changing behaviors, and negative side effects. Below is an overview of the major classes of medications used for children with FASDs; this list, however, should not be considered exhaustive. Before prescribing any medications for individuals with FASDs, current research and dosage information should be consulted.

- 1. Stimulant medications.** Attention problems are the most common behavior disorder treated by medication in children (Baren, 1999). Children with FASDs often have attention problems such as shifting their attention or encoding material (Coles et al., 1997). These problems are in contrast to those of children with ADHD, not resulting from prenatal alcohol exposure, who have difficulty with focus and maintaining attention (Coles et al., 1997). Thus, stimulant medications might or might not be effective for any particular individual with an FASD. The primary stimulant medications include methylphenidate (Ritalin), dextroamphetamine sulfate (Dexedrine, etc.), dextroamphetamine saccharate or amphetamine sulfate (Adderall), and pemoline (Cyclert). These medications stimulate the central nervous system in areas that control impulses, attention, and self-regulation. With these medications, improvements might be expected in symptoms such as overactivity, inattention, impulsivity, and noncompliance, as well as other secondary behavior issues (Baren, 1999).
- 2. Antidepressants.** Depressive symptoms in children, including children with developmental disabilities such as FASDs, have been reported to be similar to those of adults with sad mood or affect, loss of interest, and sleep problems. In addition, for children, depression often includes school disruption, negativity, irritability, aggression, and anti-social behaviors (Biederman, Spencer, & Wilen, 1997). Thus, antidepressants might be prescribed for individuals with an FASD. Older antidepressants, such as MAOIs or lithium, tend not be prescribed to children. New compounds, selective serotonin reuptake inhibitors (SSRIs), are readily prescribed to children with FASDs (Lockhart, 2003). The most familiar SSRIs are fluoxetine (Prozac), sertraline (Zoloft), paroxetine (Paxil), and fluvoxamine (Luvox). Other antidepressants that might be prescribed alone or in combination with SSRIs include alpha-2 adrenergic agonists, including clonidine (Catapres) and bupropion (Wellbutrin) (Feldman, Meyer, & Quenzer, 1997). Because mood disorders, especially in children, are often secondary to other organic or developmental issues, the effectiveness of using antidepressants is unclear. However, some reduction in behavior problems, particularly aggression, might be expected (Baren, 1999).
- 3. Neuroleptics.** Psychotic symptoms are not associated with FASDs. However, neuroleptics are prescribed to children with developmental disabilities, including FASDs, to address

aggression, anxiety, or behavior regulation (Feldman, Meyer, & Quenzer, 1997). Neuroleptics prescribed might include risperidone (Risperdal), clozapine (Clozarile), and thioridazine (Mellaril). Neuroleptics might be used in combination with antidepressants or anti-anxiety medications. There are numerous major and minor side effects associated with neuroleptics (Baren, 1999). Before prescribing these medications, providers should be sure parents understand these side effects so they can weigh the advantages and disadvantages for their child.

4. **Anti-anxiety drugs.** Anxiety disorders among children are more common than previously thought with many psychiatric conditions actually having their basis in anxiety (e.g., conduct disorder) (Szymanski, 1999). The number of children prescribed anti-anxiety medications can be expected to rise. Anti-anxiety medications include benzodiazepine (Diazepam/Valium), alprazolam (Xanax), clonazepam (Klonopin), lorazepam (Ativan), and buspirone (BuSpar).
5. **Drug “cocktails.”** As mentioned, many children, adolescents, and adults with developmental disabilities, including those with FASDs, are prescribed multiple medications, referred to as “cocktails.” Such multiple prescriptions can result from patients’ failure to disclose current medications, a lack of communication across providers, or a failure to discontinue medications that are ineffective or no longer appropriate. Patients, parents, and the education and medical communities are becoming increasingly concerned about multiple medications and their possible negative effects. Further, research into drug therapies tends not to include multiple drugs, thus their interactional effects have not been studied. As such, when new medications are considered, it is important to fully review the need and effectiveness of current medications before adding to the “cocktail” (Feldman, Meyer, & Quenzer, 1997).

C. Behavioral and Educational Interventions

Until recently, information and strategies for interventions specific to individuals with FASDs have been gleaned from interventions used with other disabilities and from the practical wisdom of parents and clinicians gained through trial and error and shared through informal networks. Although informative to a limited degree, such treatments have been implemented without being evaluated systematically or scientifically. In general, helpful interventions should include ensuring stable home environments and working with educational staff or therapists and social services (e.g., foster care) to determine individualized treatment plans.

When a developmental delay or risk of developmental problems is suspected in a child under 3 years of age, that child should be referred to early intervention programs, which encompass specialties such as physical therapy, occupational therapy, speech pathology, and special education. Early intervention programs are available in all states under the Individuals with Disabilities Education Act (IDEA), which was reauthorized under the Individuals with Disabilities Education Improvement Act of 2004 (Individuals with Disabilities Education Act [IDEA], 2004).

It is essential that practitioners understand the core cognitive issues of children with FASDs. Their learning style might not “fit” into many programs designed to address some of the

presenting difficulties. For instance, most risk-reduction programs designed to address sexual assault or drug use are based on learning theory models for students who are not learning disabled. A student with an FASD, who is a concrete thinker, might not benefit from a model that is based on intellect and common sense approaches to safety. Programs must be adapted to consider brain differences of students with FASDs.

Some systemic educational interventions could include special education placement. Currently, FASDs are not categorized or mentioned in the IDEA Part B legislation or regulations (IDEA, 2004). However there are several special education designations that might be appropriate for children with FASDs, including intellectual disability (previously mental retardation), specific learning disability, speech and language disorder, other health impaired, and even autism in rare cases. Section 504 of the Federal Rehabilitation Act of 1973 also provides for the education of children with special needs that do not qualify as special education students (Section 504 of the Federal Rehabilitation Act of 1973). These plans are often referred to as “504 plans”. The eligibility criteria and needs of a specific child should be considered when special education referrals are made. In addition to classroom placement or classroom modifications, ancillary services might be needed, such as physical therapy, occupational therapy, speech-language pathology services, sensory integration, and recreational therapy; vocational rehabilitation might be needed for older adolescents and adults (Stratton, Howe, & Battaglia, 1996).

Some physicians and other health care professionals might be asked to include documentation to support a child’s individualized education plan (IEP). An IEP is a written statement outlining goals and objectives for the child’s progress in school. Parents, teachers, and counselors collaborate to create a unique plan to meet the needs of the child based on a formal evaluation. The purpose of an IEP is to provide an appropriate educational program for a child who has specific learning disabilities or has difficulty functioning in a regular classroom setting. If a child has an FASD, that child has a right to have an IEP (U.S. Department of Education, 2000).

In addition to educational services, several adaptive interventions have been shown to be effective for children with FASDs. Project Bruin Buddies assessed a social skills training program to improve peer friendships for children with FASDs. Researchers found that after controlling for covariates, children with FASDs in a 12-week children friendship training group showed statistically significant improvement in their knowledge of appropriate social behavior compared with control children (O’Connor et al., 2007). The Georgia Math Interactive Learning Experience (MILE) Program demonstrated effectiveness of adaptive materials and tutoring methods to improve math knowledge and skills in children with FASDs, compared with control children with FASDs (Kable et al., 2007). Using the ALERT program (Chasnoff et al., 2008), researchers in Chicago have demonstrated improvement in behavior regulation and executive function in children with FASDs, compared with control children with FASDs. And finally, in Seattle, researchers have used an intensive 9-month individualized parent therapy program to improve parent effectiveness and reduce clinically significant behavior problems in school-age children with FASDs (Olson et al., 2008). These research studies are important because they offer scientifically validated, efficacious interventions that can address the needs of children with FASDs.

D. Alternative Approaches

As with any disability, injury, or medical condition, many untested therapies become known and are advocated by informal networks. A physician must work with the parents or caregivers of the individual living with the particular health condition to evaluate with an open but critical mind the risks and benefits of these therapies. Some of the therapies suggested for individuals with FASDs include biofeedback; auditory training (Linden, Habib, & Radojevic, 1995); relaxation therapy, visual imagery, and meditation (especially for sleep problems and anxiety); creative art therapy, yoga, and exercise; acupuncture and acupressure; massage, Reiki, and energy healing; and vitamins, herbal supplements, and homeopathy. This last therapy is interesting in light of recent animal findings that indicate that giving choline to offspring who were exposed to alcohol prenatally might mitigate some of the resulting problems associated with FASDs. Choline plays a number of roles in brain development and is a precursor to acetylcholine, a neurotransmitter involved in learning and cognition, among other functions (Thomas, Biane, O'Bryan, O'Neill, & Dominguez, 2007).

III. Family Support Services and Resources

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A. Parenting Strategies

Keys to working successfully with children with FASDs include structure, consistency, variety, brevity, and persistence. Because these children can lack internal structure, parents and caregivers need to provide external structure for them. It is important to be consistent in response and routine so that the child feels the world is predictable. Because of serious problems with attention, it is important to be brief in explanations and directions, but also to use a variety of ways to get and keep their attention. Finally, because of possible short-term memory problems, repetition is paramount when teaching any skill (Mitchell, 2002).

Parenting a child with an FASD involves many joys and many challenges. Although each child is unique, the following list of tips can be helpful (Mitchell, 2002).

- Concentrate on the child's strengths and talents.
- Accept the child's limitations.
- Be consistent with everything (discipline, school, behaviors).
- Use concrete language and examples.
- Use stable routines that do not change daily.
- KISS: Keep it simple.
- Be specific—say exactly what you mean.
- Structure the child's world to provide a foundation for daily living.
- Use visual aides, music, and hands-on experience to assist with the learning process.
- Use positive reinforcement often (praise, incentives).
- Supervise: friends, visits, routines.
- Repeat, repeat, repeat.

Families might need additional support such as family counseling or therapy and/or parenting classes (Mitchell, 2002). In addition, parents might benefit from local support groups, in which parents of children with FASDs can discuss concerns, ask questions, and find needed emotional support.

It should also be noted that some parents, themselves, might have FASDs (diagnosed or undiagnosed) and might need to be supported as a person with a disability.

When treating birth families where drinking might still be occurring, physicians might need to ensure that families are following up on all of the recommendations made by specialists. These families might need to access support from social services to assist them in the case management process. Birth parents might need intervention and encouragement to pursue treatment for their

addiction. Child protective services might also become involved due to the addiction of the parent and the child's risk for neglect or abuse.

B. Disability Services

The search for appropriate services for individuals with FASDs is an ongoing process. Many communities lack informed providers, and it can be a challenge to secure effective services. The local department of disabilities or the local chapter of 'The Arc of the United States' can be a good starting point in locating appropriate services. In addition, the national Arc website can also be a good starting point (<http://www.thearc.org/NetCommunity>). Potential service providers should be assessed to ensure that their method of service delivery matches the methods that are effective with the particular child. The types of services an individual with an FASD might qualify for include:

- Supported employment/job coach
- Transportation
- Assisted living
- Respite care
- Social Security disability benefits
- Supplemental Security Income

The decision to apply for Social Security disability benefits involves many legal, social, medical, vocational, and psychological considerations. Applying does not guarantee that a person will receive the benefits. Additionally, to receive Social Security benefits, individuals must show that their disability has caused them to be unemployable for at least 12 continuous months. When applying for Social Security benefits, it should be considered a team effort and should include the claimant, family members, friends, health care providers, and possibly a legal representative. The financial and medical assistance available through Social Security disability benefits can be a wonderful form of assistance for individuals living with disabilities (McKee, 1997).

Federally funded Supplemental Security Income (SSI) provides supplemental income to persons who are disabled. Some children and adults with FASDs might be eligible to receive SSI. Families need to understand that their child might be eligible for this benefit before they reach the age of 18 if the parents or guardians have limited income. A child might qualify before the age of 18 if he or she has a physical or mental condition or conditions that can be medically proven and which result(s) in marked and severe functional limitations; and the condition(s) must have lasted or be expected to last at least 12 months or end in death. Health care providers can play an integral role in helping families understand the benefits available to them (Social Security Administration, 2007).

C. Legal System

It is not uncommon for adolescents and adults with FASDs to experience issues in the legal system both as victims and perpetrators of a crime (Fast, Conroy & Look, 1999; Streissguth et al., 2004). Because of the nature of the cognitive deficits associated with FASDs, individuals are at risk for both victimization and for poor judgment or just not understanding cause and effect

as it pertains to the law. Individuals with FASDs will need a mentor or advocate to navigate the legal system. Often, physicians and other health care providers are asked to educate lawyers to properly defend a client with an FASD or to assist in developing a case for the prosecution when a person with an FASD has suffered harm. Some states offer programs for developmentally disabled offenders, and the Arc offers programs to assist disabled victims of crime.

D. Resources

The following lists of resources are by no means exhaustive, but they offer a starting place for seeking information and support.

1. Websites

- National Organization on Fetal Alcohol Syndrome: www.nofas.org
- Alcohol-Related Birth Injury (FAS/FAE) Resource Site: www.arbi.org/
- FAS Community Resource Center: www.come-over.to/FASCRC/
- Centers for Disease Control and Prevention (CDC): www.cdc.gov/ncbddd/fas
- FASD Center for Excellence: <http://fasdcenter.samhsa.gov>
- Fetal Alcohol Syndrome Consultation, Education and Training Services: www.fascets.org
- Fetal Alcohol Syndrome: Support, Training, Advocacy, and Resources: www.fasstar.com
- The Arc of the United States: www.thearc.org; The Arc's Family Resource Guide: <http://www.thearc.org/NetCommunity/Page.aspx?pid=1400&srcid=1646>

2. Newsletters

- Notes from NOFAS
A bimonthly newsletter of the National Organization on Fetal Alcohol Syndrome. To subscribe, e-mail information@nofas.org
- Iceberg
A quarterly newsletter published by the Fetal Alcohol Syndrome Information Service (FASIS). To subscribe, e-mail iceberg_fas@yahoo.com

3. Support Groups

- To locate an FASD support group near you, contact the National Organization on Fetal Alcohol Syndrome at www.nofas.org (National Resource Directory) or call (800) 66-NOFAS.
- FASLink
A free Internet mail list for individuals, families, and professionals who deal with FASDs. www.acbr.com/fas/faslink.htm
- FAS Community Resource Center has a webpage dedicated to different types of support groups. www.come-over.to/FAS/fasonline.htm

- **Circle of Hope**
An international mentoring program designed to connect birth mothers and other family members who have family members with FASDs.
To subscribe, go to www.nofas.org/coh/default.aspx
 - **Family Empowerment Network (FEN)**
 - A national resource, referral, support, and research program serving families living with FASDs and the providers who work with them. There is no fee to join FEN. <http://pregnancyandalcohol.org>
4. **Seminars for families.** There are FASD conferences and workshops held throughout the year around the world. NOFAS maintains a current calendar of FASD and related topic conferences and workshops. www.nofas.org/events.

Suggested Learning Activities

- Have an experienced case manager or social worker describe case management issues.
- Have a group discussion on the barriers, challenges, and opportunities that arise for individuals with FASDs across the lifespan.
- Use case studies to problem solve on case management issues.

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Learning Goals and Related Objectives

Goal VI-A: Describe developmental and functional concerns for individuals with FASDs and their families across the life span

Learning Objectives

<p>Level 1 The learner will be able to...</p>	<p>Level 2 The learner will be able to...</p>	<p>Level 3 The learner will be able to...</p>
<ul style="list-style-type: none"> ▪ Describe FASDs. (K) ▪ Identify characteristics of FASDs within all life stages. (K) ▪ Describe the importance of early identification and intervention. (K) ▪ Describe secondary disabilities associated with FASDs. (K) 	<ul style="list-style-type: none"> ▪ Identify characteristics of FASDs throughout the lifespan. (S) ▪ Identify secondary disabilities associated with FASDs. (S) 	<ul style="list-style-type: none"> ▪ Describe the importance of case management to other health professionals. (A, S) ▪ Explain FASDs throughout the lifespan to other health professionals. (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.

Level 2. Medical and allied health practitioners who need to use the information to provide services.

Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

Goal VI-B: Explain various treatment approaches

Learning Objectives

<p>Level 1 The learner will be able to...</p>	<p>Level 2 The learner will be able to...</p>	<p>Level 3 The learner will be able to...</p>
<ul style="list-style-type: none"> ▪ Describe the types of interventions and referrals that an individual with an FASD might require. (K) ▪ Define therapeutic and mental health interventions. (K) 	<ul style="list-style-type: none"> ▪ Describe behavioral and educational interventions that have been shown to be effective for individuals with FASDs. (S) ▪ Describe alternative approaches that can be used for individuals with FASDs. (S) ▪ Explain the current role of medications in the treatment of FASDs. (K) 	<ul style="list-style-type: none"> ▪ Explain to other health professionals about various treatment interventions that might be helpful for an individual living with an FASD. (S) ▪ Explain to other health professionals about the role of medications in the treatment of FASDs. (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.

Level 2. Medical and allied health practitioners who need to use the information to provide services.

Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

Goal VI-C: Explain family support services and resources

Learning Objectives

<p>Level 1 The learner will be able to...</p>	<p>Level 2 The learner will be able to...</p>	<p>Level 3 The learner will be able to...</p>
<ul style="list-style-type: none"> ▪ Describe parenting strategies that can be helpful in working with children with FASDs. (K) ▪ Describe disability services that might be available to individuals with FASDs. (K) ▪ Explain why individuals with FASDs often experience issues with the legal system. (K) 	<ul style="list-style-type: none"> ▪ Identify family support services and resources for individuals and families living with FASDs. (S) 	<ul style="list-style-type: none"> ▪ Explain to other health professionals the importance of family support services for individuals and families living with FASDs. (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.

Level 2. Medical and allied health practitioners who need to use the information to provide services.

Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.