



A CALL TO ACTION

**Fetal Alcohol Spectrum Disorders:
Awareness, Identification and Intervention
for Children in Pennsylvania
2011**



**Office of Mental Health and Substance
Abuse Services
*Bureau of Children's Behavioral Health
Services*
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A CALL TO ACTION

FETAL ALCOHOL SPECTRUM DISORDERS: Awareness, Identification and Intervention for Children in Pennsylvania

INTRODUCTION

The Pennsylvania Office of Mental Health and Substance Abuse Services (OMHSAS) is committed to promoting the health and well being of children in Pennsylvania. In 2009, in support of the Department of Health's *Fetal Alcohol Spectrum Disorders Action Plan* (2008), the OMHSAS Bureau of Children's Behavioral Health Services established a Fetal Alcohol Spectrum Disorder (FASD) Workgroup to address the behavioral health needs of children and their families affected by an FASD. This Call to Action document reflects the research, discussion and deliberations of local, national and international researchers and clinicians, and the input of families. The document provides recommendations to improve FASD awareness, identification, and intervention in Pennsylvania, with the goal of promoting systems of care to address this challenging problem.

Given that FASD is an invisible disability and therefore is frequently overlooked, affected children may be misdiagnosed, misunderstood, and subject to mismanagement. Typically, children with an FASD want to do well but are limited by cognitive and neurologically based factors beyond their control. When the disorder is recognized and the child and family receive appropriate services and supports, favorable outcomes can be maximized. This Call to Action promotes early intervention to increase the possibility of positive outcomes, and encourages all involved stakeholders to implement appropriate strategies for intervening effectively with children with an FASD and their families.

DEFINITION OF TERMS

Fetal Alcohol Spectrum Disorder (FASD): This is the umbrella term that describes the range of effects that may occur in an individual whose mother drank alcohol during the pregnancy. These effects may include behavioral, physical, mental, and learning disabilities with possible lifelong implications. FASD is not a diagnostic term. The diagnostic terms that fall under FASD include the following: Fetal Alcohol Syndrome (FAS); Partial Fetal Alcohol Syndrome (pFAS); Alcohol Related Neuro-developmental Disorder (ARND), and Alcohol Related Birth Defects (ARBD).

Fetal Alcohol Syndrome (FAS): Since it involves the presence of specific, identifying facial features (see below), Fetal Alcohol Syndrome (FAS) is the FASD most likely to be identified. A diagnosis of Fetal Alcohol Syndrome is made by a physician and requires the presence of three criteria:

- 1) Dysmorphia or unusual facial feature(s): a thin upper lip, small eye openings, and absence of the usual groove between the nose and upper lip.
- 2) Growth problems, and
- 3) Central nervous system abnormalities.

FAS results from significant maternal alcohol consumption during pregnancy, and typically the child has significant cognitive and behavioral impairments. However, some children with other FASDs may also experience similar levels of challenge.

Children with **Partial Fetal Alcohol Syndrome (pFAS)** present with some but not all of facial abnormalities of FAS.

Alcohol Related Neuro-developmental Disorder (ARND): This involves a range of possible central nervous system symptoms, including a range of behavioral and cognitive challenges, in the *absence* of the facial features of FAS.

Alcohol Related Birth Defects (ARBD): Physical anomalies associated with ARBD include facial malformations, microcephaly (small head size), poor eyesight, malformed teeth/dental problems, cleft lip/palate, malformed hands and fingers, hearing problems, and genital anomalies (“Child of Mine” Conference, 2010).

Although prenatal alcohol exposure is the leading preventable cause of mental retardation, not all children exposed prenatally will have intellectual disabilities. In a study conducted by the University of Washington and reported by the British Columbia Ministry of Education, the range of IQ of a person with FAS is between 20-120; the IQ of someone with ARND falls in the range of 42-142. Ten percent of those with an FASD will have an IQ under 70. This means that 90 percent will have normal to higher than average IQ (Streissguth, Barr, Kogan & Bookstein, 1996; Teaching Students with FAS).

It should be noted that the cognitive and behavioral challenges, and the impairments in adaptive functioning, may be just as severe for a child with ARND as with FAS. The difference is that the child with FAS exhibits the more easily recognized facial features and therefore is more likely to be diagnosed and offered services.

AWARENESS

FASD in the United States

In the United States, the combined prevalence of all FASDs – including FAS, Partial FAS, ARND, and ARBD – is at least 1 in 100 births or 1 percent of all births. Based on this conservative estimate, nearly 40,000 newborns are affected by an FASD each year in our country. The estimated cost of treating these children is up to \$6 billion dollars annually (Fetal Alcohol Spectrum Disorders Center for Excellence; Factsheets, 2006). Prevention of new occurrences of children born with an FASD is therefore not only an ethical priority but also a financial one.

This is not only a “women’s issue.” It is one for which all of us, women and men, mothers and fathers, families and communities need to take responsibility.

*(Institute of Health Economics
Consensus Statements, Government of
Alberta, Vol. 4, Oct. 7-9, 2009)*

Several states have enacted legislation mandating priority access to services for pregnant women. Other states have pursued various levels of public awareness of the dangers of drinking during pregnancy, generally with some type of posted warning signs. Several states, including Pennsylvania, provide priority access to substance abuse treatment for pregnant women and women with young children who are abusing alcohol or other substances.

Fetal Alcohol Syndrome (FAS) and its diagnostic criteria were described in scientific literature more than 30 years ago. The term Fetal Alcohol Syndrome was likely first used in 1973, after a physician in England identified a pattern of birth defects in eight children that was attributed to alcohol. Initially, only heavy drinking was thought to be dangerous to the developing fetus, but over time there was increasing awareness of the risk posed by *all* alcohol consumption during pregnancy. In 1981 in the United States, the Surgeon General’s “Advisory on Alcohol and Pregnancy” urged women for the first time to avoid all alcohol during pregnancy. In 1997, it was definitively stated that “alcohol causes FAS” and that “drinking during pregnancy is linked with disaster” (Streissguth & O’Malley, 1997). According to the U. S. Department of Health and Human Services, approximately 12 percent of pregnant women still drink alcohol, which means that one out of eight unborn babies are exposed to alcohol and are at risk for an FASD (2009).

In 2001, representatives of family-run groups across the country provided members of Congress with information about FASD and charged them with finding a way to diagnose all children and adults affected by prenatal exposure to alcohol. In 2002, the Centers for Disease Control (CDC) were mandated by Congress to develop diagnostic guidelines for FAS and other prenatal alcohol-related disorders in order to integrate them into medical and allied health education. The resulting report, *Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis* (2004), was issued as a starting point for defining the continuum of conditions caused by prenatal alcohol exposure. Clinical and scientific research on FAS and the spectrum of conditions resulting from prenatal exposure to alcohol is ongoing. This includes efforts to refine the understanding of FAS, and to develop clear diagnostic categories for related conditions. At present, only FAS is subject to formal diagnosis. However, based on a history of maternal alcohol

consumption during pregnancy and a range of presenting profiles, children with an FASD can be identified, so that early intervention and longer-term management can be pursued.

FASD in Pennsylvania

Pennsylvania, like many states, does not collect data related to FASD. However, using current prevalence data, it is estimated that there are 1164 children born with an FASD in Pennsylvania each year. The Prevalence and Cost Calculator, designed by Dr. Larry Burd, Director of the North Dakota Fetal Alcohol Syndrome Center and Professor of Pediatrics at the University of North Dakota School of Medicine and Health Sciences, estimates there are approximately 37,278 children with an FASD from birth to 18 years of age in Pennsylvania's child-serving systems. Expenditures associated with caring for the needs of children with an FASD include the cost of special education; treatment for speech and language disorders, medical disorders, developmental disabilities, and behavioral health disorders; and the cost of foster care and possible involvement in the justice system. As reported in the Pennsylvania Fetal Alcohol Spectrum Disorders Action Plan of 2008, the estimated economic costs per day for FASD are \$726,327. Annual costs for special education and juvenile justice for FASD are estimated to be \$62,699,280 (Burd, Prevalence and Cost Calculator).

Pennsylvania families affected by FASD bear emotional and financial burdens that cannot be underestimated. Not only do families with a child with an FASD need to address the educational, medical and emotional needs of their child, but they must also develop strategies to assist the individual for a lifetime of supports and financial planning. Lifetime costs may include the need for dependent living and the costs of unemployment, mental health treatment, and possible justice system involvement, although it should be recognized that there is a range of possible outcomes for individuals with an FASD.

In recognition of the issues related to FASD, since 2004, Pennsylvania has observed FASD Awareness Day on September 9. This has been expanded, since 2006, to include celebration of FASD Awareness Week in September. Pennsylvania has joined other states that have addressed FASD at the policy level. In 2007 the Pennsylvania Department of Health's Bureau of Drug and Alcohol Programs established a cross-systems FASD Executive Task Force. The resulting Action Plan established five goals (2008):

- **Awareness:** To eliminate alcohol use by women who are pregnant, planning to become pregnant or who are at risk for unplanned pregnancy by increasing the awareness of FASD and its symptoms.
- **Education:** To increase the knowledge of FASD within the professional community and the general population through education.
- **Systems:** To align and improve systems of care by making FASD a statewide priority, increasing the identification of those individuals affected by FASD, reducing the number of pregnancies affected by alcohol exposure and improving the ability of all systems of care to address the needs of individuals impacted by prenatal alcohol exposure.
- **Data:** To ensure the creation of a surveillance system that will collect, interpret and disseminate information on FASD.

PA Action Plan Goals, 2008

- *Awareness*
- *Education*
- *Systems*
- *Data*
- *Funding*

- **Funding:** To ensure adequate funding for prevention of FASD, as well as services for diagnosis and intervention for children, adults and families impacted by FASD.

In addition, the federal government, under one of SAMHSA's Centers for Excellence, has been awarding FASD grants throughout the country. One of these, in Pennsylvania, is the FASD Screening, Diagnosis and Treatment Project, a partnership between the Community Organization for Mental Health and Retardation (COMHAR), St. Christopher's Hospital for Children, and Center City Pediatrics, to implement a research-based FASD Screening, Diagnosis and Treatment Project in the Philadelphia area. The project includes screening, assessing, and diagnosing a child with an FASD, and providing needed interventions, treatment, and supports. Children with a positive screen for an FASD are referred for an FASD diagnostic evaluation. When children are identified as having an FASD, their intervention plans are modified to address the child's unique needs. The target is children, birth through 7 years of age, who are receiving services within COMHAR's system of care (The Philadelphia FASD-SDT Initiative Annual Report, 2010).

In 2009, the Office of Mental Health and Substance Abuse Services, Bureau of Children's Behavioral Health Services, established an FASD Workgroup to complement the work of the Department of Health (DOH) Executive Task Force, with the goal of focusing on the behavioral health needs of those children and families who are affected by an FASD. This Call to Action is the result of the workgroup's efforts over the past two years.

IDENTIFICATION AND DIAGNOSIS

Symptoms

Children with an FASD may present with a remarkably broad and varied range of physical, emotional, and behavioral symptoms. Typically, the behavioral features of an FASD do not become evident until the child is 2-4 years old. Symptoms in young children from birth to 3 that suggest the presence of an FASD includes colic and difficulty in soothing, feeding problems, disruptive sleep, sensory defensiveness, irritability, tantrums and indiscriminate attachment. The behavioral and developmental characteristics become more significant as the child gets older and is increasingly unable to meet the new age-related expectations. Since the symptoms of an FASD often mimic other mental health disorders that involve impairments in mood, impulse control, and behavior, the child may be diagnosed as having attention-deficit hyperactivity disorder, oppositional defiant disorder, bipolar disorder, and/or post-traumatic stress disorder. These diagnoses may actually coexist with an FASD, but if not recognized in context with the alcohol-related damage to the brain, the interventions may be counterproductive to the needs of the child. In addition, children with an FASD commonly have great difficulty establishing secure attachments to their parents or other caregivers, and may look similar to children with Reactive Attachment Disorder.

Primary Effects

Primary effects of an alcohol-exposed pregnancy involve permanent brain impairments, which are a result of the direct effects of alcohol on the developing brain. There can be great variability in terms of the severity of the primary effects of an FASD. This is believed to be due in part to the pattern and intensity of alcohol consumption during the pregnancy. While there is no right time for alcohol use during pregnancy, alcohol can have some of its most severe impacts when consumed during the first trimester. Unfortunately, the first trimester is when the woman may be unaware that she is pregnant. The pattern of alcohol use is also important. For example, binge drinking, in which large quantities of alcohol are consumed during short periods of time, can be particularly damaging to the developing fetus. It should be emphasized that, even though some children exposed to alcohol during pregnancy may not develop an FASD, there is no amount of alcohol, during any portion of a pregnancy, which is considered to be safe.

In general, the primary effects of alcohol exposure in a child with an FASD may include the following elements:

- Learning impairments, especially mathematics and reading comprehension
- Communication difficulties, including the lack of the ability to comprehend verbal and written concepts
- Memory problems
- Problems with decision-making
- Impulsivity
- Difficulty with cause-and-effect reasoning, which may contribute to difficulty in learning from experience, resulting in poor judgment and repetition of the same mistakes over and over

At the same time, children with an FASD are often described as having significant strengths. These may include the following:

- Highly verbal
- Bright and intelligent
- Friendly, outgoing, and affectionate
- Helpful and generous
- Persistent and determined
- Good with younger children

These positive characteristics may make it difficult for others to accept the possibility that the child may have an FASD, intensifying adult frustration. In addition, when an FASD goes unrecognized, a child may use maladaptive behaviors to compensate for or cover up an inability to meet expectations. These behaviors, referred to as the secondary effects of FASD, may also frustrate involved adults.

Secondary Effects

Secondary effects of an FASD involve behaviors and outcomes that may develop from lack of identification of the FASD and from ineffective support for the person with an FASD. Thus, in contrast to the primary effects of an FASD, secondary effects can be prevented and are subject to intervention. The range of secondary effects that may occur in individuals with an FASD is demonstrated in a five-year study conducted by the University of Washington of persons ages 6-51 with an FASD (Streissguth, Bookstein, Barr, et al., 2004):

- 94% had mental health problems, which may include depression, anxiety, impulsive behavior, and other challenging disorders.
- 83% of adults experienced dependent living
- 79% of adults had employment problems
- 60% of those 12 and older had trouble with the law
- 50% experienced inpatient treatment for mental health or substance abuse problems or spent time in prison
- 45% engaged in inappropriate sexual behavior
- 24% of adolescents, 46% of adults, and 35% overall had alcohol and drug problems (Fetal Alcohol Spectrum Disorders by the numbers, 2006)

This same study, profiling 80 women who had given birth to a child with FAS, highlighted the factors that put women at risk for having a child with an FASD:

- 23.8% had foster parents
- 17.5 % lived in a group home
- 35% had been in a juvenile detention center
- 22.5 % were involved with Child Protective Services as a child
- 80% had birth children who had been in foster care or Child Protective Services
- 57.5% were sexually abused as a child
- 46.2% were physically abused as a child

- 51.3% were sexually abused as an adult
- 85% were physically abused as an adult
- 86.3% were emotionally abused as an adult
- 95% were sexually and/or physically abused at some time (Astely, Bailey, Talbott & Clarren, 2000).

One source of secondary FASD effects may involve a misperception of the child by the family, school, or others. For example, the child with an unrecognized FASD may be seen as intentionally disobedient, and may be at greater risk of rejection or abuse. Over time, parents experience the frustration of “nothing working,” and the child feels misunderstood but is unable to explain this to the parent. Parents who are overwhelmed may appear to be inflexible and unwilling to try new therapies or approaches. The child may be referred to as an “underachiever” or be seen as “bad,” despite being intelligent and well-intentioned. While many children with an FASD draw negative attention to themselves, others may be overlooked because their behavior is not of sufficient concern, and their functioning not sufficiently impaired, to warrant the attention of parents and teachers. As a result, these children may slip through the cracks and not receive the services and supports that could promote their coping and increase their quality of life.

The chart in Attachment A identifies common behaviors of children with an FASD and misinterpretations that others may make. There is a fundamental question for adults to consider when involved with a child who is not meeting expectations and not behaving appropriately: Is the child functioning poorly because he or she *won't* do better, which implies an intentional decision by the child, or because he or she *can't* do better, due to limitations in functioning beyond the child's control? For children with an FASD, the correct inference is often that the child “can't” do better, due to cognitive limitations and problems learning from experience. The chart also serves as a useful framework for adults in contact with under-performing children whose behavior is problematic, highlighting the need to understand the child's strengths, limitations, developmental history, and complete profile, so that expectations can be developmentally appropriate.

*Is the child functioning poorly because he or she **won't** do better, or because he or she **can't** do better?*

For a child with an FASD, the social and emotional maturity level is often delayed and below that expected for the child's chronological age. Therefore, caregivers need to adjust their expectations, based on a careful understanding of the child, to a lower level than typically expected of a child of a particular chronological age. At the same time, it is important to bear in mind the variability of the child's development, with delays in some areas and competencies in others. Typically, expressive language skills are high, while receptive language may be impaired, along with other cognitive skills, social skills, and overall emotional maturity. However, each child also has areas of strength that can be used as sources of motivation, learning, and support.

Diagnosis

According to one Pennsylvania parent:

The sooner a child can learn about the challenges he faces and the parents and teachers can be taught to expect the unexpected, the greater the possibility that the teenage years will be easier.... We need to rethink and reframe a child's behavior, to understand the child is not the problem, is not "bad." The child has a problem, a disability, which with proper interventions and supports may decrease such secondary effects as depression and involvement in the justice system or the development of defense mechanisms which further alienate possible support systems.

*"Finally!
The name of the beast that
attacked my child!"*

- an adoptive mother

Another Pennsylvania parent elaborates on the frustration of having a child with an FASD which is not identified:

By the time we have tried all the typical disciplining and positive reinforcements, we begin to lose our sense of humor. Eventually, parents just throw their hands up and say, "I give up."

The prognosis of children with an FASD depends in part on early identification of the disorder, followed by developmentally appropriate management and interventions. The diagnosis of FAS, when the classic facial features are present, is a medical diagnosis and should be made by a trained physician. The situation is more complex, however, with an FASD other than FAS. This is due in part to the absence of the facial features of FAS. In addition, at present there are no agreed upon criteria for the diagnosis of an FASD other than FAS. The criteria, for example, for the diagnosis of an ARND have not yet been agreed upon, although research is being conducted to delineate the unique behavioral and developmental characteristics associated with ARND (Fetal Alcohol Syndrome: Guidelines for referral and diagnosis, 2004; see Attachment B for a summary). Due to the absence of firm diagnostic criteria for an FASD other than FAS, therefore, the goal is to identify rather than diagnose.

The foundation of effective identification of an FASD is built on awareness of the existence and prevalence of the disorder, efforts to obtain a maternal history of alcohol use during pregnancy, and routine, effective screening. There are no specific physical symptoms, laboratory findings, or imaging studies that confirm the presence of an FASD, but neuropsychological testing can be helpful. Once an FASD has been identified, the specific profile of strengths and needs of the child should be determined. Equally important is identification of the array of strengths and needs of the child, family, and community as a whole.

A barrier to identifying an FASD is its absence in the Diagnostic and Statistical Manual (DSM) as developed by the American Psychiatric Association. Mental health clinicians are less likely to identify a disorder, even though it may have many behavioral manifestations, which is not identified in the DSM. This, in turn, may mean less attention to intervention, and less access to services for children and their families. This dilemma often leads to a diagnosis of a DSM-IV disorder just to get mental health services for a child with an FASD.

One final challenge to identifying an FASD may be the absence of a confirmed maternal history of alcohol use. For example, with some children in out-of-home placements, the biological parents may not be known or are unavailable to provide information. As a result, it may not be possible to obtain clear documentation of alcohol use during pregnancy. Nevertheless, many clinicians suggest that the absence of a confirmed history of alcohol use during pregnancy should not prevent the identification of an FASD, when other evidence is present and there is reason to believe that maternal alcohol use occurred.

An important goal of FASD identification is to ensure that an FASD not be just a disorder of last resort, after all else has failed. Asking about maternal alcohol use during pregnancy and screening for FASD in children should be part of routine medical care, both in physical health and mental health, beginning at infancy. Older children and adolescents, especially those in out-of-home placements, are at particular risk for having an unidentified FASD, and so the possibility of an FASD should be considered for all children with compromised behavior and cognitive functioning. With early identification, accommodations can be developed to minimize the impact of the primary effects of the FASD, while secondary effects are prevented or minimized. A coordinated approach across settings can help the child with an FASD to remain positive and hopeful.

INTERVENTIONS

While prevention efforts are important, one cannot expect that all women of child-bearing years will uniformly refrain from alcohol use, based on even the most intensive public health approach. Thus, while we continue to warn about the dangers of drinking alcohol during pregnancy, the behavioral health system is obliged to create a system of care to identify children with and at risk of an FASD, so that intervention can occur, the family supported, and secondary effects prevented or minimized. Strategies for intervention need to be multi-faceted, culturally sensitive, and welcoming.

General Principles for Effective Interventions

Most experts in the field have highlighted the importance of early identification of an FASD, which can dramatically improve life skills, as well as provide the groundwork for a child's later development. In addition, there are a number of protective factors associated with positive outcomes for children with an FASD:

- Having a stable home environment
- Having basic needs met
- Remaining in a "quality home" for two or more years
- Being free from violence
- Being eligible for and receiving developmental disability services (Streissguth, 1996)

Effective interventions when an FASD is present involve the following general principles: 1) supporting the family and helping stabilize its environment, 2) collaborating and partnering with the family, building on the strengths of child, family, and community, 3) providing information about the disorder to multiple stakeholders, and 4) helping the child function more effectively, including understanding how the child with an FASD may be different from more typical children.

Supporting the Family

Since children with an FASD often come from families in which the parents or other caregivers experience adversity and limited resources, it is important that the family be assisted in stabilizing its environment. This may involve helping a parent who is using alcohol or other substances to receive treatment. Identifying past or current trauma, addressing violence in the home or community, and helping the parent receive trauma-related treatment may also be indicated. Mental health case management can help the family obtain other needed services to address such issues as the need for medical care, housing, employment, health insurance, and other concrete services. The interpersonal support offered can be equally important.

Principles for Intervention:

- 1. Support the family*
- 2. Collaborate and partner with the family*
- 3. Provide Information about FASD*
- 4. Help the child function more effectively*

For those parents with an FASD, the same supportive approaches used with the child are also applicable for the parent. Parents should be assisted in obtaining transportation to appointments, and in obtaining child care. Consistent, convenient appointment times along with appointment reminders may help maintain continuity. The parent should be assisted in organizing his or her time and developing useful daily schedules. Treatment plans should be clear and undertaken with the parent's direct input, with priorities identified. Peer support can be invaluable to the parent with an FASD, and can complement the efforts of case managers and other professionals.

All parents with a child with an FASD, whether or not they themselves have an FASD, need support, encouragement, and concrete services. As parents and other caregivers feel safer and more secure in their lives and communities, they will be better able to form secure attachments with their child and more effectively address and advocate for their child's needs.

Collaboration and Partnering with the Family

The family is not just a recipient of services but also a partner and collaborator with service providers and the education system. It is important to identify child, family, and community strengths, and to help the family build on and expand these. Service providers need to recognize the experiential knowledge that parents or other caregivers have about their child, which may be obscured by accumulating frustration. When supported by professionals and resource persons from the community, the child and family can accomplish a great deal more than by themselves. The importance of peer support, including support groups and networking for parents with a child with an FASD, should be kept in mind.

Providing Information about FASD

The entire community can benefit from information about FASD, and the dissemination of such information constitutes a major goal of this Call for Action document. Parents need to be informed about alcohol-related developmental disorders, for reasons of prevention, identification, and intervention. The information is relevant to birth parents, foster parents, adoptive parents, and other caregivers. The information is also relevant to both physical and behavioral health providers and to educators. Maintaining an awareness of the possibility of an FASD in children with behavioral and learning challenges, especially when there is a documented or suspected history of alcohol consumption during the pregnancy, will enable more involved children to be identified. Appreciating the common challenges of such children will enable parents, providers, and educators to be more individualized and strengths-based in their interactions with the child. In addition, awareness of the challenges involved with an FASD and how to address them can help parents and other caregivers build stronger attachments with their child, thereby promoting the child's development and wellbeing.

Helping the Child Function More Effectively

This is a very broad area, some of which is addressed in the next section. In general, Streisguth and O'Malley (1997) identify the importance of paying attention to the child's social environment, not just the specific neurologically-based limitations of the child. One important way that parents, behavioral health providers, and educators can help the child function more effectively is by recognizing how the child with an FASD may be different than a typical child, giving rise to the need for different approaches to learning and support. The following are some relevant examples:

- Due to problems with processing and memory, the child with an FASD typically has difficulty with multiple directives at the same time. Therefore, simple, uncomplicated directives may be more effective.
- Due to problems processing, the child may indicate understanding of a communication when in reality such understanding is absent. Therefore, asking the child to repeat what has been said may be of benefit.
- Due to problems with cause-and-effect reasoning, the child may not realize that a particular behavior is likely to result in a negative outcome. In addition, impulsivity may also make the child vulnerable to inappropriate or unsafe behavior. Therefore, a consistent, highly structured environment with ongoing monitoring of the child is important.
- Due to problems with cause-and-effect reasoning, the child may not understand the purpose of motivational systems or otherwise be able to benefit from them. Therefore, the imposition of negative consequences and “punishment,” and the expectation that the child will consistently work to achieve a reward, may be misguided and even harmful. The child with an FASD needs guidance and redirection, not motivational systems.
- Assuming that a child’s poor performance or functioning is a result of lack of effort or motivation may overlook significant skill deficits that handicap the child, which even the child might not recognize. Therefore, one should hesitate before concluding that the child is being “lazy” or otherwise doing poorly “on purpose.”
- While encouraging a child to persist with a task can be helpful, if the child falters the adult should be alert to the possibility that the task is beyond the grasp of the child, thereby minimizing frustration for all involved.
- Adults should recognize that a child with an FASD may also have an Attention Deficit Hyperactivity Disorder or other psychiatric disorder, so that this possibility can be explored and the disorder treated, if indicated.
- Finally, adults need to appreciate that, in the absence of a consistent ability to fully understand the environment and internalize learning, the child with an FASD is dependent on the patience, persistence, and kindness of others. When adults, especially parents and other caregivers, recognize that the child is facing genuine challenges and is doing the best that he or she can, they are better able to support rather than blame the child. Repetition and modeling are essential, and adults should view themselves as mentors for the child.

Helping the Child

Function More

Effectively

- *Give simple directions*
- *Ask child to repeat what you said*
- *Provide highly structured environment*
- *Guide and redirect; don't use motivational systems*
- *Don't assume child is lazy or doing poorly on purpose*
- *Consider whether a task is beyond the ability of the child*
- *Consider the possibility of other disorders, like ADHD*
- *Be patient, persistent and kind*
- *Support and don't blame*

The family also helps the child with an FASD function effectively by ensuring regular school attendance, providing necessary information to teachers, maintaining regular communication with the school, and ensuring regular medical care for the child to address possible physical health manifestations of the FASD and to promote wellness. Finally, to the extent possible, the family should encourage the child to identify needs and participate actively in all services and interventions.

All of the above actions by parents and other caregivers increase the likelihood that expectations for the child are developmentally appropriate, the secondary effects of an FASD prevented or minimized, and the positive and hopeful spirit of the child maintained.

Intervention Strategies and Promising Practices

Specific intervention approaches that are well-regarded in the field include the following:

Use of a Multi-Disciplinary Team

Research shows that a multidisciplinary approach is best suited to identify and treat the various needs the child may experience including physical health issues, physical therapy, occupational therapy, speech and hearing issues, learning disabilities, psychological or behavioral health problems. A model for this is the CDC-sponsored University of Washington FAS Diagnostic and Prevention Network Clinic in Seattle, which opened in 1992. This interdisciplinary diagnostic team model includes a pediatrician, psychologist, speech-language pathologist, occupational therapist, social worker, family advocate, and public health professional. These professionals work together to provide FASD diagnostic evaluations and intervention plans for individuals of all ages. This interdisciplinary FASD diagnostic program has expanded across the U.S. and Canada, and by 2004, more than 70 multidisciplinary clinical teams had been trained (Astley, 2005).

Flexible, Individualized, Collaborative Planning in Education

Fixed assumptions about the capabilities and limitations of a child with an FASD should be avoided and an individualized, multidisciplinary approach should be followed. Especially in the educational system, it is important that expectations for the child take into consideration the individual functional challenges of each child. Educational assessment and the use of neuropsychological testing can be quite helpful. The child will likely need a highly structured, consistent routine, with frequent reminders and other accommodations. In addition, when formulating a treatment plan, it is important to collaborate with parents as partners and build on parental observations and information in creating a strengths-based foundation for intervention. Needless to say, mutual blaming, and especially blaming of parents, is to be avoided.

Modeling, Mentoring and Monitoring (Alaska)

The state of Alaska has taken a lead in many aspects of FASD prevention, identification, and intervention. A particular focus has been reducing the number of children with an FASD who require residential placements. One of Alaska's major contributions to the management of an FASD has been identification of the triad of modeling, mentoring, and monitoring as core intervention elements. Modeling helps the child learn desired behaviors, mentoring provides the child with clarity and

consistent reinforcement of desired behaviors, and monitoring involves collecting data and ongoing evaluation in support of practice-based evidence.

Eight Magic Keys

Evensen & Lutke (1997) identify eight specific interventions to benefit students with an FASD. These elements complement the Alaska framework identified above, and include the following:

- Use of concrete statements
- Consistency
- Repetition
- Routine
- Simplicity
- Being specific
- Using structure
- Providing supervision

Changing One's Perspective on the Child

As discussed previously, it is important to shift one's perspective from thinking that the child *will not* do something to realizing that often the child *cannot* perform at the present time (Malbin, 2002).

Attachment A, adapted from Evensen and Malbin, identifies common adult misconceptions about the child with an FASD and more constructive ways to better understand the child's challenging behaviors.

Additional Promising Practices

Studies sponsored by the Centers on Disease Control (CDC) have found that children with an FASD are at very high risk for developing secondary conditions such as difficulties in school, trouble with the law, substance abuse problems, and mental health problems. Grantees have worked together with the CDC, through a collaborative effort, to identify, develop, and evaluate effective strategies for intervening with children with an FASD and their families. Through these interventions, researchers are trying to help children with an FASD develop to their full potential, prevent secondary conditions, and provide education and support to caregivers and families. These projects are now being implemented in community-based settings, and are summarized below, to reflect the varied nature of innovative programming.

- **Parent-Child Interaction Therapy (PCIT):** This type of therapy is intended to improve parent-child relationships, create a positive discipline program, and reduce behavior problems in children with an FASD. Parents learn new skills from a coach. A research study found significant decrease in parent distress and child behavior problems.
- **Parent Support and Management:** Children with and FASD might not respond to the usual parenting practices. Parent training has been successful in educating parents about their child's disability and about ways to teach their child many skills and help them cope with their FASD-

related symptoms. Parent training can be done in groups or with individual families. Such programs are offered by therapists or in special classes.

- **Marcus Autism Center—Atlanta, Georgia**
Math Interactive Learning Experience (MILE) Program: Specialized math tutoring: Special teaching methods and materials can help improve math knowledge.
- **University of Washington—Seattle, Washington**
Children with an FASD can have a variety of behavior and learning problems which can lead to high levels of stress for the children’s parents. This training is designed to improve caregiver comfort, meet family needs, and reduce child problem behaviors. A research study called “**Families Moving Forward**” found that this behavioral consultation model can have a positive effect on parenting and can reduce child disruptive behaviors. (Bertrand, 2009)
- **Children’s Research Triangle—Chicago, Illinois**
Executive functioning training: This type of training teaches behavioral awareness, self-control and improves executive functioning skills, such as memory, cause and effect, reasoning, planning, and problem solving.
- **University of California—Los Angeles, California**
Friendship training: Many children with an FASD have difficulty making friends, keeping friends, and engaging in social interaction with others.
- **K-12 FASD Education and Prevention Curriculum** (<http://www.nofas.org/about/K-12Curriculum.htm>): The CDC has collaborated with the National Organization on Fetal Alcohol Syndrome (NOFAS) to develop and disseminate FASD prevention and education resources for parents and family members, educators, students, professionals, and the public. As part of this project, NOFAS developed a school-based for teachers to implement with students in Kindergarten through grade 12. The curriculum provides age-appropriate information about the consequences that alcohol can have on human development while also encouraging youth to be tolerant and accepting of all individuals regardless of a person’s individual capabilities or disabilities. CDC has been working with NOFAS to disseminate and evaluate this curriculum.

Other interventions include models for environmental shaping, including the Behavior Environmental Adaptation Model (BEAM) (Kellerman, 2004), and Structure, Cues, Role models, Environment, Attitude, Meds and diet, and Supervision (SCREAMS) (Kellerman). In addition, family-focused relational approaches to treatment have been effective in supporting families and individuals living with FASD. Work is ongoing to develop these types of models and promising practices.

RECOMMENDATIONS OF THE FASD WORKGROUP

As discussed in this paper the research demonstrates significant financial cost savings and significant quality of life improvements for individuals and their families when FASD is addressed with appropriate interventions. In addition, increased awareness and identification could help prevent the development of the secondary effects of FASD through the provision of effective supports and services. In support of increased FASD prevention and initiatives to increase FASD awareness, identification, and intervention in Pennsylvania, the FASD Workgroup has developed the following recommendations:

1. The Office of Mental Health and Substance Abuse Services should distribute this Call to Action document, and develop an intensive public awareness campaign highlighting the needs of children and adolescents with an FASD – many of whom have an FASD that is unrecognized – and their families.
2. Pennsylvania program offices, systems, counties, managed care companies, providers, and families should increase awareness and knowledge related to FASD, including FASD prevention, identification, and intervention.
3. All child-serving systems should develop a coordinated FASD awareness and training plan. County child-serving systems should develop a coordinated, required FASD training plan for professional staff, provider staff, and consumer families, which includes the input and participation of applicable parents and youth.
4. Screening for FASD should be pursued in all child-serving systems. The screening process can help determine need for further assessments, including assessment of learning impairments, cognitive impairments, differential functioning skill levels, and mental health needs. Selection of potential screening tools can be guided by those currently in use in Washington State, New York, Alaska, and Canada.
5. Specialized assessment processes, including the use of neuropsychological testing when indicated, should be supported by public and private insurance companies.
6. As part of intakes, assessments, and psychiatric evaluations, behavioral health providers should ensure that medical and developmental histories, including information about the mother's pregnancy and her possible use of alcohol and other substances, are obtained and documented in writing.

Recommendation Highlights

1. *Distribute Call to Action*
2. *Increase awareness and knowledge*
3. *Screen and assess for FASD*
4. *Adopt an array of multi-disciplinary approaches*
5. *Support transition to adulthood*
6. *Link with higher education*
7. *Support families*

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7. Pennsylvania should explore and then adopt multi-disciplinary approaches – such as implemented in Washington State, Alaska, New York and Canada – known to be effective in facilitating identification and intervention of an FASD:
 - a. Potential team members should include a pediatrician/physician, physical or occupational therapists, speech pathologist, psychologist, team coordinator, parent advocate, and others as indicated.
 - b. Diagnostic centers can be developed in conjunction with established physical health centers, or separately as Centers of Excellence, using collaborative practices to ensure continuity of care for children and their families in the community.
 - c. The Department should explore ways in which to support effective and efficient diagnostic centers through the HealthChoices and Medical Assistance Fee for Service systems.
 8. Pennsylvania should develop an array of effective intervention and treatment approaches for children and their families in all child-serving systems, drawing from existing evidence-based and promising practices and expert consensus. These approaches should include:
 - a. Educational practices to support children with FASD with cognitive impairments, learning challenges, and problems with social interaction and self-control.
 - b. Supportive practices within the child welfare system for the child, biological parent, foster parent, and/or adoptive parent.
 - c. Supportive practices within the juvenile justice and criminal justice systems.
 - d. Supportive practices within the drug and alcohol system.
 - e. Specialized psychotherapeutic approaches, as indicated, which take into account the array of emotional, cognitive and behavioral impairments present in children with an FASD.
 9. Consistent with a public health approach, Pennsylvania should adopt a lifelong service model for individuals with an FASD organized around modeling, mentoring, and monitoring.
 10. Current services should be expanded to enable behavioral health providers to develop specialized treatment teams with the expertise to support and treat children with an FASD and their families. For example, Behavioral Health Rehabilitation Services (BHRS), Multisystemic Therapy, Functional Family Therapy, and Family-Based Mental Health Services (FBMHS) should all develop the expertise to address the needs of the child with an FASD and the family.
 11. Adolescents with an FASD and their families should receive developmentally appropriate services and supports for transition to adulthood.
 12. Linkages should be made with the higher education system to ensure that information about FASD is part of the curriculum for graduate students in human services and education. Linkages to higher

education can also be used to promote research on effective FASD prevention and intervention, consistent with practices in Alaska, Washington State, New York, Wisconsin and Canada.

13. Pennsylvania should support families affected by an FASD in the following ways:
 - a. Supporting the development of a Pennsylvania website as part of the National Organization on Fetal Alcohol Syndrome (NOFAS) website. Pennsylvania Families, Inc., an advocacy organization, has expressed interest in pursuing this, with appropriate state support.
 - b. Supporting additional opportunities for family networking and peer support.
 - c. Increasing the availability of respite and alternative family support models, in order to help prevent out of home placements.

ATTACHMENT A

Misinterpretations/Re-Framing Behaviors

BEHAVIOR (what we see, "how we describe"):	DUE TO (what may be going on):
<ul style="list-style-type: none"> ❖ Not listening- blank, no answer - "defiant," "willful," "unmotivated" 	<ul style="list-style-type: none"> → Delayed processing of information → Short attention span
<ul style="list-style-type: none"> ❖ Noncompliance - "defiant," "willful," "unmotivated," "attention-seeking," "stubborn" 	<ul style="list-style-type: none"> → Lack understanding → Can't translate request into action → Tired/fatigued
<ul style="list-style-type: none"> ❖ Keeps making same mistake - "on purpose," "manipulative," "not paying attention" 	<ul style="list-style-type: none"> → Difficulty generalizing → Can't link cause-effect → Unable to learn from consequences
<ul style="list-style-type: none"> ❖ No Remorse - "bad kid," "deviant," "doesn't care" 	<ul style="list-style-type: none"> → Unaware of the problem (inattentive) → Impulsive
<ul style="list-style-type: none"> ❖ Knows the rules but won't follow them - "willful," "deviant," "manipulative" 	<ul style="list-style-type: none"> → Difficulty generalizing or inferring → Poor comprehension → Forgot
<ul style="list-style-type: none"> ❖ Needs to be told over and over - "s/he knows this," "manipulative," "lazy" 	<ul style="list-style-type: none"> → Memory difficulties → Difficulty generalizing → Needs to be told over and over
<ul style="list-style-type: none"> ❖ Can't work independently - "attention-seeking," "lazy" 	<ul style="list-style-type: none"> → Memory difficulties → Can't translate verbal directions to action → Distracted
<ul style="list-style-type: none"> ❖ Doesn't complete homework 	<ul style="list-style-type: none"> → Memory difficulties

<ul style="list-style-type: none"> - “irresponsible,” “lazy,” “poor parenting” 	<ul style="list-style-type: none"> → Unable to transfer class learning to home → Poor organization
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<ul style="list-style-type: none"> ❖ Often late - “slow,” “irresponsible” “disrespectful,” 	<ul style="list-style-type: none"> → No concept of time → Difficulty organizing self
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<ul style="list-style-type: none"> ❖ Was able to do it yesterday - “isn’t trying,” “lazy,” “manipulative” 	<ul style="list-style-type: none"> → Short term memory difficulties → Can’t retrieve it
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<ul style="list-style-type: none"> ❖ Rigid, difficulty changing activities - “oppositional,” “bossy,” “controlling” 	<ul style="list-style-type: none"> → Need for consistency, routine, structure → May not understand what to do next
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<ul style="list-style-type: none"> ❖ Poor social judgment - “poor parenting,” “no common sense,” “attention-seeking” 	<ul style="list-style-type: none"> → Can’t interpret social cues → Lack of skills → Lack of cause-effect understanding
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<ul style="list-style-type: none"> ❖ Too physical - “bully,” “willful,” “poor parenting” 	<ul style="list-style-type: none"> → Hyper- or hypo-sensitive to touch → Doesn’t “get” boundaries
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<ul style="list-style-type: none"> ❖ Can’t sit still - “undisciplined,” “not trying,” “off task” 	<ul style="list-style-type: none"> → Sensory overload → Neurological need to move
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<ul style="list-style-type: none"> ❖ Constant talking or noise-making - “disrespectful,” “willful” 	<ul style="list-style-type: none"> → Poor verbal self-regulation → Impulsive
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<ul style="list-style-type: none"> ❖ Emotional outbursts 	<ul style="list-style-type: none"> → Poor emotional self-regulation
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<ul style="list-style-type: none"> ❖ Tantrums - “spoiled,” “immature,” “manipulative,” “attention-seeking” 	<ul style="list-style-type: none"> → Misinterpretation of intent of others → Immaturity → Changes in routine → Sensory overload → Unable to do what is asked (lack skills or forgot)
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|---|--|
| ❖ Upset when he doesn't get reward
- "manipulative," "spoiled," "selfish" | → Doesn't remember breaking the rule
→ Lack of cause-effect understanding |
| ❖ Steals things
- "dishonest," "no conscience," "criminal" | → Abstract concept of ownership
→ Impulsivity |
| ❖ Lies
- "dishonest," "lack of conscience" | → Unable to recall (memory)
→ Sequencing difficulties
→ Say what they think you want to hear |
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Adapted from Debra Evensen, FAS Alaska and Diane Malbin, FASCETS, consultants on FASD.

ATTACHMENT B

The Centers for Disease Control and Prevention published “Guidelines for Identifying and Referring Persons with Fetal Alcohol Syndrome” (<http://www.cdc.gov/mmwr/PDF/rr/rr5411.pdf>). The guidelines state that the following circumstances should prompt a diagnostic referral, even when knowledge of prenatal alcohol exposure is unknown:

- confirmation of prenatal exposure to substantial amount of alcohol (seven or more drinks per week, three or more drinks on multiple occasions, or both)
- any report of concern by a parent or caregiver (e.g., foster or adoptive parent) that a child has or might have FASD;
- presence of all three facial features (i.e., smooth philtrum, thin vermilion border, and small palpebral fissures);
- presence of one or more of these facial features, with growth deficits in height, weight, or both;
- presence of one or more facial features, with one or more CNS abnormalities; or
- presence of one or more facial features, with growth deficits and one or more CNS abnormalities.

The guidelines further state that the possibility of FASD should be considered for individuals who have experienced at least one of the following social or family situations:

- premature maternal death related to alcohol use (either disease or trauma),
- living with an alcoholic parent,
- current or previous abuse or neglect,
- current or previous involvement with child protective services agencies (PSAs),
- a history of transient care giving situations, or
- foster or adoptive placements (including kinship care)

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RESOURCES

Family Resources

FAS Community Resource Center: <http://come-over.to/FASCRC/>

FAS Family Resource Institute: <http://www.fetalalcoholsyndrome.org/>

FASStar Enterprises: Fetal Alcohol Syndrome Support, Training, Advocacy and Resources (parent advocate and training resource site), by Teresa Kellerman: www.fasstar.com

Fetal Alcohol Syndrome Consultation, Education and Training Services, Inc. (FASCETS): www.fascets.org

“Secondary Disabilities in FASD,” by Teresa Kellerman: <http://www.come-over.to/FAS/fasconf.htm>

General Resources

British Columbia Ministry for Children and Families: http://www.mcf.gov.bc.ca/fasd/kw_support.htm

British Columbia Ministry of Education: <http://www.bced.gov.bc.ca/specialed/fas/charstu.htm>

Canadian Public Health Agency diagnostic guidelines: <http://www.phac-aspc.gc.ca/fasd-etcaf/cdnguidelines-eng.php>

Example of Canadian system of care/supports for those with FASD (Alberta):
http://fasd.typepad.com/fasd_support_in_alberta/calgary_and_area/index.html

Fetal Alcohol Support Network of New York City and Long Island: www.fassn.org

Florida Resource Guide to FASD: <http://www.doh.state.fl.us/family/socialwork/pdf/fasd.pdf>

Maryland Department of Health and Mental Hygiene state report of approaches to FASD, prepared by NOFAS: http://www.nofas.org/resource/State_Report.htm

New York State Office of Alcoholism and Substance Abuse Services, FASD resources:
<http://www.oasas.state.ny.us/fasd/resources.cfm>

Washington State history related to FASD strategies: <http://depts.washington.edu/fasdpn/pdfs/wa-fasd-history-04-13-05.pdf>

National Organizations

Centers for Disease Control and Prevention: <http://www.cdc.gov/ncbddd/fasd/index.html>

National Institute on Alcohol Abuse and Alcoholism: www.niaaa.nih.gov

National Organization on Fetal Alcohol Syndrome (NOFAS): www.nofas.org

Alaska NOFAS: Fetal Alcohol Spectrum Disorders: <http://www.hss.state.ak.us>

Colorado NOFAS: FASD Frequently Asked Questions: <http://Nofascolorado.org/fasfaq.htm>

Minnesota NOFAS: <http://www.mofas.org/what-we-do/diagnosis/family-individuals.aspx>

United States Department of Health and Human Services. Substance Abuse and Mental Services Administration (SAMSHA) FASD Center for Excellence: <http://www.fasdcenter.samsha.gov/>

This website offers an online course, with an overview of risk factors for FASD, signs and symptoms, and prevention and treatment. The course consists of seven modules and can be taken at one's own pace.

Examples of resources developed by Dan Dubvosky, M.S.W., FASD Specialist at the FASD Center for Excellence:

- FASD Resources for Individuals New to the Field, 2009:
http://fasdcenter.samhsa.gov/documents/BFSS_2009_Dubovsky_New_to_Field.ppt
- "Strategies for Enhancing Success for Individuals with an FAS and Their Families, 2008:
<http://www.ccbh.com/valleyforgeconf/FASD.pdf>

Training Resources

"Born Drunk: Living with Fetal Alcohol Spectrum Disorders," by Susan Rose, Fetal Alcohol Support Network of New York City and Long island and Dianne O'Conner, NYS OASIS; PowerPoint training presentation: <http://www.fassn.org/acstthetrainer4-08shortenedPP.ppt#11>

University of Minnesota Continuing Education training:
<http://www.cme.umn.edu/online/mofasmodule1/home.html>

University of Washington FAS Diagnostic and Prevention Network: 4-Digit Diagnostic Code Guidelines:
<http://depts.washington.edu/fasdpn/>