

Service Coordination Practice Guide for Children Aged 0 to 3:

Fetal Alcohol Spectrum Disorders



With support from the Michigan Department of Community Health

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Why Have We Written This Guide?

Children who have been exposed to alcohol during fetal development can suffer multiple effects that range from subtle to serious disorders that are known as Fetal Alcohol Spectrum Disorders (FASDs). FASDs affect how a child grows, looks, and acts. Prenatal exposure to alcohol can interrupt or alter normal development and cause birth defects of the brain, heart, and other major organs as well as deficits in growth and development. The negative consequences of FASDs are life-long. The 1996 Institute of Medicine Report to the United States Congress stated “Of all the substances of abuse, including heroin, cocaine, and marijuana, alcohol produces by far the most serious neurobehavioral effects in the fetus.”¹ While FASDs are the largest known cause of preventable mental retardation, many individuals with an FASD have a normal to high IQ.

FASDs are 100 percent preventable if a woman does not drink alcohol during pregnancy. In 2005, the Surgeon General of the United States reported “When a pregnant woman drinks alcohol, so does her baby.”² Efforts in prevention continue nationally, as well as in Michigan; however, many children continue to be identified as having an FASD and will benefit from an early diagnosis and interventions that will help them develop to their fullest potential.

Much is now known about how children with an FASD grow, learn, and develop. Early intervention, through Michigan's *Early On* system, is hopefully the first step along the education continuum for these children and their families who will need support, information and connection to resources.

This guide was developed as a practice guide for a service coordinator or other early interventionist who is working with a child aged zero to three, and his/her family, who has been diagnosed with an FASD. The abilities of children with an FASD vary widely and must be taken into consideration when services are being implemented. This guideline provides clear, consistent information that will assist a service coordinator to individualize the services for a particular child, as well as think broadly about what is needed for a child with an FASD.

What Is My Role?

It is important to understand and know the signs and symptoms of an FASD - the facial characteristics certainly, but the growth and neurological issues as well, and how they might present in a very young child. A service coordinator is not required to understand if the structure of a child's brain affected by alcohol is 'significantly' different from the brain of a child who is not affected by alcohol. However, a service coordinator should have enough knowledge that observations of clusters of signs and behaviors in a child can be recognized as a potential FASD. A service coordinator should also understand that the journey to determine if a child does have an FASD can be a long and involved process. Many families will need support and assistance to move through that process. The information compiled during the child's time in *Early On* may assist in the process of obtaining a diagnosis later, when the child has exited from Part C.

¹ Stratton, K., Howe, C., and Battaglia, F., eds. (1996). Institute of Medicine. *Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention, and Treatment*. Washington, DC: National Academy Press.

² Carmona, R. H. (2005). *Advisory on alcohol use in pregnancy*. Retrieved May 16, 2011, from: <http://www.cdc.gov/ncbddd/fasd/documents/SurgeonGenbookmark.pdf>.

Chapter 1: Fetal Alcohol Spectrum Disorders

What are Fetal Alcohol Spectrum Disorders*?³

“Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term *describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications. The term FASD is not intended for use as a clinical diagnosis.*”⁴ The spectrum of disorders and terminology that can be used to identify conditions resulting from prenatal fetal alcohol exposure include: Fetal Alcohol Syndrome (FAS), Alcohol-Related Neurodevelopmental Disorder (ARND), Alcohol-Related Birth Defects (ARBD), Static Encephalopathy (alcohol exposed), Neurobehavioral Disorder (alcohol exposed), Fetal Alcohol Effect (FAE)**, and Partial FAS. Definitions for each condition can be found below.

* For the purposes of this document only, the terms “FASD-related condition,” “FASD spectrum” or simply “an FASD” are used to mean all conditions under this umbrella.

Conditions Under the FASD Umbrella

Fetal Alcohol Syndrome

The term Fetal Alcohol Syndrome (FAS) is a medical diagnosis and considered a birth defect reportable to the Michigan Birth Defects Registry. FAS was coined by two dysmorphologists at the University of Washington in 1973 to describe eight children who displayed the same pattern of “craniofacial, limb, and cardiovascular defects associated with prenatal onset growth deficiency and developmental delay.”⁵ The fact that all of the children’s mothers were alcoholics was an interesting piece of information, but not considered the causal factor at that time. The thought that alcohol, a substance that had been prevalent for centuries, was causing these patterns was not totally accepted at first. However, research began to emerge which identified alcohol as a teratogen (an agent that interferes with normal fetal development) and the only one that could cross the placenta. FAS represents the most severe end of the FASD spectrum while the most extreme outcome can result in fetal death.

FAS is identified as a pattern of physiological deficits that interfere with a child’s growth, learning ability, and socialization. There are *four major components required for a diagnosis of FAS*:

1. Characteristic facial features (i.e., thin upper lip, small eye openings, low nasal bridge).
2. Prenatal and/or postnatal growth deficiencies (i.e., weight, height).
3. Central Nervous System (CNS) concerns (i.e., microcephaly, structural differences of the brain, poor motor skills, cognitive deficits, behavior problems, vision & hearing problems).
4. Maternal alcohol use during pregnancy.

³ Substance Abuse and Mental Health Services Division, FASD Center for Excellence. (May 2004). *The language of fetal alcohol spectrum disorders*. Retrieved May 16, 2011, from: <http://www.fasdcenter.samhsa.gov/documents/WYNKLanguageFASD2.pdf>.

⁴ National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Department of Health and Human Services. *Fetal alcohol syndrome: Guidelines for referral and diagnosis*. (2004). Retrieved May 16, 2011, from: http://www.cdc.gov/ncbddd/fasd/documents/FAS_guidelines_accessible.pdf.

⁵ Jones, K. L., Smith, D. W., Ulleland, C. N., & Streissguth, A.P. (1973). Pattern of malformation in offspring of chronic alcoholic mothers. *Lancet*, *1*, 1267-1271.

Other terms such as Fetal Alcohol Effect (FAE) and Partial FAS came to be used to identify children who appeared to have physical and developmental effects due to prenatal exposure to alcohol, but did not have the severity or required patterns of FAS.⁶ A child may experience behavioral and cognitive difficulties such as intellectual disability, learning disabilities, difficulty using focused attention, hyperactivity, poor impulse control, and social, language, and memory deficits. Partial FAS describes persons with confirmed alcohol exposure, facial anomalies, and one other group of symptoms (growth retardation, central nervous system abnormalities, or cognitive deficits).

Alcohol-Related Neurodevelopmental Disorder⁷

Alcohol-Related Neurodevelopmental Disorder (ARND) describes a condition in which a child has behavioral and cognitive delays or deficits that are inconsistent with their developmental level, but does not have all of the physical features of FAS. Central nervous system structural and functional abnormalities may lead to symptoms such as hearing loss, sleep disturbances, and sensitivity to touch, lights, and sounds as well as attention deficits and learning disabilities.

Alcohol-Related Birth Defects⁷

Alcohol-Related Birth Defects (ARBD) describe anomalies in the skeletal and major organ systems. They may include anomalies such as holes in the heart, underdeveloped kidneys, fused bones or cleft palate. Confirmed maternal use of alcohol during pregnancy must also be documented.

Static Encephalopathy (alcohol exposed)⁸

The term Static Encephalopathy (SE) is used to describe permanent, unchanging brain damage that can be related to a number of developmental disorders. To be considered a condition under the FASD umbrella, the child must have a compromised central nervous system (structural, neurological and/or significant functional abnormalities), as well as prenatal alcohol exposure.

Neurobehavioral Disorder (alcohol exposed)⁸

Neurobehavioral Disorder (NBD) is a diagnostic term in the Fetal Alcohol Spectrum. A child with NBD will have central nervous system dysfunction (mild functional impairment with no evidence of structural or neurological abnormalities), as well as prenatal alcohol exposure.

**Fetal Alcohol Effect⁸

Fetal Alcohol Effect (FAE) is a term that has been used extensively in the past but is now considered obsolete. FAE implied a causal relationship that could not be confirmed and did not meet full criteria for FAS diagnosis. The terms listed above have more specificity and have replaced "Effect."

⁶ Premji, S., Serrett, K., Benzies, K. & Hayden K. A. (2004). Alberta Centre for Child, Family and Community Research. *Interventions for children and youth with a fetal alcohol spectrum disorder.*

⁷ Substance Abuse and Mental Health Services Division, FASD Center for Excellence. (May 2004). *The language of fetal alcohol spectrum disorders.* Retrieved May 16, 2011, from: <http://www.fasdcenter.samhsa.gov/documents/WYNKLanguageFASD2.pdf>.

⁸ FAS Diagnostic & Prevention Network. Center on Human Development & Disability. University of Washington, Seattle, WA. *What are FASD, FAS, Partial FAS and ARND?* Retrieved May 16, 2011, from: <http://depts.washington.edu/fasdpn/htmls/fasd-fas.htm>.

Alcohol and Pregnancy

For over 30 years there has been evidence of the adverse effects associated with prenatal exposure to alcohol, yet there is still an alarming misconception about alcohol consumption and pregnancy. In 2005, the Surgeon General of the United States changed the warning about the dangers of alcohol consumption during pregnancy to state “Alcohol consumed during pregnancy increases the risk of alcohol related birth defects, including growth deficiencies, facial abnormalities, central nervous system impairment, behavioral disorders, and impaired intellectual development. No amount of alcohol consumption can be considered safe during pregnancy.”⁹

Yet many physicians still tell pregnant patients that moderate levels of alcohol or “a few drinks” are unlikely to cause harm. There is evidence that the more heavily a woman drinks during pregnancy, the higher the risk for the diagnosis of FAS. But there is no evidence on how small the level of alcohol needs to be in order for there to be no effects on the fetus. Research has shown that the impact of alcohol as a teratogen on a developing fetus depends on the “Dose, Timing and Conditions.”¹⁰ Dosage refers to the amount of alcohol consumed at one time, while Timing refers to exactly when during fetal development the alcohol was ingested. Conditions refers to the overall status of the mother - metabolic capacity, nutrition status, drug use, and access to care and resources (which may be impacted by socio-economic status).¹¹

The FASD Center for Excellence¹² reports that nearly 12 percent of pregnant women report using alcohol in the past month and nearly 16 percent of pregnant women aged 15 to 17 used alcohol in the past month, consuming an average of 24 drinks in that month (i.e., they drank on an average of six days during the past month and had an average of about four drinks on the days that they drank).

Table 1 displays the most current figures of the incidence of FASDs in the United States and Michigan, along with the incidence of other conditions commonly identified in early childhood.

⁹ Carmona, R. H. (2005). *Advisory on alcohol use in pregnancy*. Retrieved May 16, 2011, from: <http://www.cdc.gov/ncbddd/fasd/documents/SurgeonGenbookmark.pdf>.

¹⁰ Streissguth, A. (2007). American association on intellectual & developmental disabilities environmental health archived teleconference series. *Prenatal alcohol exposure and the developing fetus: Links to developmental disabilities*. Retrieved May 16, 2011, from: <http://www.aaid.org/ehi/media/Streissguth%20PP%203%209%2007%20%282%29.pdf>.

¹¹ Premji, S., Serrett, K., Benzies, K. & Hayden K. A. (2004). Alberta Centre for Child, Family and Community Research. *Interventions for children and youth with a fetal alcohol spectrum disorder*.

¹² Substance Abuse and Mental Health Services Division, FASD Center for Excellence. (May 25, 2010). *Fetal Alcohol Spectrum Disorders - The Basics*. Retrieved May 16, 2011, from: <http://www.fasdcenter.samhsa.gov/educationTraining/fasdBasics.cfm>.

Table 1 - Incidence of FASDs Compared to Commonly Identified Conditions in Early Childhood.

Condition	United States	Michigan ⁵	Screening
Autism ¹	Estimates of 1 in 110 = <u>36,500</u> children	Not reported to the Michigan Birth Defects Registry	The American Academy of Pediatrics (AAP) recommends health professionals screen for an Autism Spectrum Disorder at ages 18 and 24 months.
Congenital Hypothyroidism ²	5 per 10,000 live births = <u>2,100</u> children	1 per 1,900 live births = <u>64</u> children	Congenital Hypothyroidism is one of the conditions in the mandatory Newborn Screening panel.
Down Syndrome ³	13 per 10,000 live births = <u>5,460</u> children	13.6 per 10,000 live births = <u>165</u> children	Down syndrome is screened for during gestation (voluntary).
Fetal Alcohol Syndrome (FAS) ⁴	5-20 per 10,000 live births = <u>2,100 to 8,400</u> children	1.4 per 10,000 live births = <u>17</u> children (under-reported)	The AAP does not currently recommend screening for any Fetal Alcohol Spectrum Disorder. The Michigan Department of Community Health (MDCH) encourages medical providers and other early childhood professionals to use the MDCH Fetal Alcohol Syndrome (FAS) screener. The Centers for Disease Control states that 1 in 8 pregnant women report alcohol use (Behavioral Risk Factor Surveillance System 1991-2005).
Fetal Alcohol Spectrum Disorders ⁴	100 per 10,000 live births = <u>42,000</u> children	Not reported to Michigan Birth Defects Registry	

1- Reported by Centers for Disease Control. Prevalence determined by the Autism and Developmental Disabilities Monitoring Network (ADDM). Researchers looked at the incidence of autism in eight year olds in 2004 and 2006 at 11 sites in the US, determining a range of 1:80 to 1:240 eight year olds, estimating the average to be 1 in 110 children. <http://www.cdc.gov/ncbddd/autism/research.html>.

2- Olney, Richard S., Grosse, Scott D., Vogt, Robert F., Jr. Prevalence of Congenital Hypothyroidism--Current Trends and Future Directions: Workshop Summary *Pediatrics* 2010 125: S31-S36. http://pediatrics.aappublications.org/cgi/content/full/125/Supplement_2/S31.

3- Canfield, M.A., Honein, M.A., Yuskiv, N., Xing, J., Mai, C.T., Collins, J.S., et al. National estimates and race/ethnic-specific variation of selected birth defects in the United States, 1999-2001. *Birth Defects Res A*. 2006;76(11): 747-56. <http://www.cdc.gov/ncbddd/birthdefects/DownSyndrome.html>.

4- May, P.A., and Gossage, J.P. 2001. Estimating the prevalence of fetal alcohol syndrome: A summary. *Alcohol Research & Health* 25(3):159-167. <http://pubs.niaaa.nih.gov/publications/arh25-3/159-167.htm>.

5- Michigan Department of Community Health Vital Records. *Birth Defects by Detailed Diagnostic Code Group and Birth Year, Michigan Resident Children Born in Michigan During 2000-2008, Cases Diagnosed within One Year from Birth*. <http://www.mdch.state.mi.us/pha/osr/BirthDefects/bdefcausebrk.asp>.

While it is true that if a pregnant woman does not consume any alcohol during pregnancy there is no possibility that the child would have an FASD, there are other factors that need to be considered. For example, it is important to remember that many women are not aware of the harm that alcohol consumption during pregnancy can cause and many women who drink alcohol do not know they are pregnant the first few months; thus, FASDs are not caused intentionally by the mother. In addition, it is not as simple as just “not drinking” for many women who are

chronic alcohol users/misusers. Without appropriate intervention and support that the mother is ready to accept, “100 percent preventable” may over simplify the issue of substance abuse in the United States. While FASDs are not caused by the biological father’s alcohol use, the importance of the father, extended family, community support, access to healthcare providers and treatment services that encourage women to not consume alcohol during pregnancy, especially to not engage in binge drinking (more than three standard drinks at one time) is of critical importance.

Many professionals in the medical, educational and other social services fields may still hear someone say - “One drink can’t hurt,” or “I drank when I was pregnant and my kids turned out fine.” However, stating what you know to be fact may be the only way to address these types of comments. An accurate response might be: *“I can tell you that zero alcohol is the only amount proven to be absolutely safe. Since alcohol can cross the placenta, conceivably, any amount may have an effect on the baby. I have more information if you would like to see it.”* Resources have been included in this document that provide a wealth of information on FASDs. They can be found in the Resources Section. In addition, please see Appendix A for a list of common myths associated with FASDs.

Diagnosis of an FASD

It is important to remember that only qualified, experienced medical personnel should be making a diagnosis of an FASD-related condition. A service coordinator is in a position to observe a child over time and can have a discussion with the family about a referral for a diagnosis if there is sufficient concern. Appendix E contains a checklist that a service coordinator can use to help identify if there are any distinguishing facial characteristics.

While it can be challenging to pursue a diagnosis of an FASD for a child younger than the age of three, there are many reasons to do so.

- A confirmed diagnosis of an FASD will allow a family to obtain appropriate services and resources within their medical, social, and educational community.
- Knowing that a child has a recognized condition changes the perception of many families and educators about the child. Strategies, intervention and relationships become more about supporting a child with brain damage and the subsequent symptoms, and not about “dealing with” a child who is obstinate, non-compliant, or lazy.
- A child who receives an early diagnosis and has appropriate intervention may avoid a secondary disability that may lead to delinquency or other issues. Children who do not receive early diagnosis of an FASD are often misdiagnosed with something that is negative in nature and potentially inappropriate.
- With a diagnosis, parents have the opportunity to meet other parents who are living with the same issue; finding support and potential respite opportunities that are sometimes desperately needed.

In Michigan, there are several FASD diagnostic centers located in different regions throughout the state. Please refer to Appendix B for FASD Diagnostic Clinic locations. Each diagnostic center has a qualified team of professionals who understand how to diagnose FAS and FASD-related conditions. It is helpful for service coordinators to understand what will happen when a family is referred to a diagnostic clinic so they may answer any questions a family may have.

- Each diagnostic center will require an intake packet and most likely will ask for birth records, medical records of the child, family history, and documentation of prenatal alcohol exposure. The evaluation will help parents/caretakers learn more about their child - what her strengths are, what his challenges are, how she learns, and what are

some recommended services for the child. Some parents/caretakers go to an FASD diagnostic center expecting a diagnosis of full FAS or an FASD-related condition. Sometimes that is not the outcome. For children aged zero to three with prenatal alcohol exposure, there may not be enough presenting information; thus, monitoring a child's growth and development and re-evaluating for an FASD may be the recommended outcome.

- Assessments cost money. Most diagnostic centers will attempt to medically bill insurance companies first. There may be an out-of-pocket fee (e.g., \$300.00). Diagnostic centers will explain this prior to setting an appointment for a diagnostic evaluation.
- Michigan diagnostic teams use the University of Washington four digit code which rates four (4) areas for every child: facial features, CNS/brain development, physical growth & development rate, and alcohol exposure. The diagnostic teams need documentation in each area in order to provide a comprehensive FASD diagnostic evaluation.
- Diagnostic centers may require a neuropsychological exam and sensory evaluation prior to setting the diagnostic appointment. Why? It is very helpful for the FASD diagnostic team to have a complete, comprehensive assessment of a child. Some diagnostic centers may have these services available onsite the day of the diagnostic evaluation appointment and other diagnostic centers may prefer to make referrals to external community resource locations for the multidisciplinary evaluations.
- Upon receipt of the diagnostic report, parents should take time to process the information. It can be overwhelming. Parents/caretakers should write a list of any questions they would like to clarify with the clinic, and consider if they would like to seek parent support and/or education. Depending on the community, there may be a local agency or group that can help guide a parent through learning more about life with an FASD-related condition and how to find helpful intervention services.

Refer to the Michigan Department of Community Health website for further information (www.michigan.gov/fas).

Signs and Symptoms

A service coordinator is not expected to diagnose an FASD-related condition. We hope this guideline will provide enough information that service coordinators might begin to think about an FASD-related condition as a possible reason for the clusters of signs and behaviors they have observed in a child. For example, a referred infant who is smaller than average, has difficulty sucking, is irritable and shows distress at environmental sights, sounds and touch has a cluster of behaviors that could be identified as one of several conditions. It is important that *Early On* staff begin to think about an FASD-related condition as a possibility. Appendix C lists overlapping characteristics of other mental health disorders for comparison.

Diagnostic Criteria of Fetal Alcohol Syndrome (FAS)¹³

1. Characteristic Facial Features/Dysmorphia (FAS only)

A person with FAS has all three distinct facial features:

- Smooth ridge between the nose and upper lip (smooth philtrum)
- Thin upper lip
- Short distance between the inner and outer corners of the eyes, giving the eyes a wide-spaced appearance.

2. Growth Deficits

Children with FAS have height, weight, or both that are lower than normal (at or below the tenth percentile). These growth issues might occur even before birth. For some children with FAS, growth problems resolve themselves early in life.

3. Central Nervous System Anomalies

The central nervous system is made up of the brain and spinal cord. It controls all the workings of the body. When something goes wrong with a part of the nervous system, a person can have trouble moving, speaking, or learning. He or she can also have problems with memory, senses, or social skills. Three categories of CNS problems are:

I. Structural

FAS can cause differences in the structure of the brain. Signs of structural differences are:

- Smaller-than-normal head size for the person's overall height and weight (at or below the tenth percentile).
- Significant changes in the structure of the brain as seen on brain scans such as MRIs or CT scans.

II. Neurologic

There are problems with the nervous system that cannot be linked to another cause. Examples include poor coordination, poor muscle control, visual motor difficulties and problems with sucking as a baby.

III. Functional

The child's ability to function is well below what's expected for his or her age, schooling, or circumstances. To be diagnosed with FAS, a person must have:

- a. Cognitive deficits (e.g., low IQ) or significant developmental delay in children who are too young for an IQ assessment; OR
- b. Problems in at least three of the following functional areas:
 - Cognitive deficits (e.g., low IQ) or developmental delays
 - Executive functioning deficits (e.g., lack of inhibition, planning, difficulty understanding cause & effect)
 - Motor functioning delays or deficits (e.g., delay of motor milestones)
 - Attention problems or hyperactivity
 - Problems with social skills
 - Other problems (e.g., sensory problems, language problems, not understanding cause & effect parenting practices)

¹³ National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Department of Health and Human Services. *Fetal alcohol syndrome disorders: Guidelines for referral and diagnosis*. (2004). Retrieved May 16, 2011, from: http://www.cdc.gov/ncbddd/fasd/documents/FAS_guidelines_accessible.pdf.

4. Mother's Alcohol Use During Pregnancy

Confirmed alcohol use during pregnancy can strengthen the case for FAS diagnosis. It's helpful to know whether or not the person's mother drank alcohol during pregnancy. But confirmed alcohol use during pregnancy may not always be available in foster care or adoption situations and is not needed if the child has all other criteria required for FAS diagnosis. Confirmed *absence* of alcohol exposure would rule out the FAS diagnosis.

Additional Characteristics of Children with an FASD

Listed below are characteristics that are seen in infants and toddlers who have been prenatally exposed to alcohol. It is important to emphasize that children who have not been prenatally exposed to alcohol also have some of the characteristics listed below. For example, just because a child is small for his/her age does not mean he/she has an FASD. This list of characteristics was included to help service coordinators understand the variety of symptoms that can occur with an FASD and should not be used as a checklist. Professional judgment is required to determine what the best course of action should be and may include referring the child and family to a diagnostic center. The Michigan FASD task force recommends the use of a pre-screen to help provide additional guidance and clarification to a service coordinator who has concerns about a child. The pre-screen is included in Appendix E. Children may display these symptoms with varying levels of significance depending on the inherent characteristics of that child and which areas of the brain were impacted during fetal development (dose and timing).¹⁴

Physical

Small for size
Irritable
Tremors
Erratic/poor sleep patterns
Low motor tone
Feeding problems, Failure to thrive
Hearing/vision problems
Fine/Gross motor deficits
Unusual movements
High susceptibility to illness
Sensitivity to sights, sounds and touch
Slowness to master developmental milestones

Attention and Hyperactivity

High activity levels
Perseveration
Sensory difficulties
Difficulty completing tasks
Poor impulse control
Problems with transitions

Cognitive

Concrete learner
May have deficits in pre-academic and readiness skills
Unable to comprehend danger; does not respond well to verbal warnings

Social

Socially engaging and chatty
Attachment issues
Difficulty with rules and authority figures
Difficulty with peers
Difficulty understanding cause and effect

Behavior

Mood extremes, temper tantrums

Speech and Language

Reduced vocabulary
Communication deficits and language disorders

¹⁴ Premji, S., Serrett, K., Benzies, K. & Hayden K. A. (2004). Alberta Centre for Child, Family and Community Research. *Interventions for children and youth with a fetal alcohol spectrum disorder.*

Potential Social-Emotional Issues

- Attachment - Children with all levels of an FASD may have difficulty with attachment. Some children with an FASD, especially newborns and infants, do not live with their birth mothers, and may potentially be in multiple foster care placements. In addition, young infants with an FASD can be irritable, have sensory regulation, feeding and sleep issues. They may also have significant medical needs. These behaviors can impede the attachment or bonding of an infant to his/her caregiver, placing the child at risk for more serious behavior and mental health issues including Reactive Attachment Disorder. If a parent also has a substance abuse issue, the child is at greater risk.
- Parenting - Infants and toddlers may have difficulty responding to common parenting practices, such as time out, cause and effect, consequences, etc. It may be frustrating for a parent when a child can do something one day, but not the next. It may be helpful for the parent to be educated about the potential memory issues and learning disabilities a child may have, which may impact his/her daily functioning at home, child care or other environment.
- Social-Emotional Development - Children on the FASD spectrum may have difficulty with social-emotional regulation and behavior, and they may react to things that generally are not a big problem. Early signs of social-emotional delay may be overlooked, particularly in a child under the age of three.

Social-emotional well being is a critical component of child wellness; wellness encompasses functioning across ALL developmental domains - physical health, PLUS cognitive, social, emotional, and behavioral domains. We can best support child wellness by working across disciplines and with all that are involved in the lives of young children.

Parenting

It is helpful for a service coordinator to understand what it is like to parent a child with an FASD. Parents whose children have been diagnosed with an FASD were asked questions about their child and their family experience. Parents were also asked how they felt about their *Early On* services. Appendix D lists statements from the parent perspective about what it is like to parent a child with an FASD-related condition, both the positives and the negatives. It is very easy to think only of the difficulties and the negative attributes of a child with an FASD. But there is so much that is positive. Every child deserves the chance to be seen as just a child, and not “that difficult child with an FASD.”

Chapter 2: Service Coordination

Service Coordinator Identification

No matter the diagnosis or delay a child has, each child eligible under Part C must be provided with a service coordinator who is responsible for coordinating all services across agency lines and serving as the single point of contact in helping parents to obtain the services and assistance they need. Service coordination is an active, ongoing process that involves:

- Assisting parents of eligible children in gaining access to the early intervention services and other services identified in the Individualized Family Service Plan.
- Coordinating the provision of early intervention services and other services (such as medical services for other than diagnostic and evaluation purposes) that the child needs or is being provided.
- Continuously seeking the appropriate services and situations necessary to benefit the development of each child being served for the duration of the child's eligibility.
- Facilitating the timely delivery of available services.

Discussed in this chapter are specific steps, behaviors, and procedures that are beneficial when working with a child with an FASD, including tips for evaluations, intervention, and service coordination activities that should occur.

Early On Referrals

Many children will be referred to *Early On* who potentially have an FASD-related condition. Very few of those children will be identified at birth or even by the age of three without the assistance of professionals at many levels to observe the children and identify issues or problems that are associated with prenatal alcohol exposure. Service coordinators must remember the confidentiality of the birth mother's drug/alcohol use or misuse. A Protective Services worker, for example, can document in a referral that a newborn tested positive for drugs at birth but cannot include any information about the parent. Experts within the field of substance abuse indicate there is a high likelihood of alcohol use by those who use drugs. Any child who is known to have a positive toxicology screen should, at the very least, be monitored for an FASD. Referral sources include:

- Hospital - May refer upon discharge.
- Physician - Many times a physician will refer due to concerns, but not be aware of any alcohol use during pregnancy or be able to share any information about the mother's alcohol use.
- Children's Protective Services - All children who are designated a Level I or II Department of Human Services abuse or neglect case are referred to *Early On*.
- Foster Parents - May refer a child who was just placed in their care, or at the recommendation of protective services if the child has been removed from the birth parents. "It is estimated that almost 70 percent of the children in foster care are affected by prenatal alcohol exposure in varying degrees."¹⁵
- Grandparent - The grandparent, as the caregiver, may have first or second hand information about the mother's alcohol use. Sometimes the grandparent may have suspicion, but no evidence about the mother's behavior during pregnancy.

¹⁵ National Organization on Fetal Alcohol Syndrome (NOFAS). *FASD: What the Foster Care System Should Know*. Retrieved May 16, 2011, from <http://www.nofas.org/MediaFiles/PDFs/factsheets/fostercare.pdf>

Case Studies

These are examples of cases that may be referred to *Early On*. Consider if any would generate a referral for an evaluation for one of the FASDs. If desired, refer to the FAS Pre-Screen (Appendix E). How would intervention be helpful for these children?

Amy, Age 2

Amy was born seven weeks premature. She was three pounds, four and a half ounces with no known medical problems. She left the hospital after three weeks and gained weight very well at home. In her first two years, she grew well and seemed to catch up in most of her development. Amy always had sleepy looking eyes that were wide-set. She has a smooth philtrum and a thin upper lip. Her little fingers curve in and her littlest toenails are very thick and grow out away from her toes. At about eight months, Amy learned to say "mom," but totally forgot it after a week and relearned it as a brand new word after 12 months. At 24 months she seems to have a large vocabulary, but also does a lot of "parroting" of what she hears. At one year, Amy got glasses for a lazy eye. She walked at a year and became incredibly active. At two, Amy is still very active, hits others, has sleep disturbances and shows a low tolerance for pain. She also shows absolutely no signs of being ready to be toilet trained.

Matthew, Age 15 months

Matthew was born full-term and weighed seven pounds, 15 ounces. He had no notable physical abnormalities at birth except for atypical curvature on two toes and his pinky fingers. Matthew was diagnosed with reflux at five months. At eight months he was not vocalizing consonant/vowel sounds such as ma or da and showed additional signs of possible speech/language delays. At 12 months, Matthew began receiving private occupational therapy services to address feeding problems. He had a very limited diet because of his highly sensitive gag response. He frequently vomited in response to the taste, texture and even the smell of some foods. His weight was around the 15th percentile. Matthew was noted to have difficulty focusing on a task and needing to get up frequently to move around. His mother indicates that this is typical of his behavior and described him as extremely active especially compared with other children his age. Matthew seeks out strong sensory inputs such as listening to the running vacuum cleaner for long periods, getting deep pressure hugs and swinging for extended lengths of time.

Brad, Age 2 ½

Brad weighed five pounds at birth and was adopted when he was eight days old. One of the first concerns his adoptive parents had was that it took Brad an hour just to drink one bottle. Brad walked at nine months, ran at 11 months and never stopped after that. He is still a little small for his age, but adorable, charismatic, well coordinated and athletic. Brad has a good vocabulary and seems very intelligent. Brad's behaviors are a concern. Just before Brad was a year old, he started biting people. He finally stopped biting when he got a little older and instead started bending people's fingers back. When the Sunday school routine changes, Brad bites, kicks and/or hits the teacher. He also has strange sleeping habits and he throws rather violent tantrums. In a store, such as Target, he is very active, sometime agitated and touches everything. His parents closely follow advice from parenting authorities, but the strategies have had no effect on Brad's behavior. He can't seem to learn cause and effect.

Data Systems

When entering information into a data system, programs should remember that a child who has a diagnosis of an FASD-related condition is eligible due to having an Established Condition. They would be eligible under the category: Exposures Affecting the Fetus/Child. Alternatively, a child may be found eligible due to having developmental delay. In either case, comprehensive data will provide greater understanding about the children the Part C system is serving. It is highly encouraged that programs utilize the Michigan Compliance Information System (MI-CIS) in addition to local data systems.

Procedural Safeguards

Procedural safeguards, also known as Family Rights, are legal safeguards that a family is entitled to under Part C of the Individuals with Disabilities Education Act (IDEA). *Early On* has developed materials that are provided to families to educate them about their rights. It is the role of each service coordinator to follow all appropriate procedural safeguards for the entire time a child is enrolled in Part C. The *Early On* Training and Technical Assistance website (See the Resource Guide) has a list of all the procedural safeguards for review.

Family Outcomes

Helping a family to understand their rights can enhance how a family participates in early intervention, special education and beyond. A service coordinator is the pivotal person who ensures that families enrolled in *Early On* meet the Part C Family Outcomes. Early intervention should help a family:

1. Know their rights - to be able to advocate, as a full team member, for their child within the guidelines and boundaries of the law.
2. Effectively communicate their child's needs - be able to express what needs to happen to make that child successful in their environment.
3. Help their child develop and learn - be able to reach the goals that help the child participate within their family and other environments.

Ensuring that the service coordinator is emphasizing the procedural safeguards is one way to help a family become empowered to act on behalf of their child. There are many ways to discuss rights and responsibilities with a parent, but building opportunities for discussion into home visits is one of the simplest. Rights should be reviewed with a parent at every decision making juncture - evaluation, eligibility determination, IFSP, IFSP review, etc. Families who know and use their rights become equal partners with their service coordinator to help their child meet his/her potential.

Evaluation

Considerations Specifically for Children With an FASD

Often a service coordinator and/or evaluation team will not be aware that the child being evaluated has been prenatally affected by alcohol. It is crucial that a team not base their opinions about the possibility of prenatal alcohol exposure on a child's race, culture, socio-economic status or mother's education level. FASDs affect children from all walks of life. Ideally, it is the observation of the child's behavior and his/her health status and medical history,

along with parental/caregiver report that will determine if there is the possibility of exposure. A service coordinator should consider the information listed below when determining eligibility to ensure that nothing is overlooked during the evaluation.

- Social-Emotional Assessment - Because social-emotional issues are so prevalent in children with an FASD, utilizing a tool that focuses on the social-emotional domain with more depth is helpful. The Michigan Department of Education has supported extensive training in the Devereux Early Childhood Assessment Program for Infants and Toddlers (DECA I/T) which is a strength-based tool designed to promote the protective factors central to social and emotional health and resilience in our youngest children. The program offers a systematic approach to understanding, assessing, summarizing, and planning to support children's social and emotional growth. Other tools that provide more in depth assessment of social-emotional growth may also be used.
- FAS Pre-Screen - The Michigan Department of Community Health has developed an FAS Pre-Screen (Appendix E). Ideally, a service coordinator will become aware of physical and behavioral characteristics that would indicate the need for this pre-screen to be completed to identify children who should be referred for further diagnostics at one of the Michigan's FASD diagnostic centers.
- Child Characteristics - It is widely reported by parents and caregivers that children with prenatal alcohol exposure have "on" days and "off" days. During the evaluation, the parent/caregiver should be given the opportunity to state if the child's behavior was typical, or if the behavior was much more "on" or "off" than usual. This is particularly important for children who were referred due to behavioral or social-emotional concerns. Encouraging caregivers to bring in any videotapes or other materials they have that portrays their child's behavior at home or in other settings is very helpful.
- What is Working? - Too often, a child's strengths are overlooked in the face of any deficits that exist. It is important that parents be allowed to talk about what they love about their child and what are their child's strengths. Intervention, then, should focus on developing skills within the context of the child's strengths. For example, many children with an FASD enjoy listening to and producing music. Even from a very young age, music can be built into interventions and routines to elicit language, positive behavior or social responsiveness.
- Hearing Evaluation - If one has not already been completed, a complete hearing evaluation is recommended. Hearing loss is associated with FASDs.
- Brain Damage - Assessing a child can be complicated when one considers how brain development is tied to the age of the child especially given the wide range of what is considered typical behavior for a child under the age of three. If there are any concerns that the child has brain damage, he/she should be referred to his/her pediatrician or pediatric neurologist for further evaluation.
- Don't Minimize - If there is any suspicion or concern of prenatal alcohol exposure, or if a parent is expressing concerns for an FASD, it is important not to minimize even slight delays. The service coordinator should pay attention to any clusters of behavior or symptoms that could indicate a diagnosable condition.

What if There Aren't Any Indicators?

If there aren't any indicators of exposure, such as documentation of possible prenatal alcohol and/or other drug exposure in the referral, evident physical characteristics, or significant global developmental delay, the service coordinator and evaluation team, as part of the standard, comprehensive evaluation may want to ask questions related to prenatal care and maternal history to identify any areas that might need further inquiry. There is a benefit of having this discussion with a family and it cannot be assumed that the doctor or someone else has asked these questions which can be scary and uncomfortable. The family interview component of the Infant-Toddler Developmental Assessment (IDA) might provide additional assistance; however, these questions may identify possible alcohol related concerns.

- What are your concerns that brought you here today?
- What kind of temperament does your child have? Is he/she easy going, difficult, slow to warm up?
- How is he/she eating and sleeping?*
- How was your prenatal care? When did it start?
- Tell me how your social drinking or alcohol consumption changed when you found out you were pregnant.
- Tell me how your smoking pattern changed when you found out you were pregnant.**

It can be very difficult to ask questions of birth parents or other caregivers about alcohol use. There is debate over whether those questions should be asked at one of the first meetings or later when the team has had a chance to build a relationship with the family. The timing of the discussion may differ for each family but should be part of *Early On's* family centered approach to services, proceeding in as non-judgmental and family focused a way as possible. Chapter 3 focuses on family support and how to bring up concerns about an FASD with the caregivers.

*Refer back to Chapter 1 to be reminded of why these questions are pertinent to FASDs.

**Babies born to mothers who smoked tobacco may have characteristics similar to children who were prenatally exposed to alcohol. For instance, they are more likely to have low birth weight and slowed fetal growth. In addition they may appear jittery or difficult to soothe.¹⁶

Eligibility Determination

Children are evaluated for eligibility by professionals who represent at least two different disciplines using a comprehensive evaluation tool. Children are found eligible in one of two categories: 1) developmental delay if they have a delay of 20 percent or one standard deviation below the mean in one or more developmental domains, or 2) established conditions when there is documentation of a current diagnosis provided by a health or mental health care provider who is qualified to make the diagnosis.

Early On must have clear written evidence (test scores, genetic reports, ophthalmology reports, etc.) that matches one of the eligibility category definitions. *Early On* uses informed

¹⁶ March of Dimes. (2011). *Smoking during pregnancy*. Retrieved May 16, 2011 from http://www.marchofdimes.com/professionals/19695_1171.asp.

clinical opinion, in addition to the documented evidence, when deciding if the identified conditions for the child and/or family are associated with developmental concern and there is a need for early intervention.

In most instances, children under the age of three will not be referred to early intervention due to having a diagnosis of an FASD-related condition since diagnosing an FASD under the age of three is difficult and the average age of diagnosis is six years. More likely, comprehensive evaluation procedures will determine if the child is eligible due to a developmental delay. The following examples might be helpful:

- Child has a diagnosis of an FASD-related condition. He/she is eligible due to having an Established Condition: Exposure Affecting the Fetus/Child.
- Child does not have a diagnosis, but has a positive blood alcohol level at birth. He/she is eligible due to having an Established Condition: Exposure Affecting the Fetus/Child.
- Child does not have a diagnosis, nor a positive blood alcohol level. Determine if a developmental delay is present through evaluations.
- Child does not have a diagnosis, a positive blood alcohol level at birth, nor a developmental delay. Child's relative caregiver indicates the birth mother consumed alcohol during pregnancy. Due to absence of developmental delay, determine if there is sufficient information to use Informed Clinical Opinion to make the child eligible.

Case Studies Summary

	<i>Update</i>	<i>Reason to Refer for an FASD Evaluation</i>
Amy	<p>Amy was not enrolled in <i>Early On</i>. She began in private OT at age six for sensory integration issues. There were noticeable improvements in balance and coordination. Amy is now 14. She was home schooled and worked on letter recognition for two years and two more years on forming letter sounds. She is behind in mathematics, but can add, subtract, and understand money values. She is accepted socially and has formed close relationships with peers and family.</p>	<ul style="list-style-type: none"> • All three Facial Characteristics • Physical Anomalies (pinkies, toes) • Developmental Delay • Sleep Disturbances • Attention Problems/impulsive • Regulatory Disturbances • Maternal Alcohol Use undetermined • Birth weight less than 10th percentile <p>Amy was given a diagnosis of full FAS from a geneticist.</p>
Matthew	<p>Matthew was enrolled in <i>Early On</i> at the age of 15 months due to delay in the areas of fine motor and communication. He remained in <i>Early On</i> for one year.</p> <p>He received periodic home visits and participated in play groups.</p> <p>He participated in a school based feeding group facilitated by an OT, and made significant improvement in his sensory tolerance.</p> <p>By 19 months his speech production began to increase.</p> <p>Matthew is currently five years old and still struggles with sensory processing disorders and has a limited diet. His family is having trouble accessing affordable treatment options.</p> <p>Matthew still displays a lack of focus and need for frequent movement, but this has not triggered further reassessment at this time.</p>	<p>Matthew was never referred for an evaluation for an FASD despite meeting the following referral criteria:</p> <ul style="list-style-type: none"> • Feeding concerns • Attention problems/impulsive/restless • Speech/Language delays <p>Mother reports that at no time during the pregnancy nor during any physician or specialist visit, did any professional inquire about her alcohol use during pregnancy.</p> <p>Mother reports that she did not use any alcohol during pregnancy. She shares Matthew's story because she feels more physicians and those in the helping professions should be more aware of the signs of Fetal Alcohol Spectrum Disorders and become comfortable asking questions about alcohol use.</p>
Brad	<p>Brad is now 26 years old. He did not receive services from <i>Early On</i> nor did he receive other supportive services. Brad is struggling with many secondary disabilities, although he has the support of a loving family.</p>	<ul style="list-style-type: none"> • Self-report of birth mother confirming alcohol use during pregnancy • Appears small for his age • Potential learning disability - difficulty learning cause and effect • Sleep disturbances <p>Brad was given a diagnosis of Alcohol-Related Neurodevelopmental Disorder.</p>

IFSP/Intervention

Who to Include on the Individualized Family Service Plan (IFSP) Team

A child may have a large medical team or support network. It is recommended that a service coordinator set a time for the IFSP with the parents and discuss with them who they would like to invite, obtaining the appropriate release of information as needed. One way to include team members would be to mail a copy of the Written Prior Notice (WPN) that is given to the parents, to those individuals the parents wish to invite. If necessary, a cover letter can be included with the WPN describing the process and asking for their input if they are unable to attend the meeting. In this manner, the IFSP is not delayed, and important information is considered for its development.

Developing the IFSP/Intervention

As with many other conditions, a child aged birth to three with a possible FASD will most likely not yet have received a diagnosis that could help to guide intervention strategies. While prenatal alcohol exposure affects each child differently, there are some intervention strategies that have been shown to be effective with children with an FASD related condition (potential or diagnosed). It is worth mentioning that there is a decided lack of evidence-based materials that focus on children aged zero to three with an FASD. It will be important for programs to consider the appropriateness of each of the strategies for an individual child; however, the strategies described do have strong documentation of being effective with many children enrolled in early intervention.

Goodness of Fit - Intervention for a child with an FASD can be thought of in relation to the concept “Goodness of Fit.” The principle behind “Goodness of Fit” is that a child’s development is not influenced by temperament alone. Thomas and Chess¹⁷ proposed that a child’s unique characteristics, along with temperament, interact with the environment in a way that impacts a child’s development. The unique characteristics of the child’s caregivers will also be a factor of the interaction. Dr. Ann Streissguth, an expert in the field of FAS, suggests that early diagnosis and intervention as well as a stable, nurturing home life, are protective factors against secondary disabilities that are very common for older children/adults with FAS.¹⁸ One could extrapolate that children in those situations are experiencing a “goodness of fit” with their environment, compared to children who do not have that advantage. It is not easy to achieve a “goodness of fit” for many children with an FASD. Their brain damage is such that their inherent temperament is compromised, as is their interaction with the environment. In addition, consider a parent who has his/her own mental health, social-emotional or abuse issues that prevent him/her from responding to a child in a manner that will enhance or impact the “fit.” Focusing on strategies that look at the ‘whole child,’ not individual domains will be beneficial.¹⁹

¹⁷ Thomas, A., & Chess, S. (1977). *Temperament and Development*. New York: Brunner/Mazel

¹⁸ Streissguth, A. P., Bookstein, F. L., Barr, H. M., Sampson, P. D., O’Malley, K., & Kogan-Young, J. (2004). Risk Factors for Adverse Life Outcomes in Fetal Alcohol Syndrome and Fetal Alcohol Effects. *Developmental and Behavioral Pediatrics, 25* (4), 228-238.

¹⁹ Florida State University Center for Prevention and Early Intervention Policy. (2005). Baldwin, S. *Fetal alcohol spectrum disorders: A florida resource guide*. Retrieved May 16, 2011, from: <http://www.doh.state.fl.us/family/socialwork/pdf/fasd.pdf>.

Sensory Integration - Parents often report that their infant with an FASD is particularly irritable, difficult to soothe, sensitive to sounds, lighting and touch and has sleeping and feeding difficulties. Harwood and Kleinfeld²⁰ state “the cornerstone of intervention with alcohol-exposed infants is discovering their tolerance for interactions.” It is a recommendation that a child who is showing signs of being unable to regulate his/her behavior, is under or over aroused to stimuli, or irritable and unable to be soothed, may benefit from an assessment to determine if he/she is having difficulty processing sensory stimulation. Some strategies that may help parents of infants who have been prenatally exposed to alcohol include:

- Facing the child away from the caregiver may help to decrease the overall level of stimulation during feedings.
- Playing soft music.
- Swaddling the infant (a technique that wraps an infant snugly in a blanket). Some feel it recreates how an infant felt in the womb and is good for those infants who require a means to help them calm. Not every infant will prefer to be swaddled, and infants should not sleep swaddled.
- Swaddling the infant and placing in a darkened room to decrease stimulation.
- Using a white noise machine to decrease background noise.

Each infant is different. It may be a matter of “trial and error” to determine what works for a particular child. Encouraging strategies that allow caregivers to take turns and be able to rest is recommended.

Infant Cues - Infants use subtle cues to indicate they are over stimulated. Infants may hiccough, be drowsy or fall asleep unexpectedly, arch, avoid a gaze, grimace, have changes in breathing or skin color, or be irritable. Many resources are available to help teach parents how to recognize their baby’s cues. “Understanding My Signals,” published by the Vort Corporation, is an example of one resource. This short booklet describes coping and avoidance behaviors demonstrated by premature infants. While not geared toward infants with an FASD-related condition, this booklet could help parents understand and respond to their infant in a manner that particularly benefits that child.

Brevity - Children with an FASD are usually concrete thinkers. They do very well when directions are kept brief and simple and direct. Children with an FASD-related condition, as well as many other children, do well with tasks that are broken down into smaller steps; particularly when the steps are combined with a visual cue such as a pictorial social story or chart.

Routine and Structure - Most children with an FASD-related condition thrive on routine and structure, as do many typically developing children aged zero to three. But a child with an FASD may have dramatic reactions to changes in routine or environment. Julie Gelo, an adoptive/foster parent of seven children, all diagnosed with an FASD, recounts in her trainings a story about her daughter who, when confronted with new furniture in the living room, could no longer find the bathroom on her own. She thought the bathroom had been moved. Carolyn Hartness, a colleague of Julie’s and an expert on FAS thinks perhaps the child unconsciously used the living room furniture as a marker for the bathroom. Once it was changed, she no

²⁰ Harwood, M. & Kleinfeld, J. (2002). Up front, in hope: The value of early intervention for children with fetal alcohol syndrome. *Young Children*, 57(4), 86-90.

longer had that external prompt.²¹ Imagine daily events such as this for an infant or toddler who is non-verbal; how would he/she respond? Parents of children with an FASD quickly discover that even slight changes to the child's environment can be an issue. The following interventions may be helpful to assist with routine:

- Designating areas for specific activities
- Limiting toy choices
- Maintaining consistency among all caregivers
- Preparation for transitions
- Providing external cues such as timers, sounds or songs
- Providing start/finish baskets (for slightly older children)
- Using picture schedules
- Using the exact same words for desired actions

New Experiences - Children with an FASD can have very curious and friendly personalities. Even though it seems counter intuitive, given their need for structure and routine, children with an FASD do enjoy new experiences. They may need extra preparation, so parents and caregivers need to plan carefully, but new learning opportunities should be presented often. Children with an FASD-related condition do not generalize their skills easily. Kinesthetic learning, learning through a variety of senses and modalities, has been shown to help children with an FASD learn many skills.

First/Then Statements - Children with an FASD, as well as typically developing children, understand the concrete statements of "first you do this, then you do (get) this." It limits the amount of arguing, and when followed through, sets up very clear expectations of behavior at the child's developmental level. A two-year old can be told "first put your cars in this box, then you can have a cookie." If the child is older, he/she may be able to understand more general statements such as "first put your toys away, then you can have a snack." Self-esteem, even at this young age, is greatly improved with consistent and specific expectations, discipline and praise. First /then statements can be combined with other techniques such as timers to indicate the length of time left in the activity and transition songs. "First put your cars in this box, then you can have a snack. Let's sing the clean up song."

Safety - Children with an FASD need continuous supervision. They often have no understanding of danger or strangers. At this age, they will most likely not tell strangers information they should not share (name, address, phone, etc.). However, they may run into the street, fall off play equipment, approach a stranger in a store, jump off furniture, etc. Some children have been known to unlock front doors and walk out of the house. The service coordinator may want to discuss with the caregiver if there are any concerns and look for ways to make the house safer (i.e., bolt, flip or chain lock on front door well above the child's reach).

Environment - Parents might need assistance in modifying the child's environment. Many parents, grandparents, friends, etc. are very excited to buy lots of fun, "stimulating" toys for the infant or toddler. But for a child with an FASD-related condition, that type of environment might not be conducive to his/her development. Not every modification is appropriate for every family.

²¹ Washington State Department of Social and Health Services. Washington State Foster Parent Training Series. (2001). *Fetal alcohol syndrome and fetal alcohol related conditions with Carolyn Hartness and Julie Gelo*. Retrieved May 16, 2011, from: <http://www.dshs.wa.gov/ca/fosterparents/videoFAS.asp>.

But caregivers may be able to consider what changes they are able to make and monitor them to see if they make a difference.

- Create a calm environment by considering a subtle paint color.
- Create less distraction in child's bedroom by having fewer pictures or objects hanging from walls and the ceiling.
- Designate areas for eating, sleeping, playing, etc.
- Develop rules for putting away objects, which can help with transition and compliance.
- Hang curtains over open shelves to reduce distraction.

Think creatively. If a child is having difficulty sleeping, consider setting up a tent on the floor. Or place orange safety cones in an area a child is not allowed to go. The visual cue will be a helpful reminder to the child of the boundaries and expectations.

Attachment - Infants and toddlers with an FASD are at risk for attachment disorders. Intervention that promotes attachment is recommended:

- Follow the child's lead during play.
- Limit number of caregivers, if possible.
- Face the infant when playing rather than sitting behind him/her.
- Respond to the child as soon as possible. A child with possible attachment issues should not be left to sit and cry.
- Show warmth and loving behaviors to child.
- Talk often with the infant or toddler about what is happening in his/her world (i.e., I am making your bottle now. You sure look hungry. Time for your bath. The water is warm and silky). The child should not be left in silence. However, follow the child's cues to make sure he/she does not get over stimulated.
- Try to increase a child's tolerance for physical affection by stroking his/her hair, patting or rubbing his/her back, using infant massage, cuddling, etc.

New Information - There is some information available that shows that interventions used for children with autism also work for children with an FASD-related condition; but there is not a magical combination of strategies or services that will work for every child. As with much of intervention, it may take time to determine the strategies that work for each individual child.

Linking to Services

A child with an FASD may need many services. Consider the slide on the next page depicting the services for a child with full FAS.²² The parents of this particular child, and his team, obviously felt each of these providers was necessary. Not every child will need this level of service; however, it is important that a service coordinator understand the social, medical and educational needs of a child and family. Listed below the slide are the social supports and services that should be considered for a child with an FASD and his/her family.

²² Substance Abuse and Mental Health Services Division, FASD Center for Excellence. (May 25, 2010). *Many doors, no master key: Resources needed for Brandan, age 1-2 years*. Retrieved May 16, 2011, from: <http://www.fasdcenter.samhsa.gov/grabGo/manyDoors.cfm>.

Many Doors, No Master Key: Resources Needed for Brandan, Age 1-2 Years

Health

- Pediatrician
- Feeding Specialist
- Neurologists (2)
- Nutritionist
- Pediatric Ophthalmologist
- High-Risk Infant Clinic
- Audiologist
- FAS Diagnostic Clinic
- Otolaryngologist
- Lab and X-Ray Services
- Pharmacy
- Surgeons
- Medical Supply Providers
- Pulmonologist
- Gastroenterologist
- Respiratory Therapist

Education

- Physical Therapist
- Speech/Language Pathologist
- Infant Educator
- Cultural Recreational Therapy (e.g., drumming)
- Birth-3 Program: Occupational Therapist, Speech/Language Pathologist, Teacher, Aide, Play Therapist

Social and Community Services

- Local Indian Child Welfare Advisory Committee
- Daycare
- Tribal Social Worker
- Div. of Dev. Disabilities/Case Worker and Family Resource Coordinator
- Child Welfare/Case Worker
- Substance Abuse Treatment (birth mother)
- Tribal Council
- Mental Health Counseling (birth mother)
- Respite Providers
- Parenting Education (birth mother)
- Foster Care System

Legal and Financial Services

- SSI
- Medicaid
- Guardian Ad Litem
- Judge-Foster Care Issues
- Attorneys for Birth Parents



~ About 40 service providers



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Substance Abuse and Mental Health Services Administration
www.samhsa.gov



SAMHSA
Fetal Alcohol Spectrum Disorders
Center for Excellence

FAS Diagnostic Clinics - Currently, there are five Diagnostic Centers in the state of Michigan (Appendix B). Children should be referred for full FAS evaluation if:²³

- there is known prenatal alcohol exposure (seven or more drinks per week or three or more drinks on multiple occasions, or both).
- there is unknown prenatal alcohol exposure but report of concern by a parent or caregiver (birth, foster or adoptive parent) that the child may have FAS or an FASD-related condition.
- a behavioral or physical evaluation indicates concern that there are potential symptoms of FAS or an FASD-related condition.
- one or more facial features are present in addition to growth deficits or one or more CNS abnormalities are identified by the prescreen indicators for an FASD.

Just as we do not want inappropriate referrals coming to *Early On*, we do not want inappropriate referrals going to the diagnostic centers. However, there is a screening process that each caller undergoes when they call to schedule an appointment. If you have information that makes you suspect an FASD-related condition, please don't hesitate to refer the family to a clinic. This is just the first step in their journey.

Department of Human Services (DHS) - A child who is in foster care will have a DHS worker, although the emphasis for intervention may focus more on parent issues. There will need to be coordination between the DHS case worker and the *Early On* service coordinator to determine how to split up service coordination activities for the child. A child in foster care can potentially have his/her medical services, those that Medicaid doesn't cover, paid for by DHS. This includes outpatient occupational therapy, physical therapy, or speech therapy. Other items such as braces, shoe inserts, glasses, etc. may also be covered by DHS. The DHS worker can be a strong ally in helping the caregiver with addiction issues, engaging families who are reluctant to participate and providing extra support for the team.

Community Mental Health (CMH) - CMH provides home-based parent-infant support and intervention services to Medicaid enrolled families where the parent's condition and life circumstances, or the characteristics of the infant, threaten the parent-infant attachment and the consequent social, emotional, behavioral and cognitive development of the infant. Services reduce the incidence and prevalence of abuse, neglect, developmental delay, behavioral and emotional disorder.

Special Education - Infants and toddlers may be eligible to receive special education services that are appropriate to their ages and individual needs. A referral to special education is indicated for any child with a diagnosed FASD-related condition, as well as children who appear to have a 50 percent delay in at least one area of development.

Medicaid/Insurance - For those families whose children are not insured, the Michigan Primary Care Association (MPCA) currently has an outreach program to assist families in signing up for public insurance easily and quickly in order to ensure that Michigan's children have medical coverage. (See Resource Guide).

²³ National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Department of Health and Human Services. *Fetal alcohol syndrome: Guidelines for referral and diagnosis*. (2004). Retrieved May 16, 2011 from: http://www.cdc.gov/ncbddd/fasd/documents/FAS_guidelines_accessible.pdf.

Respite - Respite is very beneficial to any parent of a child with special needs. The goal of respite is to provide opportunities for caregivers to have time to refresh and recharge themselves, and have small amounts of time in which they are not a 24/7 caregiver. It is important to stress the idea of respite to parents, and to ensure that parents/caregivers have supports when they have most need of them. Listed in the Resource Guide are a few of the respite services in the state of Michigan. The service coordinator and parent should work together to find a respite provider in their community.



Chapter 3: Family Support

Families of children with an FASD may face a lot of challenges. One parent stated “*Our lives would have been so much less complicated if all those born with A.R.B.D. (Alcohol Related Birth Defects) were also born with F.B.H. (Fluorescent Blue Hair)*” –Leon’s Mom.²⁴ A big issue for parents of children with an FASD is that their child, on the surface, can appear to be very typical. It is difficult for those outside the family to understand the child’s behaviors that the family deals with on a daily basis.

Having a Conversation about FASDs

Although a child may be involved with many systems, *Early On* staff are often the first to discuss with a family the possibility that there are developmental concerns for their child. While an interventionist is quite used to discussing developmental delay, it is not always easy to bring up something like FASDs. There are ways to approach the issue that are professional and delivered in as family friendly a manner as possible.

To begin, prepare mentally for the discussion, particularly if it is the first time you have had this type of conversation with a family. Identify your feelings about FASDs.

- How do you feel about the mothers who drank during their pregnancy?
- Do you feel that some mothers have a disease that they cannot control, or that some mothers unfortunately did not know the harm alcohol could cause?
- Do you have feelings that any mother should have known that drinking while pregnant could cause problems and they could have stopped if they wanted to?
- Do you feel that lots of children are exposed to alcohol and they are just fine? Or do you feel that even a tiny amount of alcohol could affect a child so they should be enrolled in services?

It is important that you work through your feelings associated with FASDs so you are able to work with the family in a non-judgmental a way, and meet the needs of the child and family.

- Understand your role - As a service coordinator, you are not in the role to provide a diagnosis but to identify for a family that there is a concern for an FASD-related condition based on all the available information and help them to know what to do with that information. It is also not within your role to determine the progress you feel the child can make. Without appropriate evaluation, you can not be certain how that child’s brain has been impacted.

Evaluate the pros and cons of the discussion. Every parent deserves the right to know that there is a potential concern about his/her child. Do not assume that you are going to spare the family pain by not bringing up FASDs, but do consider what you are going to say in order to be as sensitive and family friendly as possible.

²⁴ Society of Special Needs Adoptive Parents (SNAP). 1999. *Parenting children affected by Fetal Alcohol Syndrome: A guide for daily living*. (Ministry for Children and Families, British Columbia, ed.).

How Do You Discuss FASDs with Birth Parents?

The parent has already taken action to get help for his/her child by bringing him/her to early intervention. Many parents are relieved to know that there may be an underlying issue that is contributing to their child's development. Birth moms may have to work through issues of guilt or anger but your approach to the discussion can help.

- Make sure the parents are comfortable before having the discussion in a non-threatening location. Some parents feel uncomfortable in an environment that appears to be very clinical.
- Pick someone from the team that the mom knows and trusts to discuss the concerns for an FASD related condition, one-on-one. This decreases the chance that mom will feel she is being confronted by a team.
- Find common ground with the parent. You both share concerns about the child's development or behavior. Discuss your observations and how they match up with hers. Let mom know that FASDs are not fully understood by medical professionals and that many doctors still tell their patients that some alcohol is ok to drink.
- Most early intervention teams do not have the experience needed to explore issues related to substance use. However, the parents may want to share family history of alcohol use or information about their partners' alcohol use. It is appropriate to ask the family if they would like referrals to community agencies that can assist them with their concerns.
- Use empathy when speaking with the family. Remember, many mothers are not aware of the dangers of drinking alcohol while pregnant, or drank before they knew they were pregnant.
- You should have a healthy skepticism. This is a very sensitive topic and you cannot be certain you are getting all of the information or if it is all accurate.

How Do You Discuss FASDs with Foster or Adoptive Parents?

Foster parents are in a different position than birth parents. Most foster parents ask questions prior to the placement or adoption to determine if there are any concerns of which they should be aware. Too often, a foster/adoptive parent is told there is no history of anything that could cause harm to the child. But 'no history' does not mean 'no exposure.' When bringing up the possibility of an FASD-related condition to a foster or adoptive parent, similar steps to discussing it with a birth parent should be followed.

- Find common ground. Discuss your concerns about the child with the parent and emphasize what he/she has observed.
- This is just a suspicion on your part, not a diagnosis. Share any information that you can with the foster parent to decide if pursuing a diagnosis is worthwhile.
- Do you or the foster parents know of any family history of substance abuse, or if there is any reference to alcohol in the child or mother's history that has been shared with him/her?
- Is he/she aware of any prenatal drug exposure or maternal mental illness?
- Is he/she aware of any siblings having been diagnosed?

- Has the child been adopted from a region that has endemic alcohol abuse (e.g., Russia, S. Africa, etc.)?

Much of this information is confidential and may not have been shared with you or the foster parent. But sharing what you can in an open manner will help with the discussion about the next steps.

Stages of Change

Understanding how adults deal with change has been a focus of research for many years, particularly in the field of substance and/or alcohol use, and can be described in a series of five steps that a person moves through.²⁵ Often, families find themselves going through the same series of steps when they are confronted with information that is unexpected or difficult (i.e., child has a potential FASD-related condition) and they find themselves questioning what they thought they knew about their child. They may not want to take the next steps to confirmation a service coordinator, understanding the stage a family is going through will help with not only the intervention, but building a relationship with a family as well. Many times early intervention personnel believe a family is non-compliant. But the parents may be in one of the stages of change and not yet ready to move through it or they may be facing barriers that prevent them from moving through it. The stages of change are listed in Table 2 along with examples of statements parents might say that help a service coordinator identify their stage of change. Also included are strategies that might assist a service coordinator in his/her interactions with a family. A service coordinator is not a therapist, but should understand and be prepared to assist those families who need time to change or take a long time to change.

Table 2 - Stages of Change

Stage of Change	What a Parent in this Stage Might Say	Strategies for Service Coordinators
Pre-Contemplation Not ready for change; unaware of the need for change.	<ul style="list-style-type: none"> • There is nothing wrong with my child. • My mom drank when she was pregnant with me and I turned out fine. 	<ul style="list-style-type: none"> • Offer straightforward education on FASDs. • Avoid arguing with the parent. Pushing against resistance can cause someone to push back, not see things differently.* • Be empathetic; use active listening and behaviors that show you are open to what the parent has to say.*
Contemplation Aware that an issue exists and thinking about changing it. (Ambivalence)	<ul style="list-style-type: none"> • Tell me what you think is going on with my child. • I am wondering if my drinking could have affected my child. • I think I may need to have more information. 	<ul style="list-style-type: none"> • Identify the pros and cons of an evaluation for an FASD-related condition. • Share that you understand it might be difficult to find out if the child has a diagnosis of an FASD.* • Accept that the parent is thinking about the next step, but don't push.

²⁵ Prochaska, J.O., & DiClemente, C.C. (1992). Stages of change in the modification of problem behaviors. In M. Hersen, R. M. Eisler, & P. M. Miller (Eds.), *Progress in Behavior Modification*, (pp. 184-214). Sycamore, IL: Sycamore Press.

Stage of Change	What a Parent in this Stage Might Say	Strategies for Service Coordinators
<p>Preparation Committed and planning to change (address the issue) within the next month.</p>	<ul style="list-style-type: none"> • I am going to make an appointment for an evaluation. Can you give me the phone number again? • Tell me exactly what makes you think my child needs an evaluation for an FASD. 	<ul style="list-style-type: none"> • Remember: “It’s not a goal unless it’s a goal to the client.”* • Provide information about what to expect during the diagnostic process. • Provide resources about FASD diagnostic services. • Discuss what it might be like if he/she receives a diagnosis of an FASD. What if he/she doesn’t? • Acknowledge small steps and self-advocacy.
<p>Action Beginning the steps of change; new behaviors (actions) are still being developed.</p>	<ul style="list-style-type: none"> • I took my child for an evaluation and shared a lot of information with the team. • I talked to my pediatrician who agreed to provide medical records for the evaluation. • I am concerned I won’t be able to take time off from work to go to the evaluation. 	<ul style="list-style-type: none"> • Acknowledge there might be difficulties and ask if the parent would like assistance to overcome the barriers.* • Discuss any barriers the parent has encountered. • Support the steps the parent has taken to help his/her child.
<p>Maintenance Have been working to sustain change for at least six months.</p>	<ul style="list-style-type: none"> • The doctor thinks my child has an FASD-related condition, but we won’t know until the test results are back. • He is too young for a diagnosis. What can I do to help him now? 	<ul style="list-style-type: none"> • Acknowledge the family’s successes.* • Provide education to the family and other potential partners about how knowing the diagnosis can help. • Review long term outcomes the family would like to achieve.
<p>Relapse Returning to an earlier stage in the process; evaluation of what is needed to maintain the change.</p>	<ul style="list-style-type: none"> • How am I going to handle this on top of everything else? • I think we need to postpone visits for a little while; too much stuff has been going on. 	<ul style="list-style-type: none"> • Obtaining an evaluation was successful, but consider what new stage of change the parent may be in regarding the next steps for his/her child. • Affirm the parent’s feelings. (Is he/she overwhelmed, sad, angry, resigned?)* • Continue to stay supportive/ find supports for the family.

*Statements marked with an asterisk are principles of a counseling technique called Motivational Interviewing (MI) developed by Dr. William Miller. MI is a collaborative way of working with a client that elicits or draws from the client the motivation to change, thus giving all autonomy and responsibility for change to the client. MI, as it was originally intended for use with clients with substance abuse issues, is an evidence-based practice. MI is a promising practice for other behavioral change counseling. For more information on MI please see the Resource Guide.

Engaging Reluctant Families

Working with any family requires trust by all participants. When working with families who may be experiencing stress, who have substance abuse issues, or are mistrustful of “government,” it may be difficult to build a trusting, caring relationship. Families may be reluctant to engage in services for a number of reasons. Understanding the process of change can help, but equally helpful is utilizing behaviors and skills that can ensure engagement between an agency and a family. Skills that are important for a professional to learn are:²⁶

- Tuning into self and others
- Focused listening
- Clarification of role and purpose
- Respect
- Clear and accurate response to a family’s questions
- Honesty
- Dependability
- Identification and support of family strengths
- Seeking to understand the family’s point of view
- Culturally responsive practice
- Regular feedback

Generally, most families want to be able to help their children and will engage with their teams and service coordinator. However, there are also families whose current circumstances or previous experiences may be barriers to engagement. Service coordinators may need to use a variety of skills before a true relationship develops with a family. Please see the footnote at the bottom of the page for further information about engaging difficult families. The referenced presentation describes how adult and infant attachment affects the trust that is necessary to build a relationship. Ms. Solchany provides suggestions on how to identify potential barriers and issues that impede relationship building, as well as strategies to work with families who are difficult to engage.

Confidentiality

A parent must agree to share information about his/her substance abuse. A separate Authorization to Share form must be obtained for any information regarding a person’s involvement in a federally funded substance and/or alcohol use or misuse program, per 42 C.F.R, Part 2 (Federal Regulations - Confidentiality of Alcohol and Drug Abuse Patients). In addition, 45 C.F.R, pts 160 & 164 (Federal Regulations - Security and Privacy) provide further patient rights and protection under the Health Insurance Portability and Accountability Act.

Service coordinators should be aware of what information needs to be part of service documentation (progress notes). Only information that is pertinent to services for the child, or that is being specifically addressed for the family, should be included. A family has the right to decide who is and who is not aware of their personal issues.

²⁶ Solchany, J. (2008). *Reaching the most difficult to reach families: An attachment perspective*. Presentation to the Maternal Health Infant Program at the Michigan Department of Community Health (9/17/08). Retrieved May 16, 2011, from: <http://mediasite.mihealth.org/mediasite/Viewer/?peid=9094265d7c7942b1be7594c271baba54>.

Families whose children are diagnosed or potentially have an FASD-related condition need support and understanding. As one of the most under reported and under diagnosed health conditions, children with an FASD and their families may have a difficult time receiving appropriate supports and services. It is important that all early intervention personnel understand the importance of recognizing and managing potential delays as soon as possible.



Resources

Resources

Respite	
MOCHA MOMS	Organization for mothers of color. www.mochamoms.org
LAP Respite Center	Community respite - Lansing. http://www.laprespitecenter.com/
Bridges 4 Kids	Resource for Michigan families with children with special needs. http://www.bridges4kids.org/CC.html#3
Community Respite Center, Inc.	Community respite - Jackson. http://www.communityrespite.com/
Chapel Hill Training Outreach Project	National respite locator through Chapel Hill, NC. The status of each agency would need to be checked. http://chtop.org/ - Click on Respite Locator Service or click use the link: http://archrespite.org/respitelocator .

FASD Websites	
State of Michigan FASD website	Resource for information on Michigan FASD local community project initiatives and FASD diagnostic clinic locations. www.michigan.gov/fas .
National Organization on Fetal Alcohol Syndrome	National FASD Advocacy Organization http://www.nofas.org/default.aspx
Centers for Disease Control and Prevention (CDC)	Resource for evidence-based scientific information on FAS/FASD birth defects and developmental disabilities. http://www.cdc.gov/ncbddd/fasd/index.html
Substance Abuse and Mental Health Services Administration (SAMHSA)	A reputable site with information on FASD. http://www.fasdcenter.samhsa.gov/ SAMHSA FASD Center for Excellence resource for Fact Sheets & Brochures. http://www.fasdcenter.samhsa.gov/grabGo/factSheets.cfm

Training	
CDC - Guide to Referral and Diagnosis	Information to assist in referral and diagnosing FAS. http://www.cdc.gov/ncbddd/fasd/documents/FAS_guidelines_accessible.pdf
SAMHSA	SAMHSA FASD Center for Excellence: Online FASD Training Module http://www.fasdcenter.samhsa.gov/educationTraining/courses/FASDTheCourse/index.cfm
CDC Drinking and Reproductive Health	Drinking and Reproductive Health: A Fetal Alcohol Spectrum Disorders Prevention Toolkit. (American College of Obstetricians and Gynecologists-ACOG). http://www.acog.org/departments/healthissues/FASDToolkit.pdf
Video series by Carolyn Hartness and Julie Gelo	Filmed in 2002, this series was originally for foster parents in the state of Washington. http://www.dshs.wa.gov/ca/fosterparents/videoFAS.asp
Great Lakes FASD Regional Training Center	Provides an array of training opportunities. http://www.fasdeducation.org

Resources

FASD Videos

Journey Through the Healing Circle	Series of four stories about children/adults with an FASD, told using a traditional Native American approach (approx. 30 min each). Each video has a companion book. http://www.dshs.wa.gov/ca/fosterparents/videoJourney.asp
“Picture This - A Photovoice Project”	A powerful short photo-video project narrated by mothers of children with FAS (about 18 minutes). http://citizenshift.org/picture-this
“Story of Iyal”	A seven minute video describing life with Iyal who is diagnosed with FAS. http://www.cdc.gov/ncbddd/fasd/videos/index.html

Preschoolers/Additional Resources

Michigan Primary Care Association (MPCA)	The MPCA is concerned about children without health insurance and engages in outreach activities to help families get enrolled in the MICHILD or Healthy Kids programs. http://www.mpca.net/enroll.html
MOPS - Mothers of Preschoolers	International mothers organization that provides support to mothers of young children. www.mops.org
Michigan Association for Infant Mental Health	Website/organization provides good information on infant mental health issues. www.mi-aimh.org/
Motivational Interviewing	Website that features research and information on Motivational Interviewing. www.motivationalinterview.org
Motivational Interviewing	Motivational Interviewing video series. www.michigan.gov/mihp .
PCIT - Parent Child Interaction Therapy	Therapy originally designed for work with young children with conduct disorder. Currently, this is being offered at Central Michigan University. Only for children 3-6. http://pcit.php.ufl.edu/
“Understanding My Signals”	“Understanding My Signals”. Vort Corporation. http://www.vort.com/products/188.html

Appendices: A-E

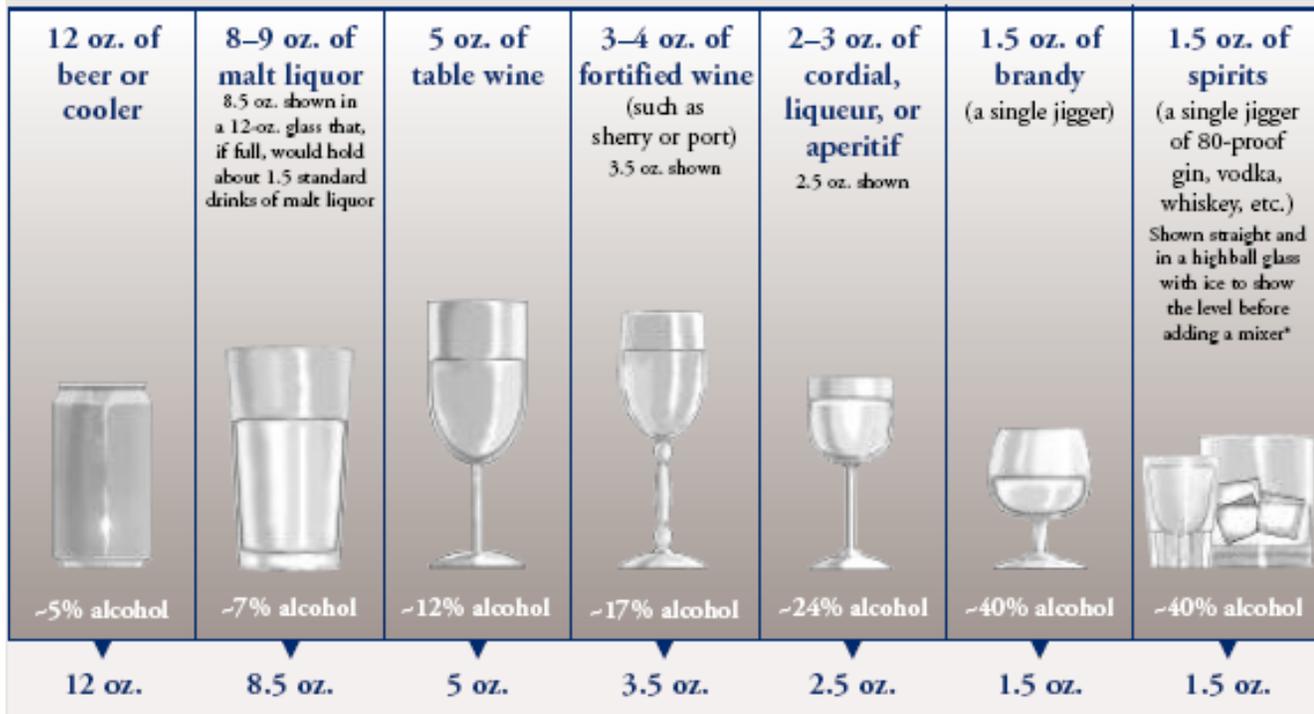
Appendix A: Common Myths About
Fetal Alcohol Spectrum
Disorders²⁷

²⁷ Florida State University Center for Prevention and Early Intervention Policy. (2005). Baldwin, S. *Fetal alcohol spectrum disorders: A florida resource guide*. Retrieved May 16, 2011, from: <http://www.doh.state.fl.us/family/socialwork/pdf/fasd.pdf>.

1. MYTH - Beer and wine are fine to drink; only hard liquor should be avoided.

FACT - Any type of alcohol can harm a fetus. Many times, women consume larger drinks than what is considered standard (see Figure 1 below).

Figure 1 – Standard Drink Size. Reproduced with permission from FASD Center for Excellence, Substance Abuse and Mental Health Administration. www.fasdcenter.samhsa.gov



2. MYTH - Alcohol or drugs taken after the first trimester will not affect the unborn baby.

FACT - While many organs have formed during the first trimester, brain development continues throughout pregnancy and after birth. Exposure to alcohol anytime during the pregnancy can affect the baby's brain.

3. MYTH - It is ok for a woman to have an occasional drink during pregnancy, such as for a special occasion.

FACT - There is no known safe amount of alcohol to drink during pregnancy.

4. MYTH - A breastfeeding mother can provide more milk for her baby by drinking beer.

FACT - Alcohol passes through the breast milk to the baby and can affect the baby's brain development. Studies have shown that infants take in less breast milk when alcohol is present.

5. MYTH - If a woman drinks early in her pregnancy, there is no reason to stop drinking, the damage is done.

FACT - As soon as a pregnant woman stops drinking, she prevents further risk of damage to her baby. It is never too late.

6. MYTH - Children eventually outgrow FASDs.

FACT - FASDs last a lifetime. Specific problems vary during different stages in development, but the brain damage is permanent.

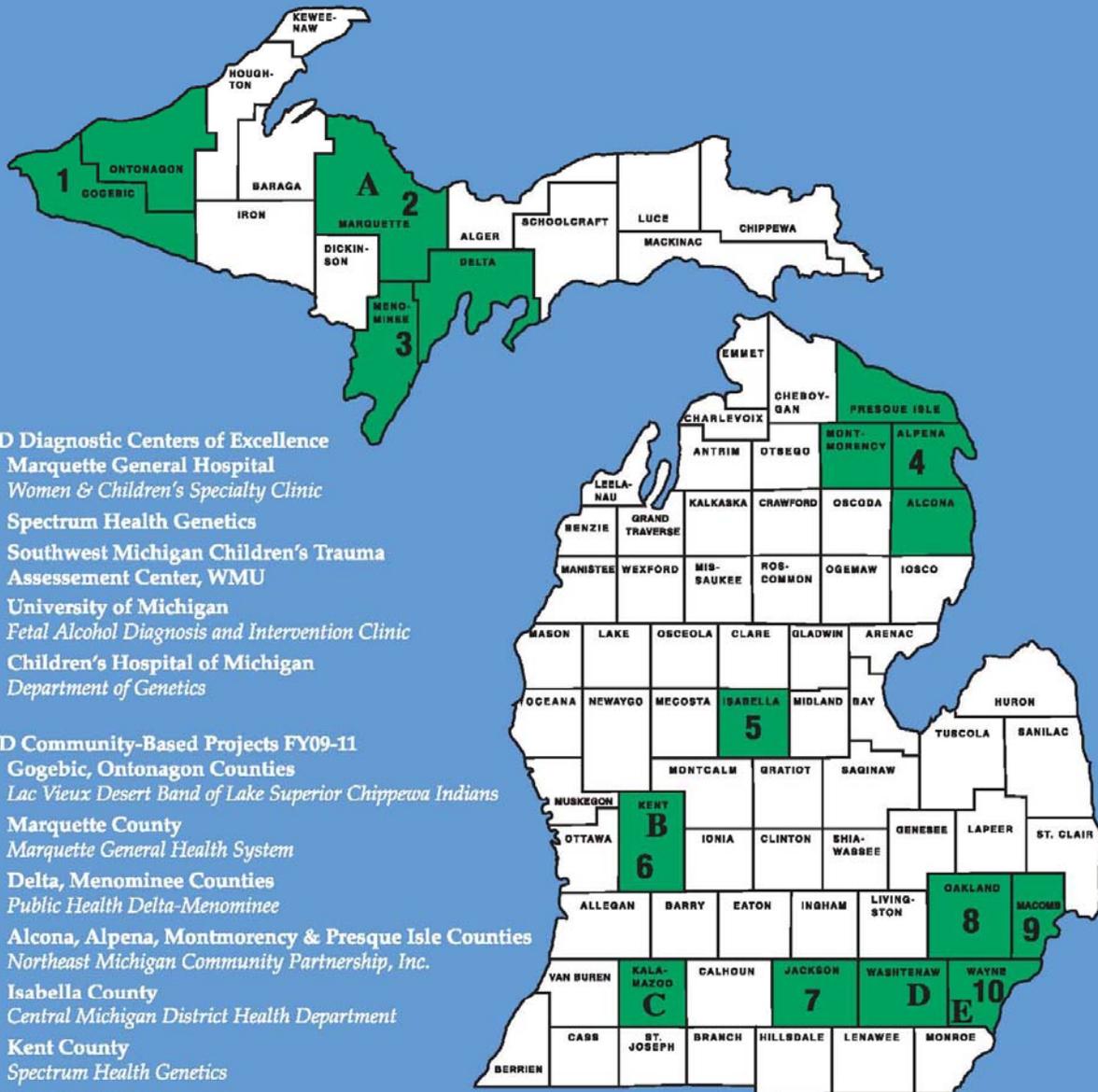
7. MYTH - People with an FASD always have mental retardation.

FACT - Some people with an FASD have mental retardation, but IQ's vary. People with an FASD can have normal levels of intelligence, but have problems in specific areas such as the concept of time.

Appendix B: Diagnostic Centers in
Michigan²⁸

²⁸ www.michigan.gov/fas.

FASD Michigan Program



FASD Diagnostic Centers of Excellence

- A** Marquette General Hospital
Women & Children's Specialty Clinic
- B** Spectrum Health Genetics
- C** Southwest Michigan Children's Trauma
Assessment Center, WMU
- D** University of Michigan
Fetal Alcohol Diagnosis and Intervention Clinic
- E** Children's Hospital of Michigan
Department of Genetics

FASD Community-Based Projects FY09-11

- 1** Gogebic, Ontonagon Counties
Lac Vieux Desert Band of Lake Superior Chippewa Indians
- 2** Marquette County
Marquette General Health System
- 3** Delta, Menominee Counties
Public Health Delta-Menominee
- 4** Alcona, Alpena, Montmorency & Presque Isle Counties
Northeast Michigan Community Partnership, Inc.
- 5** Isabella County
Central Michigan District Health Department
- 6** Kent County
Spectrum Health Genetics
- 7** Jackson County
Community Action Agency
- 8** Oakland County
St. Joseph Mercy Oakland
- 9** Macomb County
CARE (Community Assessment Referral & Education)
- 10** Wayne County
The Guidance Center

Appendix C: Overlapping Characteristics
of FASDs and Related
Mental Health Diagnoses

Overlapping Behavioral Characteristics of FASD & Related Mental Health Diagnoses in Children

Overlapping Characteristics & Mental Health Diagnoses	FASD	ADD/ADHD	Sensory Int. Dys.	Autism	Bi-Polar	RAD	Depression	ODD	Trauma	Poverty
	Organic	Organic	Organic	Organic	Mood	Mood	Mood	Mood	Environ	Environ
Easily distracted by extraneous stimuli	X	X								
Developmental Dysmaturity	X			X						
Feel Different from other people	X				X					
Often does not follow through on instructions	X	X					X	X	X	X
Often interrupts/intrudes	X	X	X	X	X		X			X
Often engages in activities without considering possible consequences	X	X	X	X	X					X
Often has difficulty organizing tasks & activities	X	X		X	X		X			X
Difficulty with transitions	X		X	X	X					
No impulse controls, acts hyperactive	X	X	X		X	X				
Sleep Disturbance	X				X		X		X	
Indiscriminately affectionate with strangers	X		X		X	X				
Lack of eye contact	X		X	X		X	X			
Not cuddly	X			X		X	X			
Lying about the obvious	X				X	X				
Learning lags: "Won't learn, some can't learn"	X		X			X			X	X
Incessant chatter, or abnormal speech patterns	X		X	X	X	X				
Increased startle response	X		X						X	
Emotionally volatile, often exhibit wide mood swings	X	X	X	X	X	X	X	X	X	
Depression develops, often in teen years	X	X				X			X	
Problems with social interactions	X			X	X		X			
Defect in speech and language, delays	X			X						
Over/under-responsive to stimuli	X	X	X	X						
Perseveration, inflexibility	X			X	X					
Escalation in response to stress	X		X	X	X		X		X	
Poor problem solving	X			X	X		X			
Difficulty seeing cause & effect	X			X						
Exceptional abilities in one area	X			X						
Guess at what "normal" is	X			X						
Lie when it would be easy to tell the truth	X				X	X				
Difficulty initiating, following through	X	X			X		X			
Difficulty with relationships	X		X	X	X	X	X			
Manage time poorly/lack of comprehension of time	X	X			X		X			X
Information processing difficulties speech/language: receptive vs. expressive	X			X						
Often loses temper	X		X		X		X	X	X	
Often argues with adults	X				X			X		
Often actively defies or refuses to comply	X				X			X		
Often blames others for his or her mistakes	X	X			X		X	X		
Is often touchy or easily annoyed by others	X				X		X	X		
Is often angry and resentful	X						X	X		

Appendix D: Statements from
Parents

Parents who agreed to contribute statements for this document were recruited from an FASD parent list-serve or were asked by work group members if they would be interested in participating. All identifying information has been removed and every effort was taken to maintain the confidentiality of the family. Little to no editing was done on the statements since we wanted to keep the statements in the parent's own words. The questions that were asked of the parents were:

1. Looking back, what characteristics of FASD did you notice in your child from birth to three years old?
2. Before your child was four years old, did you suspect any of his or her delays, health problems or behavioral challenges were related to FASD? Why or why not?
3. Did your child receive *Early On* services?
4. What behaviors related to prenatal alcohol exposure were most challenging during the first three years of your child's life?
5. What aspects of raising your child with an FASD were most rewarding during the first three years of his/her life?

Adoptive parents, Livingston County

1) Looking back, what characteristics of FASD did you notice in your child from birth to three years old?

- *He was obsessed with stuff from the very beginning - Perseveration!!!*
- *He was always busy (ADHD) - When I took him to the doc about ADHD meds, we chatted for a while, the whole time my son was being himself, and after about 10 minutes the doctor said, "I think I can guess why you're here." Ya think?!? :-)*
- *He didn't pick up on social cues.*
- *We had to use very short sentences - one to two words. Now that he's 13 we are up to 5 - 7.*
- *He had strabismus - one eye crossed, or lazy eye. He had intentional tremor. Both of those have either been surgically corrected or gone away with the use of Lego's.*
- *Didn't like to transition (but then a lot of kids struggle with that).*
- *Terrible sleep patterns. We did a sleep study (waste of time), checked his adenoids.*
- *Impossible to potty train; not cuddly.*
- *Never stopped talking once he learned how (still talks toooooo much).*
- *Startled easily; took speech therapy.*
- *Definitely responded to stimuli differently.*
- *His sensory integration issues were obvious.*
- *Information processing difficulties - like he couldn't hear us; Anger; Blamed others.*

2) Before your child was four years old, did you suspect any of his delays, health problems or behavioral challenges were related to FASD? Why or why not?

I knew they were FASD related because he was diagnosed at age 3 or 4.

3) Did your child receive *Early On* services?

No

4) What behaviors related to prenatal alcohol exposure were most challenging during the first three years of your child's life?

ADHD stuff, Sensory integration stuff, his inability to control himself. It's kinda hard to say, because looking back, those were easy years compared to now!

5) What aspects of raising your child with an FASD were most rewarding during the first three years of his life?

Knowing that I was giving him a loving home, and one in which he would be surrounded by people who will help him live his life. His life will always be a challenge for everyone.

Adoptive parent, Washtenaw County

1) Looking back, what characteristics of FASD did you notice in your child from birth to three years old?

He had sleep problems. He awoke frequently during the night, got up wandered the house and even tried to go outside which was very frightening.

2) Before your child was four years old, did you suspect any of his delays, health problems or behavioral challenges were related to FASD? Why or why not?

We knew nothing about FASD as we adopted him in 1968, 5 years before FAS was formally identified in this country.

3) Did your child receive *Early On* services?

No

4) What behaviors related to prenatal alcohol exposure were most challenging during the first three years of your child's life?

Memory problems and inability to organize himself. He had problems in pre-school using the Montessori equipment, didn't remember meeting the teachers, was unable to pick up things in his room or remember what he did in pre-school, etc.

5) What aspects of raising your child with an FASD were most rewarding during the first three years of his life?

He was usually very happy and fun to be around. His smile melted my heart.

Adoptive parents, Macomb County

1) Looking back, what characteristics of FASD did you notice in your child from birth to three years old?

We noticed after professional intervention the facial features of FASD.

2) Before your child was four years old, did you suspect any of her delays, health problems or behavioral challenges were related to FASD? Why or why not?

No, foster care did not fully disclose the impact + effects on our family due to FASD behaviors. We assumed she was oppositional defiant and very challenging is what we called it for many years.

3) Did your child receive *Early On* services?

No, Early On came to our home and evaluated our child, final assessment our child did not qualify for Early On Services - another of many agencies mistakes thru the years.

4) What behaviors related to prenatal alcohol exposure were most challenging during the first three years of your child's life?

Screaming at the top of her lungs for no apparent reason, stomping, kicking, hanging on to parent legs tightly etc.

5) What aspects of raising your child with an FASD were most rewarding during the first three years of her life?

When the brain is rational (ON) and functioning appropriately - our child is very affectionate, kind, and happy.

Adoptive parent, Kent County

1) Looking back, what characteristics of FASD did you notice in your child from birth to three years old?

One of the first things was that he had trouble sucking. It would take him an hour to get through his bottle (which was really miserable in the middle of the night).

There was a lot of trouble with his naps. If you weren't there IMMEDIATELY to get him when he woke up, he would scream and keep screaming. And I mean SCREAMING!!! He also took a short morning nap and a short afternoon nap. After a while I tried to combine them into one longer afternoon nap. So I would keep him awake all morning. Then in the afternoon he would take his normal short nap. It never worked. About once a month he would (without notice) take a really long, as in 2 - 3 hour afternoon nap.

He walked at 9 months, then went right back to crawling. At 11 months he got up and ran - literally. And he immediately started running into ladies behinds. At first we thought it was mishaps, but when it kept happening, we realized it was intentional. How a little kid knows to do something like that is beyond me, but I later found out about another kid with FAS who did the same thing. Our son later showed many signs of inappropriate sexual behavior at a very young age. It was scary. He really just seemed to be born knowing about those things. He had no way of ever seeing anything like that on TV or movies or anything.

Sleeping through the night was always a problem. Normal for an infant, but it continued on through for years.

There were many tantrums, and he very often threw things when he threw a tantrum - and with very good aim. And, yes, in his very early years.

I couldn't get him potty trained until after 3 years of age.

I can't remember what the symptoms were, but there were symptoms that often made me wonder if he had been abused in the foster home. And then I would remember that he was only there for 7 days.

5) What aspects of raising your child with an FASD were most rewarding during the first three years of his life?

The hugs and kisses and he was an adorable child in looks. Other than that it was probably just the normal things, like him learning to talk, walk, eat with utensils, etc. He was also a humorous child. But when you don't know that your child has FAS, you can't look at rewards through the perspective of the disability. Now that I think of it, he could really make his baby sister laugh. He could do it better than any of the rest of us. And it continued on for years and years. There was a really cool bond between them.

Adoptive parent, Washtenaw County

He was seldom "neutral" but either quite happy or quite angry. It was hard to get him settled down at nights and he pushed the limits. If the rule was he had to stay in his room, he'd finally fall asleep on the floor in the doorway. When we only insisted that he not come downstairs, he'd fall asleep on the stairs.

Parent, Grand Traverse County

I remember from early on that my FASD daughter (now 18) was unable to keep herself occupied or play by herself. Even at time when other infants and toddlers were able to do that, she was not.

The other thing that sticks in my mind, and this may also be due to her early neglect, is how her agitation/frustration level was (and still is) VERY low and how she could go from whimpering to full-blown screaming in a matter of seconds!

Adoptive parent, Kent County

1) Looking back, what characteristics of FASD did you notice in your child from birth to three years old?

No fear of strangers, need for structured schedule to maintain his equilibrium, failure to thrive when it came to eating (had no concept of hunger).

2) Before your child was four years old, did you suspect any of his delays, health problems or behavioral challenges were related to FASD? Why or why not?

No, we weren't given that information about his birth mother until he was 15.

3) Did your child receive *Early On* services?

Went to (name deleted for confidentiality) school for speech help due to cleft pallet from 18 months on.

4) What behaviors related to prenatal alcohol exposure were most challenging during the first three years of your child's life?

Not understanding how far he could push a toy before it broke and because of this not playing with certain toys that belonged to his older siblings. He was not able to tolerate changes in schedule without a big fuss.

5) What aspects of raising your child with an FASD were most rewarding during the first three years of his life?

His friendliness with everyone, and his seemingly secure self image, his unselfish nature, and his wonderful laugh.

Parent, Allegan County.

1) Looking back, what characteristics of FASD did you notice in your child from birth to three years old?

My daughter was born with full FASD. She developed slower than the other children. She did not roll over or started to crawl until much later than average. She did not sleep well. She wanted to be held ALL the time. Even if she was fed, fresh diaper, burped etc. She would want to be held. It was very, very hard to get her to go to sleep.

3) Did your child receive *Early On* services?

My daughter did receive Early On services. These services were very helpful for both her and me. Having someone coming to our home who could help me - help her was very appreciated.

5) What aspects of raising your child with an FASD were most rewarding during the first three years of her life?

She was always smiling

Adoptive parent, Eastern Michigan

Note: This parent did not have a positive experience with *Early On* and felt that the diagnosis of Fetal Alcohol Syndrome that her daughter was given was ignored. She also felt her daughter did not receive services appropriate to her needs. This adoptive parent felt she had met some people in *Early On* who were very helpful and supportive. Unfortunately, they were overshadowed by the rest of her negative experience. Her entire written communication was not included in this document, rather only a portion which directly expresses her feelings as a parent.

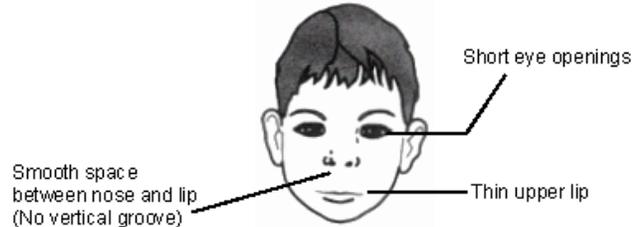
I hope you help educate your people on Fetal Alcohol and Reactive Attachment Disorder and listen to the moms who walk this journey daily. They know their child or children the best. Don't call us attention getters; we need help in dealing with the behaviors we deal with daily. We ask for help and we are turned down.

This statement was included to demonstrate that at times it is very difficult to determine what is appropriate for a child who may or may not have a diagnosis of an FASD. It is not meant to show judgment or take sides. Rather, it reinforces the idea that it is not always clear what is happening with these young children and careful observation of the child and family, along with listening to the family will help to ensure that children with prenatal alcohol exposure get the early intervention they need.

Appendix E: FAS Pre-Screen

**Michigan Department of Community Health
Fetal Alcohol Spectrum Disorders Program
FETAL ALCOHOL SYNDROME (FAS) PRE-SCREEN**

FAS is a birth defect caused by alcohol use during pregnancy. FAS is a medical diagnosis. This form is not intended to take the place of a diagnostic evaluation.



FACIAL FEATURES

Last Name:	First Name:	Sex: <input type="checkbox"/> Male <input type="checkbox"/> Female
Address:		Race:
City/State/Zip code:		Birthdate:
Parent/Caregiver Name(s):		Home Phone:
<input type="checkbox"/> Bio <input type="checkbox"/> Foster <input type="checkbox"/> Adopted <input type="checkbox"/> Other		Work Phone/Cell:

If 2 or more of the identifiers listed below are noted, the individual should be referred for a full FAS Diagnostic Evaluation.

IDENTIFIERS	Check or explain if a concern exists
1. Height and weight seem small for age	
2. Facial features (See diagram above)	
3. Size of head seems small for age	
4. Behavioral concerns: (any one of these qualifies as an identifier) <ul style="list-style-type: none"> • Sleeping/eating problem • Mental retardation or IQ below familial expectations • Attention problem/impulsive/restless • Learning disability • Speech and/or language delays • Problem with reasoning and judgment • Acts younger than children the same age 	
5. Maternal alcohol use during pregnancy	

Any previous diagnosis: _____

Screener _____ Agency _____

Contact the nearest center to schedule a complete FAS diagnostic evaluation.

FAS DIAGNOSTIC CENTERS IN MICHIGAN		
Ann Arbor: 734-936-9777	Grand Rapids: 616-391-2319	Marquette: 906-225-4777
Detroit: 313-993-3891	Kalamazoo: 269-387-7073	

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