UNDERSTANDING FASD AND ADVOCATING FOR CHILDREN

A guide for caregivers

MILE

Understanding FASD and Advocating for Children: A Guide for Caregivers

Prepared by,

Claire D. Coles[1,2], Julie A. Kable[1,2], Elles Taddeo[1],

[1]Emory School of Medicine, Emory University
[2]FAS Center, Marcus Autism Center

Funding provided by the U.S. Department of Health and Human Services, Centers for Disease Control and Prevention.

Acknowledgments

The authors would like to thank the children and families who participated in this research. Their efforts inspire us. In addition, we would like to thank Pat NeSmith who helped us develop our preschool curriculum for the project and the following staff members who helped us along the way: Vivianne Aponte, Deeba Ashraf, Tameka Atkins, Jodee Atkinson, Cindy Barnes-Schoell, Ryan Beck, Dwain Blackston, Grace Burch, Julie Carroll, Leslie Carson, Lauren Christiansen, Christiana DeGregorie, Donna Dent, Maddie Eason, Ryakkia Edmond, Andra Fee, Trace Frederick, Latoya Glen, Mia Hadley, Christy Hall, Tohfa Hassan, Sara Hoffenberg, Katrina Johnson, Brandi Jones, Jerry Jones, Leigh Ann Kabatra, Claire Kerner, Sam Maddox, Aisha Magee, Erica Mattison, Thonda McMillan, Betsy Meeks, Shakti Mehrotra, Kristen Michener, Molly Millians, Michelle Mitchell, Jaymie Nelson, Lynne Padgett, Michelle Plymel, Dora Soublis, Kim Stevenson, Michelle Thomas, Elinore Trotter, Liana Valentin-Scott, Maureen Wahkisi, Liz Walsh, Joe Walsh, Kim Wigington, Austin Yang.

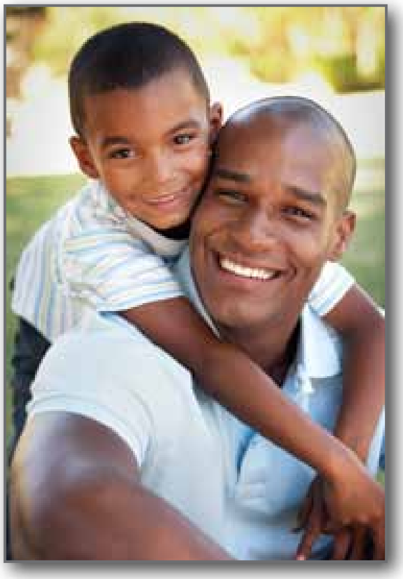
We would also like to thank our community partners who assisted us with evaluating the program in traditional community settings: Brookwood Christian Language School, Clayton State University, The Howard School, Porter Academy, Special Needs Preschool of Gwinnett.

Contents

Introduction

Overview/Purpose of Manual

The following manual is designed to educate caregivers of children with Fetal Alcohol Spectrum Disorders (FASD) about the different effects FASD may have on their children's lives and what they can do to help them cope and learn. This manual provides information on what FASD is, the effects of alcohol exposure on the child's growth and development, and information on meeting educational needs. The information included in these materials is based on the accumulated knowledge of over 35 years of research on the effects of prenatal alcohol exposure and working with children with FASD and their families for over 15 years.



Training Goal

The goal of this manual is to provide information about Fetal Alcohol Spectrum Disorder to caregivers in order to assist them in meeting their child's physical, emotional, and educational needs.

Objectives

The following are the objectives of this manual:

- Caregivers will learn the difference between FAS, pFAS, and FASD
- Caregivers will learn how alcohol exposure affects the brain
- Caregivers will learn how the educational system can help children with special needs and how parents can collaborate with their child's school

Section 1: What Are FAS, pFAS, and FASD?

Topics in this Section:

- Defining FASD, FAS and pFAS
- Types of Fetal Alcohol Syndrome (FAS)
- Medical Diagnosis of FAS and pFAS
- Exposure
- Facial Features Associated with FAS: "What is the Face of FAS?"
- Growth Pattern Associated with FAS
- Brain (Neurodevelopmental) Features Associated with FAS
- Behavioral Effects Associated with FAS
- Disorders Associated with FAS
- Effects of Prenatal Exposure to Other Drugs

Defining FASD, FAS and pFAS

Fetal Alcohol Spectrum Disorder (FASD) is caused when a fetus is exposed to alcohol while still in the mother's womb. The term describes the *range* of possible effects of prenatal alcohol exposure. This range includes:

- Fetal Alcohol Syndrome (FAS)
- Partial Fetal Alcohol Syndrome (pFAS)
- Alcohol-Related Neurodevelopmental Disorder (ARND)

FASD is not a medical diagnosis and cannot be used to obtain medical or educational services.

FASD is caused when a fetus is exposed to alcohol while still in the mother's womb.

Fetal Alcohol Syndrome (FAS) is the most severe outcome of prenatal alcohol exposure. There are three categories of FAS, one of which is Partial Fetal Alcohol Syndrome (pFAS). Partial FAS suggests that not all the "rules" for FAS are met or that the effects are less severe. Shortly in this manual, you will learn how experts can detect FAS and pFAS through evidence such as facial features, growth patterns, and other development signs.

Alcohol-Related Neurodevelopmental Disorder (ARND) is a disorder which is considered part of FASD. With ARND, there are no outward physical signs that suggest prenatal exposure to alcohol, but damage to the brain is suspected.

Not every child whose mother drank during pregnancy has Fetal Alcohol Syndrome (FAS), however. Only about 40% of those born to alcoholic mothers are diagnosed with FAS. Classifying those individuals who do not meet all the standards for an FAS diagnosis has been difficult. We now often describe the effects of prenatal alcohol exposure as being on a spectrum and refer to each disorder on that spectrum as Fetal Alcohol Spectrum Disorder (FASD).

Types of Fetal Alcohol Syndrome (FAS)

The most severe outcome of prenatal alcohol exposure is fetal alcohol syndrome (FAS). There are three types of FAS defined by the Institute of Medicine (IOM):

- FAS *with* confirmed maternal alcohol exposure
- FAS *without* confirmed maternal alcohol exposure
- *Partial* FAS (pFAS) with confirmed maternal alcohol exposure

FAS with Confirmed Maternal Alcohol Exposure.

The following evidence is characteristic of the FAS with confirmed maternal alcohol exposure diagnosis:

1. Confirmed maternal alcohol use.
2. Evidence of a characteristic pattern of facial anomalies that may include:
    - Short palpebral fissures
    - Abnormalities in the premaxillary zone
    - Flattened or thin upper lip
    - Absent or indistinct philtrum
    - Flat midface
3. Evidence of growth retardation, as in at least one of the following:
    - Low birth weight for gestational age
    - Persistent low weight over time not due to nutrition
    - Low weight for height
4. Evidence of central nervous system (CNS) neurodevelopmental problems in at least one of the following:
    - Decreased head size at birth or later
    - Structural brain abnormalities (for example, partial or complete agenesis of the corpus collosum; cerebellar hypoplasia)
    - Neurological hard or soft signs
    - Impaired fine motor skills or poor eye-hand coordination
    - Neurosensory hearing loss
    - Impaired gait
    - Cognitive delays
    - Neurodevelopmental abnormalities

FAS without Confirmed Maternal Alcohol Exposure.

The following evidence is characteristic of the FAS without confirmed maternal alcohol exposure diagnosis:

1. Alcohol use is *not confirmed*, but there is evidence of the same characteristics which exist when alcohol use is confirmed. These are repeated here as numbers 2 – 4 below.
2. Evidence of a characteristic pattern of facial anomalies that may include:
    - Short palpebral fissures
    - Abnormalities in the premaxillary zone
    - Flattened or thin upper lip
    - Absent or indistinct philtrum
    - Flat midface
3. Evidence of growth retardation, as in at least one of the following:
    - Low birth weight for gestational age
    - Persistent low weight over time not due to nutrition
    - Low weight for height
4. Evidence of central nervous system (CNS) neurodevelopmental problems in at least one of the following:
    - Decreased head size at birth or later
    - Structural brain abnormalities (for example, partial or complete agenesis of the corpus collosum; cerebellar hypoplasia)
    - Neurological hard or soft signs
    - Impaired fine motor skills or poor eye-hand coordination
    - Neurosensory hearing loss
    - Impaired gait
    - Cognitive delays
    - Neurodevelopmental abnormalities

Partial FAS with Confirmed Maternal Alcohol Exposure.

The following evidence is characteristic of the partial FAS with confirmed maternal alcohol exposure diagnosis:

1. Confirmed maternal alcohol use and either 2, or 3, or 4 below.
2. Evidence of growth retardation, as in at least one of the following:
    - Low birth weight for gestational age
    - Persistent low weight over time not due to nutrition
    - Low weight for height
3. Evidence of CNS neurodevelopmental abnormalities:
    - Decreased head size at birth or later
    - Structural brain abnormalities (for example, partial or complete agenesis of the corpus collosum; cerebellar hypoplasia)
    - Neurological hard or soft signs
    - Impaired fine motor skills or poor eye-hand coordination
    - Neurosensory hearing loss
    - Impaired gait
    - Cognitive delays
    - Neurodevelopmental abnormalities
4. Evidence of a complex pattern of behavioral or cognitive abnormalities that are inconsistent with developmental level and can not be explained by familial background or environment alone.

Medical Diagnosis of FAS and pFAS

FAS and pFAS are medical diagnoses made by specially-trained pediatricians. Diagnosis is based on four "rules":

1. Exposure - Drinking while pregnant confirmed
2. Face - Distinctive facial features
3. Growth - Low birth weight and/or slow growth
4. Brain - Damage to the central nervous system

Exposure

Exposure refers to heavy and frequent alcohol drinking by the mother. Women who are older than 30 and who have a history of substance use, hospitalizations and problems with alcohol are more likely to have a child with FAS or pFAS. FAS is not caused by having a "few drinks" during pregnancy or by having "one drink with dinner".

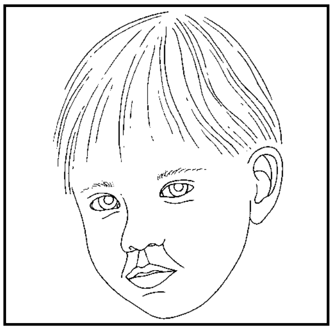
Binge drinking means heavy drinking (more than 4 drinks at a time for women), but not on a daily basis. This can be a problem during pregnancy.

Another problem is that women who drink alcohol often use other drugs as well. For instance, many women who drink also smoke cigarettes. Smoking cigarettes is associated with having a smaller baby (low birth weight).

Some women who drink and smoke cigarettes during pregnancy may also use illegal drugs. Drugs, like marijuana, cocaine, and heroin can cause additional problems in pregnancy. Women who use illegal drugs while pregnant may not take proper care of themselves. Also, they may not get the prenatal care they need.

Facial Features Associated with FAS: "What is the Face of FAS?"

There are certain facial features that are often seen in children exposed to alcohol prenatally. In the drawing below, a child with the features of FAS is compared to a typical child who does not have these features. Please notice the size of the head, the shape of the lips and eyes.



Typical Child

Alcohol-Affected Child

Other head and facial characteristics associated with FAS are detailed below:

Head	Eyes	Ears	Mouth
• Smaller than average (i.e., *microcephaly*). • Flat mid-face. • Low nasal bridge.	• Openings are smaller than average with narrow eye slits (i.e., *palpebral fissures*). • May have fold of skin at the inner corner of the eye that covers the point where the two eyelids meet (i.e., *epicanthal folds*). • Vision may be affected due to defects of the retina or may be nearsighted. • Some may have motor problems to the eyes such as *ptosis* or *nystagmus*.	• Ears may be low set and rotated. • In some children, the Eustachian tubes leading from the ears to the throat may be smaller or different in shape making ear infections more common.	• Thin upper lip that lacks the characteristic "bow." This part of the lip is called the *vermillion*. • The groove above the upper lip may be less noticeable or absent. This is the *philtrum*.

Growth Pattern Associated with FAS

Alcohol-affected children weigh less when they are born. They may also be shorter than other babies. Most alcohol-affected children continue to be smaller throughout childhood. At puberty, growth can sometimes "catch-up." Yet, most alcohol-affected teens and young adults are shorter than average.

Brain (Neurodevelopmental) Features Associated with FAS

Neurodevelopment refers to how the brain develops over time. "Neuro" means "nerve" and refers to the central nervous system or the brain. "Development" refers to how a child grows and changes over time. Children with FASD have problems in their neurodevelopment or how their brain develops over time.

Neurodevelopmental outcomes are the observable results of these changes in the brain. Children with heavy prenatal alcohol exposure may have differences in the physical structures of their brains. These differences may have very broad impact on the child or small effects on specific tasks. The differences depend on the location and the amount of damage to the brain.

There can be many neurodevelopmental outcomes of alcohol exposure. Some of those that are seen frequently are:

- Developmental delay or intellectual disability
- Attention and arousal problems - but not classical attention-deficit hyperactivity disorder
- Learning problems or learning disabilities – particularly in math
- Speech and language delays - more noted in the use of complex speech and poor understanding of the meaning of paragraphs
- Specific problems with judgment and social behavior
- Motor Problems
- Visual/spatial problems

Behavioral Effects Associated with FAS

Alcohol-exposed children show many different behavioral problems. You can find lists of negative traits that are supposed to describe children with FAS and FASD. Most of these lists are based only on opinions and not research. Scientific studies have found that the problems experienced by alcohol-affected children come from many causes. Children may have developmental or mental delays resulting from damage to the brain caused by alcohol exposure or by other things. Also, bad life experiences, poor education and a possible family history of going from one foster family to the next, can affect children. There is no "typical" alcohol-exposed child. Each child may have difficulties that are unlike others, based on his or her unique background.

Disorders Associated with FAS

Some disorders are found more often in children with FASD than those who are not on the fetal alcohol spectrum.

Attachment Disorders. A good example of a disorder associated with FASD is attachment disorder. An attachment disorder is a complex problem. It happens in children who have not been able to form an attachment to an adult in the way children usually do during their first year. This problem is caused by neglect, abuse, and poor caregiving. With proper early care, attachment problems do not typically occur. Because many children with FAS spend time in bad environments, they may develop attachment disorders.

Developmental, Intellectual, and Learning Disorders. In addition, children and adolescents with FAS and other alcohol-related disorders may be developmentally delayed, intellectually disabled, or learning disabled. These challenges often result in social, emotional, behavioral, and academic problems for the child. When these challenges are not identified early in life, children may be viewed as "being bad" or misbehaving on purpose. These labels can be damaging to the child's self-esteem. In fact, a study on "secondary disabilities" associated with FAS and fetal alcohol effects found that when a child's real condition was known before school age, long-term behavioral and social problems were less likely. The study specifically found that the earlier FAS was identified, the fewer *secondary problems* were reported.

A secondary disability is something that a person is not born with but develops because of a first (primary) disability. Secondary disabilities can be prevented through interventions and education.

Adolescence can be a particularly difficult time for young people with FAS. Without early diagnosis, secondary problems can continue into adolescence and beyond. An adolescent with FAS may have trouble doing the academic and social things that most teenagers are learning to do.

Problem areas include life skills, independence, social skills, school, and work.

Children with FAS may have behavioral and emotional problems. Some problems may result from the effects of prenatal alcohol exposure. Other problems result from their life experiences. Understanding these problems is important. Sometimes treating them can require help from professionals experienced in working with such children.

Effects of Prenatal Exposure to Other Drugs

Alcohol is not the only drug used during pregnancy. Often the woman who uses alcohol in pregnancy will also use other drugs. The effects of marijuana, cigarettes, cocaine, and opiates on pregnancy have been studied for a long time. Thus, we have ideas about their effects. Others, like methamphetamines and ecstasy, are still being studied. Many of these drugs are associated with lower birth weight. We are still not sure whether this slowed growth results from the drugs themselves or from the mother's habits during pregnancy (i.e., diet, vitamin intake, stress).

Like those exposed to alcohol, children of women using illegal drugs often have home lives that are stressful. Such care also may be less supportive of learning. For this reason, children may show delays in development or have behavioral problems. The studies of heroin and methadone done many years ago suggested that poor environments affect the child more than the prenatal drug exposure.

Section 2: Prenatal Alcohol-Exposure and Neurodevelopment: How are Learning, Thinking, and Behavior Affected?

Topics in this Section:

- Neurodevelopment and FASD
- Problems with Motor Functioning
- Cognitive Functioning
- How Do Cognitive Disabilities Affect Everyday Life?
- Alcohol's Effect on Cognition
- Specific Problems in Cognition and Behavior
- Visual-Spatial Skills
- Attention
- Memory
- Executive Functioning
- Problems with Language Function

Neurodevelopment and FASD

Development means change over time. We use this term to describe how a child grows and changes from infancy to adulthood. Neurodevelopment is change over time that depends on the brain and other parts of the nervous system. When we talk about *neurodevelopment*, we are talking about motor skills, language, thinking and learning, which we call "cognition," as well as social development and behavior. All of these areas depend on the brain and how it works. Prenatal exposure to alcohol can change the way the brain grows and develops. Changes in the brain, in turn, can influence all these developmental outcomes. In this section, we will talk about the neurodevelopmental outcomes that are more common with FASD.

It is important to understand how alcohol impacts neurodevelopment because children with FASD may have problems that affect learning and behavior.

These problems may cause people to misunderstand what the child does. For instance, children with FASD may act younger than you would expect children their age to act. Or they may not cooperate as much as most children. Here are two examples of behaviors that often upset parents and teachers of children with FASD. There are lots more.

- **Noncompliance. Not doing what people ask them to do.** When children do not respond to a request or follow a rule, their behavior may be seen as refusing to listen or obey. However, the child may not understand what is being asked. Or he/she may have forgotten parts of the request due to a memory failure.
- **Forgetting. For instance, not remembering homework assignments or forgetting to feed the dog.** Your child might know something one day and plan to do it but the next day, all is forgotten. It is easy to get angry about what looks like irresponsible behavior. Children with FASD often lose track of information and have trouble organizing their plans.

Living with or teaching a child with FASD is much easier if you understand how alcohol exposure has affected neurodevelopment. In the next sections, we review the specific problems that have been found in alcohol exposed children.

Problems with Motor Functioning

Motor skills and motor development is often the first thing noticed. These problems can be seen in babies and toddlers. Motor problems also can continue during childhood and may affect adults as well. Motor problems can include:

- Poor muscle tone and weak grasp. This can make it difficult for children to do the following skills:
  - Use utensils
  - Pour liquid
  - Tie shoes

- Poorly developed gross motor skills. The child may be delayed in learning to crawl or walk. Later, gross motor problems may make your child appear to be clumsy; Problems in this area may make it difficult or embarrassing for your child to participate in physical activities such as:
  - Running

  - Playing ball
  - Learning to ride a bike

- Fine motor delays. In infancy, the child may not grasp objects or pick up small objects as early as other children. Later on , there may be a delay in:
  - Handwriting
  - Coloring
  - Tying shoes
  - Use of scissors

- Coordination problems often with eye-hand coordination. Eye-hand coordination problems lead to difficulty doing tasks in which the hand is guided by visual information (e.g. craftwork, paper, and scissors).

- Other motor problems include:
  - Deficits in balance
  - Tremors
  - Abnormal gait
  - Right/left hand dominance confusion

But, remember that each child is different. Some may excel in sports, while others shy away. It is important that your child become involved in some type of physical activity or exercise. Let your child choose what he or she is interested in.

Cognitive Functioning

Children with FASD often have cognitive disabilities because of alcohol's impact on the brain. Cognition is a term used to describe the higher mental processes by which people learn, solve problems, and plan for the future. A cognitive disability is a weakness that makes it more difficult for a child to do these important things as well as other children of the same age. Cognition is so important for success in school and in life that we often measure these abilities. One common way of measuring is a test of ability (usually called an IQ test) which measures intelligence. In addition, we measure the child's everyday coping or adaptive abilities. A child who scores below a certain point on an ability test (IQ test) and has every day (adaptive) problems may have a cognitive disability. It is possible to have either a "global" cognitive disability if many areas are delayed or a "specific" disability, in which one area is more delayed than others.

An IQ test is used to measure a child's level of cognitive development ("mental age"). The results are compared to other children the same age. The "average" person has an IQ score of 100. About 67% of all people (2 out of 3) have IQ scores between 85 and 115, which is considered in the "average range". Scores below 70 indicate that the person has a cognitive disability. The older a child is when ability is measured, the more likely the score will stay the same over time.

How Do Cognitive Disabilities Affect Everyday Life?

In the following table you can see the relationship of the child's age, level of cognitive functioning, and approximate mental age of children who have cognitive disabilities (which used to be called, "mental retardation", and now is called "intellectual disability"). The first column indicates the category of cognitive impairment and the second column contains the associated IQ range. The last two columns contain the estimated mental age or functional level for individuals at 8 or in adulthood, respectively. For example, a child who has an IQ of 65 would be categorized as Mildly Intellectually Disabled and would be expected to function at a 5-6 year-old level at 8 years of age and at an 8 to 10 year-old level in adulthood. It is important to remember that these are just estimates and each child's functional level is influenced by many factors. It is also important to remember that caregivers and teachers are most helpful to children when they use a child's **mental age** rather than the **actual age** to establish behavior and learning goals.

Level of Intellectual Disability	Range in IQ (x=100, std 15)	Approximate Mental Age at 8	Approximate Mental Age in Adulthood
Borderline	70-79	6-7	Early adolescent
Mild	69-55	5-6	8 to 10
Moderate	54-40	4-5	5 to 8
Severe	39-25	2-3	3 to 5
Profound	< 25	<2	<3

Alcohol's Effect on Cognition

In FASD, as the result of maternal alcohol abuse, ability levels can range from severe intellectual deficit to the very superior range of functioning. The average level of ability of children with full FAS is usually in the borderline to the mildly intellectually disabled range. (That is, IQ of 60-75); but, some are more affected and have lower IQs.

People with FAS are the most severely affected. They often have an overall problem with ability and achievement. This overall problem can be called a "global" disability because it affects all areas of functioning. This difficulty may be seen in their inability to learn as quickly as other children. It may also be seen as poor school performance and difficulty "coping" with life outside school. People with FASD who do not have full FAS may not have global cognitive disabilities.

Specific Problems in Cognition and Behavior

In addition to global problems, alcohol exposure can result in specific problems in cognition and behavior. Some of these cognitive and behavioral problem areas are:

- Visual-spatial skills
- Attention
- Memory
- Executive functioning
- Language

Visual-Spatial Skills

Visual-spatial functioning refers to perceiving, judging and storing images and symbols and experiencing space and location. These skills are involved in judging shape, patterns, and relationships in space. Understanding "left" and "right" in relation to yourself and other objects is also involved. Visual-spatial skills also affect visual memory. Visual memory involves storing images in memory, recognizing symbols, reading and using "mental imagery".

A person who has a visual-spatial deficit has difficulty using visual cues and may be confused about spatial relations. This may lead to:

- Poor recall of visual information
- Problems with math or sight reading
- Poor writing
- Difficulty reading facial expressions
- Being unable to pick one line from print while reading
- Trouble using a separate answer sheet
- Trouble using a detached mouse for the computer
- Difficulty copying from the board
- Difficulty judging distance

Attention

Attention is one of the most basic cognitive skills. Problems in attention affect learning, memory, and behavior. Even though this is such an important skill and everyone thinks that they know what "attention" means, it is hard to describe. That is because there are a number of elements that make up attention.

Attention					
Noticing	Self-Regulating	Focusing	Sustaining	Encoding	Shifting

Some of the parts of attention are:

- **Noticing.** Alerting and orienting to something, particularly when it is new.
- **Self regulating.** Controlling your reaction to something so that you can pay attention.
- **Focusing.** Deciding what the IMPORTANT thing to attend to is and attending to that.
- **Sustaining.** Keeping your attention in the right place as long as you need to.
- **Encoding.** Learning what you need to while you are paying attention.
- **Shifting.** Changing your focus when the time comes to do that. For instance, when you have learned everything you need to and it is time to move to the next thing.

We have found that prenatal alcohol exposure can interfere with attention in many areas. The three areas that seem to cause most problems for FASD are self regulating, encoding, and shifting attention.

FAS and ADHD. There has been a lot of discussion about FAS and ADHD. Research suggests that these are two separate, but similar conditions.

FAS and ADHD	
Problem Areas For Children With ADHD/ADD	**Problem Areas Alcohol-Affected Children**
• Focusing attention.	• Learning information (encoding).
• Inhibiting impulsive responses.	• Flexibility in problem solving.
• Higher activity level.	• Slower information processing.
• Behavior problems.	• Less efficient processing of visual information.

Memory

Memory can be affected by prenatal alcohol exposure. Memory results from the coordination of several skills: Sensing, Attending, Learning, and Remembering. Any of these can be affected by alcohol exposure:

Memory			
Sensing	**Attending**	**Learning**	**Remembering**
• Information is not attended to or understood.	• If the person does not attend to what is to be remembered, it will not be learned.	• Short term, long term memory and active working memory strategies are not used to help one learn and store information.	• Information is stored in memory, but cannot be retrieved or found. • "I know it is there, somewhere, but how do I find it?"

Sensing. Sensing refers to seeing, hearing, and touching. Failure to sense properly means that information is not attended to or understood correctly. If it is not sensed correctly, it will not be remembered.

Attending. If the person does not attend to what is to be remembered, it will not be learned.

Learning. When learning is affected, short term memory, active working memory, and long term memory strategies are not able to be used to help one learn and store information.

Short term memory	Active working memory	Long term memory
• Initial encoding of information that lasts a few seconds if you don't do something to retain it (i.e. repeating it to maintain in working memory or encoding it into long term memory).	• Working memory is the system that temporarily stores and manages information needed for cognitive tasks. For example, adding numbers "in your head" occurs in working memory.	• A store house where information is stored fairly permanently similar to a filing cabinet or "Drive C" on your computer

Remembering. Remembering means bringing back to mind what has been learned. Problems can occur in finding what has been stored in memory (i.e., "I know it is there, somewhere, but how do I find it?"). Most of us have this experience sometime but alcohol-affected children may have it more often. Short-term memory problems result in difficulty *registering new information* and can be seen as:

- Failure to attend and/or
- Difficulty with spatial patterns, sequences or with verbal input.

Problems with memory can be frustrating for your child. Here are some examples of problems that happen when your child has a memory problem:

- Does not remember the "steps" of a task even though you have explained them repeatedly.
- Cannot keep in mind more than one instruction. Always forgets the last thing you told him.
- Repeatedly forgets to bring home assignments from school.
- "Memorizes" the spelling words, but can't recall them for the test.

When your child has memory problems, he or she has trouble retrieving information from memory and trying to hold several different ideas or processes in memory at the same time.

Executive Functioning

Executive functioning is the sensible "adult" part of your brain and is in charge of the coordination of memory, organization, and planning.

It is a "higher" order skill and depends on other skills and abilities, like memory, perception and self regulation.

Executive functioning depends on the front part of your brain (frontal lobes) that sends out messages that you should **control your emotions** and:

- Focus on the problem
- Predict what is needed
- Plan the approach and select necessary tools and method
- Act on the plan

- Stay on task and check progress
- Monitor performance
- Evaluate that performance by reflecting on process and result

This is the part of the brain that takes the longest to develop. It begins when children are young and continues all through the teen years. It is not finished until you are in your twenties. Prenatal exposure to alcohol can delay or prevent the development of mature executive functioning.

Executive Functioning Deficits Affect Learning. When children have delays in the development of executive functioning they may have difficulties in controlling their emotional reactions. They may also have more problems in learning.

Learning requires a student to *attend* to the task at hand. Learning will be impaired if the student is not able to:

- Receive the information
- Process the information
- Apply the needed strategies and control processes
- Organize plans to direct the information

Organization and Planning Deficits Result from Problems with Executive Functioning. Students with FAS/pFAS may be disorganized. Your child will need a lot of support and help to maintain organization and to know what to do, when to do it, and how to do it.

Problems with Language Function

While language and language development are not as affected as other areas by alcohol exposure, people with cognitive problems often have language problems. Sometimes alcohol-affected children have problems with vocabulary, fluency, and the general ability to communicate effectively.

Language Problems. Some of the language problems seen are:

- Language Comprehension:
  - Vocabulary may not be as rich and varied as that of other children
  - Understanding others' ideas may be delayed
  - Staying "on-topic" in a conversation can be hard

- Social discourse (pragmatics). This is the practical use of language. Having a problem in pragmatics means that the child may not be able to use language effectively to communicate needs.

- Other areas of communication difficulty involve understanding the social use of language. For instance, they may have problems:
    - Engaging in speech in a tactful manner;
    - Starting or ending a conversation;
    - Listening attentively

Difficulties with Written Language. You may also notice difficulties when your child has to:

- Organize thoughts into a logical sequence
- Remember how to form certain letters
- Write thoughts down on paper
- Remember rules of capitalization, spelling, and punctuation.

Section 3: How Can the Child's Educational Needs Be Met at School and Home?

Topics in this Section:

- Educational/Academic Needs of Children with FAS
- Eight Universal Protective Factors in Alcohol Affected Children
- Federal Laws and Public School Systems
- No Child Left Behind (NCLB) and the Individuals with Disabilities Education Act (IDEA)
- IDEA and Special Education Services
- Steps to Receive Special Education Services
- Your Rights Under IDEA
- Determining the Need for Special Education Services
- Response to Intervention (RTI) Framework
- Evaluations
- The Evaluation Report
- The Individualized Education Program (IEP)
- Development of an IEP Team
- Creation of the IEP
- Key Features of the IEP
- Alternative Pathway To Receive Supports At School
- Examples of Accommodations Provided by a Section 504 Plan
- Strategies to Help Parents Cope
- Tools for Helping at Home
- Encouraging Collaboration with the School
- Assertive Communication
- Collaborative Planning Is Key To Obtaining Effective Services

Educational/Academic Needs of Children with FAS

Children diagnosed with fetal alcohol syndrome or partial FAS often need educational and therapeutic support to achieve their potential. Sometimes this means that they will qualify for special educational or other services. Parents often find it difficult to understand the laws about the child's rights in the educational system. Parents may find it difficult to work with the schools and other agencies. This section will help you understand what your child's rights are, how to find the needed educational support and how to "negotiate" the system.

Much of the education legislation over the past 25 years has been focused on getting appropriate services for children with disabilities. There are many ways you work with the school. Learn as much as you can. Seek help through different agencies. Be a positive presence at your child's school. In addition, you can read, listen and learn. Ask questions. Understand the spirit of the federal legislation for the rights of each child. By sharing information, getting training and teamwork, parents and schools meet children's needs.

FAS is a medical diagnosis. A diagnosis of FAS does not mean your child will be eligible to receive services in school. So you may be wondering what good it does you and your child to have this diagnosis.

A written medical diagnosis of FAS or for problems in learning and behavior will help people working with your child understand why there are problems. It helps others understand and plan for the challenges your child may face. Studies have found that early diagnosis is a "***protective factor.***" A protective factor is anything that prevents one problem from causing another to develop. Two protective factors that have been identified are qualifying for and beginning Special Education. These factors can contribute to better outcomes for your child.

Eight Universal Protective Factors in Alcohol Affected Children

1. Diagnosis before the age of 6 years
2. Having a diagnosis of FAS
3. Having basic needs met for at least 13% of life
4. Living in a stable home for over 72% of life
5. Never having experienced violence against oneself
6. Staying in each living situation for an average of more that 2.8 years
7. Experiencing a good quality home from 8-12 years
8. Having applied for and been approved by (DDS) U.S. Division of Develop-mental Disabilities Services

---

Streissguth and Kanter, 1997.

Streissguth & Kanter (1997) The challenge of Fetal Alcohol Syndrome; Overcoming secondary disabilities. pp. 25-39

Federal Laws and Public School Systems

U.S. Congress has passed public laws stating that all children deserve a chance to learn. Discrimination against people with a disability is illegal. They cannot be excluded or denied benefits from any program that gets federal funding. Since most schools receive federal funding, they are required to follow these laws.

Here are some of your rights under the law:

- States are required to provide free appropriate education to infants, toddlers and school-aged children up to age 21.
- They are required to identify, evaluate, and provide educational placement and individualized education programs.
- Parents have the right to look over their child's personal files (under 18).
- Both custodial parents and non-custodial parents have full rights under the law unless legally removed.

No Child Left Behind (NCLB) and the Individuals with Disabilities Education Act (IDEA)

Presently, two federal laws, No Child Left Behind Act of 2003 (NCLB) and the Individuals with Disabilities Education Act of 2004 (IDEA), work together to guide education. However, with a change in federal administration, the laws regarding education sometimes change. To obtain the latest information check the federal education website www.ed.gov, or http://idea.ed.gov.

The purposes of No Child Left Behind (NCLB) are as follows:

- Raise the academic achievement of all students.
- Close the achievement gap among high and low performing students.

NCLB says that schools must:

- Have high academic standards for all students.
- Develop assessments to measure student achievement.
- Ensure teachers are highly qualified.
- State the ways to make sure all students reach proficiency in reading and mathematics by 2014.
- Ensure students with disabilities have reasonable adaptations and accommodations.
- Develop ways to measure the schools Adequate Yearly Progress (AYP).
- Produce a public report card showing the performance of schools in each state.

The purposes of IDEA (Individuals with Disabilities Education Act) are as follows:

- To ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment and independent living.
- To ensure that the rights of children with disabilities and parents of such children are protected.

IDEA says that if a child is found to have a disability, the child has the right to the following:

- **Free Appropriate Public Education (FAPE)** - A child with a disability is provided the appropriate education with the necessary supportive services at the public expense.

- **Least Restrictive Environment (LRE)** -A child with a disability is to receive instruction with non-disabled classmates as much as possible.

- **Individualized Education Program (IEP)**.
  - Instruction is based upon the same academic standards as those for children who do not have a disability.
  - Instruction must be provided by a "highly qualified" teacher.
  - Instruction must be scientifically based – (this means instruction must have been investigated using systematic, empirical research methods).

- **Related Services and supportive services provided as needed including**:
  - Speech, physical, and occupational therapy
  - Recreation/therapeutic recreation
  - Parent training, parent counseling, rehabilitation counseling
  - Transportation
  - Audiology
  - Counseling services, social work services
  - Medical services (this excludes maintenance of implanted medical devices such as cochlear implants)
  - Psychological services

Through IDEA (Individuals with Disabilities Education Act), your child may qualify for special education services if he/she has one or more of the following disabilities:

- Intellectual disabilities
- Blindness/visual impairments
- Deafness/hearing impairment
- Specific learning disabilities

- Serious emotional disabilities
- Autism
- Orthopedic impairments
- Multiple disabilities
- Traumatic brain injury [TBI]
- Other health impairments
- Deafness-blindness

If your child has academic deficits, and/or exhibits limited strength, vitality, or alertness that interferes with learning at school, he/she is entitled to services. Often children with FAS qualify as Other Health Impaired (OHI) but they may have other, related diagnoses based on learning and behavior problems. It should be noted though, that even if your child has a medical condition such as FAS, this does not automatically entitle him/her to receive special education services.

A multi-step intervention process to ensure your child requires special education services and a comprehensive evaluation are used to determine if your child is eligible for special education services.

IDEA and Special Education Services

IDEA and NCLB work together to address the concerns about children's academic progress.

IDEA specifies rights for the child. This includes the right to receive appropriate education in the least restrictive environment. IDEA protects the child and his/her parents. It gives direction to the family and school. It safeguards the family's interests in a complicated process. Basically, it determines if, <u>what</u>, <u>when</u>, and <u>how</u>, placements and services should be provided.

The protections for children and their parents supported by IDEA include:

- Filing a written grievance with your state's department of education, office of monitoring and complaints
- Mediation
- Due process procedures

Steps to Receive Special Education Services

There are several steps to receiving special education services. These will be explained in detail next:

1. Performance monitoring
2. Response to Intervention
3. Evaluation

Your Rights Under IDEA

Important information to keep in mind about your rights under IDEA.

- If a parent does not agree to the special education services recommended, the school cannot refuse to give the child access to regular education.
- Both parents and the school have the right to request a due process hearing. This is done if they cannot agree or if a parent's rights or the student's rights have been violated.
- Parents or the school may request mediation by a neutral third party to settle their differences. This is to prevent court action that occurs in due process.
- The school must develop an Individualized Education Program (IEP) with parent involvement in decision-making. However, a parent may give permission in writing to excuse a member of the IEP team from attendance.
- The IEP must be designed to meet the student's unique needs. It must be in effect before special education service(s) or placement(s) are begun.
- Changes to the IEP may occur without an IEP meeting. The changes need to be made in writing. A copy of the updated IEP is given to the parent. It must be noted on the IEP document that changes were made without an actual IEP team meeting.
- The IEP must be reviewed at least once a year. However, some districts allow the parent to choose a multi-year (3 year) IEP.
- The parent may seek more IEP reviews and changes whenever needed. (You will learn more about the IEP below.)
- To obtain services, a group effort is needed to best help your child. Depending on your child's needs, the following persons may be involved:
  - Parents
  - School related personnel
  - Other agencies or individuals who are involved with the child

There are many services and support people who may be involved in getting the best care for your child. These include social services and advocacy, specialty consultative personnel, medical personnel and school related personnel. But remember, a team approach works best. All the people and agencies involved will need to work together to provide effective services.

Determining the Need for Special Education Services

How do you get services for your child within the school system? IDEA states that there needs to be a multi-step process. The purpose is to increase the intensity of the services at each level to meet the child's needs. This process is an attempt to meet the learning needs of all children. Also, this process can help to accurately identify children who have a learning difficulty. This is called the Response to Intervention (RTI) model.

If you have concerns about your child's learning and education, discuss them with your child's teacher and principal. The teacher will be able to begin to implement strategies in the classroom.

The teacher will monitor your child's progress and responsiveness to the interventions (RTI). If your child continues to exhibit difficulties with the implemented interventions, request that a Student Support Team (SST) or Multi-disciplinary Team (MDT) be convened.

The members of the SST or MDT include general education and special education instructors and specialists. They will target academic areas to work on and devise strategies to implement in the classroom. The SST will outline how your child responds to the classroom interventions (Response to Intervention or RTI).

Response to Intervention (RTI) Framework

The use of a multi-level intervention process is mandated under IDEA. The purpose is to ensure that children receive the necessary instruction at all times and to prevent placing students who do not have disabilities in special education.

Many states use four tiers or levels in their Response to Intervention (RTI) model. Other states use three tiers. There are also states that use a different name for this process; however, the research literature uses the term "response to intervention". The most important aspect of the process is that your child's progress will be monitored on each level. The intensity, the time of monitoring, and the analysis of a child's progress increases as the child moves through the levels.

The levels or tiers of the RTI model are as follows:

1. **Tier 1: Standards Based Classroom Learning**
   All children are administered standardized assessments to monitor their academic performance. Classroom instruction must follow the rules established by No Child Left Behind. Children's progress is assessed three times a year using state approved tests. The tests measure your child's skills on their grade level. If a child does not show progress on the benchmark testing, the child will receive more intensive intervention at tier 2.

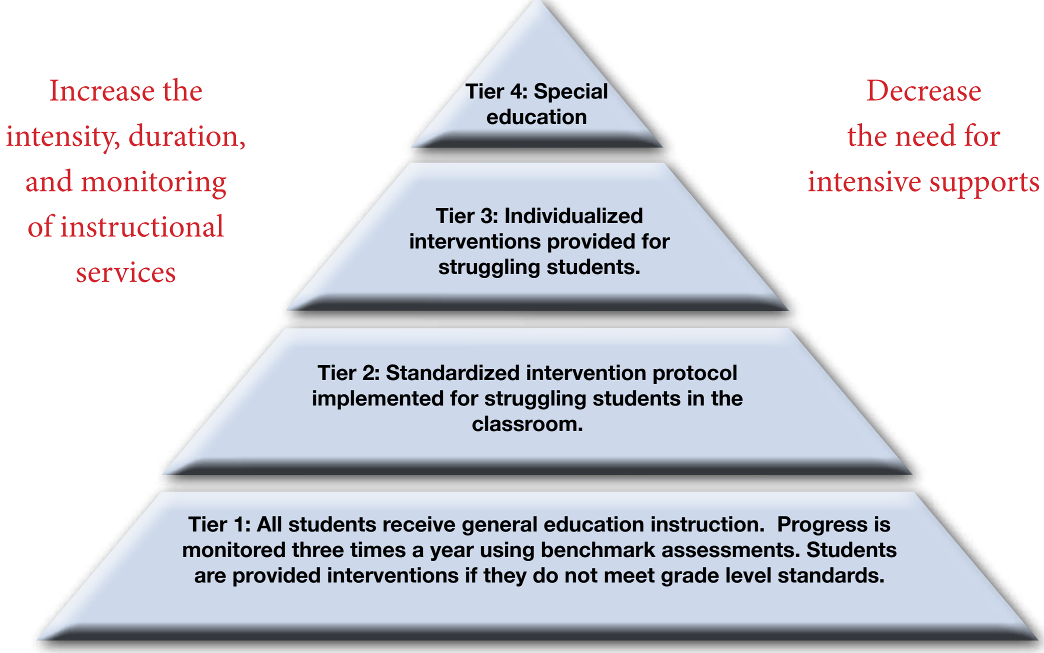
2. **Tier 2: Needs- Based Learning**
   Interventions from tier 1 will remain. Your child may receive specific interventions in the classroom. Also, your child may be referred for supplemental instruction such as tutoring.

   Your child's progress using the interventions at this level will be monitored for approximately 4 to 6 weeks. If your child does not show progress at the end of the monitoring period, interventions will increase.

3. **Tier 3: Student Support Team (SST) Driven Learning**
   Interventions from tiers 1 and 2 will remain. A Student Support Team (SST) meeting will be called by the school at this time, unless you have already requested an SST meeting. Your child may receive small group instruction that adjusts the curriculum to your child's needs. This often is provided through the Early Intervention Program (EIP). Your child's progress will be monitored for approximately 9 to 12 weeks. If your child does not show progress, then your child will be referred to tier 4.

4. **Tier 4: Specially Designed Learning**
   The interventions from the previous tiers will continue. Also, your child will be provided specialized instruction to address his/her academic deficits. Your child will be referred to receive a comprehensive psychological/educational evaluation to determine if your child would qualify for special education instruction and related services.

Response to Intervention (RTI) Framework.



IDEA states that the RTI process cannot be the only method to determine if a child requires special education. Information provided by comprehensive psychological and developmental evaluations and other information need to be considered when determining a child's eligibility for special education.

Evaluations

If your child does not make progress when provided interventions, your child may be referred for a comprehensive evaluation to be completed by the school's psychologist. The evaluation will be administered by a team including the school psychologists, special education instructors, and other specialists, such as the speech and language pathologist or occupational therapist. The evaluation will assess your child's cognitive and academic skills. The results from the evaluation will be combined with the data collected through the RTI process to determine eligibility.

The results from the evaluation will be combined with the RTI data to determine eligibility.

Under the Law, you must give permission (sign an informed consent) for this evaluation and for each re-evaluation. The evaluation and placement process shouldn't take any longer than a specified number of calendar days, except for school holidays or if the parent agrees to a different calendar. This number may vary from state to state, so check your state's department of education website to find out what it is for your school system.

Before giving written consent for evaluation here are some questions to ask:

- What is the purpose of the testing?
- How will the test results be used?
- What tests will be given?
- What are the qualifications of the testers?
- How will you be informed of the results?
- What is the next step in the process when the evaluation is done?

You may ask to see the actual test materials, pictures, or books used in the assessment. You may ask to be present during the evaluation or to observe from another room. You have the right to refuse to give consent/permission for the evaluation and have the right to withdraw consent at any time.

Before the evaluation, it is important to clarify that the child's hearing and vision are normal or acceptable for testing needs. Any sensory limits (sight, hearing, touch, speech) the child has, need to be discussed so that appropriate changes can be made (test selection, method of testing and/or time of testing).

Remember that a test only reflects what the child was able to do on that day, with a test, and with a particular examiner. Usually several tests are done. You may be asked to give input (comments, ratings of the child ability and performances).

The Evaluation Report

The evaluators should be available to answer your questions about the test results and give you a written copy at your request.

The information you want to get from the report (or examiner) includes:

- An explanation of the strengths and limitations of the tests.
- The child's strengths, aptitudes, and abilities according to the test.
- A description of ways the child's strengths and abilities can be developed.
- How the outcome will affect the child's educational work.

You may not agree with the results or information. You do have the right to ask for an independent evaluation, but the school system does not have to pay for it.

However, the local school authorities must give you the criteria, information, and sources for getting such evaluations. Also, the school can request a due process hearing to show that its evaluation is appropriate.

Eligibility. Once the evaluations have been completed, a group of general and special education staff will meet with you. This is the Eligibility meeting. The group will review the findings from the evaluation and your child's progress with the interventions provided through RTI. The group will determine which, if any, of the special education categories are applicable to your child. If the standards of a particular category have been met, then services may be given to meet your child's needs.

Parents/guardians are required to be a part of the team that decides eligibility. Parents are encouraged to bring relevant information to the Eligibility Committee meeting and be an active participant in the decision. If you do not attend, the information from the Eligibility Committee should be shared with you. You should get copies of all evaluation reports at the end of the meeting.

Anyone providing care for your child should be told about this meeting. Their input can affect the planning process. If your child is seeing a mental health counselor, he/she should attend or send documentation. This will help the school staff develop a coordinated program for your child. Professional teamwork creates a stronger united program. Brainstorming and problem solving help make a more consistent and stable environment for your child.

The Individualized Education Program (IEP)

Under the provisions of the Individuals with Disabilities Education Act of 2004 children who are found to have a disability that impacts their education are provided specialized instruction and supports. Their educational plan is outlined in a document called the Individualized Education Plan or IEP.

It is the parent/guardian's job to oversee and conduct business on the child's behalf. The parent/ guardian needs to understand the components of the child's IEP. The parent/guardian needs to monitor the child's progress and ask questions if there is anything in the IEP he/she does not understand.

If a parent is not available, each public agency is required to determine a child's needs. Also, they are required to assign a surrogate parent to represent the child. The surrogate parent, like a parent/legal guardian, may represent the child in all matters. These matters may relate to the recognition, evaluation, educational placement and the terms of a free appropriate public education.

Development of an IEP Team

Persons required as members of an IEP team include:

- Parents (includes biological and adoptive parents, guardians, and surrogate parents)
- At least one regular education teacher if the child is, or may be, participating in the general education environment
- At least one special education teacher or, if appropriate, a special education provider
- A representative of the local school system who:
  - is qualified to provide or supervise the provision of specially designed instruction to meet the needs of children with disabilities.
  - has knowledge of the general curriculum.
  - has knowledge of the resources in the local school system.
  - is an individual who can interpret the instructional implications of evaluation results.
- Other individuals who have knowledge or special expertise about the student, at the discretion of the parent or local school system or state-operated program.

Creation of the IEP

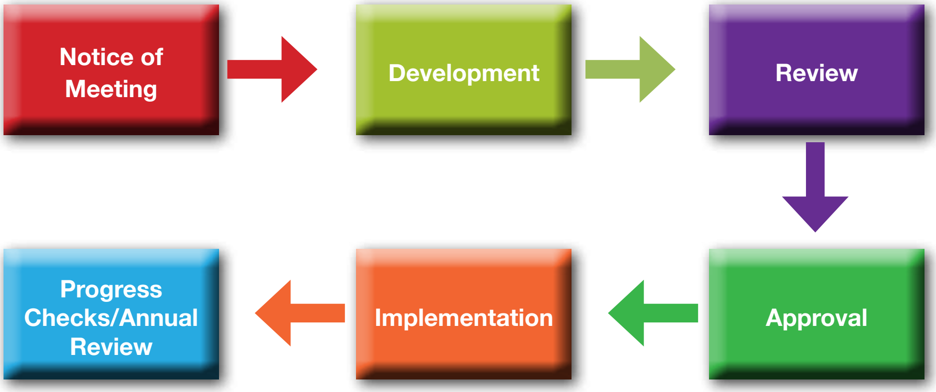
After your child has been identified, evaluated, and found eligible to receive special education services an Individualized Education Plan (IEP) will be created. This may be the most important meeting you will have for planning for your child's educational needs. It is important for parents to provide input to make sure the concerns about their child's learning are addressed. Parents and the IEP Committee create the written IEP.

Before the IEP Committee meets, a notice must be sent to notify all participants of the IEP meeting. The notice should include the purpose, time, location of the meeting and names of who will be attending.

Parents are equal partners with school personnel in developing, reviewing, and revising the IEP. Parents must be members of any group that makes decisions on the educational placement of the child. If the parent/legal guardian/surrogate parent does not attend the IEP meeting, the school system must have written proof of its attempts to arrange a mutually agreed on time and place for the meeting.

However, a parent, legal guardian, or surrogate parent may give written permission for the meeting to be held in their absence. If this occurs, a copy of the IEP is provided for their review and signature after the meeting is held.

In either case, a copy of the IEP is sent to the parent or guardian. This includes evaluation reports, eligibility reports, and placement minutes. It serves to notify them of the actions proposed or refused. The IEP Plan will be implemented on the date listed on the IEP, unless the parent or guardian notifies the school in writing objecting to the plan.



Other important options parents have:

- To bring in people to support them during the IEP meeting.
- To take as much time as needed to complete the IEP (No time limit pressure).
- To speak and/or write agreements and disagreements about parts of the IEP.
- To assist in deciding what is needed to allow the student to take part in the general curriculum, if applicable.
- To assist in deciding supplementary aids and services, program changes, and supports for school personnel.
- To assist in deciding appropriate behavioral interventions and strategies.
- To show agreement with the IEP Committee decisions for placement and education services by signing the document. This will immediately set the IEP in effect.

Key Features of the IEP

Key features of the IEP include:

- Present Functioning Ability (abilities, weaknesses, and needs) - Formal and informal testing should be used to evaluate these areas:
  - Language ability - receptive and expressive
  - Social skills

  - Motor ability - fine and gross motor, coordination, and sensory integration
  - Self-help skills
  - Pre-vocational skills (pertinent at age 14)
  - Academic achievement
  - Maladaptive behaviors - hyperactivity, aggressiveness, self-injury
  - Developmental skills - if child is at a pre-academic level

- Annual Goals (statements of expected educational outcomes by end of school year) – A goal should be listed for each curriculum area included on the IEP. The goals will be taken from your state's approved curriculum standards. These standards were created under No Child Left Behind (NCLB).

- Short-Term Instructional Objectives - For each annual goal, you may desire to plan at least three objectives. Each objective should contain these features:
  - Statement of the skill to be taught. Example: "Toby will count by two's to 100 without help."
  - Level of skill mastery being worked toward.
  - Identify who will be responsible for teaching a skill.
  - Identify dates/times for reviewing the child's progress toward objective.

- **Placement –** Where the child receives educational services. The goal is for children to receive their education in the least restrictive environment (LRE) and to participate as much as possible with their non-disabled peers.

- **Related Services** (occupational therapy, physical therapy, speech, adaptive, assistive technology, vocational instruction) – Information about services should state clearly the name of the special service or material. It should state the name of the service provider. It should state the objective(s) of the service and how they will be delivered. It should show the dates the service will be provided and the date(s) it will be reviewed. Keep in mind your child is not eligible to receive occupational therapy at school unless your child has an IEP. Related services provide interventions on skills to support academic performance.

- **Participation in Regular Education –** Each child placed in special education should be given opportunities for contact with other school children. This could include being in regular classes, joint physical education, peer tutoring, access to the cafeteria, and/or taking part in art and music courses. The IEP should note the activity and its frequency per week.

- **Transition Services –** Transition refers to the change from school services to work-related services after high school. Starting at age 14, if appropriate (or age 16) each annual IEP must state the transition services provided. Also, the IEP needs to state the responsibilities and services provided by the collaborating agencies before the child leaves the school setting.

- **IEP Minutes –** Minutes should clearly state all discussion of services or options that are not added to the IEP. Parents should ask that minutes be taken and that they are given a copy. Parents have the option of audio taping the IEP session. However, you need to let the school know you will be taping the session before the meeting. Some systems require the school to make their own audiotape when the parent tapes the session. Letting them know ahead of time avoids confusion.

- **Extended School Year Services (ESY) –** ESY can be discussed at any IEP meeting. This should include what will happen during winter, spring, and summer recesses. A statement of needed services should be in the IEP. The minutes should reflect the discussion as well as the final decision. Your child may be considered for ESY services if your child showed regression toward meeting his/her IEP goals. ESY provides instruction during school breaks. It is not considered summer school instruction.

The IEP should include a detailed explanation of the reasons the team decided that the student is not able to be with non-disabled students in the regular class or in extracurricular and nonacademic activities. The IEP should also address the extent to which the child will be involved in and progress in the general curriculum. The parent can share information with the regular education classroom teacher. This will give the teacher resource ideas that can enhance the child's time in general education.

Once parent approval for placement is signed, the IEP plan is to be implemented in the current year. At least one annual review of the IEP goals and child's progress must be scheduled before the end of the school year. At that time another IEP may be written for the next year's service. The parent has the right to request more frequent reviews.

The next phase is to carry out the process. You want a good relationship with the school staff carrying out your child's IEP. Thus, checking on the child's progress should be handled with sensitivity and care. It is within your rights to ask for communication and progress reports. You may have opportunities to meet with the regular and special education staff.

Alternative Pathway To Receive Supports At School

Some children exhibit challenges in general classrooms. The challenges may not be related to academic difficulties that are addressed through RTI. An alternative pathway that can be used to meet the unique needs of these children is the Section 504 Plan.

The Section 504 Plan. Section 504 of the Rehabilitation Act of 1973 guarantees a child with a disability receives equal access to accommodations and modifications that enable them to interact in the general education setting. However, the accommodations cannot change the curriculum standards established by No Child Left Behind (NCLB).

Section 504 of the Rehabilitation Act does not allocate special education services. Special Education services are provided through IDEA. The purpose of the law is to seek changes or accommodations within the regular school environment so that the child who learns differently (or needs different supports) is given assistance.

The school may be required to provide services without moving/placing the child in a special education program.

The parent can request that a 504 Plan be developed for the child. The first step is to contact the 504 Coordinator, designated by the local school Board of Education. Keep a record of all your contacts with the 504 Coordinator (personal appointments, phone, and/or mail) and any other school personnel.

Section 504 provides for:

- Appropriate accommodations testing and/or evaluation
- A group decision based on the evaluation results
- A written plan be designed to serve the child

Examples of Accommodations Provided by a Section 504 Plan

1. **Teaching Accommodations**

   A variety of teaching accommodations may be used. One might tailor class and homework assignments using different problem or page formats. For example, a worksheet might contain four problems instead of ten on one side. One might use technology (computers, calculators, and tape recorders). One might provide class notes, fact sheets, assignment sheets, or supply duplicate textbooks for use at home. The methods selected must not change the grade-level standard curriculum.

   Use of alternate materials need to be considered. Student's sensory avenues, preferred learning style, areas of strengths and needs, and interests may vary. This includes providing text with large print or administering tests orally. Variations in task levels and reading levels should be considered in the teacher selection of alternate materials. Again, the alternative materials must not deviate from the state's standards and approved curriculum.

2. **Communication**

   Regular contacts (phone, written or emails) will help keep everyone informed about progress, needs, and supports. Daily or weekly journals and logs are a good way to keep track of home and school information. Schedule parent-teacher meetings as often as necessary to ensure your child's educational needs are being met.

3. **Management**
   Time management can be a critical element for success. The length of the school day or week may need to be adjusted. Additional time may be needed for changing classrooms. Extra time for test taking and for producing answers, class work, and homework (such as by electronic equipment) may be needed. Seating arrangement is another management task that can be varied. Seats near the teacher, individual study carrels, or small group clusters for shared learning may be useful.

4. **School-wide or Classroom Tests**
   Different ways of testing can be selected based on the child's needs, without changing the content of the test. Length of test, spacing of test questions, and the way the test is presented (i.e. live, oral/spoken; tape-recorded; computer generated; standard paper and pencil) are factors to consider.

No Child Left Behind (NCLB), the Individuals with Disabilities Education Act (IDEA), and Section 504 of the Rehabilitation Act of 1973 all help to meet the educational needs of children with FASD at school. Next are some ways parents can help meet their children's educational needs at home, beginning with how parents can help *themselves* to cope.

Strategies to Help Parents Cope

Here are some guidelines to help parents cope as you advocate for your child's education:

- Be aware of your own feelings. If your child requires constant attention or supervision, you may feel drained or frustrated. You will have to remember to take care of yourself so you can take care of your child.
- Recognize that your child's needs may change from time to time. Don't get discouraged when what worked before no longer works.
- Be persistent. Identify your child's needs, resources, and support services. Be an advocate to help your child grow up feeling positive and secure about life.
- Find someone to talk to. Just talking to someone can help you feel better and help you think clearer.

Tools for Helping at Home

Your child needs a structured home environment. He/she needs to know what behaviors are expected (i.e. chores and responsibilities) and when they need to be done (i.e., using checklists and schedules). Let's think about how to make things easier. Think about:

- Morning time responsibilities.
- Homework time (funwork time).
- After school routines help your child be organized (time management).
- A consistent place for keeping things. Labeled shoeboxes or containers can be used to store items.
- Have the same comfortable place for your child to do homework every day.

Things That Will Help Your Child.

- Schedules - helps your child know what is expected
- Routines/structure - helps your child be more organized

Things That Will Help <u>You</u> Help Your Child.

Use an organizational notebook and have your child bring it to and from school every day. The notebook should include a daily schedule of events, homework assignments, and comments about behavior.

The benefits of an *organizational notebook* are that you can check homework every day, and give praise for achievements and good behavior. You can also praise your child for remembering to bring the notebook home.

Another benefit of the notebook is that it will enable you to monitor homework progress and alert you if your child is having a problem. Problems can then be talked out immediately as they arise. You can also show how something is done, or rehearse the steps to solve the problem with your child.

It is important to encourage self-monitoring and self-talk. For example: "OK, I am home from school. Now I should go to my checklist to see what I need to do." After a task is completed the child should check it off his/her list (a visual reminder). This can be part of a reward system. In other words, the child gets a reward or token if all the items/chores on the list are checked off.

Encouraging Collaboration with the School

You will need to communicate with school personnel. The desired end result is that you develop good relationships for collaboration to get services for your child. It will be useful, therefore, to go over a few basic aspects of communication.

- Focus on the Goal. The goal is obtaining services to meet the educational needs of your child. This is your bottom line. Don't get sidetracked by personalities.

- Give a consistent message. We communicate through verbal, written, and body language. So, keep your messages consistent between all of these forms of communication.

- Attend to the facts. As others are speaking to you, sort which information is subjective (personal attitude or opinion) and which is objective (facts, events, records, tests, data).

- <u>Be a good listener.</u> **There are Seven Rules to Good Listening.**

    1. Listening requires time: Ask yourself if you have the time to listen. If not, it is only fair to state that before starting a conversation. This shows respect.

    2. Choice of location: Is this the right place for the conversation? Again, this shows respect. If not, set another time. Let the teacher know when you are most available (leave a phone number where you can be reached.

    3. Quiet Please: Once someone starts talking, don't interrupt. Allow a flow of communication.

    4. Hold on: Do not jump to conclusions. Don't get over excited, defensive, and reactive.

    5. Hear the Message: Listen to the message, not what you want to hear. Be open to new viewpoints and ideas. Listen and digest what is said, and then explain your viewpoint.

    6. Get the Point: Listen to what is being said, not to who is saying it. It is sometimes difficult to separate the messenger from the message.

    7. Beyond Words: When talking pay attention to how you are treating others and how they are treating you. One's eye contact, facial cues, and body posturing can tell how someone feels about what's being said and who is saying it.

If there is a problem, here are some other Ways for Improving Communication with School Staff:

- When calling the school, ask the person giving you information to identify him/herself.
- Be aware of the chain of command.
- Have someone go with you to meetings about your child.
- Be reliable about your attendance at scheduled meetings.
- Collect facts and your thoughts before attending a meeting (Write them down so you don't forget).

- Control your emotions. Stay calm.
- Realize that spoken messages sent by your child to the teachers or other school officials may not get to them (or may be miscommunicated).
- Ask questions about your child.
- Try to resolve one problem at a time.
- Keep your child's file in order (keep all written communication).
- Give solutions an opportunity to work.
- If there is a serious problem, ask for specifics in writing.
- Ask for a copy of school policies and procedures.
- Avoid thinking and saying, "I'm just a parent."

Assertive Communication

Asserting oneself can be done without aggression, ugliness, and threatening behaviors. Assertiveness does not equal aggression.

Sometimes parents feel that communication is difficult or that people are not listening. When that happens it can be helpful to be "assertive" in communicating with schools and other professionals. But remember, being assertive is not the same thing as being aggressive. It is useful in taking charge, reaching goals, resolving conflicts, and finding answers. Learning this skill will be useful in preparing for school conferences and IEP meetings.

Ask for help. Sometimes it takes courage to ask for help, clarification, and direction. The first step is to assert your need for a meeting with the school staff.

Be prepared. The next step is to prepare for your meeting. The key words are *be prepared*. Often parents are not prepared for what they encounter in a meeting. As a result, they become embarrassed, frustrated, angry, and/or stuck. If you are unprepared, your needs may not get met.

In preparing for a meeting it is helpful to mentally walk through your plan of action before the actual event. Talk it out with a spouse, friend, or advocate. Make sure you are clear and focused. Remember you'll get better with practice. You will learn from each meeting and improve each time. Be positive and patient with yourself.

Put it in writing. Asserting your needs, wishes, or viewpoints in writing can also be effective. You may choose to write your concerns through letters asking for various services.

Other tips for good self-management and communication during a problem-solving meeting:

- **Negotiated time and place:** Make sure the time and place of the meeting is good for everyone.
- **Introductions:** Introduce yourself and anyone else you brought with you. Acknowledge others who are there. At the beginning of the meeting invite constructive input from everyone.
- **Attention:** Maintain eye contact and speak directly to those present.
- **Statement of concern:** Clearly state your concern. Be specific, by giving specific examples. Avoid both 'down-playing' and exaggerating a problem. Stick to the facts.
- **Level with others:** Admit your own feelings without blaming others. [Examples: "It bothers me when you say…." and "I feel uncomfortable when . . ."] Praise others when they do positive things. Admit errors and misunderstandings, and move on.
- **Precision:** Present your feelings, facts, and concerns precisely. Stop when you are finished. Be brief and to the point. Use humor if the situation is appropriate. Wait for others' constructive remarks.
- **Remember the 5 "Be" Traits:**
  1. Be direct
  2. Be consistent
  3. Be accepting
  4. Be confident
  5. Be involved
- **Avoid negative responses:** Do not threaten or put down others. Do not blame. Keep the focus on what you need. Do not let negative feelings pile up until you explode. Deal with them as they arise.
- **Watch sidetracking:** When persons are uncomfortable they will avoid the issue by changing the subject. Go back to the point.
- **Giving suggestions:** Make statements, such as "I'd like you to notify me when this happens" or "I would prefer that my child would get/do/have …"

Collaborative Planning Is Key To Obtaining Effective Services

An "interagency collaborative effort" (many agencies working together) is needed to make sure services are:

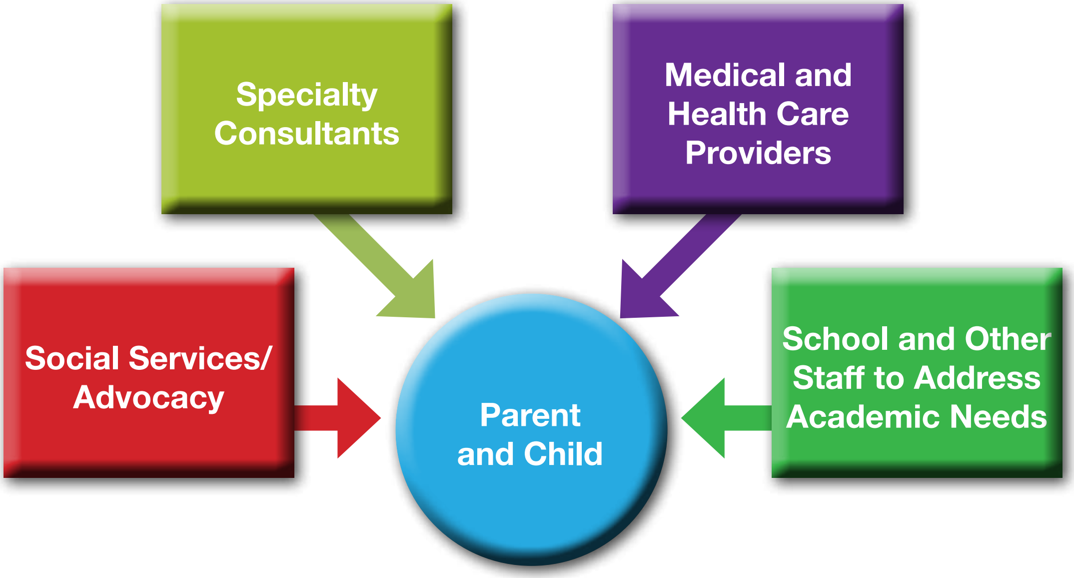
- Coordinated (everyone working together)
- Complimentary (everyone understands the plans/goals)
- Not neglected (nothing is left out)

If the right hand does not know what the left hand is doing, then services are disconnected and ineffective.

Some of the possible agencies and services that might be needed in order for effective collaborative planning to take place for a child and family might include the following:

- Social Services/Advocacy
    - Social Worker
    - Case Manager
    - Lawyer

- Specialty Consultants, for Behavioral and Other Issues
    - Psychologist
    - Therapist
    - Psychiatrist for medication
    - Psychologist for testing, counseling/therapy
    - Behavior Specialist (for serious behavior issues). Each school district has one to help set up behavior management plans.
    - Dietitian



- Medical and Health Care Providers
  - Primary care physician
  - Obstetrician
  - Pediatrician
  - Psychiatrist
  - Neurologist
  - Endocrinologist
  - Ophthalmologist
  - Developmental Medicine Doctor
  - Psychiatrist
- School and Other Staff to Address Academic Needs
  - Teachers
  - Counselors
  - Special Ed Teacher
  - Behavior Specialist
  - Psychologist or other specialist for classroom behavior management
  - Special education personnel for the educational planning
  - Speech and language pathologist for language therapy
  - Occupational for fine motor skills

Section 4: Resources

Resources in this Section:

- National Organization on Fetal Alcohol Syndrome (NOFAS)
- SAMHSA – Substance Abuse and Mental Health Services Administration
- FAS Community Resource Center (FAS-CRC)
- FASlink
- FAS Family Resource Institute
- Fetal Alcohol Drug Unit
- Canadian Centre on Substance Abuse
- The Arium Foundation
- Building the Legacy: IDEA 2004
- National Center for Learning Disabilities
- RTI Action Network
- Internet Sites for FAS
- Books

The following is not an endorsement of specific programs, but only a list to assist caregivers as they attempt to locate services.

National Organization on Fetal Alcohol Syndrome (NOFAS)

900 17th Street N.W., Suite 910
Washington, DC 20006
Phone: (202) 785-4585
Toll Free Phone: (800) 66NOFAS
Fax: (202) 466-6456
www.nofas.org
Email: information@nofas.org

NOFAS is a nonprofit organization dedicated to eliminating birth defects caused by alcohol consumption during pregnancy and improving the quality of life for those individuals and families affected. NOFAS takes a multicultural approach to prevention and healing. NOFAS raises public awareness and develops and implements innovative ideas in prevention, intervention, education and advocacy in communities throughout the nation.

Program areas: national and community-based public awareness campaigns; a curriculum for medical and allied health students; training workshops for professional and lay audiences; peer education and youth outreach initiatives; and the NOFAS information, resource and referral clearinghouse.

SAMHSA – Substance Abuse and Mental Health Services Administration

http://www.samhsa.gov/

This is a website of the US Department of Health and Human Services. Following some interesting links on FAS. For more information on Fetal Alcohol Syndrome type FAS in the search-box.

http://ncadi.samhsa.gov/govpubs/bkd110/5d1.aspx
http://ncadi.samhsa.gov/about/services.aspx

FAS Community Resource Center (FAS-CRC)

Teresa Kellerman
FAS-CRC
7725 E. 33rd Street
Tucson, Arizona 85710-6059
Phone: (520) 296-9172
www.come-over.to
Email Teresa Kellerman: teresa@come-over.to

The FAS Community Resource Center (FAS-CRC) focuses primarily on PREVENTION. It offers resources related to FASD (Fetal Alcohol Syndrome Disorder).

FASlink

CEO: Bruce Ritchie
2448 Hamilton Road
Bright's Grove, Ontario Canada
N0N 1C0
Phone/Fax (519) 869-8026
Toll Free Phone (877) 213-3115
www.faslink.org

FASlink is the Canadian Fetal Alcohol Syndrome Internet support, information, advocacy and discussion forum. They are a free Internet mail list for individuals, families and professionals who deal with Fetal Alcohol Syndrome.

FAS Family Resource Institute

The mission of the FAS Family Resource Institute, a non-profit organization, is to identify, understand and care for individuals disabled by prenatal alcohol exposure and their families, and to prevent future generations from having to live with this disability.

http://fetalalcoholsyndrome.org

Fetal Alcohol Drug Unit

Director: Dr. Therese Grant, PhD
180 Nickerson St., Suite 309
Seattle, WA 98109
(206) 543-7155 phone
(206) 685-2903 fax

The Fetal Alcohol and Drug Unit is a research unit dedicated to the prevention, intervention and treatment of Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE). Our main goals are to conduct research on fetal alcohol and drug effects across the life span, to disseminate information on fetal alcohol and drug effects, to provide consultation for persons of any age thought to be affected by prenatal exposure to alcohol, and to provide training in human behavioral teratology.

Canadian Centre on Substance Abuse

75 Albert Street, Suite 300
Ottawa, ON Canada K1P 5E7
Phone: (613) 235-4048 Fax: (613) 235-8101
www.ccsa.ca

A non-profit organization working to minimize the harm associated with the use of alcohol, tobacco and other drugs. Promotes informed debate on substance abuse issues and encourages public participation in reducing the harm associated with drug abuse; disseminates information on the nature, extent and consequences of substance abuse; and supports and assists organizations involved in substance abuse treatment, prevention and educational programming

The Arium Foundation

A non-profit organization dedicated to the prevention of addictions and their effects upon individuals, families and our communities, through the provision of resources, information and research concerning drug and alcohol abuse, fetal alcohol syndrome and other substance abuse issues.
www.arium.org/

Building the Legacy: IDEA 2004

This website provides a complete overview of the Individuals with Disabilities Act (IDEA) revised in 2004. It is maintained by the U.S. Department of Education.
http://idea.ed.gov/

National Center for Learning Disabilities

The National Center for Learning Disabilities provides information about learning differences, educational policy, and special education.
The website is www.ncld.org.

RTI Action Network

The website provides information about the Response to Intervention (RTI) model.
The website is www.rtinetwork.org.

Internet Sites for FAS

www.thearc.org
www.fetalalcoholsyndrome.org
www.do2learn.com
www.betterendings.org
www.thechancerchronicles.com

Books

(The following books are all available at bookstores or at Amazon.com)

- “The Broken Cord”, Michael Dorris
- “Fantastic Antone Succeeds” Judith Kleinfeld, Barbara Morse, Siobhan Wescott, ed.
- “Fantastic Antone Grows up”, Judith Kleinfeld, Barbara Morse, Siobhan Wescott, ed.
- “Fetal Alcohol Syndrome”, Ann Streissguth
- “How to Talk so Kids can Learn, at Home and in School”, Adele Faber and Elaine Mazlish
- “Nonverbal Learning Disabilities at Home”, Pamela Tanquay
- “Nonverbal Learning Disabilities at School”, Pamela Tanquay
- “Negotiating the Special Education Maze”, Winifred Anderson, Stephen Chitwood, Deirdre Hayden
- “Helping Schoolchildren with Chronic Health Conditions: A Practical Guide, Daniel Clay”
- “How to Compromise with your School District without Compromising Your Child,” Gary Mayerson
- “Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention and Treatment”
- “Institute of Medicine, Committee to Study Fetal Alcohol Syndrome,” Washington DC, National Academy Press, 1991 (This is a more technical book and needs to be ordered from the Institute of Medicine)

Conclusion

This manual discussed the different effects Fetal Alcohol Spectrum Disorder (FASD) may have on children's lives and what caregivers and children can do to cope and learn.

Fetal Alcohol Spectrum Disorder (FASD) is a "catch-all" term used to describe the range of possible effects of prenatal alcohol exposure. Among the most severe outcomes of prenatal alcohol exposure included on this spectrum are Fetal Alcohol Syndrome (FAS) and Partial Fetal Alcohol Syndrome (pFAS). However, because not all prenatal alcohol exposure results in FAS or pFAS, the spectrum term *FASD serves* to capture all resulting effects and degrees of severity.

There are three types of FAS defined by the Institute of Medicine (IOM):

- *FAS with confirmed* maternal alcohol exposure
- *FAS without* confirmed maternal alcohol exposure
- *Partial* FAS (pFAS) with confirmed maternal alcohol exposure

Each of these is diagnosed by specially-trained pediatricians based on four "rules" which were described in *Section 1: What Are FAS, and pFAS, and FASD?*

1. Exposure - Drinking while pregnant confirmed
2. Face - Distinctive facial features
3. Growth - Low birth weight and/or slow growth
4. Brain - Damage to the central nervous system

In addition, there are several secondary disorders associated with FASD (and the life experiences of those with FASD), including attachment, developmental, intellectual, and learning disorders. These in turn can result in social, emotional, behavioral, and academic problems for a child with FASD. However, studies have shown that the earlier FAS is identified, the fewer secondary problems are reported.

Problems resulting from prenatal exposure to alcohol occur because exposure changes the way the brain develops. *Section 2: Prenatal Alcohol-Exposure and Neurodevelopment: How are Learning, Thinking, and Behavior Affected?* of this manual went into detail about how prenatal exposure affects the child's neurodevelopment, or how the brain develops to help the child learn, think, and behave.

Motor skills are often the first thing noticed as problematic, and these show up as issues with muscle tone, fine and gross motor skills, and coordination—which includes everything from grasping to walking.

Cognitive functioning (or "cognition") is another neurodevelopmental issue for children with FASD. This area of functioning has to do with the higher mental processes by which children learn, solve problems, and plan. It is often measured through intelligence tests, such as a test of "IQ." Cognition can be affected as a result of prenatal exposure to alcohol in areas including:

- Visual-spatial skills, which refers to perceiving, judging, and storing images and symbols, and experiencing space and location
- Attention, which involves many processes, including self-regulating, encoding, and shifting attention
- Memory, which involves sensing, attending, learning, and remembering
- Executive functioning, which has to do with the coordination of memory, organization, and planning
- Language, including spoken and written language

Although a child diagnosed with FAS or pFAS may have trouble learning, there are many ways to meet this child's educational needs. Children diagnosed with fetal alcohol syndrome or partial FAS often need educational and therapeutic support to achieve their potential. Sometimes this means that they will qualify for special educational or other services. *Section 3: How Can the Child's Educational Needs Be Met at School and Home?* discussed how to help meet a child's educational needs through special services.

First it is important to observe the eight universal protective factors in alcohol affected children. A protective factor is anything that prevents one problem from causing another to develop. These protective factors include:

1. Diagnosis before the age of 6 years
2. Having a diagnosis of FAS
3. Having basic needs met.
4. Living in a stable home for over 72% of life
5. Never having experienced violence against oneself
6. Staying in each living situation for an average of more than 2.8 years
7. Experiencing a good quality home from 8-12 years
8. Having applied for and been approved by (DDS) U.S. Division of Developmental Disabilities Services

Second, it is important to know your rights under the law and understand the applicable federal laws which guide education. No Child Left Behind (NCLB) and the Individuals with Disabilities Act (IDEA) are two such laws. Section 3 outlined many of the key points under these laws relevant to children with special needs.

One important component of the IDEA law is the Response to Intervention (RTI) Framework, which is a multi-level intervention process mandated under IDEA. Its purpose is to ensure that children receive the necessary instruction at all times and to prevent placing students who do not have disabilities in special education. The four tiers of the RTI model include:

- Tier 1: Standards Based Classroom Learning
- Tier 2: Needs- Based Learning
- Tier 3: Student Support Team (SST) Driven Learning
- Tier 4: Specially Designed Learning

The intensity, duration, and monitoring of instructional services increase the higher the tier.

Evaluations are also an important fixture under the law, which are required to assess a child's cognitive and academic skills, and secure services. The results from an evaluation will be combined with the data collected through the RTI process to determine eligibility for instructional services and support.

IDEA also provides for Individual Education Programs (IEPs), which are educational plans suited to meet the unique requirements of individual students. Outlining a plan for students with special needs is important to keep all services, supports, and instructional goals focused and monitored. An IEP is put together by an IEP team, including parents, teachers, and other school representatives and experts.

Another law which can affect the education of children diagnosed with FAS or pFAS is Section 504 of the Rehabilitation Act of 1973. This law seeks accommodations for the child within a regular school environment so that the child who learns differently or needs different supports is given assistance without placing the child in a special education environment.

Although supporting and advocating for a child with FASD can be overwhelming, many helpful tools are provided throughout this manual. Section 3 lists several ways for collaborating with schools to help the process go most smoothly. It also gives several strategies for helping parents cope and gives ideas for structuring the home environment for a better outcome. Finally, *Section 4: Resources* lists an array of programs and other resources to help caregivers locate services for a child with FASD.

Notes and Questions

Notes and Questions

MILE