



# Fetal Alcohol Syndrome:

A Parents Guide to  
Caring for a Child  
Diagnosed with FAS

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Fetal  
Alcohol  
Syndrome



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# FETAL ALCOHOL SYNDROME



## Introduction

Learning that your child has fetal alcohol syndrome (FAS) may make you feel disappointment, a sense of loss, angry, or overwhelmed. You also may feel relieved that you now know **why** your child has problems with learning and/or behavior. Now that your child has been diagnosed with FAS, you may be asking, “What do we do now?”

The purpose of this book is to explain FAS, which we hope will inspire you to learn more about your child’s diagnosis. The more you and your family learn about FAS, the easier and less frustrating it will be to raise your child. One of the best ways to prevent some of the problems that children with FAS may have is to learn parenting and teaching skills to help you work with your child.

While this book gives the basic information about FAS, we have also listed some other resources such as books and support groups that we believe will help you to learn more about FAS. You are welcome to share all of this information with other family members, teachers and healthcare workers.

Although this book is aimed at helping families with a child diagnosed with FAS, this information is also useful for the families and caregivers of children who have brain damage due to alcohol exposure, but have not been given the FAS diagnosis.

# OVERVIEW OF PRENATAL ALCOHOL EXPOSURE

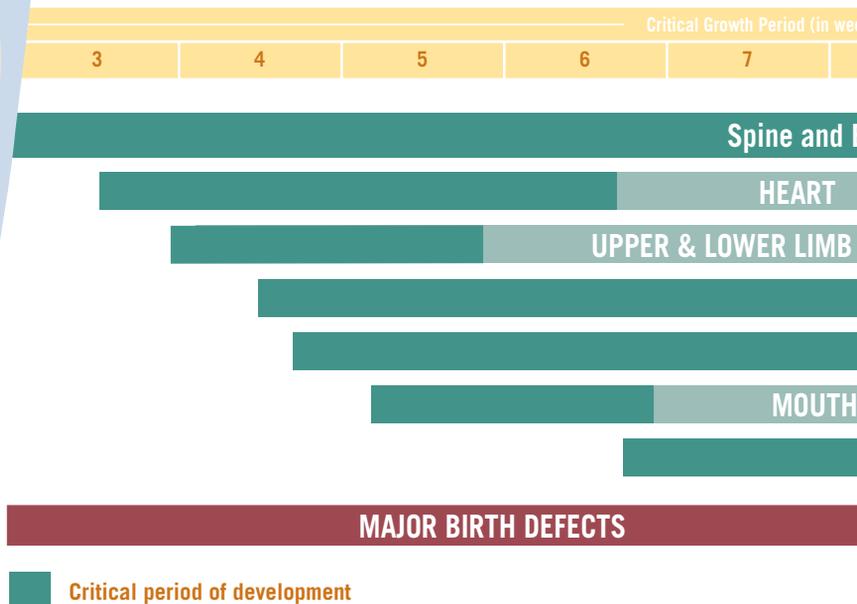
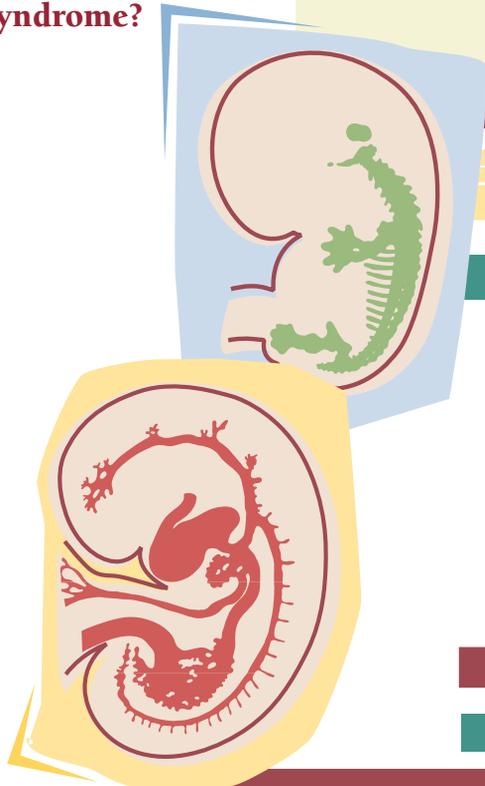
## What is Fetal Alcohol Syndrome?

Fetal Alcohol Syndrome (FAS) affects some children who have been exposed to alcohol during pregnancy. We will be using the term “prenatal alcohol exposure,” which means the mother drank alcohol during her pregnancy. Alcohol includes beer, wine, and liquor.

Children with FAS are smaller than other children their age, have learning and behavioral problems, and look different. They may have smaller heads, may grow and mature slower than other children, and have birth defects.

## Will all children who are exposed to alcohol during pregnancy have Fetal Alcohol Syndrome?

The effects of drinking alcohol during pregnancy can vary widely. Some children may have little or no problems. Others may be severely affected. FAS is the most serious outcome of the mother drinking alcohol during her pregnancy.



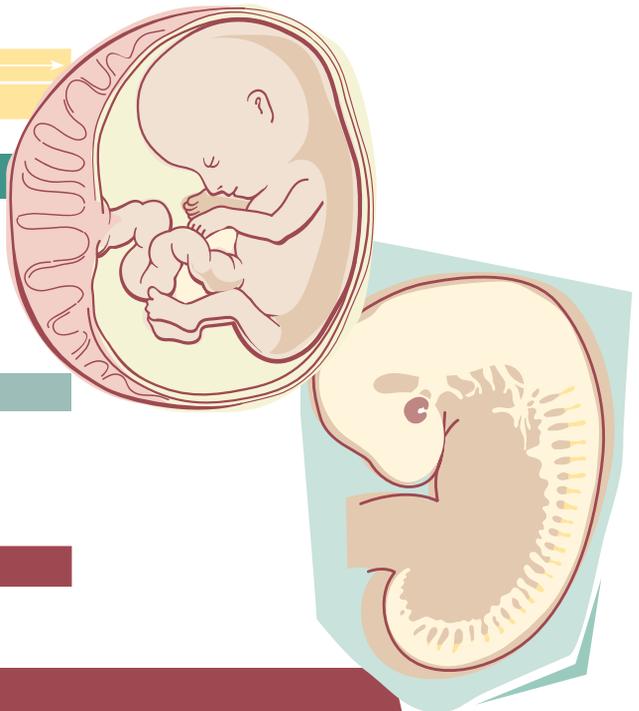
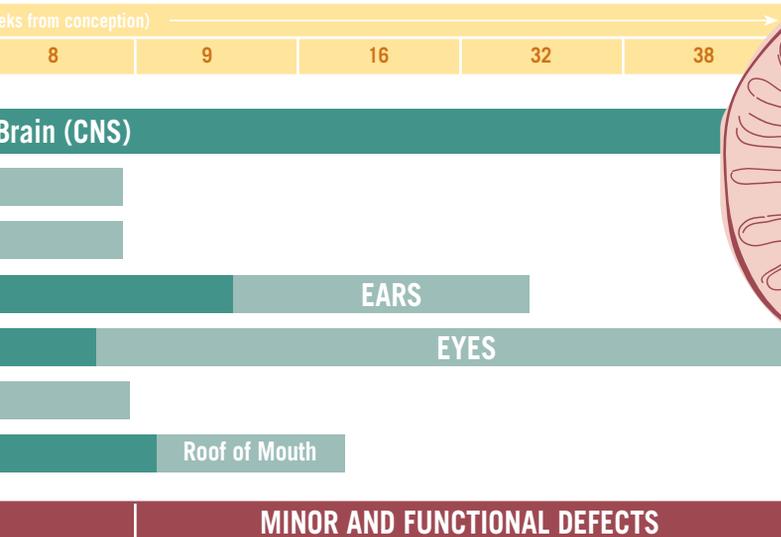
# THE ONLY WAY TO PREVENT FAS IS NOT TO DRINK ALCOHOL DURING PREGNANCY.

## Why are some children affected more than others?

Lots of factors play a role in how alcohol will affect the baby in the womb. One of the main factors is the **amount of alcohol** that the mother drank while she was pregnant. As a rule, the more the mother drinks, the greater the chance that the alcohol may harm the baby.

Another major factor is the **time during the pregnancy** in which the mother drinks. The first trimester (the first 12 weeks) is a critical period in the baby's growth. During this time, the baby's organs, limbs, and face are developing. Drinking alcohol during the first trimester can cause serious defects in these organs. During the second trimester, the baby is growing bigger. Alcohol can slow the baby's growth, making the baby smaller than expected. Also, the brain still develops during the 2nd and 3rd trimesters. Alcohol can lead to problems with the forming of the brain and with the way it works.

Other factors that can change the effects of FAS are the way in which a mother's body handles **alcohol**, the **genetic make-up** of the baby and **other drugs or medicines** that the mother may take.



## Are there other conditions that children may have if they are exposed to alcohol during pregnancy?

## How does alcohol cause FAS?



Fetal alcohol spectrum disorders (FASD) is the new term used to describe anyone who has been affected by prenatal alcohol exposure, including FAS. In order for a doctor to give someone a diagnosis of FAS, they must have all three of these findings:

- Growth problems
- Certain differences in their face
- Brain damage

If a person has one or two of these findings, they will not get a diagnosis of FAS. There are other terms used to describe persons affected by alcohol, who do not have FAS. These terms are not actual diagnoses. However, you may hear or read these terms used as you do more research.

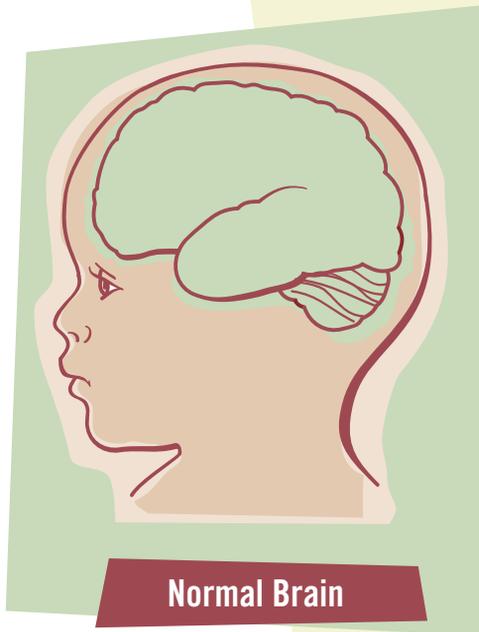
■ **Partial Fetal Alcohol Syndrome (PFAS)**—children with PFAS have faces that look different and one of the following: growth problems, unexplained learning or behavioral problems.

■ **Fetal Alcohol Effects (FAE)**—an older term used to describe children with some degree of brain damage, growth problems and/or other birth defects, but do not have the facial features seen in FAS. Although this term is still used, the Institute of Medicine has replaced this term with ARBD and ARND.

■ **Alcohol-Related Neurodevelopmental Disorder (ARND)**—children with ARND have learning and/or behavioral problems that are associated with prenatal alcohol exposure but do not have the typical facial differences or growth problems.

■ **Alcohol-Related Birth Defects (ARBD)**—children with ARBD have confirmed prenatal alcohol exposure and alcohol related birth defects. They do not have the typical facial features you see with prenatal alcohol exposure or learning problems.

When a pregnant woman drinks alcohol, it enters the baby's blood stream. Within minutes after the mother drinks alcohol, the blood-alcohol level of the baby is almost equal to that of the mother's.



**Normal Brain**



**Brain affected by alcohol**

Research with animals has shown that alcohol can cause brain damage, facial changes, and physical and growth problems. It is believed that there are many ways that alcohol can cause birth defects. Alcohol can kill cells that help parts of the body grow, such as the brain, face, heart, limbs, kidneys and/or other organs. When certain cells die, the body parts that are supposed to develop from these cells cannot grow properly. As a result, a “birth defect” occurs. Alcohol also limits the amount of nutrients, energy and oxygen that the baby receives, which affects how the baby grows and develops.

### **How does prenatal alcohol exposure affect the brain?**

The brain is the organ that is most affected by alcohol before the baby is born. In most cases, the brain will not look different, but the alcohol can damage parts of the brain that cannot be seen. We don’t know why, but alcohol damages parts of the brain that gives us our memory, self-control, coordination and judgment. As a result, children with FAS tend to have problems learning, poor attention spans, problems with behavior, and problems trying to do things like grasp an object or brush their teeth (we call these “fine motor skills”). These children can be hyperactive, have seizures, or develop slowly.

A child who was exposed to alcohol during pregnancy may still have brain damage even though he or she may not have the typical facial features or other birth defects that you might see with FAS.



**What kinds of birth defects may be seen in a child with FAS?**

Below are some types of birth defects that may be seen in children with FAS. All of these features DO NOT occur in each child. However, some features are more likely to occur than others.



Cleft palate (opening in the roof of the mouth)

Small teeth

Eye problems

— Nearsightedness

— Farsightedness

— “Lazy” eye

— “Crossed” eyes

Hearing Problems

Heart Defects

Kidney Changes

Genital Changes

Sacral dimple (a dimple at the base of the spine)

Unusual chest shape

Curved fingers

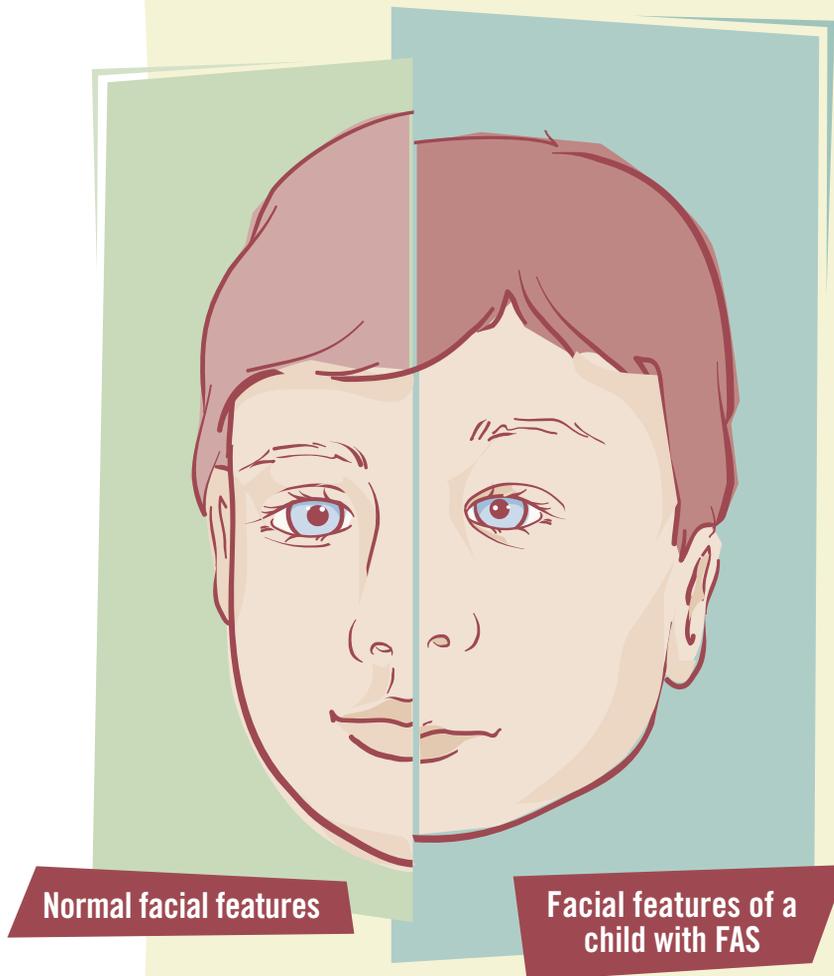
Shortened fingers/ toes

Small Finger- and toenails

Floppiness (low muscle tone)

## What are the facial features associated with FAS?

Most people can not tell that a child has FAS just by looking at the child. Yet, children with FAS have very subtle changes in their faces that are noticed only by professionals who are specially trained to recognize these features. The picture below shows some of the facial features that are common in children with FAS.



*Not all children with FAS will have all these facial features. But, children with FAS have small eye openings, a smooth area between the nose and lip and a thin upper lip.*

## How does alcohol affect child development?

The following tables give an overview of the developmental problems a child with FAS may face.

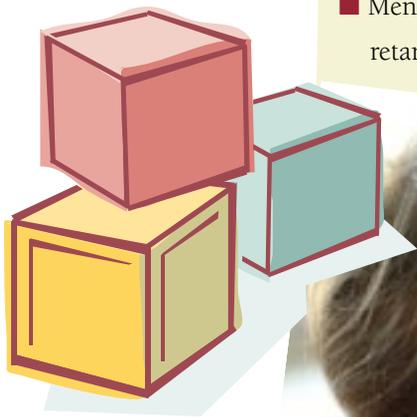


### NEWBORN (*birth to 9 months*)

- Irritable (or fussy)
- Feeding problems/poor suck
- Super sensitive to loud noises, strong odors or rough clothing
- Problem adapting to new things and new situations
- Poor bonding with caregivers
- Abnormal sleep cycles and frequent waking at night
- Low muscle tone (or floppy)
- Small head size

### TODDLER (*9 months-4 years*)

- Head banging
- Poor small muscle (fine motor) and large muscle (gross motor) skills development
- Language delays
- Poor coordination and balance
- Poor memory
- Hyperactivity (can't sit still)
- Developmental delay (new skills are not learned by the expected age)
- Mental retardation (about 1 in 4 or 25% of children with FAS have mental retardation, which is an IQ below 70)



## EARLY SCHOOL AGE (4-12 years)

- Learning disabilities
- Trouble getting along with others
- Short attention span
- Impulsivity (acting before thinking)
- Aggressiveness
- Problems talking and listening
- Hearing problems
- Frequent temper tantrums/mood changes
- Longer time to complete tasks



## ADOLESCENT AND ADULT (12 years and up)

- Poor judgment
- Memory problems (poor long-term and short-term memory)
- Poor problem-solving abilities
- Trouble with applying knowledge and higher thinking
- Problem understanding why something happened (*cause and effect*)
- Trouble with time and money management
- Lack of common sense



NOT EVERY CHILD WHO IS EXPOSED TO ALCOHOL DURING PREGNANCY WILL HAVE ALL OF THE PROBLEMS LISTED ABOVE.

EVERY CHILD WITH FAS IS DIFFERENT AND HAS HIS OR HER OWN POTENTIAL FOR SUCCEEDING IN LIFE!

## Is there a cure for FAS? Can children outgrow FAS?

No, there is no cure for FAS. Likewise, the effects of prenatal alcohol exposure are life-long and cannot be corrected. However, the effects of prenatal alcohol exposure can be lessened when the symptoms of FAS are recognized early and the child receives the appropriate care.

## When was FAS first recognized?

For nearly 2,000 years it has been known that babies exposed to alcohol during pregnancy can have physical and mental differences. However, it was not until the 1960's and 1970's that the problems these babies have were described in detail, and the term "fetal alcohol syndrome" came into use.

## How many children are affected by prenatal alcohol exposure?

Fetal alcohol spectrum disorders affects one out of every 100 babies that are born. That's 40,000 babies every year who are born with some amount of problems due to prenatal alcohol exposure! About one out of every 1000 babies is born with full-blown FAS.

Fetal alcohol spectrum disorders are seen in all different ethnic groups. In certain groups FASD is seen more often. For example, children from some Native American populations, Eastern Europe, and South Africa are at a high risk for having FASD because drinking among pregnant women is much more common than in other parts of the world.

### PREVALENCE OF FETAL ALCOHOL SYNDROME (FAS) BY RACE/ETHNICITY

	FAS cases N (%)	Prevalence per 10,000
Black	710 (47.0)	8.1
White	537 (35.6)	1.1
Native American	77 (5.1)	31.0
Hispanic	45 (3.0)	1.2
Asian	3 (0.2)	0.3
Other	137 (9.1)	1.7
Overall	1,509 (100.0)	2.1

## How is FAS diagnosed?

There is no test to diagnose a child with FAS. It can only be diagnosed by a clinical exam. Because FAS can be missed or misdiagnosed, it is important that the doctor or clinic staff doing the evaluation have special training or experience in diagnosing fetal alcohol syndrome. Parents should feel free to ask the doctor or clinic staff about his or her background in diagnosing children with FAS.

During the exam, the doctor or specialist looks to see if a child has any of the features associated with FAS. There are three groups of features (also called criteria) in FAS (see below). A child must have features within all three groups to be diagnosed with FAS. Parents may want to ask which features are considered necessary to “meet diagnostic criteria,” since some features mean more than others.

## The three diagnostic criteria for FAS are:

### ■ Growth deficiency

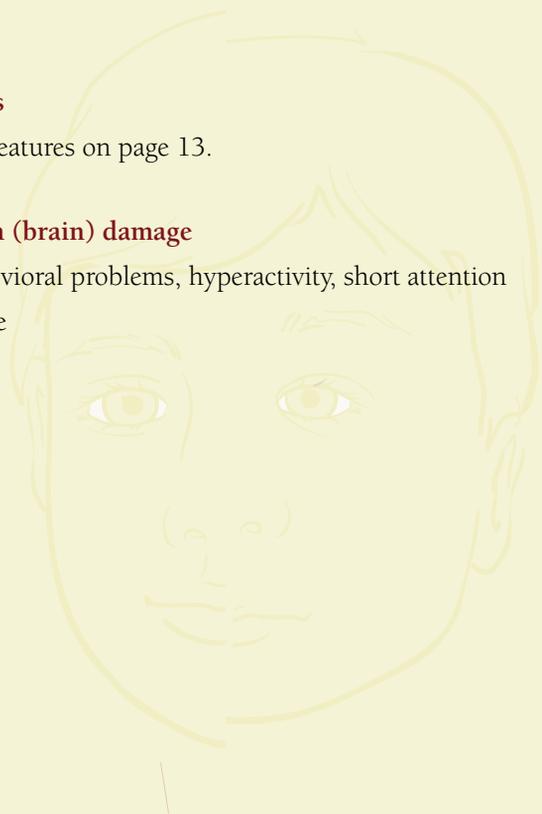
Problems growing in the womb and/or after birth. Children tend to be in less than the 10th percentile in height and/or weight when compared with other children their age.

### ■ Minor facial differences

See section about facial features on page 13.

### ■ Central nervous system (brain) damage

Learning problems, behavioral problems, hyperactivity, short attention span, and small head size



# FAS THROUGH THE YEARS



**What problems can individuals with FAS have as they get older?**  
(These problems are called “secondary disabilities.”)

The effects of prenatal alcohol exposure last throughout life. Individuals with FAS may “outgrow” some of the facial features that go with FAS and may put on weight as they get older, but they will continue to have learning and behavioral/social problems.

Studies show that children with FAS are more likely to have mental health problems and trouble in school and with the law. They are more likely to have poor judgment regarding sexual behaviors and to abuse alcohol and illegal drugs. These issues are discussed in more detail below. It is important to note that early intervention and a loving, structured home can lessen the chance of a child with FAS having some of these problems.

## **Mental Health Issues:**

Attention deficit/hyperactivity disorder (ADHD) is the most common mental health issue for children and adolescents with FAS. Other mental health problems that are often seen include depression (seen more in adults), suicidal thinking, anxiety (panic attacks), and schizophrenia. These conditions often require treatment by a doctor or other healthcare worker. It is very important for parents and caregivers to be familiar with the warning signs for these mental health problems.

## **Leaving School:**

Being suspended or expelled from school and dropping out of school are common. These problems occur more frequently among teens with FAS than among younger children. Younger children with FAS, as well as teens, tend to have problems with behavior and with completing their schoolwork. These problems can cause feelings of failure, low self esteem, and lack of drive, which can lead to a desire to drop out of school.

**IT IS IMPORTANT TO NOTE THAT EARLY INTERVENTION AND A LOVING, STRUCTURED HOME CAN LESSEN THE CHANCE OF A CHILD WITH FAS HAVING SOME THESE PROBLEMS.**

**Trouble with the Law:**

Because individuals with FAS tend to act before they think and have poor judgment, they often have trouble obeying the law. Many individuals with FAS, especially teens and adults, have problems such as stealing and shoplifting. These individuals can be sent to jail or may be sentenced to other types of punishment including juvenile detention, probation, or community service.

**Being jailed or hospitalized:**

As mentioned above, many older persons with FAS experience problems with the law and, therefore, can be sent to jail. Additionally, many people with FAS are admitted to hospitals for mental health reasons or placed in drug treatment programs for substance abuse problems.

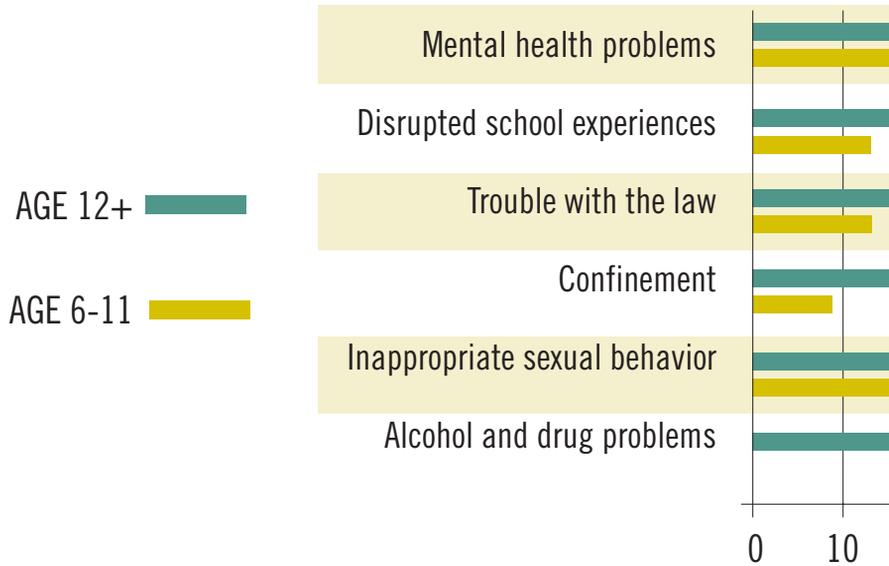
**Inappropriate Sexual Behavior:**

Inappropriate sexual behaviors (behaviors that show poor judgment) shown by individuals with FAS include unwanted sexual touching, sexual advances uncomfortable to others, and having numerous sexual partners.

**Alcohol and Drug Problems:**

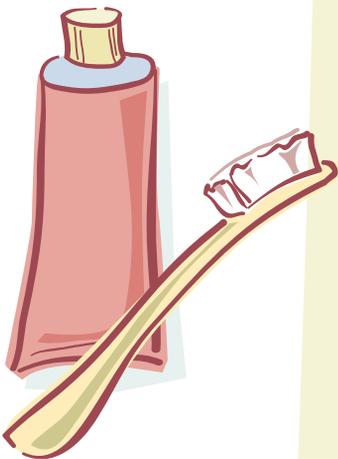
Alcohol and drug problems are common for teens and adults with FAS.

## SECONDARY DISABILITIES

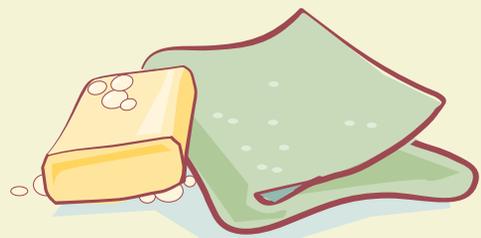


Adapted from Streissguth's "Fetal Alcohol Syndrome: A Guide for Families and Communities" (1997).

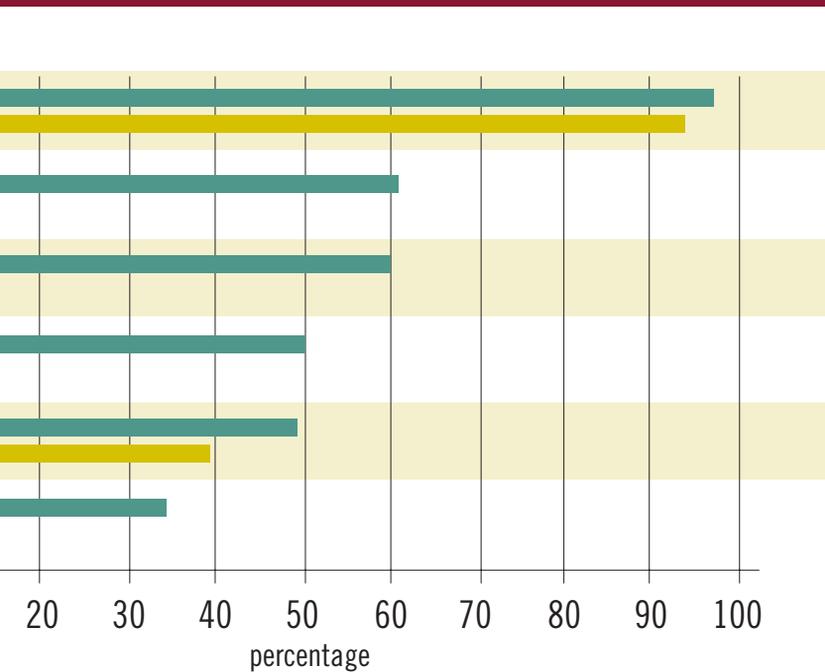
### Can adults with FAS live on their own?



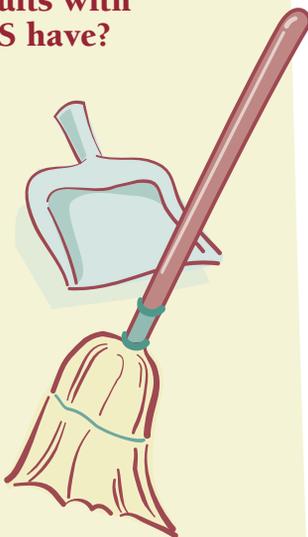
Because adults with FAS have trouble understanding the concepts of time and money and have poor judgment, it is difficult for them to keep a job and live on their own. Approximately 80% of people with FAS are not able to live on their own and are not able to find or keep a job. However, many individuals with FAS are able to learn a skill or trade that will allow them to work with someone watching over them, allowing them to be important, contributing members of the community. Likewise, some adults with FAS can feel a sense of freedom from their families by living in group homes that offer support for individuals with special needs.



# ILITIES IN FASD



## What types of jobs do some adults with FAS have?



People with FAS may have more success finding and keeping jobs if they attend a vocational school in which they learn a specific trade. There have been some young adults with FAS who have attended college, but it typically takes them a bit longer to complete a degree. Adults with FAS do best in jobs where there is hands-on training or apprenticeship experience. Additionally, they are more likely to succeed in a job that is very structured and well supervised by a manager who understands FAS.

It is important to remember that individuals with FAS do have special needs that will impact their lives. However, these individuals can have very successful and fulfilling lives if they are given the chance to show the world what they have to offer and are allowed to grow to their fullest potential.

# REACHING YOUR POTENTIAL:

## *How to take care of and advocate for a child with FAS*

### **How can I help my child reach his/her potential?**



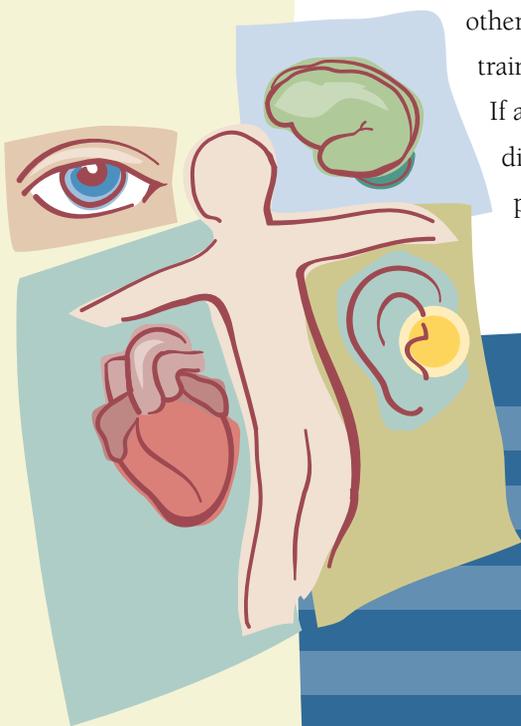
### **Individuals with FAS need caregivers that:**

Every child with FAS is unique and has different abilities, but all children with FAS have the potential to live a fulfilling and meaningful life despite the challenges they face on a daily basis. However, these children will need extra help from you and others involved in their care in order for them to reach their potential. Parents play an important part because they are their child's primary supporter ("advocate") in the school system, the healthcare system, the community, and the outside world. Other people involved in the care of a child with FAS can also be advocates, such as teachers, doctors, and family friends. There is no doubt that caring for, and advocating for, an individual with FAS takes a lot of work, but it is well worth the effort.

- Create a loving, ordered, and stable setting for them to live in
- Help them to get the medical and support services that they need
- Understand and support their special needs
- Help them to see their own strengths and know their limits
- Teach others about their special needs

**WHILE YOU ARE YOUR CHILD'S MAIN CAREGIVER AND ADVOCATE, IT IS IMPORTANT TO HAVE OTHERS WHO CAN HELP YOU CARE FOR YOUR CHILD.**

**Medical care**



Because your child has FAS, your doctor may want him/her to be evaluated by other medical specialists (doctors/healthcare workers with special training in a specific area) to look for any other medical problems. If a medical problem is identified, then the medical specialist will discuss what care your child needs to best treat or watch the problem. Below is a list of some medical specialists that your child may be sent to see.

SPECIALISTS	AREA OF SPECIALTY
Cardiologist	Heart
Ophthalmologist	Eyes
Otolaryngologist	Ears, Nose and Throat
Nephrologist	Kidneys
Urologist	Urinary system and genitals
Gastroenterologist	Stomach and intestines
Neurologist	Brain and seizures
Orthopedist	Bones and joints
Radiologist	Interprets X-rays, ultrasounds, and other imaging studies
Endocrinologist	Growth, hormones
Geneticist	FAS and other conditions causing abnormal formation/growth/development



## Developmental evaluation

Because children with FAS can have delays in their physical, mental and social development, it is best for them to have professionals check their progress from time to time (“developmental evaluations”). During a developmental evaluation, a child is typically seen by a team of specialists including some or all of the following: developmental pediatricians, psychologists, physical therapists, occupational therapists, language/speech therapists, audiologists, dietitians, and social workers. These specialists work together in order to:

- Estimate the child’s present developmental level
- Identify the special abilities and needs of the child
- Recommend educational programs and therapeutic services to help the child learn and develop
- Help families get in touch with community services and other sources of help

Typically, developmental evaluations are performed at a Developmental Evaluation Center or D.E.C.. Your child’s pediatrician should be able to help you contact your D.E.C., or similar program, to schedule an appointment.



## Childhood Intervention Services

Childhood intervention services are in place in each state. They are designed to provide support and special programs to children who are developmentally delayed or have developmental disabilities. The goal of childhood intervention services is to aid in the development of skills that will help these children to reach their full potential. Typically, services for children aged birth-3yrs. are community-based, while services for children over 3 yrs. are public school-based. Some of the services that are offered are listed below:

### SERVICE

Physical Therapy	help to improve motor skills, strength, muscle tone, sensitivities to touching or eating certain things, etc.
Occupational Therapy	improves skills used in daily activities like brushing teeth and tying shoes
Speech Therapy	helps to improve speech, language, feeding
Community Inclusion	programs that include both typically developing and special needs children
Hippotherapy	therapy with horses
Parenting Skills	teach approaches for effective parenting
Infant-toddler Specialist/ Child Service Coordinator	your contact person for intervention services
Counseling	for behavioral and emotional problems
Preschool	Headstart, for example

## Tips for Parents and Caregivers for Raising a Child with FAS

Research shows that the most important factors that help children with FAS reach their potential and limit the problems they may have later during their teenage years are:

- A stable home setting
- A loving and nurturing home
- Plenty of structure and routine



Below are some tips that parents have found to be helpful in raising their children with FAS.

### Speech and Language

- Use a calm voice
- Teach through repetition
- Read out loud, sing songs, listen to tapes
- Use more than one form of communication:  
— i.e. words, pictures, signs
- Use “language” toys to teach communication
- Avoid use of idioms such as “save your breath”
- Avoid sarcasm
- Avoid use of names such as Wise guy, Buddy

### Learning skills

- Use simple, clear language
- Break skill into smaller steps
- Teach skill in various ways using concrete examples
- Teach visually, verbally and physically
- Teach skill through a topic that interests the child
- Teach skill in the environment in which the skill is to be used
- Give positive feedback
- Limit stimuli and distractions in the learning environment
- Re-teach skills
- Use frequent reminders
- Use multisensory approach
- Allow for longer periods of time to learn and complete a task

### Adolescent Management

- Focus education on job training and daily living skills
- Moderately increase responsibilities to foster a sense of independence
- Closely monitor and supervise peers and peer activities
- Provide clear guidance and rules for appropriate behavior
- Educate about sexual development, birth control, and protection from STDs
- Provide appropriate and safe recreational activities

### Adult Management

- Establish guardianship funds to help manage money
- Help adult attain sheltered employment, where the employer understands the individual’s abilities and limitations related to FAS
- Enroll in FAS residential program or attain subsidized living

### Family Management

- Seek out other families coping with FAS
- Ask friends and families for help
- Make arrangements for caregivers to have time off each week
- Trade babysitting with other families
- Seek respite care
- Limit time with people who are unsympathetic or not supportive

### *Poor habitation (adaptation)*

- Create an environment that is calm and soothing, modulated and predictable
- Reduce stimuli
- Calm colored walls, avoid busy wallpaper, limit number of objects and toys in the room

### *Transition*

- Give ample warning about up coming changes
- Use signals or signs to indicate when it is time to transition
  - i.e. set a timer, give the child a massage or a warm bath to indicate when it is bedtime

### *Eating*

- Avoid stimulation during feedings
  - Such as phone, television, loud noises, lots of activity
- Use a simple table setting
- Allow ample time to eat
- Follow routine schedule for meal times
- An infant may be encouraged to sucking by gently tapping the mouth
- Swaddle an infant during feeding
- Avoid very hot/cold foods: serve food at a warm temperature

### *Sleep*

- Have a consistent bedtime routine
- Develop a list of acceptable bedtime activities:
  - activities to do before bedtime and if the child wakes up during the night
- Use fan or soft music to settle child down and drown out background noises
- Remove stimuli from the bedroom, including busy wallpaper and bright colors
- Avoid naps for older children

### *Sensory and Sensitivity*

- Choose clothes that are soft and don't over stimulate sense of touch
- Avoid crowded places
- Provide sunglasses

### *Management of behavior*

- Be attentive to nonverbal communication
- Have a "safe place" or "safe person" for the child to go to
- Remove child to a quiet room
- Remove trigger source
- Change activities
- Help child to communicate his/her needs
- Decrease demands on the child
- Praise good behavior

### *Discipline*

- Establish realistic expectations and goals
- Use clear, concrete and immediate consequences for behavior
- Calmly give short and clear corrections

# INDIVIDUALS WITH FAS AND SCHOOL



School is hard for many children, but it can be especially so for children with FAS. Their learning differences and behavioral problems make it difficult for these children to succeed in school. Often their behavioral problems are not understood, and the children are seen as trouble makers. Without special help, these children often get frustrated with their school work and develop poor self esteem.

Children with FAS often need special educational services to help them overcome their learning and behavioral problems in order to succeed in school. All public schools and most private schools provide such services to children who qualify to receive them.

## **What happens when a child with FAS begins school?**

It is a good for parents to work closely with their child's teachers and other school staff. This will allow the parents and teachers to work as a team, gathering the resources that will best help the child.



## **How can I make sure that my child will receive special educational services in school?**

Several laws have been made that require that special education has to be given to children with learning disabilities and other mental handicaps. The Individuals with Disabilities Education Act (IDEA) is a very important federal law that explains how students with possible learning disabilities are to be assessed and educated.

Under IDEA, any student who may have a learning disability or mental handicap must be properly tested (assessed) to determine his/her learning abilities and needs. An Individualized Education Plan (IEP) is then created based on the results of the tests. The IEP lists the child's specific learning needs and sets practical goals for him/her to achieve during the school year. The IEP also lists specific methods that the school will use to help the child meet these goals.

## **What is an Individualized Education Plan (IEP)?**

An IEP is just what it sounds like—an agreement that states what special learning needs the child has. It also states what the school and teachers plan to do to meet those specific needs. The IEP should list, in detail, what services that school will offer to the student and it should also list short-term learning goals (objectives) that are realistic. This plan is written by the team that evaluated the child together with the child's parents. It must be written within 30 days after the child qualifies for special education. The IEP then must be approved by the parents before it can be started. It is very important that the parents are involved in each step of this process so they can advocate for their child. Each year a new IEP should be written according to the student's progress and current educational needs.

## What steps are involved in the testing of a child for an IEP?

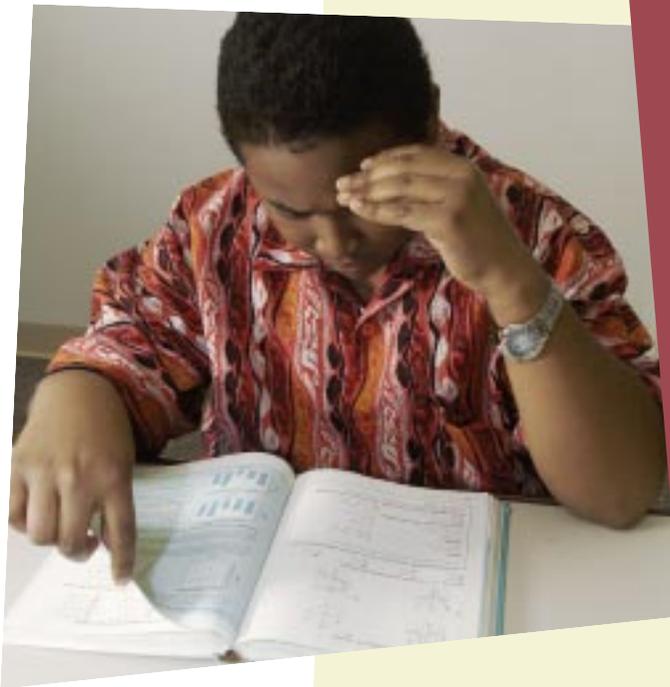
There are many steps involved in determining a child's learning needs and how and where he/she should be placed in a special education program.

- 1 The teacher or the child's parent asks for the child to be tested** (evaluated) by a team of special professionals. These professionals include teachers, psychologists, therapists, and, sometimes, nurses. They determine if the child is eligible to have a special education plan.
- 2 The team of professionals evaluates the child.** This evaluation can only take place after the parents give their consent. It must be performed within a certain time (usually within 60 days) of the request/consent. This evaluation usually includes observing and testing the student.
- 3 An IEP is written** if the IEP team feels that the student is eligible for special education. The IEP lists the child's learning needs, based on the results of tests and observations. An IEP must be in writing before a child can receive special education. The team tries to design a plan that puts the child in the "least restrictive environment." *Parents have the right to meet with the IEP team. Parents also have the right to agree or disagree with their recommendations.*
- 4 The child receives special education** as written in his/her IEP throughout the school year.
- 5 The child must be reevaluated every year** to monitor his/her progress. It is at this time that the IEP is changed or continued. New goals may be set. A full evaluation is done every three years to see if the child's program should change or remain the same.

**What if a student has behavioral problems or other mental handicaps?**

The assessment process described above should include an evaluation of the child's behavior to see if he/she has any behavior problems. If the evaluating team finds that the child has behavioral issues that require intervention, then this should be included in the IEP. Specific methods to help change the student's behavior should be listed. Again, the student's parents should be involved in creating these objectives.

It is very important that children with FAS have people who are advocating for them, or supporting them, because lots of people do not understand what FAS is. A child with FAS needs someone who knows and understands him/her and will take action when it is needed.

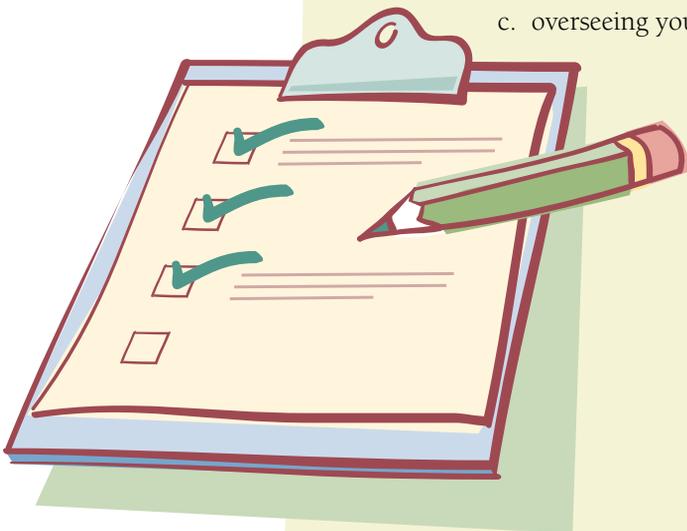


**A CHILD WITH FAS  
NEEDS SOMEONE  
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## What are some specific things that parents and caregivers can do to become advocates for their child with FAS in the school setting?

There are many ways that parents and caregivers can advocate for their child with FAS in the school system. Teresa Kellerman of the Fetal Alcohol Syndrome Community Resource Center offers many suggestions for ways that parents and caregivers can help their child with FAS before an IEP is written:

- 1** **Collect information about your child and his/her academic and behavior problems.** One way to gather this information is to keep a journal. Take notes on any situations you observe that might have a negative effect on the child's ability to learn in school.
- 2** **Keep a detailed log of all the meetings** that you have with your child's teacher or school staff.
- 3** **Make a list of all of your concerns** regarding your child and his/her learning and/or behavior problems. This will help you to remember the areas you want the IEP to focus on.
- 4** **Make sure that the IEP includes statements regarding:**
  - a. how and when the school staff will be trained on FAS and related disorders
  - b. sharing information on your child's progress between his or her school and home
  - c. overseeing your child at all times while at school



**5**

**Have information about FAS** and related disorders, such as brochures or books, **to give to your child's teachers** and other school staff. This will help them learn about your child's condition and his/her special needs. *It is very important that everyone involved in your child's life understand that each child with FAS is unique and should be treated as an individual.*

**6**

**Know your rights regarding special education** so that you will know what is appropriate and what is not.

**7**

**Most importantly, know the ins and outs of the IEP assessment process** that will determine if your child is eligible for special education and placement in a program. If you know the steps involved, then you will have an excellent chance of helping your child get the appropriate education and support that he/she needs in school.

This is just a short list to help parents get started in becoming advocates for their school-aged children with FAS. There is no doubt that it is hard work, but the rewards will make it worth the effort. Teresa Kellerman has an outline with more detailed information for parents who wish to learn more about this process. It can be found on the Fetal Alcohol Syndrome Community Resource Center website, which is listed in the section entitled "Resources for Parents" on page 34.

It is important to realize that schools are in a good position to offer intervention services for individuals with FAS. **So make them aware of what they can do to help your child reach his/her potential!**

## Resources for Parents

### National Resources for Families

#### ■ National Organization on Fetal Alcohol Syndrome (NOFAS)

900 17th Street, NW, Suite 910  
Washington, DC 20006  
1-800-66-NOFAS  
[www.nofas.org](http://www.nofas.org)

The National Organization on Fetal Alcohol Syndrome (NOFAS) is a nonprofit group that is committed to the prevention of birth defects caused by prenatal alcohol exposure and to raising the public's awareness of FAS. This organization strives to improve the quality of life for individuals and families affected by prenatal alcohol exposure by developing new ideas for intervention, education, and advocacy. This organization offers many different training programs and workshops for health professionals and the community.

#### ■ Fetal Alcohol Syndrome Community Resource Center (FAS-CRC)

4710 E. 29th Street #7  
Tucson, Arizona 85711  
Coordinated by Teresa Kellerman  
[www.come-over.to/FASCRC/](http://www.come-over.to/FASCRC/)

The Fetal Alcohol Syndrome Community Resource Center (FAS-CRC) is a comprehensive website that provides information about FAS and almost every aspect of the condition from diagnostic information to information about adults with FAS. It has information that is appropriate for affected individuals, their families, and anyone else who may come in contact with them. This website also provides different brochures and fact sheets that can be downloaded and printed off the Internet. Tips about becoming an advocate for an individual with FAS can also be found on this site.

#### ■ Fetal Alcohol Syndrome Family Resource Institute (FAS-FRI)

PO Box 2525  
Lynnwood, WA 98036  
(253) 531-2878  
[www.fetalalcoholsyndrome.org](http://www.fetalalcoholsyndrome.org)

The Fetal Alcohol Syndrome Family Resource Institute (FAS-FRI) is a non-profit organization, which works 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.” This organization provides information about FAS for parents and health care professionals, parent support and advocacy groups, and a newsletter that is printed quarterly. FAS-FRI also

has training programs that are available for parents, health care professionals, and other individuals in the community that may come in contact with people with FAS.

■ **The ARC of the United States**

1010 Wayne Avenue, Suite 650  
Silver Spring, MD 20910  
(301) 565-3842  
[www.thearc.org](http://www.thearc.org)

The ARC is a national organization committed to advocating for people who have mental handicaps and related developmental disabilities and their families. The ARC has developed many different resources about FAS and related disorders that are available on their website (some must be purchased). The ARC also has local and state chapters in most every state that can be located on their website.

■ **Fetal Alcohol Spectrum Disorders (FASD) Center for Excellence**

SAMHSA FASD Center for Excellence  
1700 Research Boulevard, Suite 400  
Rockville, MD 20850  
1-866-STOPFAS (786-7327)  
[www.fascenter.samhsa.gov](http://www.fascenter.samhsa.gov)

The Fetal Alcohol Spectrum Disorders (FASD) Center for Excellence is a project of the Substance Abuse and Mental Health Services Administration (SAMHSA), devoted to preventing and treating FASD. The program's website provides information and resources about FASD free to the public and professionals. They also have information about other FASD organizations that are statewide, nationwide and international, including a **free lending library** with many resources on FASD.

■ **Organization of Teratology Information Services (OTIS)**

1-866-626-OTIS (626-6847)  
[www.otispregnancy.org](http://www.otispregnancy.org)

Teratology Information Services (TIS) are comprehensive and multidisciplinary resources for medical consultation on prenatal exposures. **This booklet can be viewed on their website or can be requested by calling their national toll-free number.**



**Books for  
Families and  
Communities  
about Fetal  
Alcohol  
Syndrome**

**Fetal Alcohol Syndrome:  
A Guide for Families and Communities**

*By Ann Streissguth (1997)*

To order, contact:

Paul H. Brookes Publishing Co., PO Box 10624, Baltimore, MD 21285-0624

1-800-638-3775

[www.brookespublishing.com](http://www.brookespublishing.com)

This easy-to-read book uses case studies, personal stories, photographs, illustrations and research data to demonstrate the cultural, racial, and economic diversity of FAS. Topics include identification and diagnosis, teratology (the study of conditions resulting from substances that do harm to the developing baby), physical and behavioral characteristics, education, intervention and prevention strategies, employment, advocacy and public policy.

**The Challenge of Fetal Alcohol Syndrome:  
Overcoming Secondary Disabilities**

*Edited by Ann Streissguth and Jonathon Kanter (1997)*

To order, contact:

University of Washington Press, PO Box 50096, Seattle, WA 98145

1-800-441-4115

[www.washington.edu/uwpress/](http://www.washington.edu/uwpress/)

This book records the recent findings and recommendations from a four year study on individuals of all ages with FAS conducted at the University of Washington at Seattle as well as the proceedings from the International FAS Conference in Seattle, September, 1996. Twenty-two experts from multiple disciplines describe how to help individuals with FAS and offer practical suggestions for managing the diverse and multiple needs of these individuals across the lifespan.

## **Fantastic Antone Succeeds! Experiences in Educating Children with Fetal Alcohol Syndrome**

*Edited by Judith Kleinfeld and Siobhan Wescott (1993)*

To order, contact:

University of Alaska Press, PO Box 756240, Fairbanks, AK 99775-6240

1-888-252-6657

[www.uaf.edu/uapress/](http://www.uaf.edu/uapress/)

This book provides practical solutions for education and effective parenting of children with FAS/FAE that have been worked out by parents, teachers, and social workers. Personal stories highlight school-age children and their successes of varying degrees.

## **Fantastic Antone Grows Up: Adolescents and Adults with Fetal Alcohol Syndrome**

*Edited by Judith Kleinfeld with Barbara Morse and Siobhan Wescott (2000)*

To order, contact:

University of Alaska Press, PO Box 756240, Fairbanks, AK 99775-6240

1-888-252-6657

[www.uaf.edu/uapress/](http://www.uaf.edu/uapress/)

This book is a field guide to life with an teenager or young adult with FAS/ARND. A sequel to *Fantastic Antone Succeeds*, the book reports the experiences of young people with FAS/FAE and their caregivers and how they cope with the problems of teenage years and adulthood. Topics discussed include the meaning of success to young people with FAS/ARND, strategies to prevent secondary disabilities, community needs and innovative programs aimed to help these individuals.

## **The Broken Cord**

*By Michael Dorris (1989)*

Available at most bookstores. To order, contact:

Harper Collins Publishers, 10 E. 53rd St, NY, NY 10022

(212) 207-7000

[www.harpercollins.com](http://www.harpercollins.com)

This book is a touching story about the author's experience adopting a Native-American child with FAS. It is the winner of the "Bestselling National Book Critics Circle Award" as well as the source for an ABC-TV movie.



This book was made possible by a grant from the American Legion Child Welfare Foundation, Inc. Support was provided by the Wake Forest University School of Medicine and the NC Department of Health and Human Services, Division MH/DD/SAS, Community Policy Management and the US Department of HHS.

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ORGANIZATION  
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This booklet has been reviewed by the Executive Council at the Organization of Teratology Information Services (OTIS).

For more copies of this booklet, contact OTIS toll-free at (886) 626-OTIS or view it on-line at [www.otispregnancy.org](http://www.otispregnancy.org).

