

# SELF-STUDY COURSE

## Adolescents with Fetal Alcohol Spectrum Disorder

4.0 Hours Credit

*Revised June 2006*

*CREDITS: Please see bibliography on last page of course*

If you wish to receive training credit for reading this self-study, please fill out the “CHECK YOUR UNDERSTANDING” Questionnaire at the back of this course. Return the questionnaire to the Alaska Center for Resource Families for 4.0 hours of training credit. This course is yours to keep for further reference.

This self-study course was developed by Aileen M. McInnis, Southcentral Training Coordinator, for the Alaska Center for Resource Families.



### **RETURN YOUR QUESTIONNAIRE TO:**

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**FOSTER PARENT COMPETENCIES:** This self-study module addresses the following competencies

- 929** Caring for Children and Youth with Developmental Disabilities
- 929-2** The foster caregiver knows the nature, causes, symptoms and treatment of mental retardation, cerebral palsy, epilepsy, autism, spina bifida, Down syndrome, attention deficit disorder, fetal alcohol syndrome, and other conditions.
- 939** Substance Abuse
- 939-2** The foster caregiver knows the signs and symptoms of Fetal Alcohol Spectrum Disorder, can advocate for appropriate diagnosis and treatment, knows strategies to stimulate development, and can deal with the physical, social, cognitive, and emotional problems that effect children and youth with FASD.

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# ADOLESCENTS WITH FETAL ALCOHOL SPECTRUM DISORDERS

## *Introduction to Course*

Often, when people speak of Fetal Alcohol Syndrome, the image of a young child comes to mind. But what happens when these young children grow up? What is the world like for adolescents with a Fetal Alcohol Spectrum Disorder? What are their special needs as they mature into adulthood? What do foster parents; residential providers and adoptive parents need to know to help these individuals be the best they can?

Adolescent with Fetal Alcohol Spectrum Disorders will give you an understanding of the special needs of adolescents impacted by prenatal exposure to alcohol. This self-study is divided into four sections:

- One:**            *Understanding the Impact of Fetal Alcohol Spectrum Disorders*
- Two:**            *Developmental Effects of FASD upon Adolescents*
- Three:**          *Parenting the Adolescent with FASD*
- Four:**           *Families Who Care For Adolescents with FASD*

At the end of this course is a “Check Your Understanding” questionnaire. Please follow the directions for completing this questionnaire. When you have completed it, please return the questionnaire to the Alaska Center for Resource Families for scoring. You may keep this course for future reference.

**NOTE TO READER:** *In an effort to keep this material readable, sources used to write this course will be not be footnoted, but will be listed at the end of this course.*

## **PART ONE:** ***Understanding the Impact of Fetal Alcohol Spectrum Disorder***

Before we can explore how Fetal Alcohol Spectrum Disorders (FASD) impacts adolescents, we must have a general understanding of FASD itself. **Part One** gives an overview of what we currently know about the effects of prenatal exposure to alcohol.

### ***How Does Exposure To Alcohol Affect The Developing Fetus?***

Alcohol's impact on the fetus is more powerful than any other drug, including cocaine. Alcohol has a very small molecule that can pass into developing parts of the fetus throughout pregnancy. When a pregnant woman drinks, the blood alcohol level of her developing child reaches the same concentration as her own. Whatever is developing at the time the fetus is exposed to alcohol runs the risk of being damaged. Since the brain is developing throughout pregnancy, it is at the highest risk for being affected or damaged. Damaged parts of the brain may include nerve cells, the myelin sheath around cells, receptors and transmitters between the brain cells, and neurochemicals. Alcohol exposure may cause the corpus collosum, the connection between the right and left sides of the brain, to be damaged or underdeveloped. Alcohol can also affect the physical development of skin, organs, muscles, the central nervous system, and the brain.

How a child is affected by alcohol exposure depends on the level of maternal drinking, the mother's tolerance to alcohol, the fetus's resistance, and when alcohol exposure occurs during fetal development. Research shows that chronic drinking poses great risk to a fetus; binge drinking (or sporadically drinking large amounts of alcohol) also causes a very high risk for damage to a fetus.

### ***Fetal Alcohol Spectrum Disorders***

The resulting cluster of effects caused by alcohol exposure is commonly referred to as *Fetal Alcohol Spectrum Disorders*. FASD is an umbrella term that includes all of the effects that result from prenatal exposure to alcohol. It includes the medical diagnosis of Fetal Alcohol Syndrome which is a birth defect syndrome that is applied when a child has symptoms in all four of diagnostic categories. FASD also includes other conditions where the individual is experiencing the effects of prenatal alcohol exposure such as when a child may experience neurological damage and growth retardation, but may not have the facial characteristics associated with full Fetal Alcohol Syndrome. FASD is not a diagnosis, but is a descriptive term that can be applied to an incredibly wide range of conditions.

One of these resulting conditions may be Fetal Alcohol Syndrome (FAS). FAS is a medical diagnosis of a birth defect syndrome. A syndrome is a cluster of symptoms that indicate a disease or a disorder. A teacher, social worker, judge, or parent cannot make a diagnosis of FAS. This diagnosis can only come from a medical professional. In Alaska, many communities use a team approach to evaluate and diagnose the level of impact that prenatal exposure has had on a child.

In order to make a medical diagnosis of Fetal Alcohol Syndrome, symptoms must be present in the following categories:

## THE FOUR DIAGNOSTIC CATEGORIES OF FETAL ALCOHOL SYNDROME



1. **PRE- AND/OR POST-NATAL GROWTH RETARDATION:** *weight, length and/or head circumference below the tenth percentile when corrected for gestational age.*

2. **EVIDENCE OF CENTRAL NERVOUS SYSTEM INVOLVEMENT:** *signs of neurological abnormality, developmental delay, or intellectual impairment.*

3. **CHARACTERISTIC FACIAL DYSMORPHOLOGY** *with at least three of the following signs: microcephaly (head circumference below the third percentile), short palpebral fissures (short eye openings), poorly developed philtrum (vertical groove between upper lip and nose), thin upper lip or flattening to the midface. (See GRAPH # 1)*

4. **A HISTORY OF MATERNAL DRINKING DURING PREGNANCY.**

GRAPH #1: *The Face of Fetal Alcohol Syndrome*

### ***Impact of Pre-Natal Exposure to Alcohol***

Alcohol affected children, especially those with full Fetal Alcohol Syndrome, may have malformations of the ears, eyes, lips and palate. Skeletal abnormalities and aberrant development of internal organs are common; one third of these children have heart defects. Liver, skeletal system and genital-urinary systems may also be affected. Alcohol affected children are at high risk for central nervous system damage including mental retardation, seizures, and eating or sleeping disorders that can lead to failure-to-thrive. Other signs of central nervous system damage include slower development, problems with perception, hyperactivity, learning disabilities and behavior disorders caused by damage to the brain. Other conditions may include extreme irritability and restlessness in infancy, delays in learning to talk, fine and gross motor abnormalities, intellectual impairment, clumsiness, fearlessness, inappropriate social behavior, and memory deficits.

Persons with FAS average an IQ of about 75-80 but can range between 25 and 120. Ranges for IQ for persons prenatally exposed to alcohol but not having the full syndrome have IQs that average between 40 and 140, averaging about 90. IQ measures only one part of intelligence, but is often used as qualifying criteria for special education services. Children can have severe learning deficits due to FASD, but may not qualify for some special education programs due to a normal IQ.

Rather than depending on I.Q., it is more helpful for a foster parent to know how prenatal exposure to alcohol has affected the development of a particular child's brain. Alcohol exposure impacts how individuals think about the world. It impacts how they translate that thinking into meaning and action. These difficulties are called **information processing deficits**. Each child is affected differently. Some common brain related effects include difficulty with abstraction, difficulty with number and mathematics, difficult with time concepts, difficulty with cause and effect, and chronic memory problems. It is as if someone spills a soda on the keyboard of a computer and as a result, the computer circuitry becomes scrambled. Examples of information processing deficits include:

**A child may have trouble with information coming in through the senses.** (Called an **INPUT DEFICIT**.)

EXAMPLE: *Brian is easily distracted by people coming into the room or by noises outside the door. He is also very sensitive to light. He has great difficulty with the overhead fluorescent lights in his school.*

**A child may have trouble processing the information he receives.** (Called an **INTEGRATION DEFICIT**.)

EXAMPLE: *Sam can repeat to his foster mother the rule that he needs to finish his homework before he turns on the television. When he comes home from school the next day, he immediately turns on the television. He is puzzled when his foster mother becomes upset with his actions.*

**A child may have trouble remember or recovering information.** (Called a **MEMORY DEFICIT**.)

EXAMPLE: *Sally struggles in her evening homework to learn a list of spelling words. She finally gets them all correct. But the next day, she gets 8 of 10 words wrong during the test.*

**A child may have trouble communicating information to others.** (Called an **OUTPUT DEFICIT**.)

EXAMPLE: *Mikey often stumbles when he speaks. He gets frustrated because he knows what he wants to say, but seems unable to find the words to say it.*

These deficits affect how a child interacts and functions in his world. This explains why a child may not seem to learn from consequences or why a parent finds herself repeating directions over and over again. Or why a child cannot generalize concepts from one situation to another or has difficulty with abstractions such as telling time, doing math or planning ahead. This explains why a child may be a good talker, but may not really understand what he is saying. A child does not outgrow alcohol effects because FASD has changed the physical formation of the brain. But we can build on the strengths and abilities a child has, and form realistic expectations of what a child can do. In learning about the child's disabilities, we can "try differently, instead of trying harder."

*I have to remind myself that he's not just being stubborn and refusing to learn. He just can't remember. He can't remember it because there is no place to remember it in his brain. --ADOPTIVE MOTHER OF A SON WITH FAS*

A more extensive listing of FASD characteristics is listed in **GRAPH #2** on the next page.

### ***Children With FASD In Foster Or Residential Care***

Children with FASD in foster or residential care may also have a history of abuse, neglect, abandonment or molest. It is sometimes difficult to separate what may be a result of FASD or the result of maltreatment or trauma. Up to 80% of the families involved with Office of Children's Services are impacted by alcohol or drug abuse. The children of these families are at higher risk for being alcohol or drug affected. Sometimes a mother may have used other drugs during pregnancy as well as alcohol. Many times, the family history will not be known. Other children may also show signs of mental health problems or severe emotional disturbance, which makes working with these children even more difficult. All of these complicate establishing a diagnosis for children whom we suspect may be alcohol affected. Foster parents or residential providers should be aware of the common effects of alcohol exposure because many children with FASD have not yet been identified. The most common effects of FASD are listed in **GRAPH #2** on the following page. If you suspect a child is alcohol affected, talk to your caseworker about your suspicions.

# EFFECTS OF PRENATAL EXPOSURE TO ALCOHOL

This is a composite of possible effects in children and adolescents exposed to alcohol during pregnancy.  
*Not all children will show all of these effects.*

## POSSIBLE PHYSICAL EFFECTS

- More vulnerable to infection
- Skeletal abnormalities
- Aberrant development of internal organs
- Malformations of ears, eyes, and cleft lip
- Heart defects
- Liver or genital-urinary system damage
- Central nervous system damage (shakes, tremors, weakness)
- Growth retardation
- Physical and facial malformation
- Visual impairment or difficulties
- Misaligned teeth due to overcrowding
- Trouble with urinary control
- Malformed hands and fingers
- Limited rotation of joints
- May be very stiff or very limber
- Scoliosis, rounded shoulders
- Poor coordination
- Delayed fine motor skills

## POSSIBLE PROCESSING EFFECTS

- Unable to determine social clues
- Undersensitivity, oversensitivity
- Chronic memory problems
- Problems with abstractions
- High verbal and creative skills
- Sounds like he understands more than he does (talks better than he thinks)
- Overly sensitive to stimuli
- Inability to learn from consequences
- Difficulty generalizing rules from one situation to another
- Concrete and literal in thinking

## POSSIBLE BEHAVIORAL EFFECTS

- Impulsivity
- Learning disabilities
- Attention deficit disorders
- Attachment difficulties
- Poor social judgment
- Poor conscience development
- Perseverance (doing the same thing over and over again)
- Trouble with transition from one activity to another
- Trouble distinguishing between friends and strangers
- Emotional immaturity

## GRAPH #2: *Effects Of Prenatal Exposure To Alcohol*

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### MAIN POINTS:

1. Alcohol can affect both the physical and neurological development of a fetus. Each child will be affected differently depending on when and how much alcohol was consumed during pregnancy.
2. Fetal Alcohol Syndrome refers to a cluster of symptoms in each of the following categories: growth retardation, central nervous system damage, facial characteristics, and a history of maternal drinking. Fetal Alcohol Spectrum Disorder refers to all of the conditions, including Fetal Alcohol Syndromes, where a child impacted by prenatal exposure to alcohol.
3. Alcohol exposure can result in a number of information processing deficits resulting in children who may have difficulty receiving, processing or acting on information from their environment. These deficits will shape how a child interacts and behaves in the world.

## PART TWO:

### *Development Effects of FASD upon Adolescents*

Teens with FASD have the same developmental challenges that face teens without FASD. Acceptance by peers and having friends becomes very important. Teens are developing physically and are getting used to their new bodies. Sexual feelings and relationships with the opposite sex are growing. Separating from parents is also a developmental task shared by all teens.

But the teen with FASD has the added stress of his disability. An alcohol-affected teen may be physically mature. But his emotional maturity, social communication, and daily living skills may be that of a much younger child. The information processing deficits discussed in Part 1 will continue throughout the teen and adult years. Parents may struggle to find the balance between letting a teen have some independence and providing the limits he needs due to his disabilities. Adolescents with FASD may also have behaviors that may have been manageable in childhood, but become unacceptable or even dangerous in an older child. For example, what was a temper tantrum as a 3-year-old turns into a violent outburst as a teen? The need for physical closeness and “cuddliness” that is adorable in a young child can be intrusive and seen as sexual harassment in a teen or young adult.

Following are some of the ways in particular adolescents can be affected by FASD:

- High risk for victimization of self or sexual aggressiveness toward others.
- Trouble maintaining attention, completing assignments and mastering new academic skills.
- School attendance may be increasingly stressful and may result in decrease in motivation and school attendance. Possible school drop out, refusal to go to school and truancy.
- Hyperactivity may decrease during adolescence.
- Teens and adults may be smaller than average though weight may increase slightly.
- Some facial features related to the syndrome may disappear and be harder to detect. Teens may look more like their peers and less “FAS.”
- May be an increase in disruptive classroom behavior.
- Egocentric, difficulty comprehending or responding to other’s feelings and needs.
- Poor social skills (little social savvy, little desire to please, poor judgment, impulsivity, trouble understanding motives of others). May be more aware of being different from everyone else.
- Cognitive deficits (difficulty with abstraction, memory problems, difficulty in intuitive thinking, and problems in organizing and planning) become more evident as the demands for more self-control and discipline increase in adolescence.
- Teens might be misjudged as being lazy, stubborn and unwilling to learn when in fact they are having difficulty learning.
- School achievement in some areas may peak. May fall further and further behind their peers.
- Clinical or serious depression may be present. Diagnosis of mental illness may be made.



For adolescents who do not have the outward physical signs of alcohol effects, their difficulties may be interpreted as behavior problems rather than the result of a disability.

*Most of the time I worry a lot, and make problems seem impossible to handle. When I worry, I make myself sick. At school sometimes, I get sick to my stomach or get a fever and feel awful. Some people find it impossible to believe when I explain my problem, since they can't see the sign of FAS.*

--SIDNEY HELBOCK, 16-YEAR-OLD GIRL WITH FETAL ALCOHOL SYNDROME

## ***What Is It Like To Be A Parent To A Teen With FASD?***

Parents who were able to manage the behavior of their alcohol-affected child when he was younger may be severely put to the test with an adolescent. Joyce De Vries from Seattle interviewed other parents of her FAS Support Group to find out what parents of teenagers were seeing in their children. According to these parents, their teen children with FASD:

- Still need limits and protection like 3-year-olds because of their disability in reasoning, judgment and memory.
- *Are demanding more and more freedom to be with their peers while they may still need the same structure as toddlers.*
- Are at risk for being drawn into destructive antisocial behavior such as running away, stealing, lying and drug addiction.
- *Have difficulty understanding who is a friend and who is an enemy.*
- Are terrified of big changes or transitions (like moving into high school) which involve meeting and dealing with large numbers of people.
- *Are often fascinated by concrete issues such as sexual activity or setting fires.*
- Are able to recover emotionally from a confrontation with parents or siblings very quickly. Parents report that the discrepancy between the emotional recovery time of teens with FAS and their parents is a significant factor in parent burnout.
- *Are seriously impaired when it come to making decisions. Parents describe teens with FASD as not having the judgment or reasoning skills to logically make decisions.*
- Are increasingly angry toward parents who continually try to get them to follow basic social rules of family, school, and society.
- *Continue to have uneven sleep patterns and sleep-wake cycles.*
- Are usually negligent and defiant to parents about cleanliness and personal care issues. This can be humiliating to the family of teenage girls who are menstruating.
- *Are extremely vulnerable to suggestions from movies, TV programs, and advertising campaigns.*
- Have great difficulty handling money.

## ***Diagnosing Fetal Alcohol Spectrum Disorders In Adolescents***

*The majority of victims of FASD are not children. They are adults and are often undiagnosed.*

-- MICHAEL DORRIS, AUTHOR OF THE BROKEN CORD

Many children with alcohol effects go undetected. You may be fostering a teen who you suspect may have FASD, but who does not have a medical diagnosis of Fetal Alcohol Syndrome. A diagnosis has both positive and negative aspects. A diagnosis can open up doors to services. A diagnosis helps explain the frustrations of parenting this child. An accurate diagnosis gives professionals and parents a clearer picture of a child's condition and suggests more effective therapies and teaching strategies. A diagnosis may qualify a child for specific assistance such as group home admission or financial subsidy. On the other hand, many people are reluctant to "label" a child. Labels may cause people to treat children differently or limit a child's ability to be challenged in school. In Alaska, diagnostic clinics and trained professionals are scarce both in urban and rural areas. Diagnosis of FASD in adolescents is more difficult because facial features associated with FAS may have lessened or behaviors may be attributed to other past trauma.

Without an accurate diagnosis, problem behaviors are often attributed to environment, poor parenting, learning disabilities and mental health problems. Teens with FASD may have only one part of their condition diagnosed. While it may accurately describe a child's behavior, it is an incomplete picture of the teen's true functioning and ability level. An adolescent may be diagnosed as:



Attention Deficit Disorder  
Learning Disabled  
Oppositional Defiant Disorder

Conduct Disorder  
Attachment Disorder  
Emotionally Disturbed

Sexually Aggressive  
Post Traumatic Stress Disorder  
Clinical Depression

For children with abuse or neglect in their history, unusual behavior is often attributed to past trauma. A child's behavior may also be blamed on a foster parent or birth parent having "poor parenting skills." It is important to remember is an organic condition. It demands a different approach than many of the standard behavioral or medical therapies often used for the conditions listed above.

*The results of studies and statistics on FASD were not yet available. Ben's labels were at various times between the years 1971-88, M.B.D. (minimal brain dysfunction) E.D. (emotionally disturbed) L.D. (learning disabled), A.D.D. (Attention Deficit Disorder) and then social disabled. By 1988, we could add FASD to the list.*

--- ADOPTIVE MOTHER OF A 25-YEAR-OLD WITH FAS

Diagnosis for adolescents is a difficult procedure. Few medical professionals skilled in this area are available in Alaska. The following tools may be helpful in establishing grounds for a diagnosis.

1. Early pictures showing facial characteristics during childhood (especially preschool and early elementary). During teen years, these facial characteristics are not as prominent and may escape detection.
2. Any known history of maternal drinking and bingeing during, before and after pregnancy. May include history from relatives or service providers, or include a history of alcohol treatment.
3. Behavioral or cognitive signs that may indicate a pattern reflective of alcohol effects (including information from school, teachers, previous caretakers, employers and family members).
4. Any psychological or educational testing results from school, mental health or private assessments.
5. Past medical records including: dental records showing abnormalities; height and growth records; evidence of hearing, speech or language disorders; or evidence of learning difficulties in school.

If you suspect you have a teen in your home that is alcohol affected, discuss the matter with your caseworker. A diagnosis won't change a child. But an accurate diagnosis can outline a child's specific disabilities and help caregivers make better plans in providing care. Even without a diagnosis the guidelines presented in this self-study should be helpful in providing effective care for the teens suspected of alcohol effects.

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## MAIN POINTS:

1. Adolescents with Fetal Alcohol Syndrome or Effects experience the same developmental challenges that all adolescents face. The adolescent with FASD has the added stress of his disability which presents added impact on their level of functioning.
2. Parents of adolescents with FASD struggle with balancing the need to let their teen grow and develop and the need to provide limits and safety he requires. This struggle for balance is a frequent source of frustration and conflict for parents and teens.
3. In youth with undiagnosed FASD, a misdiagnosis may result in a label that describes one aspects of teen's behavior but does not reflect his full organic condition.
4. A diagnosis may be helpful to establish eligibility of services and for more effective interventions. But diagnosis of an adolescent is difficult and limited in the state of Alaska. Even without a diagnosis, however, foster parents may find information about FASD helpful in learning new skills to work effectively with the teen in their

care.

## **PART THREE:** ***Parenting the Adolescent with FASD***

Each adolescent is affected differently by FASD. There is no “cookbook” for the right way to parent these teens. It is important to tailor your parenting toward a youth’s specific needs. Some teens need a high level of structure and intervention; others need extra assistance in specific areas. Some behaviors that cause the most difficulty for parents are actually behaviors continued from childhood. These may not be appropriate or may even be dangerous because of a teen’s increased size and strength. Earlier in this training packet, the example of temper tantrums was given. Some teens turn more aggressive, more impulsive and less in control of their anger. This can be both frustrating and frightening for a parent.

Instead of trying to “make a teen behave,” it is more helpful to focus on using strategies and setting up situations so that teens with FASD will be able to succeed. Parents of adolescents can also use repetition, rehearsal and practice of appropriate behaviors in various situations. An adoptive father suggests that constant dialogue and discussion about “what would you do if...?” with a teen gives a parent an idea what interventions and what level of monitoring is needed. This helps you detect potential problems.

Focus on practical daily living, social, and self-care skills. Ideally, this should begin before adolescence. A good rule of thumb is to think younger and practice more often. Remember that FASD affects the way the brain works. If a child has a memory problem or problems with predicting what will happen next, he will have to work harder and practice more often to learn a new skill. These children and teens do best with a model of “*rule governed behavior*”. This means having very explicit rules about behavior, and repeating, reteaching, and visually posting rules to help a youth conduct himself correctly. The ability to apply general concepts of behavior to different situations is very difficult for teens affected by FASD. Supervision, rehearsal, and repetition of specific rules are more effective in guiding behavior than general moral guidelines such as “don’t steal” or “be polite.” Be as concrete and as specific as you can be.

Several issues are particularly challenging for adolescents with FASD. These include *sexuality, education, social skills, and transition into adulthood.*



### ***ISSUES OF SEXUALITY AND FASD***

*Sexuality is one thing that FAS does not diminish. My daughter had lots of questions about what was happening to her body. With FAS kids, we have to look at the topic of sexuality with reality. The issues of S.T.D.s, issues of birth control, issues of innocence and naiveté. And we have to look at the issue of a higher risk for molestation for these kids*

--LINDA LAFEVER, MOTHER OF A 17-YEAR-OLD WITH FAS

The area of adolescent sexuality is always difficult for parents. We want adolescents to develop healthy attitudes towards their bodies and toward relationships. We want them to learn self-responsibility, control, and values. We also want them to avoid poor choices, which may lead to pregnancy, sexually transmitted diseases and violent relationships. Common characteristics in FASD adolescents make this a challenging area for adults and youth alike. While the alcohol-affected teen might not have all the coping

skills he or she needs, the drives, desires and pressures are all there.

A youth may be physically sexually mature but may be emotionally immature. For example, a curious 5-year-old may engage in exploration of body parts with a child of a similar age. But when an emotionally 5-year-old boy is in a 13-year-old's body, others see it as abuse. Developmental delays combined with the hormonal urges of adolescence puts youth at risk for inappropriate sexual behavior. An adoptive mother related her story of her teenage son who was trying to kiss and touch the 10-year-old girls in the neighborhood. Once she realized that her son emotionally was on a 10-year-old level, but in the body of an 18 year-old man, she realized that his behavior made sense from his point of view. Knowing her son was a very concrete thinking person; she put a piece of tape on the wall at eye level. She then told her son that he was not allowed to date or kiss anyone that wasn't as tall as that piece of tape. That made sense to him and helped him curb his behavior.

Many youths with FASD have characteristics that put them at risk for abuse, sexual exploitation or suggestibility for sexual acts. They may crave physical closeness to people in order to feel accepted and wanted. They may have difficulties predicting what the consequences of a certain action may be. They may have trouble telling strangers apart from friends and will respond to anyone who acts friendly towards them. Many individuals with FASD have a high need for closeness. Some of this may be not having a good sense of boundaries; some could be attributed to a need to feel loved and accepted. Sexual behavior does not require abstraction or intellectual functioning in order to perform, feel pleasure or gain immediate gratification. Adolescent girls may find acceptance and belonging by using their bodies. They may like petting and necking because it makes them feel loved and accepted.

*We parents know all too well what this can lead to. The girl with FASD will most likely not have the skills needed to stop things before they have gone too far, and may not even be able to see there things are going.*

--ADOPTIVE FATHER OF TWO ALCOHOL AFFECTED TEENS

Information about responsible relationships, reproduction, sexuality and values needs to be ongoing. A "one time" talk on reproduction is useless. For teens with FASD, repetition and concrete examples are the best way to teach. Rehearse appropriate social skills related to being with someone, and knowing how to act in dating situations. Talk to your caseworker about the issue of birth control for young adults at risk for sexual activity. Help youths have positive nonsexual social relationships with peers in order to prevent loneliness and isolation.



## ***ISSUES OF EDUCATION AND FASD***

Those challenging, fun and stressful years of junior high and high school can be a trying maze for the adolescent with FASD. Subjects change from semester to semester. Classes move from room to room. Seating arrangements change constantly. All these can throw a teen off balance. Attending school can be increasingly stressful and may result in a decrease in motivation and school attendance. Learning in some areas may peak; so keeping up with others will be a challenge. Areas such as reading and mathematics may be particularly challenging because of the information processing deficits often related to alcohol affects. A teen's reading comprehension may not match his word recognition, so he may be able to read material that doesn't make sense to him.

But it is important not to fall into stereotypes. Individuals with FASD can and have been artists, high school principals, business people, technical engineers, and insurance salesmen. Some students do well

in the technical fields and the trades such as horticulturists, electricians, janitorial services and trucking. Others have gone on to college and graduate schools. Adults with FAE have been caring and competent parents. It is not what we want these teens to do-- it is what they are realistically able to achieve. The key to education seems to be a realistic assessment of a child's abilities and style of learning with a good fit with the school system. Knowing or learning your child's abilities helps you assist the child at home and helps you communicate valuable information to the school.

*It took us two tries to find the right high school for Cindy. The first, a very structured girls school made her feel inadequate and despite our efforts to intervene, few teachers responded to her special needs. They saw her messy writing as carelessness, chided her for not trying hard enough and assumed that more drill would enable her to "catch up."*

-- ANN GERE AS QUOTED IN FANTASTIC ANTONE SUCCEEDS

Most communities in Alaska don't have a choice in high schools. In smaller communities, special education services may be severely limited. Many individuals with FAS are already in special education by the time they reach adolescence. Adolescents with FAE may experience a variety of educational situations such as resource rooms, tutors, regular classrooms or special education. Foster parents may be at a disadvantage by not knowing a child's learning history. Get as much information as you can from past teachers, former caregivers, caseworkers and therapists. Share what you can with a child's teacher. Educators unfamiliar with the normal responses of children with FASD may wrongly assume that a teen is misbehaving when in fact he may be trying desperately to do what is expected.

*An eighth grade boy with FAS had been suspended from school 15 times in a three-month period. Thirteen of the suspensions were due to his uncooperative behavior during lunchtime. When a specialist familiar with the challenges of FAS asked him to tell her the rules for lunch behavior, he could tell her all the rules perfectly. Then she walked with him to the empty lunchroom and said, "Show me." He was unable to demonstrate the correct behavior, even missing where he was supposed to sit. The specialist spent the rest of the session actually practicing the rules and procedures with the student. She also took pictures of him so he could review them later.*

-- DEBRA EVENSEN IN "INTEGRATED ACTIVE LEARNING AND THE CHILD WITH FASD"

In Alaska, in-service training in FASD for all teachers is required, but most parents find they need to provide specific information about their child's needs. It is easy for adolescents to be passed over, especially in larger schools. If you feel your child needs extra help, request a special education evaluation. If your child is receiving special education, he must be provided with an Individualized Education Program (IEP) that specifies in writing what education and related services will be provided. Make sure it is being followed. Do not assume that your teen's teacher is familiar and skilled with working with adolescents with FASD. Share handouts and give specifics on what you have found successful with your teen. *PARENTS, Inc.* is a statewide parent advocacy organization devoted to assisting parents of children with special needs. They are a great source of materials and information about the Individualized Education Program, special education, and FASD. *PARENTS, Inc.* can be contacted at 1-800-478-7678.



## ISSUES OF SOCIAL BEHAVIOR AND FASD

Adolescence for most teens is a time of friends, hanging out, and being involved in activities. It can be both exciting and painful. The pressure to fit in and "belong" is very strong. Youths with FASD may have perceptual or judgment problems that interfere with successful social interactions.

*By 13, most kids can determine the mental states of others. FAS kids have a very difficult time determining mental states, so they miss important social cues such as facial expression, tone of voice, and body language.*

-- SANDY MCAULIFF, THERAPIST, UNIVERSITY OF WASHINGTON MEDICAL CENTER ADOLESCENT CLINIC

As children mature into teenagers, they tend to be more isolated from their peers. Their peers advance intellectually and socially while teens with FASD tend to fall further and further behind. Rather than compete with their age level peers and risk rejection, these youth tend to become loners or stick with one or two friends. They may imitate the behavior of a group they want to be associated with. Or they may seek ways to be accepted by the group by giving money and possessions, or participating in illegal activities.

During the critical years of adolescence, a teen can feel isolated and shunned by peers if he is lacking in social skills. Patricia Tanner-Halverson has compiled a list of basic social skills we all need to know to be successful in dealing with the people around us. Most children, by the time of adolescence, have picked up these skills by experimenting and watching. But you may need to be explicit in teaching these to alcohol-affected youth. Tanner's list of social skills includes knowing the following items:

*What basic hand gestures or facial expressions may mean*

*How to negotiate to get what you want*

*How to disagree with someone appropriately*

*How to show someone you like them*

*How to get someone's attention in a positive way*

*How to greet another person*

*How to start a conversation*

*How to say no to peer pressure*

*How to act when riding public transportation or when in a public place*

*What to do when you feel scared or angry*

Begin as soon as you can to teach children and youth basic skills in relating to others. Practice and rehearse these skills. Remember, repetition is the key. In addition, teach basic skills of how to cope with the world around them. As young adults leave structured environments for the bigger world around them, not all people will be kind. Young adults need some preparation of how to cope when someone teases them, calls them names or makes fun of them. Walking away, saying a phrase to excuse themselves or save face, or taking a time out may give people a concrete skill to keep themselves protected.

Many parents fear that their teen may fall in with a "bad crowd." For adolescents who have a hard time with peer relationships, belonging to a group or gang can provide a sense of acceptance that is so desperately wanted. Teens with FASD are great mimics, that is, they can copy what people are doing around them, especially if they are unsure of what is expected of them. If there are good role models around them, they will probably do fairly well. If there are not so good role models around him, he may be at risk. If an adolescent has poor judgment skills, he may not know when people are taking advantage of him. The adolescent may also find himself in trouble with the law or making poor judgments.

*Our neighbors had asked Sidney to feed their dog for them while they took a vacation. They came home early in the middle of the night, to discover Sidney, Steve and the gang having a party in their house. "There was sex going on in every bedroom." they said. The gang and Steve abandoned Sidney by running from the house, leaving her by herself to face the neighbors. She was devastated.* -- MOTHER OF AN ADOLESCENT WITH FAS

Difficulties will happen and mistakes will be made. When you are calm and have your thoughts together,

talk about what happened and what the teen wanted to happen. If possible, use the experience as a springboard to practice behaviors to use in similar situations. Because a parent cannot totally control a teen's behavior, problems at school, in the community, and sometimes with the law can happen. Don't give up on your teen. Help him understand what he did wrong and look toward preventing it from happening again. It is important for parents to get support during these difficult times. Parenting the FASD teen is challenging and difficult in the best of circumstances; so do not blame yourself when things go wrong. Get help so you and your adolescent can get through it.



## ISSUES OF TRANSITION INTO ADULTHOOD

Preparing for adulthood needs to begin well before a child turns 18. Your adolescent may be fairly average or maybe even above average in some areas of development. He may be far behind in others. A gradual catch up is noted in young adults with FASD, but the timeline to independence may need to be extended. Rather than being able to leave a structured care situation at the age of 18 or 21 years, a more realistic timeline for these young adults may be between 25 and 30. This can be difficult for a child in foster or residential care who needs more time to transition into some form of independent living. Most young adults with FAS will always need a structured care situation. Many youth will also need a more supervised situation.

Many serious difficulties present themselves when the young adult is no longer in the highly structured setting and routine of school life. This is the period when the young adult with alcohol effects needs a tremendous amount of concrete support from family and friends.

*I guess once we got him through school, some of the hard work would ease. Boy, was I wrong! The challenges of having an adult child with FAS are even bigger than school struggles. At least the school environment provides a little buffer some of security. We have had a year of our son being battered by a world that cannot or will not try to accept him.*

-- MARILYN MOORE AS QUOTED IN FANTASTIC ANTONE SUCCEEDS

Utilize any programs you can to help a youth in this area. Some adolescents are eligible for services through the Division of Behavioral Health. *PARENTS, Inc.* and *Stone Soup Group* are also great resources to find out what the law requires and how to advocate for your adolescent.

Transition into independent living involves both internal skills and external resources. Internal resources mean adolescents need to have skills to take care of themselves and make their way in the world. External resources include job training programs, transitional housing or shelter care, and recreational activities. Internal skills need to be worked on early and repeatedly for the adolescent with FASD. The skills inventory in **GRAPH #3** gives parents a simple tool to assess a teen's competency level in basic self-sufficiency skills. This informal inventory may give a parent some clues to what skills a teen could use help in.

Finding transitional services, vocational skills training or special college preparation for your child will depend on where you live in the state. Work with the child's caseworker to develop a plan for the child. For information about what is available, contact the Division of Behavioral Health in your region, the Division of Vocational Rehabilitation, and your school district. For additional assistance in finding resources, contact these very fine parent networking resources:



**P.A.R.E.N.T.S. INC.:** 1-800-478-7678 OR 563-2246  
**FASD STATEWIDE PARENT SUPPORT GROUP:** 1-800-770-5437  
**STONE SOUP GROUP:** 1-907-561-3701

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## **MAIN POINTS**

1. Every adolescent with FASD will have varying skills and levels of competence. Some teens will need an extra dose of supervision and assistance while others will need an intense level of structure.
  2. Preparation for transition into adulthood should begin early by teaching self-care skills and social skills. Preparation for adulthood should take into account a child's strengths and abilities. Individuals with FASD may need a longer timeline to complete the transition into adulthood.
  3. Issues of sexuality, social skills and education are of a particular challenge to the adolescent with FASD. In addressing these areas, parents need to focus on skill building through practice, rehearsing responses, and discussion. Skill building should be concrete and realistic.
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## SKILLS INVENTORY

Following is a review of major skills young adults need in order to function well. For your foster teen or adopted child, review the skill in Column A and mark "Competent" in Column B if you are satisfied with your child's skill in these areas. Mark "Some Skill" or "No Skill" if he needs assistance in this area. Use this list to prioritize which skills to begin to work on first. You may need to add other areas to make this a complete list for your child.

<u>COLUMN A</u>	<u>COLUMN B</u>		
	COMPETENT	SOME SKILL	NO SKILL
<b>Daily Personal Hygiene (Brushing Teeth, Dressing, Washing, Self-Care)</b>	_____	_____	_____
<b>Home Skills (Cooking, Laundry, Cleaning)</b>	_____	_____	_____
<b>Knowledge of Sexuality: Exhibits Appropriate Touch</b>	_____	_____	_____
<b>Knowledge Of Safe Sex, Birth Control And Self-Responsibility</b>	_____	_____	_____
<b>Alcohol/Drug Awareness</b>	_____	_____	_____
<b>Social Skills: Relationship Skills</b>			
<b>Can Manage Anger</b>	_____	_____	_____
<b>Asks For What He Wants/Needs</b>	_____	_____	_____
<b>Knows What To Do When Scared</b>	_____	_____	_____
<b>Can Start A Conversation</b>	_____	_____	_____
<b>Can Say No To Peer Pressure</b>	_____	_____	_____
<b>Knows Not To Take Things That Are Not His</b>	_____	_____	_____
<b>Is in Contact With Resources To Help With Independent Living Skills</b>	_____	_____	_____
<b>Knows What FASD Is And How He Is Affected</b>	_____	_____	_____

**GRAPH #3:** Skills Inventory

## **PART FOUR:** ***Families Who Care For Adolescents With An FASD***

*The following material is excerpted from a chapter in the upcoming book **Fantastic Antone Grows Up**, due out fall of 1997 from the University of Alaska Press. It is used here with permission by the author. Jim Slinn is a Parent Support Technician with PARENTS, Inc. in Anchorage.*

### **A PARENT'S PERSPECTIVE**

*by Jim Slinn*

*"I don't know what to do about Daniel any more. When he was younger, I was able to keep him under control most of the time. He was doing pretty well in school and seemed to have plenty of friends. But now that he's a teenager, he seems to be in some sort of trouble all the time and I just can't seem to get him under control anymore. Not only is his behavior worse most of the time, but it's so different now. What can I do?"*

I hear remarks like this almost daily. This parent is expressing a common concern experienced by those raising FASD teenagers. Although their behaviors are the same as those demonstrated by FASD children, they appear to be different and far more excessive in teenagers. For the child afflicted with FASD, developing new and age appropriate behaviors in response to new and more abstract situations seem insurmountable. Parents often fall into the trap of thinking they can control the behavior of their FASD child. However, when that child enters the teenage years, those parents more and more frequently find themselves unable to sustain anything akin to control and they begin to fault themselves for this perceived failure. However, the concept of controlling behavior is not really applicable to FASD children. Instead, their behavior is managed by establishing and maintaining well-structured environments and by repetition and rehearsal of appropriate behavior in various situations.

### ***Go Slow, Think Long Term***

Transitioning into adulthood requires considerable patience and a long-term approach for the youth with FASD. Moving from a parent's home into the community involves the creation of structured levels of increased independence while continuing to practice proper behavior in as many realistic situations as possible. Although the same guidelines for dealing with younger children with FAS are relatively successful with youth, the influence of peer pressure and post-puberty biological drives intensify the need for rehearsing appropriate behavior with the goal of independent living in mind.

As these FASD youth transition into adulthood, they may physically appear to be "grown up", but they still require considerable guidance and supervision. If we want youth to learn age-appropriate behaviors, there needs to be age-appropriate consequences. Time-out in the corner is not as applicable a consequence for a teen as it was when he was younger. The problem is how to substitute a more age suitable consequence. Moving from using one consequence to another requires gradual staging to prevent the perception of change. Sending a misbehaving FASD teenager to her room, for example, might be seen as the elimination of a consequence for that behavior. She is no longer being sent to the corner, so she might not understand why she is being sent to her room. Instead, gradually move "time out" from the corner into her room so that she understands that the consequence has not changed, but now time out will be taken in her room.

One parent shared with me that it took them over a year to make this change. At first, the change proved disastrous. The parents regrouped and decided to focus on what was acceptable behavior rather than trying to control behavior. Once the youth understood the change in focus, the parent began sending him to his room for “unacceptable behavior” and he was not allowed to stay in the general living area with the rest of the family.

Just as with younger FASD children, there can be no “gray areas.” All inappropriate behaviors have to be addressed as soon as possible with consistent and predictable consequences. Letting down for even a weekend will result in chaos for many days. Any change must be introduced with allowances for a long learning time.

### ***Dealing With the Problem of Imitating Behavior***

Another problem is that children with FASD are great mimics. This does not change with maturity. This trait can be a blessing or a curse. The FASD youth will mimic the behaviors of whatever groups that he or she becomes involved. If those behaviors are antisocial, the result can be painful for the youth and the parents. However, just as they will mimic the inappropriate behaviors of one group, they will mimic the appropriate behaviors of another. The trick is to help them form relationships with a positive peer group. With FASD children, this is relatively simple since parents have greater control over those with whom their children associate. As the child grows older, the control becomes more difficult. With one of my sons, I have been able to use some of his positive behaviors to help in the selection of friends and associates. He likes to earn money and is very good with cars. Playing on both of these, I was able to get him a job at a small local gas station. There he was recognized and accepted for his abilities and his early teen years were very positive.

While it is normal for children and youth with FASD to have one or two close friends, they long to be accepted as part of a larger group. The few friends they have, as they grow older is more of a way of not being rejected rather than a preference. So they learn to watch carefully the behavior of different groups, and then mimic those behaviors. This is why they seem to act so differently in different group environments. To keep this trait from getting them into trouble, they may need closer monitoring and supervision by parents. One key is to continue maintaining a dialogue with them. Ask them open-ended questions about what is happening in their lives. Listen to what they are saying as well as reading “between the lines.” Since FASD youth perceive the world in very concrete and literal terms, they may not see a situation as being a problem and therefore may not tell the parent about a situation before it is too late for intervention. It is not that they are trying to hide anything. They really did not know that they needed help. Use questions such as “What would you want to do in this situation?” or “What would happen if you did that?” or “Do you really want to do that?” to stimulate discussions between you and your adolescent.

The answers to these questions will also give parents a better idea of what the youth is experiencing and how he would handle certain situations. This type of discussion allows the youth to think about appropriate behavior and responses while at the same time giving parents an idea of how much guidance and monitoring might be needed. With this information, the parent can then verbally practice and rehearse appropriate behavior with the youth.

### ***Consistency, Consistency, Consistency***

Consistent structure works well. Any changes in routine are viewed by the FASD afflicted youth as being completely different. Write notes about household chores to be done on one color paper and notes about what's needed at the store on another. When shopping for groceries, always go to the same store, enter in the same place, start at the same end and systematically go up and down each aisle in the same direction. Shopping lists should be organized in accordance with this systematic approach.

My son loves to do the shopping and now does quite well as long as he does not have to worry about the money. This skill did not happen overnight. It took many months of training and practice. The problem surfaced when I sent him into a different store for bread and he returned without it. He said the store didn't have any. I took him back into the store and he proceeded to show me where the bread aisle "should be" according to the layout of our familiar store. Since not all stores, even in the same chain, are laid out in the same manner, the bread would not always be on Aisle 15 or just after the packaged desserts. In his mind, because Aisle 15 in this different store did not contain the bread "as it was supposed to," the store did not have any bread. After that, I simply sent him to the same store all the time.

The next step was to send him in for more than one item. I found that if I sent him in for *milk and* bread, I would get what I asked for within a reasonable time. But if I asked for *bread and* milk, it took twice as long. Why? He would always go through the store the same way. If I asked for the items in order according to the store layout, he found them very quickly. If I asked for them out of order, he would go through the entire store looking for the second item and have to start over until he found it. To make this easier, I have (1) tried to ask for items in order according to store layout; and (2) I have worked with him so he now know where about 25 common items can be found from anywhere in the store!

### ***Behind the Wheel***

Teenage driving brings the most trusting parents to their knees, but for parents of FASD youth, life support systems may be needed! To make matters worse, FASD teens do not seem to have any trouble getting their driver's license. Passing the multiple choice written exam is not as difficult as might be expected. Youth with FASD do well with computers which are literal and concrete; most drivers' tests are now given on computers. Multiple choice questions with one right answer are easier than essay questions requiring abstract thinking. The road test is also easy. The examiner is only asking them to do one thing at a time, and as long as all the other drivers are "doing what they are supposed to," actual driving by a FASD youth can be peaceful.

However, in the real world, when teens are driving on their own, they quickly find out that other drivers do dumb things and don't always follow the Rules for the Road. These deviations upset the very concrete and structured FASD youth. It is true that by keeping them focused on what they are doing; we can help to alleviate their frustration. However, when they are on their own, there is no one to keep them focused. In fact, peers with them can actually create distractions which result in problem driving.

### ***Dealing With the Dating Question***

Interaction with members of the opposite sex is another area requiring a large amount of discussion and rehearsal between parents and youth. Because those afflicted with FASD have poor boundaries and a great need for physical closeness, these can result in accusations of inappropriate behavior and even

sexual molestation by others. Beginning at an early age, proper and appropriate behaviors must be introduced then constantly rehearsed as the child matured into adolescent. Discuss and practice appropriate behavior with the opposite sex, including the use of condoms. Chaperoned dating for an extended period of time followed by discussion of appropriate behavior after each date will increase the likelihood of a more successful transition in this area. We must remember (1) youth with FASD have the same drives as any other youth their age; (2) the problem is that their ability to think through a situation is not at the same level as their peers; and (3) they have a hard time interpreting and understanding the complex social cues important to success in this area.

One parent approached this in a very systematic way. She started with practice dates between her son and his sister who had been placed with another family. During these dates, she would walk him through step-by-step from how to ask for a date to how to say good night. The parent then allowed the boy to ask a girl he liked to go with them for ice cream, again walking him through the outing step-by-step. She made it a point to have a very open and honest line of communication with the girl's parents. As time went on, she changed from walking between them to walking beside them to walking behind them gradually increasing their space and freedom. She used the same approach at home. At first she would plan what was going to happen while the girl was visiting, then retreated to being a part in what they were doing. From there she moved to just being around, then slowly faded into the background. She has continually emphasized open and honest discussion after each date to work out appropriate responses as needed. A large number of parents and professionals have said that this is a good training tool to use in any of the areas where the child needs to learn social skills.

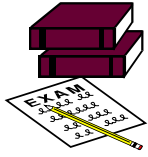
Raising FASD children and youth requires discussion, discussion, discussion and practice, practice, practice. Debra Evensen says it is important to remember, "Structure is the glue that holds the walls of their world together." If the structure is there, children with FASD can grow into positive and productive adults.

### ***Remember To Take Care Of Yourself!***

There is another point I would like to make here. Rearing any child can be stressful and frustrating at times. This is even more so with an FASD child. A basic but often forgotten requirement is parent self-care. We cannot become so wrapped up in trying to meet the need of our afflicted children that we ignore, deny or forget about our own needs. We must take time-out for *ourselves*. WE are not "Super Parents" nor should we feel we have to be. WE need to have places in the house where we can go to be alone. WE need to be able to take time-out when we feel we are losing it. WE need to have time for adult friends and interests that have nothing to do with FASD without feeling guilty. Parents of children with FASD are under a great deal of pressure to maintain consistency and to be ever vigilant for problem areas. Remember, we are of little help if we are burned out.

***TO BE IN CONTROL, WE MUST BE UNDER CONTROL.***





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**TEST**