Barbie is a bright and beautiful young lady. She was adopted and raised by her grandparents since she was one year old. Barbie was diagnosed with Fetal Alcohol Syndrome (FAS) when she was still very young. Her grandparents were open and honest with her about her diagnosis, but it was hard for her to understand what that meant.

Barbie has an IQ in the normal range, but was enrolled in special education. At age 18, she has written language skills of age 16, reading comprehension of age 10, math skills of age 9, and problem solving skills of age 8.

Barbie’s grandparents have educated themselves about Fetal Alcohol Spectrum Disorders (FASD) and they continue to seek support and assistance to help Barbie succeed in a safe, supportive environment.

What do teens and young adults with Fetal Alcohol Spectrum Disorders need?

A “REASONABLE” Plan:

1. Remove invisible barriers, such as denial, stigma, blame.
2. Educate everyone at all levels about the nature and neurology of FASD.
3. Assessments, such as IQ, Vineland, functional assessment, journal.
4. Service plan based on individual needs, capabilities, and talents.
5. Objectives with reasonable expectations to ensure success.
6. New definition of “success” (survive) and new dream for the future.
7. Acceptance by everyone of the reality that FASDs are brain disorders.
8. Build a Circle of Support to nurture, guide, and mentor the individual.
9. Life-long plan for sustaining that support so he/she can thrive.
10. Everyone is responsible for FASD, its prevention and intervention.

In Barbie’s Words

A story about how a shy young woman came to terms with having a Fetal Alcohol Spectrum Disorder.

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In Barbie’s Words...

My Mother died when I was six, because she was very sick, and I could not do a thing about it, even though I knew why she got that sick. I would blame myself sometimes, telling myself, “You knew what was in that bottle was not water. Why didn’t you stop her?”

I drew myself in more and more as the years went by. Elementary school did not help me get over the pain. The kids treated me different, as if I had the plague. I did not understand why.

Then one day while I was walking to class, a girl from one of my classes wanted to beat me up. When I asked her why, she replied, “Because you’re retarded.” I was shocked. Why would she say that?

I started to think about it, and could not figure it out, until one day I was asked a simple math question, and I could not figure it out. The problem was times tables. I was not very good at it in 5th grade, like the other kids. It frustrated me when I knew how slow I was in learning. My grandparents always tried to help me with my homework, but in the end I would get mad and quit.

Animals were my escape from all the pain I was feeling. I felt alone because no one wanted to be my friend. The only way to get a friend was to tell my sad past. I did not want people to be my friend because they felt sorry for me, so I made my own world, where I was liked for who I was. This world of mine lasted all through middle school.

When I began high school, I decided to work hard and try to make friends. I went to each class, worked hard, and tried to talk to anyone. Finally a girl named Crystal came up to me, and we started talking. We became friends instantly. I was so happy, and we had all our classes together.

Each year in high school, it got easier to make friends, and I became less shy. I even had a couple boyfriends. Things were finally going good.

Until one day I was visiting the doctor, and my Nana talked about FAS, that I had it. My world was turned upside down, all the unanswered questions made sense. That I could not learn at a normal pace was because of this FAS.

I had to tell my best friend. But how would I explain this to her? My mind started to race. “What if she won’t like me no more,” I asked myself. The best thing to do was swallow my pride and tell her. The next day I sat her down and told her. When I finished, she didn’t do what I was expecting her to do. She looked at me and started laughing! When I asked her why she was laughing, she simply looked at me and said, “So do I. It’s nothing to freak about.” I was so glad she told me that, because I had the courage to tell my other friends. I found out that half my friends had FAS. I knew when I met them that there was something that made us all click with each other.

So with that behind me, I was able to make it through high school and graduate and be the woman I am today. I am 18 now, and I’m learning to be a dog trainer.

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I'll never forget the day that I first realized the success I had achieved as a mother of a young adult with FAS. When the light of awareness went on in my mind, it was bright in contrast to the darkness I had been carrying for years. I had been somewhat depressed over the hopelessness of the idea that FAS is permanent brain damage for which there is no cure. What made this concept so devastating is that it is 100% preventable - theoretically speaking anyway.

My son John had just turned 18, that magical age when a person legally becomes an adult. But I knew that he really was and always would be a boy in a man's body, never able to function independently in the true sense of the word. He would always need supervision and support services. I had tried so hard all his life, worked so diligently, to help him achieve his potential, and it was hard for me to accept that, in spite of all my efforts, he would always need to be in the care of others to stay safe and well and living with a decent quality of life.

When I started my journey as John's mother, I was a foster parent for special needs babies, and John came to me a scrawny little thing a few weeks after his birth, only 4 pounds, with a diagnosis of FAS. As delighted as I was to have a diagnosis, it was not long until I learned that there was almost no information available regarding prognosis or intervention. His future was a big question mark, and I realized I might have to rely on my "whatever works" philosophy of intervention. After I adopted John, I followed Ann Streissguth's continuing studies on children and adolescents with FAS, and that helped me to know what behaviors to expect and what problems to try to prevent. As other parents know, day to day life was challenging, sometimes joyful, sometimes frustrating. And as John reached adulthood without the abilities to live as an adult, I felt discouraged that nothing I could do for him would reverse the physiological damage of FAS. Until my "awakening" to a new reality.

It was that September day in 1996 that Dr. Ann Streissguth revealed the results of her long-term studies on secondary disabilities associated with FAS disorders. I was sitting in the auditorium in Seattle with other conference attendees. Streissguth noted the primary disabilities associated with FAS - the delayed growth, the facial characteristics, the physiological anomalies, and the dysfunction of the central nervous system. I recognized that John had just about every primary disability that was mentioned. Then Streissguth talked about the secondary disabilities that the individuals in her study developed: mental health issues such as clinical depression that in 23% of adults led to suicide attempts; dropping out or getting kicked out of school, getting in trouble with the law, sexual assault, abuse of alcohol and other drugs. These are among the secondary disabilities that can result from having FAS disorders, more devastating than the primary disabilities, and all preventable! It was at that moment that I realized that John had reached the legal adult age of 18 without having incurred any of the secondary disabilities! Streissguth reported that the protective factors include early diagnosis, stable home environment, and appropriate support services. John came to me with the first, and I provided the others. The joy I felt, the pride that I must have done something right in raising John to have helped him get at least this far in his life with absolute success!
The strategies I had been using all the years John was growing up were not just haphazard ideas applied blindly, they were carefully thought out strategies based on what I had learned from Streissguth and other FASD experts. There was a method to my madness, and that method was something I decided to record and distribute for other parents to use as guidelines in helping their children achieve success as well. My model for intervention has been used by many other families with great success, according to the feedback I have received.

There are seven basic components that I apply, and they happen to form the acronym **SCREAMS**.

- **Structure**: a regular routine with simple rules and concrete, one-step instructions
- **Cues**: verbal, visual, or symbolic reminders can counter the memory deficits
- **Role models**: family, friends, TV shows, movies that show healthy behavior and life styles
- **Environment**: minimized chaos, low sensory stimulation, modified to meet individual needs
- **Attitude**: understanding that behavior problems are primarily due to brain dysfunction
- **Meds & Diet**: most individuals can increase control over behavior with the right medications and good diet
- **Supervision**: 24/7 monitoring may be needed for life due to poor judgment, impulse control

**Structure**: Most people who know about Fetal Alcohol Spectrum Disorders are aware of the need for structure, but sometimes this is confused with control. While providing structure as a foundation, we need to offer choices they can handle, remain flexible, and remember KISS - Keep It Simple Sweetie! Here is a simple, concrete explanation of FASD that a parent can read with an affected child: [SCREAMS Article](#). There are three simple, concrete rules at the end of this article that every parent and child can discuss and memorize. The most important rule is the "B" rule: Be Respectful!

**Cues**: Giving cues can be tricky, as we tend to only give verbal reminders. I call it cueing; John calls it nagging. Kids with FAS respond well to visual cues, to symbols and signs, to music and rhythm. Check out [Do2Learn](#) for printable picture cards.

**Role models**: Children with FAS disorders learn behavior primarily by mimicking the behavior of others. This makes healthy role models extremely important. I am reminded of this saying: "Children learn by example; unfortunately they can't tell a good example from a bad one." We need to provide positive examples for dealing with frustration and anger, for appropriate social interactions, and for life styles that are healthy. Our kids need to be shown how to act in ways that will keep them out of trouble. John learned to walk away from being shoved or hit. He learned to express his anger with words that explain what he is feeling rather than words or actions that might hurt others. When we have observed unhealthy behavior, like inebriation or violence or disrespect, we talk about it and we play act healthy reactions to difficult situations that are likely to occur.
**Environment:** Behavior modification is not on my list, because it has not been reported to be very effective when dealing with FAS behaviors. Our kids might understand consequences, but they usually aren't able to learn from them. Time-out may not teach them to change their behavior either, but quiet time can be used when they are overwhelmed or over-stimulated as an opportunity to self-calm before rejoining a group. Behavior mod implies changing the child. What works better for our kids is to change the environment. Avoid noisy, crowded places; reduce the chaos; and prepare in advance some coping strategies for unavoidable situations that might be too stimulating. One overlooked factor in environment is diet - avoid all artificial additives (preservatives, coloring agents, aspartame, etc.), which may increase behavior issues. Here are some guidelines for healthy discipline.

**Attitude:** Understanding the nature of FAS as a neurological disability helps to minimize unrealistic expectations. Dr. Calvin Sumner stated that the greatest obstacle our kids must overcome is chronic frustration from unreasonable expectations of others. I believe this attitude of understanding by all who are in the individual's life could reduce the risk of depression and suicide tendencies later. The parents whose children experience the most success are those who have achieved an attitude of acceptance that their child may not fulfill their dream of "normalcy." Again, unrealistic expectations for full independence might set the teen up to fail. The teens and young adults who enjoy the most success are those who have accepted the limitations of their disability and the need for protective restrictions. FASD and the Brain explains alcohol's impact on the developing brain that affects behavior later.

**Meds & Diet:** The right combination of medications can normalize the balance of brain chemicals, and can somewhat restore function and give the individual more control over behavior, increase memory and learning, and enable the individual to function more appropriately in social interactions. The individual can also function better with daily vitamin, extra B vitamins, Lecithin, and a diet that is free of artificial additives (read online article here) and preservatives. Here is a list of medications that parents and doctors have reported as helpful.

**Supervision:** Close monitoring is difficult to impose, especially as the child reaches the teen years and wants the same independence as they think their peers are given. Unfortunately, giving privileges due to an 18-year-old to a person with the judgment, conscience, and impulse control of a 6-year-old could result in total loss of freedom, if they end up in the hospital, on the streets, in jail, or in the morgue. Here is an explanation of the "External Brain" concept.

I have overcome criticisms of being overprotective and of not letting go. But my son is healthy and happy and productive, and I am proud of the success he has achieved. His quality of life is better than that of most non-disabled people. The only screams in our family are screams of excitement and joy. Especially now that John is pursuing a romantic relationship with a new female friend. But that's another story!

Once you get the hang of these SCREAMS strategies, you will be more likely to refer to them as the SMILES strategies!
INDEPENDENT LIVING FOR PEOPLE WITH FETAL ALCOHOL SPECTRUM DISORDERS

In the film “Big,” a 13-year-old is stuck in an adult body. He has to get a job, find a home, and pay his own bills. The film is a fantasy, but these tasks can be a scary reality for adults with fetal alcohol spectrum disorders (FASD).

WHAT ARE FETAL ALCOHOL SPECTRUM DISORDERS?

FASD is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications.

FASD is not a clinical diagnosis. It refers to conditions such as fetal alcohol syndrome (FAS), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD). Each year, as many as 40,000 babies are born with an FASD. Hundreds of thousands of adults have these disorders.

Most adults with an FASD look like you or me, but they have cognitive problems that make it hard to live independently. In particular, their social development is stunted and they have poor judgment. Their behavior is unpredictable from one day to the next and can get them into serious trouble.

Many people with an FASD do not understand how impaired they are, which puts them at even greater risk. They have a strong desire to be “normal.” Most appear normal to others, raising unreasonable expectations and setting the stage for failure.

FASD may be associated with substance abuse, unemployment, and jail time. With appropriate support, such negative outcomes can be avoided.¹

WHAT IS INDEPENDENT LIVING?

Independent living refers to the ability to function in a community without support. However, many people hire others to help repair their cars, cut their grass, and fix broken windows. In collaboration with a spouse, friends, and paid service providers, people can run their households more efficiently. Thus, “interdependent living” is a more accurate term than independent living.

CAN PEOPLE WITH AN FASD LIVE INDEPENDENTLY?

A supportive community is important for everyone, but it is essential for people with an FASD. They need a strong circle of support made up of family members, mentors, social workers, job coaches, and others who understand the realities and limitations of FASD.

Parents or guardians of children with an FASD should start planning early for the transition to adulthood, when eligibility for many services will end.

Most adults with an FASD will need more help than others to meet the more routine demands of work and home. Areas where assistance may be important include employment, money management, housing, and social skills. Many require close supervision to help them make day-to-day decisions and stay safe.

In a 1996 study of adults with an FASD conducted by the University of Washington:

- 50 percent had trouble finding a job.
- 60 percent had trouble keeping a job.
- 18 percent achieved independent living, but most had employment problems.
- About 80 percent had trouble managing money and making decisions.¹
The box shows the percentages who require help with other daily tasks.

- Getting social services, 70%
- Getting medical care, 69%
- Having relationships, 56%
- Shopping, 52%
- Cooking meals, 49%
- Staying out of trouble, 47%
- Structuring leisure time, 47%
- Keeping clean, 36%
- Using public transportation, 24%

**HOW CAN PEOPLE WITH AN FASD SUPPORT THEMSELVES?**

Appropriate training and assistance can help many people with an FASD find and hold jobs. Job training for persons with an FASD should begin during high school, with the student’s education team taking the lead in planning the transition from school to work.

The Federal Rehabilitation Services Administration may be able to help with job placement and support services such as job coaches. States and private organizations, such as the Arc, may also offer assistance.

The key to successful employment for individuals with an FASD is an employer who understands FASD, has reasonable expectations, and can provide a supportive environment. Helpful strategies include:

1. Using concrete language
2. Establishing consistency and routine
3. Providing ongoing training
4. Reviewing job expectations frequently
5. Helping to interpret the wishes and actions of other employees and customers

People with an FASD often find it difficult to access financial benefits. Many States base eligibility for developmental disabilities benefits on IQ. Many people with an FASD have normal IQs and do not qualify. They may be eligible for Social Security Disability Insurance or Supplemental Security Income from the Federal Government if they can meet the strict definition of disability needed to qualify.

Individuals with an FASD typically lack skills managing money. They may receive a paycheck or benefits check and immediately spend it, rather than budgeting for rent and other expenses. Consulting a lawyer about designating a “representative payee” can help. The payee can be a family member, case manager, or other person who receives an individual’s checks, pays their expenses, and provides spending money on a daily or weekly basis.

**WHAT ABOUT HOUSING?**

Housing for adults with an FASD may be hard to find. Those who meet certain criteria may be eligible for Federal housing programs such as public housing, housing vouchers, Section 811 for persons with disabilities, and rural housing programs. States, localities, and nonprofit organizations also may offer housing, but their eligibility criteria and accessibility vary widely.

Supportive housing that offers help with tasks such as cleaning, grocery shopping, and bill paying would be ideal, but few programs are designed for people with an FASD. Group homes for individuals with mental retardation or mental illness may be an option. However, they can be a poor fit for people with an FASD, who may function at a higher level than their housemates or have different needs. Independent living with services may work for persons who do not need constant supervision.

**RESOURCES**

- Rehabilitation Services Administration, www.ed.gov/about/offices/list/osers/rsa/index.html?src=mr
- National Council on Independent Living, 703-525-3406, ncil@ncil.org, www.ncil.org

**REFERENCE**


If you’re pregnant, don’t drink. If you drink, don’t get pregnant.

For more information, visit fascenter.samhsa.gov or call 866-STOPFAS.
FASD Circle of Support
Finger Game

Directions:

1. Cut out the large square along outer edge. Place face down.
2. Fold opposite corners together diagonally (big triangle).
3. Crease and unfold. Repeat in the other direction.
4. Fold each corner almost to the center, along the gray lines.
5. Flip it over. Fold each corner to the center. 6. Fold in half.
7. Write the name of each of four people in your circle of support under each corner figure. Example: Mom, Dad, Counselor, etc.
8. Color each person/corner square a different color (four colors).
9. Put your thumbs and index fingers in the four corner pockets.
10. Ask a friend to pick a Circle of Support person’s name.
11. Spell the person’s name: open and close as you spell.
12. Ask the friend to choose a number from the inside.
13. Count the number (open, close). Choose a category.
14. Lift the flap and read 5 ways to be smart about FASD!

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HELPING FAMILIES DEAL WITH FASD: Suggested Readings

PUBLICATIONS


Text for kids and teens living with FAS/E. Also contains tips for advocating for services for children.

This book chronicles the life of the author’s son, Adam who was born with FAS. It received the 1989 National Book Critics Circle Award and the 1989 Christopher Award.

Damaged Angels: A Mother Discovers the Terrible Cost of Alcohol in Pregnancy by Bonnie Buxton 2004 Toronto: Alfred A. Knopf Canada
An adoptive mother welcomes a little girl not knowing she struggled with Fetal Alcohol Spectrum Disorder.

Dear World: We Have Fetal Alcohol Syndrome – Experiences of Young Adults FASNET Information Series, 1997, FAS/E Support Network of B.C.
This booklet was written with the help of a group of young people with FAS/E. It is meant to be a guide to help young people with FAS/E understand what FAS/E is and what it means to them.

Faces of FAS: Putting a Personal Face on FAS by Beth McKechnie 2001. Winnipeg, MB: Manitoba Association for Community Living (MACL)
This booklet provides a personal perspective on the daily challenges and situations that families and parents face in raising their children with FASD. Contact: MACL, #210-500 Portage Ave, Winnipeg, MB R3C 3X1, Phone (204) 786-1607

or Email: aclmb@mb.sympatico.ca and Website: www.aclmb.ca

Fantastic Antone Grows Up: Adolescents and Adults with Fetal Alcohol Syndrome by Judith Kleinfeldm, Barbara Morse and Siobhan Wescott (eds.) 2000. University of Alaska Press
This is a guide to life with a teen or young adult with FAS or pFAS. The first section discusses the meaning of success for teens and adults with FAS. The second section discusses strategies that work in areas such as counseling, education, sexuality, trouble with the law, and independent living. Section three covers what families need from the community, including innovative programs that help individuals with FAS and how to get a diagnosis at adolescence. The book also contains important resources, organizations to contact, and Internet addresses.

FASD Strategies not Solutions by Stephanie Jones and Laura Cunningham, 2004, Region 6 Edmonton and Area Child and Youth.
This Booklet is designed for caregivers and professionals who, in their everyday lives, encounter children and youth affected by Fetal Alcohol Spectrum Disorder. Readers should be aware that this Booklet provides strategies and suggestions for people who already have a base understanding of FASD. Available for on-line viewing and download at www.faslink.org/strategies_not_solutions.pdf

Fetal Alcohol Spectrum Disorder: A message to Police Officers about FASD. The Pas Family Resource Centre Inc. & RCMP ’D’ Division 2003. Pas, MB
Developed for police officers, this pamphlet on Fetal Alcohol Spectrum Disorder (FASD) is a sample of materials being developed for a policy and community training initiative. With information on the physical and mental defects caused by alcohol use during pregnancy, this pamphlet outlines: key terminology, ways to identify those who may be affected by FASD; and ideas for working more effectively with FASD individuals in emergency situations.


Fetal Alcohol Syndrome: A Parents Guide to Caring for a Child Diagnosed with FAS Wake Forest University Health Services, 2004, Wake Forest University, School of Medicine. This booklet is aimed at helping families with a child diagnosed with fetal alcohol syndrome (FAS). It explains what causes FAS, the symptoms of FAS, statistics, and how you can help your child with FAS reach his or her potential. Available at www.otispregnancy.org/readResource.php?r=108654


Letters To Our Children, Letters From Our Children: Living with Fetal Alcohol Syndrome and Alcohol Related Effects by Dorothy Badry and Liz Lawryk 2000. Alberta Association for Community Living


This is not a clinical textbook but a collection of stories written from the heart by parents, relatives, and caregivers who love their children and children who know they live life with a difference.

What Early Childhood Educators, Caregivers and Doctors -- Need To Know About Fetal Alcohol Syndrome (FAS) Manitoba Child Care Association and the Manitoba Healthy Child Initiative, Manitoba Education and Training, 2000 Winnipeg, MB: Manitoba Child Care Association; Manitoba Healthy Child Initiative, Manitoba Education and Training

This guide provides an overview of the characteristics and behaviors of children affected by prenatal alcohol exposure and highlights who both have FAS/E. It explains in a very simple way what FAS/E is and how children are affected by it.


The story of a young teen diagnosed with FAE - permanent neurological brain damage due to prenatal exposure to alcohol. The book includes creative approaches in reaching and loving children with attachment issues; understand how alcohol affects the growing brains of children and become familiar with brain terminology; uncover ideas to help a child nutritionally; and wade through school and behavior issues with tears, laughter and strategies you may not have tried.


This parent/caregiver guide outlines the challenges faced by parents of children affected with FAS/E. It contains many easy to implement strategies.


Offers practical advice on dealing with FAS's lifelong effects on behavior and learning. It covers the historical, medical, and social aspects of FAS, and details common behavioral characteristics associated with the condition. Taking a developmental approach, the guide offers specific behavioral management techniques to be used with children with FAS from infancy through late adolescence. The author's own case studies are used to clarify psychological concepts and personalize FAS for the novice.
general and specific guidelines to use in caring for infants, toddlers, and children.

- What Educators Need to Know About FAS audio cassette and manual
- What Early Childhood Educators Need to Know About FAS audio cassette and manual
- What Doctors Need to Know About FAS - CD and laminated FAS resource guide

Contact: Healthy Child Manitoba, 219 - 114 Garry St., Winnipeg MB R3C 4V6, Phone (204) 945-2266 Email: healthychild@gov.mb.ca
Website: www.gov.mb.ca/healthychild/fasd/fasdearly_en.pdf

WEBSITES

Advocating for the Student with FASD
www.come-over.to/FAS/schooladvocacy.htm
2001 Teresa Kellerman

Behavior Environmental Adaptation Model (BEAM)
www.come-over.to/FAS/BEAM.htm
The 15 BEAM Rules of FASD Behavior Management (Also known as the Fasstar Trek Model) by Teresa Kellerman 2004.

FAS Community Resource Center (FAS-CRC)
www.come-over.to/FASCRC
The website offers 164 articles written by Teresa Kellerman (FAS Consultant/parent and Coordinator of FAS Community Resource Centre) about FASD issues, both intervention and prevention. In addition to these, there are various non-article items such as an online quiz, an online simulation of FASD disabilities, an online store for FAS books, posters, handouts, brochures, guidelines for FAS Awareness Day, a collection of news reports and research abstracts, a collection of FASD resources, a list of online support groups, conference reports, collection of parents’ poems, a collection of families’ stories, and several photo galleries.
Contact: FAS Community Resource Centre Contact: FAS-CRC, 4710 E. 29th St. #7, Tucson AZ 85711.

The FAS Online Video Training Website:
www1.dshs.wa.gov/ca/fosterparents/videoFAS.asp

FASaholics Anonymous
www.come-over.to/FasaholicsAnonymous
Support site for parents/caregivers of children with FAS.

FASD Connections: Serving Adolescents and Adults with FASD
www.fasdconnections.ca
The website has a resource listing of FASD key documents on numerous subjects concerning adolescents and adults with FASD. Email: info@fasdconnections.ca

Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Related Conditions with Carolyn Harness and Julie Gelo
These Internet online training videos on FAS are produced by Washington State Department of Social Services and are part of the Foster Parent Webcast Archive. Carolyn Harness and Julie Gelo are the presenters and they provide an overview of FAS/FAE and intervention strategies that are helpful for the care of children or adults with FASD. The training consists of 2 separate sessions consisting of 3-45 min lectures.

SAMHSA Fetal Alcohol Spectrum Disorders Center for Excellence Download the What You Need To Know Series by SAMHA:
- Independent Living for People with Fetal Alcohol Spectrum Disorders
  www.fasdcenter.samhsa.gov/documents/WYNKIndLivin
- Understanding Fetal Alcohol Spectrum Disorders: Getting a Diagnosis
  www.fasdcenter.samhsa.gov/documents/WYNKDagnosis_5_colorJA_new.pdf
- The Language of Fetal Alcohol Spectrum Disorders
  www.fasdcenter.samhsa.gov/documents/WYNKLanguageFASD2.pdf
- Tips for Elementary School Teachers
  fasdcenter.samhsa.gov/documents/WYNKTechersTips2.pdf
Contact: SAMHSA FASD Center for Excellence, 1700 Research Boulevard, Suite 400, Rockville, MD 20850; Phone 1-866-786-7327 or Email: fascenter@samhsa.gov

SCREAMS Model
www.come-over.to/FAS/ScreamsArticle.htm
How to minimize screaming, yours, not theirs by Teresa Kellerman.
Social Behavioral Challenges in Children with FAS/E  
www.fasalaska.com/behavior.html  

Staying Alive with the FASD Survival Plan  
www.come-over.to/FAS/StayingAlive.htm  
Sponsored by Teresa Kellerman

VIDEOS

FAS: When the Children Grow Up 2002. Knowledge Network B.C & Magic Lantern. This program tells the stories of adults living with FAS and FAE – some who were diagnosed early and others who were not – and the events, programs, and people who made a difference in their lives. 40 min

Fetal Alcohol and Other Drug Effects: A Four-Part Training Series for Parents and Professionals 2000. Fetal Alcohol Syndrome Consultation, Education and Training Services, Inc. (FASCETS)  
Set of 4 hour-long videos were developed to provide accessible, practical information and training to help parents, families, professionals, and to support program development. Part 1: Diagnostic Criteria: Effects of Prenatal Exposure, Part 2: Common Learning and Behavioral Characteristics, Part 3: Behaviors and Overlapping Diagnoses, and Part 4: Barriers to Identification: Historical, Cultural, Professional and Personal. Contact: FASCETS, PO Box 83175 Portland, OR 97283 Phone (503) 621-1271 or Email: dmalbin@fascets.org.
EDUCATION OF THOSE WITH FASD
**Fetal Alcohol Spectrum Disorders:**
**Tips for Elementary School Teachers**

- John, a 5th grader, constantly returns late from recess.
- Susan, a fourth grader, acts out in the lunch line, screaming and kicking.
- Peter, a second grader, cannot do addition problems on worksheets.

Lazy? Uncooperative? Victims of poor parenting? No. These students may have fetal alcohol spectrum disorders (FASD). Some of the most challenging students in schools today have FASD. Many have no formal diagnosis but their grades and behavior indicate a problem.

### What Are Fetal Alcohol Spectrum Disorders?

FASD is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, behavioral, mental, and/or learning disabilities with possible lifelong implications. Children do not grow out of the disorders.

FASD is not a diagnostic term. It includes conditions such as:

- **Fetal alcohol syndrome (FAS)**—a pattern of neurologic, behavioral, and cognitive deficits, as well as specific facial features (smooth philtrum, small palpebral fissures, thin upper lip)
- **Alcohol-related neurodevelopmental disorder (ARND)**—neurologic abnormalities such as problems with memory and motor skills
- **Alcohol-related birth defects (ARBD)**—defects in the skeletal and major organ systems

Imaging studies have shown structural changes in various regions of the brain. These include thinner or absent corpus callosum, reduced basal ganglia, and smaller cerebellum.¹ These changes contribute to a lack of understanding that manifests behaviorally. For example, persons with FASD may have difficulty with executive function and have trouble with problem solving and planning.

### How Are Students Affected by FASD?

Students with FASD may have many learning challenges, such as:

- Visual and auditory processing problems
- Difficulty with reading comprehension
- Memory problems
- Sensitivity to sensory input
- Attention deficits
- Problems with social behaviors
- Problems following multiple directions or rules
- Difficulty with math and abstract reasoning
- Inability to understand cause and effect
- Difficulty organizing tasks and materials

Due to auditory processing problems, these students may not respond to traditional teaching methods, such as lectures. They may act out in frustration because they do not understand what is going on. They may “melt down” due to sensory overload and may fidget a lot. They may struggle in math class.

Most do not learn from punishment because they cannot generalize rules. In addition, many have impulse control problems. Children with FASD typically lack social skills, such as listening, asking for help, waiting their turn, and sharing.
**How Can We Recognize FASD?**

FASD may be difficult to spot. In fact, many students with FASD are undiagnosed or misdiagnosed. Most people with FASD do not have facial anomalies. Some have low IQs but many have normal or above-average IQs.

If a student exhibits behavior or learning problems, you might want to suggest psychoeducational testing. These tests can help identify central nervous system dysfunction. The information also can provide a foundation for a diagnosis by a physician trained in FASD. It is important to provide a supportive, nonjudgmental environment. Encourage parents to talk about possible FASD, seek a diagnosis, and share the results with the school.

**How Can We Help Students With FASD?**

Every child is different, and much of what works with students with FASD may be learned through trial and error. Here are some general tips for working with students with FASD:

1. Use literal terms. Avoid words with double meanings, slang, and idioms (e.g., “school of hard knocks”). Do not use metaphors and similes.

2. Be consistent. Use the same words for key phrases and oral directions.

3. Repeat, repeat, repeat. You may need to reteach information multiple times.

4. Follow a routine. Routines help students with FASD know what to expect and decrease their anxiety.

5. Keep it simple. Students with FASD learn better in a simple environment with few distractions. One-on-one or small groups work best when possible.


7. Provide structure. Structure helps students with FASD make sense of their world.

8. Supervise. Students with FASD can be naïve and gullible and lack social skills. They need constant supervision to develop patterns of appropriate behavior.

In addition, recognizing the underlying reason for challenging behaviors can help in developing strategies. For example:

- John does not process the passage of time. Use daily reminders, such as music, a peer mentor, or a teacher prompt.

- Susan is often overstimulated. Have her stand at the front or back of the lunch line so that she is not stuck between other students. Eating in a quiet room with a small group and an adult would help.

- Peter cannot add numbers in his head. Use manipulatives, such as blocks.

**Where Can I Learn More?**

For more information, see:

- “8 Magic Keys: Developing Successful Interventions for Students with FAS,” by Deb Evensen and Jan Lutke, fascenter.samhsa.gov/go/fact_sheets.cfm

- Resources for Educators, depts.washington.edu/fasu


**References**


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**Reminder for Teachers and Parents**

If you’re pregnant, don’t drink. If you drink, don’t get pregnant.

For more information, visit fascenter.samhsa.gov or call 866-STOPFAS.
Advocating for the Student with FASD
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updated May 2007

This is a general outline to follow, step by step, to advocate in the U.S. education system for the child who has or may have Fetal Alcohol Syndrome (FAS) or Fetal Alcohol Effects (FAE), collectively referred to as Fetal Alcohol Spectrum Disorders (FASD). Before an actual IEP is written up, there are several actions to take in preparation for that step.

I. Gather Information. When asking for services for children with FASD, some school personnel may view the problems as ordinary behavior problems due to poor parenting, and may perceive the child as "lazy" and the parents as either "too lenient" or "overprotective." In cases where the school might be reluctant to evaluate the child for special ed, it is helpful to have some record of problems in the recent past that you have seen with your child that would have an adverse affect on the child's ability to learn. Collect all information from past testing or appointments and keep them in one place, and start an advocacy file.

A. Journal. Keep a journal and record all incidents and situations you observe. Write the date and time of each incident or behavior. Use the "ABC" method, listing the antecedent (a trigger to behavior, or what happened before the incident, or what might have contributed to it), the behavior, and the consequence, whether natural or imposed. Here is a pdf form you can use to chart behavior: http://www.dbpeds.org/pdf/abcform.pdf. Use this worksheet to identify behaviors: http://come-over.to/FAS/FBAworksheet.pdf

B. Documentation. Keep a log of every conversation you have with school personnel regarding your child.

C. Identify your concerns. Make a list of all your concerns. Pick out the most important ones that you want to deal with first. Besides areas of need that will be revealed by evaluations (below), areas of concern regarding a child's needs in a school setting include the following issues, which should be written into the IEP:

- Training of all staff on FASD issues
- Communication log for sharing information between home and school
- Supervision at all times, including on the bus, before school, on the playground, in the cafeteria, in the locker room, and all other times in and out of the classroom.

II. Educate yourself. Know your rights. Check up on current law regarding special education. Sometimes parents know more about IDEA law than the school, and this can work in your favor because no one will try to get away with sidestepping the law with regard to your child's IEP, and they will be least likely to intimidate you at IEP meetings.

A. IDEA stands for Individuals with Disabilities Education Act Amendments. Here are some links that can be helpful:

- http://www.reedmartin.com/ - Reed Martin is a lawyer with practical suggestions, articles, and a newsletter.
- http://www.wrightslaw.com/ - Wrightslaw has a Game Plan for New Parents and an article on Getting Started.

B. Protection and Advocacy. Every state has a Protection and Advocacy agency, paid for by your tax dollars, that can provide you with answers to questions, quotations of the law, training workshops, handouts and booklets, legal advice, and even legal representation in certain cases they
may choose to take and fight on your child's behalf. It is good to be familiar with your local P&A. Sign up for a class, or talk to a lawyer or volunteer, just to have a contact. Here is where to find your local P&A office: http://www.napas.org/aboutus/PA_CAP.htm. At the very least, ask them for a copy of your rights as a parent of a child with special needs.

C. FASD Information. Educate yourself well about FASD and be ready to offer information on FASD to the school personnel. Rather than hand them a stack of papers that you have downloaded off the Internet, which is too overwhelming to read and might end up in the waste basket, give them each a copy of the brochures on FASD that are available here: http://comerover.to/FAS/brochures/ Find someone locally who knows what FASD is and who understands how it can impact a child's ability to learn, and ask that person to advocate with you. Although you as the parent are THE expert on your child, and probably know more about FASD than anyone else on the team, your credibility might be questioned, and they are more likely to listen to an outside party that you bring in as an expert, even though you know just as much as they do.

D. Disability Groups. If your child is developmentally disabled (IQ under 70), join The Arc. If your child has normal IQ but has an attention deficit like ADD or ADHD, join CHADD. If your child has co-occurring mental health issues, join NAMI. You will learn more about how to access local services from other parents than from any other source.

III. Assessments and Evaluations. Sometimes parents or others only suspect that the child may have FASD. In most cases, the effects of prenatal alcohol exposure are not recognized early and often a diagnosis has not been made before the child enters the school system.

A. Medical Assessments. Concerns and suspicions should be taken to the child's primary care physician, who can either make a diagnosis or make a referral to a geneticist or neurologist who is trained in making a diagnosis of FASD. Sometimes a geneticist will suggest DNA tests to rule out genetic disorders. If there is any documentation of alcohol exposure during pregnancy, that will be helpful to provide. This can be an admission by the birth mother or it can be a report from a family member or physician or other reliable witness. Having anything in writing that suggests there was alcohol consumption during pregnancy, such as a social worker's report, might be valuable. The IEP must consider all outside reports from private sources that you submit.

B. Psychological Evaluation. A psych eval can and should be done by the school system. A parent can request that an evaluation be performed. Call the principal and tell him/her of your concerns. Follow up with a written request for an evaluation of your child. If the school refuses, they must provide a written explanation. Although most children with alcohol related disorders test in the normal range, they may have areas of high ability and areas of difficulty, and these problem areas are not reflected in an IQ score. There are areas of concern that should be assessed, including fine motor skills, social skills, visual-spatial skills, adaptive behaviors, and functional ability. Be sure to include this information in your written request.

a. IQ test. Schools most frequently use the Wechsler test, known as the WISC-III. Other IQ tests may show similar results in children with FASD. The WISC-III gives a composite score of 10 subtests, with a composite score for Verbal IQ and a composite score for Performance IQ. A "normal" IQ score does not actually mean a child has normal cognitive function. Most often, children with FASD will have an composite score in the normal range, but a composite score will not show scatter scores of highs and lows in specific subtests, such as auditory processing or short term memory. In some states, a child's eligibility for DD services (services for individuals with developmental disabilities) could depend on getting a score under 70. These services are separate from educational services, but the tests administered at school now could assist in getting other services later, such as respite care and medical services. To understand test scores, see the link under "Reports" below.
b. **Visual-spatial test.** The Bender Visual Motor Gestalt (BVMGT) can determine visual processing ability, and the Human Figure Drawing (HFD) can be administered to assess ability to conceptualize visually.

c. **Social skills test.** Functional abilities, communication skills, and social skills can be measured best using the Vineland Adaptive Behavior Scales (VABS). There is a test being developed called the FAS Adaptive Behavior Scales (FABS), but until it is released, we can rely on the Vineland to show problems in functional abilities. This is a questionnaire with several hundred questions about the child's ability to perform tasks, communicate, and participate in typical daily living activities. There is a version for parents and a version for teachers. It is recommended that the version for parents be administered to get a more thorough idea of how the child performs over-all. The score of the Vineland for a child with FAS or FAE is expected to be much lower than the child's IQ, sometimes by 20 or 30 points. Parents should answer the questions honestly, in a way that truly reflects the child's ability. If the question asks if the child can brush his own teeth, a parent might want to answer "yes" but if the child forgets to use toothpaste unless reminded, and needs to be watched to be sure he brushes adequately or can't really do a thorough job without help, then the correct answer should be "no, not by himself, he needs assistance." This is not the time to "brag" about the child's one-time or infrequent accomplishments. How the question is answered could determine how the psychologist scores the points on the test. Here is a sample letter requesting a school to administer the Vineland: http://www.come-over.to/FAS/VinelandRationale.htm

**C. Reports.** Every test or evaluation should have a report written by the professional who administered the test and should be given to the parent, with an opportunity to explain the results. Sometimes parents can request "raw data" from the testing, which will show subtests such as those on the Woodcock-Johnson or the Vineland that will be helpful to understand and use for planning to meet the child's needs when writing the IEP. Be sure to request copies of these reports and any data to which you might legally be entitled. Here is a site that will show you how to interpret the scores: http://www.wrightslaw.com/advoc/articles/tests_measurements.html

**IV. M.E.T.** The M.E.T. stands for Multidisciplinary Evaluation Team. This team is formed before an IEP is written to determine if the child qualifies for special ed and what evaluations will be performed. Typically, the team includes the school psychologist, the child's teacher, and a special education teacher. If the child has a suspected or confirmed disability, then an expert in the field of the disability should be on the team. Often the parent is more of an expert than anyone else, but to find someone in your area that can act as the FASD expert, look in the USA FAS Resource Directory: http://www.nofas.org/resource/directory.aspx It is important to have an FASD expert give input to the team to ensure that all the proper assessments are done. If the team decides that your child is not eligible for an IEP, refer to the following article on how to resolve an eligibility dispute: http://www.wrightslaw.com/advoc/ltrs/eric_eligibility_disputes.htm

**V. Individualized Education Planning Team** The IEP team includes the regular teacher, a special ed representative, and a member of the MET. By law, parents must be invited to be active participants in the meeting. An explanation of the IEP team can be read here: http://www.resa.net/sped/parent/iept.htm

**A. Labels.** There are many labels for classification of special ed, including but not limited to: MR (mental retardation), LD (learning disabled), EH (emotional handicap), MH (multiple handicaps), and OHI (other health impaired). If your child has an IQ low enough to qualify for the MR label, that is an appropriate classification. If your child's disabilities are mild, then the LD label could be helpful. If your child has mental retardation and physical disabilities, then MH would be appropriate. The least favorable label for the child with FASD is EH because placement in the EH
classroom is not the best environment for a child with FASD to learn, and the approach to behaviors is based more on psychological basis than on a neurological basis. The best classification for the child with FASD is **OHI, Other Health Impaired**. This is appropriate because FASD is a neurological impairment of a physiological nature.

**B. Objectives.** Goals and objectives for your child should be based on the results of the assessments made earlier. Goals and objectives for a child with FASD should include social skills, and expectations should be reasonable and based on the child's level of development as noted in the Vineland test results. Here is a game plan for writing goals and objectives: http://www.wrightslaw.com/advoc/articles/plan_iep_goals.html

**C. Placement.** Become familiar with the legal meaning of the term "least restrictive environment." Sometimes, for children with FASD, restrictions offer needed structure and reduce factors that contribute to some of the problems. In most cases the "least restrictive environment" for a child with FASD is one with many environmental controls. Just because your child has an IEP does not necessarily mean your child will be placed in a special ed classroom. The classroom and classification that is right for your child depends on your child's unique needs, on the environment of the classroom, and on the education and attitude of the teacher.

1. **Regular Classroom.** Inclusion in the regular classroom might work, if the teachers and aides are educated about the nature of alcohol related disorders and if adequate one-on-one is provided. However, the regular classroom is usually too chaotic and the child with FASD is likely to become frequently overwhelmed from sensory overload due to the level of noise. Regular teachers are seldom trained to work with children with FASD, and conventional behavior management might not only be less effective but could make the problems even worse.

2. **EH Classroom.** Many children with FASD are placed in a classroom with children who have serious behavior problems. This may or may not be the best placement for the child with FASD. If the other children's inappropriate behavior is a model for your child to imitate, or if the teachers approach your child's behavior problems solely from a psychological perspective, then the EH classroom will probably not work well. But if the teacher is knowledgeable about the nature of FASD and knows and practices the techniques that are known to work well with children with alcohol related disorders, then this placement could work.

3. **Special Ed Classroom.** Other classrooms, such as those for children with MR (mental retardation) or MH (multiple handicaps) classifications, can be an option for the child with FASD, as a full time placement or as a "pull out" for special assistance. Some experts believe that the ideal classroom for the child with FASD is the one designed for students with autism, because that provides for a quiet environment with adequate structure and favorable staff ratio.

4. **Homeschool.** Some parents do not wish to go through the struggles of changing the school system to meet their child's needs, and choose to homeschool. After having suffered from chronic frustration of unrealistic expectations and feelings of failure in the school system, children with FASD seem to do very well when homeschooled. Some parents would like to homeschool but fear they will not have the information or stamina to do so, but most who try it wish they had not waited so long to pull their child out of regular school. Here is how to get an idea if homeschooling is for you: http://www.come-over.to/homeschool/

**D. Conflict Resolution.** Here is a simple plan to help you resolve IEP conflicts easily: http://www.come-over.to/FAS/IEP123Plan.htm Print it out and take it with you to every IEP meeting. Even if you don't have a conflict, this will help prevent any conflicts from occurring.

**VI. Teresa's Tips**
- **Know where to go for help.** Bookmark this page so you can find it when you need it. Ask a friend to go with you to the IEP meeting. Talk to someone at one of the organizations mentioned above.

- **Do your homework.** Think of this as a class you are taking. Give yourself time to study the information on the links provided, and take notes to put in your folder or notebook.

- **Avoid becoming an adversary.** When it's you against them, they usually win. Think "team work" and remind everyone that we all have the same goal, to set up a program that will help your child succeed in school. Everyone wants your child to succeed. It's okay to get angry, but vent your emotions with a trusted friend or family member, and go into the IEP meeting with a cool head, armed with facts. It is much easier to work WITH the team than to work against the team.

- **Think positive.** When making a complaint, be ready to propose some possible solutions. When you go in to discuss a problem, begin the conversation with a few issues you are pleased with to balance your attitude and defuse the need for defensiveness. Visualize how the situation will look when your child's needs are being met in school.

- **Stay healthy.** Protect yourself and your child by following these important Dietary Recommendations: [http://come-over.to/FAS/DietRecommendations.pdf](http://come-over.to/FAS/DietRecommendations.pdf)

- **Give yourself a pat on the back.** You deserve credit for having read this article all the way through. You also deserve credit for seeking ways to make your child's life easier. FASD issues are difficult enough to cope with on a daily basis, but struggling with educators and professionals who don't understand FASD is even more difficult. Know that you are not alone, and that you can do it. Now go take a break and do something nice for yourself.
EDUCATION OF THOSE WITH FASD: Suggested Readings

PUBLICATIONS

Challenges and Opportunities: A Handbook for Teachers of Special Needs with a Focus on Fetal Alcohol Syndrome (FAS) and Partial Fetal Alcohol Syndrome (pFAS) by P. Lasser 1999. Vancouver, BC: Vancouver School Board
Written by a teacher and reviewed by teachers, parents, and advocates of students with FAS/E, this handbook puts a “human face” on FAS/E by providing pictures and quotes of students who live with FAS/E and vignettes from their lives. It contains 200+ teaching strategies.

This book is a field guide to life with an adolescent or young adult with FAS/E. Chapters include information on how prenatal alcohol exposure affects children and their families; parenting approaches and strategies that work (i.e. education, counseling, sexuality, trouble with the law, & living skills); and what families need from the community.

This booklet was written to help parents of children with FAS/E advocate for services within the school system. It outlines steps to follow in keeping records about their child, explains the IEP (individual education plan) and how to work with the teacher. Various cognitive, behavioral and language assessment scales are described. Contact FAS/E Support Network of B.C. #108, 17767- 64th Avenue, Surrey, BC V3S 1Z2, or Phone (604) 576-9911 Email: info@fetalalcohol.com

This manual has four main purposes: 1. It is a resource that educators can use to make a difference in the lives of their students. 2. It offers hope in cases where educators may feel their efforts are failing to help students grow to their full potential. 3. It provides guidelines for establishing relationships with individuals afflicted by FASD, as well as with their families and communities. 4. It provides educators with easy access to information that can be used in their classrooms to help students with FASD. Available on-line at www.education.gov.yk.ca/pdf/fasd_manual_2007.pdf

Reach to Teach: Educating Elementary and Middle School Children with Fetal Alcohol Spectrum Disorders, DHHS Pub. No. SMA-4222. Rockville, MD: Center for Substance Abuse Prevention, Substance Abuse and Mental Health Services Administration, 2007.
Reach to Teach is a resource for parents and teachers to use in educating elementary and middle school children with fetal alcohol spectrum disorders (FASD). It provides a basic introduction to FASD, which results from prenatal alcohol exposure and can cause physical, mental, behavioral, and/or learning disabilities, and provides tools to enhance communication between parents and teachers. Available on-line at www.fasdcener.samhsa.gov/documents/Reach_To_Teach_Final_011107.pdf

This resource includes: background and terminology that will help educators understand the current diagnostic definition of FASD. It also explains the diagnostic process, primary and secondary disabilities, and the strengths and protective factors often seen in students with FASD; key considerations for planning effective education programs; suggestions for how to build a positive classroom climate and maintain a supportive learning environment; overarching strategies on how to structure the learning environment, develop effective routines, build skills for whole class instruction, teach social and adaptive skills, and help students generalize new skills and concepts. Available on-line at education.alberta.ca/media/377037/fasd.pdf

This resource guide is organized around areas of concern identified by experienced classroom and integration support teachers. Its goal is to provide teachers with a clear understanding of the needs of students with FAS/E. Includes section on social skills and how to teach them. Many of the strategies are general and may be appropriate for use with students who are not diagnosed with FAS/E, but who do share some of the learning needs of students with FAS/E. Download the resource: www.bc.ed.gov.bc.ca/specialed/fas/ or contact: BC Government Publication Services, 563 Superior Street PO Box 9452 Stn Prov Govt Victoria, BC V8W 9V7 Phone: (250) 387-6409


This resource provides information to assist educators and school health care professionals in understanding FASD. Section One discusses the problems children with FASD have, provides an introduction to FASD, and explains the latest terminology. Section Two explains how and when alcohol consumption affects fetal development, brain development, and sensory integration. Section Three discusses the possible misdiagnosis and/or the co-occurring diagnosis of students with FASD, the differences in strategies depending on the diagnosis, and realistic expectations of students with FASD. Section Four discusses implications for educators and outlines strategies by age group. Available on-line at www.fldoe.org/ese/pdf/fetalco.pdf


A guiding principle of the authors was that, although all children have the capacity to learn, they do not all learn in the same way. These suggestions are intended for teaching children with ARD.


This is a planning resource intended to provide support to student service administrators, principals, classroom teachers, resource teachers, school counselors, clinicians, and other community professionals who will help in assisting schools in developing approaches for students who are alcohol-affected. Specifically, the planning resource will provide:

- strategies and interventions for individual students
- sample tools including forms and support materials

Download the resource: www.edu.gov.mb.ca/ks4/specedu/fas or contact: Program and Student Services Branch: Manitoba Education, Citizenship and Youth, W110-1970 Ness Ave., Winnipeg, MB R3J 0Y9 or Phone (204) 945-2070 or Email: lmclean@gov.mb.ca

Your Victory: A Happy Child...Supportive Strategies for the Staff of Children's Summer Camps and Recreation Programs by R. deBree, 2001, Duncan, B.C.

This booklet provides basic information on FAS and strategies for staff who will be coordinating or working with children in recreational and summer programs.

VIDEOS

Learning Disabilities and Social Skills with Richard Lavoie PBS Home Video 1994 62 min Subtitle is Last One Picked On. Parent’s guide on helping children who have learning disabilities address social problems these children often encounter and the video helps explain why this happens and what parents can do to help with practical solutions.
Students Like Me  Vida Health Communications, Inc. 1996. 49 min
Students Like Me was created to help elementary and special educators understand what Fetal Alcohol Syndrome is and provide teaching methods to help children affected by fetal alcohol reach their full potential. Includes:

• How to recognize a child with FAS in the classroom
• How to modify the class environment and adjust teaching methods
• How to communicate clearly and plan transitions and unstructured time

Contact Vida Health Communications toll free phone: 1-800-550-7047.
FASD AND THE COMMUNITY
Ain’t Misbehavin’

Without an understanding of the physically-based cognitive challenges faced by people with Fetal Alcohol Related Conditions, typical, normal behaviors can be misinterpreted as willful misconduct or deliberate disobedience, when it is often just the opposite.

Information Processing Differences

Due to the way the brain is formed while the fetus is exposed to alcohol, people with Fetal Alcohol Related Conditions have difficulty with the following:

- Input, or taking in of information
- Integration of new information with previous learning
- Memory, especially short-term memory
- Output, or ability to use information

Children and adolescents prenatally exposed to alcohol have difficulty with:

- Abstract Reasoning – Abstract concepts are the invisible foundation that structures our world.
- Cause and Effect Reasoning – Imagination! People with Fetal Alcohol Related Conditions often can’t imagine something they haven’t experienced.
- Generalization – They don’t have moveable parts in the thinking process; so, when you change a piece of the routine for the child, you have created an entirely new routine.
- Time – Telling time, feeling the passage of time, associating specific activities to numbers or a clock, cyclical nature of events.
- Memory – Especially short-term memory.

They often talk better than they think. They can “talk the talk” but can’t “walk the walk.”

They have difficulty with socialization and skills of independence.

Fetal Alcohol Syndrome is a lifelong disability, but “Secondary Characteristics” may occur, such as:

- Fatigue, tantrums
- Irritability, frustration, anger, aggression
- Fear, anxiety, avoidance, withdrawal, shutdown, lying, running away.
- Trouble at home and/or school
- Legal trouble, drug/alcohol abuse
- Mental health problems

These secondary conditions are preventable when parents and professionals understand the cognitive challenges associated with a child’s history of prenatal exposure to alcohol.

Behavioral Expectations of Children and Adolescents with FAS/E:

Age-appropriate vs. developmental age-appropriate expectations:

Typical 5-year olds...
- Go to school
- Follow 3 instructions
- Interactive, cooperative play
- Share
- Take turns

Developmental Age with FAS/E: 5-years going on 2-years...
- Take naps
- Follow one instruction
- Help mommy
- Sit still for 5-10 minutes
- Parallel play
- Are active

Typical 10 year olds...
- answer abstract questions
- get along with others, solve problems
- learn inferentially
- academic and social
- physical stamina
- generalize information learned from worksheets

Developmental age with FAS/E: 10 years going on 6 years...
- learn by doing, experientially
- mirror and echo words, behaviors
- supervised play, structured play
- learn from modeled problem solving
- easily fatigued by mental work

Typical 18 year olds...
- on the verge of independence
- maintain a job and graduate from school
- have a plan for life
- budget own money
- organize

Developmental age with FAS/E: 18 years going on 10 years...
- needs structure and guidance
- limited choices of activities
- in the “here and how,” little projection
- giggles, curiosity, frustration
- gets an allowance
- gets organized with help of adults

“...My way or no way”

www.fasstar.com
Fetal Alcohol Syndrome

Fetal Alcohol Syndrome (FAS) and other alcohol related birth defects refer to a group of physical and mental birth defects resulting from a woman drinking alcohol during pregnancy.

Four primary diagnostic criteria indicate full Fetal Alcohol Syndrome:
- Growth deficiencies – stunted prenatal and/or postnatal growth.
- Permanent brain damage resulting in neurological abnormalities, delay in development, intellectual impairment, learning/behavior disorders.
- Abnormal facial features: short eye openings, short nose, flat mid-face, thin upper lip, small chin.
- Maternal alcohol use during pregnancy.

Some but not all of the primary diagnostic criteria for FAS can lead to such diagnoses as:
- Fetal Alcohol Effect (FAE)
- Alcohol Related Neurodevelopmental Disorder (ARND)
- Fetal Alcohol Related Conditions (FARC)
- Alcohol Related Birth Defects (ARBD)

Alcohol is a teratogen that affects whatever is developing in her fetus when a pregnant woman drinks. Whether or not her child has the specific physical characteristics of FAS simply depends on when and how much the other drank alcohol. However, the brain is developing throughout gestation, and prenatal exposure to alcohol at any time during pregnancy can alter the development of the baby’s brain.

Prenatal exposure to alcohol causes an “invisible disability” that manifests behaviorally. Many children have the brain damage without all of the physical dysmorphology of full FAS, which reminds others of their disability.

“We see what we look for, and we look for what we know.”
- Goethe

FAS in a Nutshell

- FAS is the leading known cause of mental retardation.
- Most individuals with FAS have normal intelligence.
- FAS causes serious social and behavior problems.
- Each year in the US 5,000 babies are born with FAS.
- Ten times as many are born with alcohol related disorders.
- No amount of alcohol is known to be safe during pregnancy.
- Alcohol causes more damage to baby than any other drug.
- FAS and related conditions are 100% preventable.

www.fasstar.com

Ain’t Misbehavin’

Understanding the Behaviors of Children and Adolescents with Fetal Alcohol Syndrome

By Deb Evensen
debevensen@alaska.net

For more information on Fetal Alcohol Syndrome and related conditions please visit:
www.fasstar.com
**PSYCHOSOCIAL NEEDS ASSOCIATED WITH FAS & FAE**
Prepared by Robin LaDue, Ph.D., Fetal Alcohol & Drug Unit, Dept.of Psychiatry & Behavioral Sciences, University of Washington School of Medicine, Seattle, Washington
(Reprinted with permission)

**General Issues**
- Early and adequate identification and diagnosis
- Safe, stable and structured home or residential placement
- Unrealistic expectations of persons with FAS/E due to the outward appearance and verbal, gregarious manner
- Appropriate academics, vocational and living skills training programs

**Infancy & Early childhood:** Ages 0-5 Years

**Problems and Concerns**
- Poor habituation
- Sleep disturbances; poor sleep/wake cycle
- Poor sucking responses
- Failure to thrive
- Delays in walking and talking
- Delayed toilet training
- Difficulty following directions
- Temper tantrums and disobedience
- Distractibility

**Recommendations**
- Early identification
- Intervention with birth and/or foster parents
- Education of parents regarding physical and psychosocial needs of as infant or child with FAS/E
- Careful monitoring of physical development and health
- Safe, stable and structured home
- Assignment of a case manager for coordination of services and support to parents
- Placement of the child in preschool
- Respite care for caretakers

**Latency Period:** Age 6-11 Years

**Problems and Concerns**
- Easily influenced and difficulty predicting and/or understanding consequences
- Give an appearance of capability without actual abilities
- Difficulty separating fact from fiction
- Temper tantrums, lying stealing, disobedience and defiance of authority
- Delayed physical and cognitive development
- Poor comprehension of social rules and expectations

**Recommendations**
- Safe, stable and structured home or residential placement
- Careful and continued monitoring of health issues and existing problems
- Appropriate education and daily living skills placement
- Help caretakers establish realistic expectations and goals
- Caretakers establish realistic expectations and goals
- Caretaker support group
- Psychological, educational and adaptive evaluations on a regular basis
- Use of clear, concrete and immediate consequences for behavior
- Respite care for caretakers
- Case manager role expands to include liaison between parents, school, health care providers and social service agents
Adolescence: Ages 12-17 Years

Problems and Concerns
· Lying, stealing and passivity in responding to requests
· Faulty logic
· Egocentric; has difficulty comprehending and/or responding appropriately to other people's feelings, needs, and desires
· Low motivation
· Low self-esteem
· Academic ceiling, which is usually around grade 4 for reading and grade 3 for spelling and arithmetic

Recommendations
· Education of caretakers and patients regarding sexual development, birth control options and protection from sexually transmitted diseases
· Planning and implementation of adult residential and vocational training and placement
· Appropriate and mental health interventions as needed
· Respite care for caretakers
· Caretakers support group
· Safe, stable and structured home or other residential placement
· Shifting of focus from academic skills to daily living and vocational skills
· Careful monitoring of social activities and structuring of leisure time
· Working towards increased independence by teaching to make healthy choices (taught at the child's level)

Adulthood: Ages 18+ Years

Problems and Concerns
· Residential placement
· Economic support and protection
· Job training and placement
· Depression and suicidal ideation
· Pregnancy or fathering of a child
· Social and sexual exploitation, or inappropriate behavior
· Increased expectations of the patient by other people
· Increased dissatisfaction towards the patient by others
· Withdrawal and isolation
· Unpredictable behavior

Recommendations
· Guardianship for funds
· Specialized residential and/or subsidized living
· Specialized vocational and job placements
· Medical coupons
· Acceptance of the patient's "world"
· Acknowledgement of the patient's skills limitations
· Patient advocates to ensure the above occurs
Understanding the cognitive differences associated with a history of prenatal exposure to alcohol is crucial in supporting a child with FAS/E from infancy through adulthood. With this knowledge comes the ability to provide positive behavioral and academic support so that the child does not develop secondary disabilities (i.e., emotional problems, trouble in school, addictions) and is able to develop according to full potential.

**Information Processing Deficits**

Difficulty with input, integration, memory and output of information results in an inability to understand cause and effect. This means that, although a child is able to communicate a surface understanding of expectations he/she may be unable (not unwilling) to perform as expected. Developmentally, social and emotional functioning is far below the child’s chronological age. For example, a teenager with FAS could be described as a "stretch toddler" in understanding of social situations. Typically, a child with FAS/E will need consistent management and structure from childhood into adulthood.

**Lack of Generalization Skills**

The inability to generalize information learned puts a child with FAS/E at high risk for getting into trouble during childhood, adolescent, and adulthood years. Because of this lack of generalization skills, a child/adolescent/adult who experiences FAS may be unable (not unwilling) to "see the whole picture," and has difficulty linking ideas together or taking what is learned in one setting and putting it into practice in another.

**Concrete vs. Abstract Understanding**

A common characteristic of people with FAS/E is the inability to understand the abstract meanings of the concepts which structure our social world. Many are able to "talk the talk, but not walk the walk," and this incongruity leads to misinterpretation of their behaviors/intent by those not understanding the disability. People with FAS/E need a nurturing, stress-free, simple environment with few changes from day to day where lifelong habit patterns of behavior can be learned.
Socialization and Skills of Independence

The emotional/social understanding of a child with FAS/E is far below chronological age. Due to the way his/her brain processes information and remembers what has been learned, it is essential that education be based on daily life.

Anxiety/Frustration Levels

Due to the difficulty a child/adolescent/adult with FAS has understanding expectations and combining ideas to make a whole, he/she can easily be over-stimulated and frustrated. Anxiety can lead to the inability to make sense of a situation or to think things through or "FAS Shutdown". People with FAS/E need a stress-free environment to in order to learn.

developed by Deb Evensen and Jan Lutke
FASD AND THE COMMUNITY: Suggested Readings

PUBLICATIONS

Adults Living with FAS/E: Experiences and Support Issues in British Columbia by Rutman Deborah, Corey La Berge, and Donna Wheway: FAS/E Support Network of BC 2002. Surrey, BC: FAS/E Support Network of B.C. This report includes excerpts of life stories of individuals with FAS as well as a discussion of a number of issues and experiences that participants have told about day-to-day living with FAS/E. These issues and experiences have been divided into different topic areas (e.g. accomplishments, employment, education, parenting with FAS/E, independence, justice.). The Implications section outlines directions for advocacy, supportive policies and effective practices for adults living with FAS/E as identified through this research.

FASD Strategies not Solutions by Stephanie Jones and Laura Cunningham, 2004, Region 6 Edmonton and Area Child and Youth. This Booklet is designed for caregivers and professionals who, in their everyday lives, encounter children and youth affected by Fetal Alcohol Spectrum Disorder. Readers should be aware that this Booklet provides strategies and suggestions for people who already have a base understanding of FASD. Available for on-line viewing and download at www.faslink.org/strategies_not_solutions.pdf


Fetal Alcohol Syndrome and the Criminal Justice System by Julianne Conry and Diane Fast (ed). 2000. Law Society of British Columbia and BC FAS Resource Society, Vancouver, BC This book provides information about people with FAS/E in the criminal justice system. Judges, Lawyers, probation, and parole officers, those working in the legal system with find this tool an excellent resource. Available from the Asante Centre Tel: (604)467-7101 Email: info@asantecentre.org

Fetal Alcohol Spectrum Disorder (FAS) and the Role of Family Court Judges in Improving Outcomes for Children and Families by Diane Malbin, Juvenile and Family Court Journal, 55(2): 53-63, Spring 2004

Fetal Alcohol Syndrome: Implications for Correctional Service by Correctional Service of Canada 1998. Corrections Canada: Ottawa, ON This report reviews the literature on Fetal Alcohol Syndrome from the perspective of the implications this condition might have for the criminal justice system and for Correctional Service Canada. The report is presented in three parts. Part 1 provides a basic background about the disorder. Part 11 traces the course and consequences of this condition, including the connection to delinquency and crime. Part 111 considers the possibility of identifying fetal alcohol syndrome and related effects in individuals who come in contact with the criminal justice system, and how institutional and post-release programs might best fit their needs. Download the resource: www.csc-scc.gc.ca/text/rsrch/reports/r71/r71_e.pdf

Teaching for the Prevention of Fetal Alcohol Spectrum Disorder, Grades 1-12: A Resource for Teachers of Health and Life Skills and CALM 2002. Edmonton, AB: Alberta Education The goal of this resource is to raise awareness of the effects and characteristics of fetal alcohol spectrum disorder (FASD) through learning activities that teachers can incorporate into the health and life skills, and Career and Life Management programs. It provides strategies, activities and student information sheets focusing on the prevention of alcohol use and abuse during pregnancy. A handout for community resource people offers tips for working with students and outlines the specific goals and learning outcomes for the health program. Contact: Learning Resources Centre, 12360 - 142 Street, NW Edmonton, AB T5L 4X9; Phone (780) 427-2767 or toll free 1-888-310-7777; Email:
This drug awareness program targeted to “tough kids” provides educators and other youth community professionals with practical strategies related to educating this group about alcohol, inhalant and other drug issues.

Provides a general overview of FAS and offers advice for individuals affected by prenatal alcohol exposure. It provides strategies and suggestions to help them manage in a number of areas including daily routines and structure, life skills, and community issues. It also stresses self-care for parents and caregivers.

WEBSITES

FAS Community Resource Center (FAS-CRC)
www.come-over.to/FASCRC
The website offers 164 articles written by Teresa Kellerman (FAS Consultant/parent and Coordinator of FAS Community Resource Centre) about FASD issues, both intervention and prevention. In addition to these, there are various non-article items such as an online quiz, an online simulation of FASD disabilities, an online store for FAS books, posters, handouts, brochures, guidelines for FAS Awareness Day, a collection of news reports and research abstracts, a collection of FASD resources, a list of online support groups, conference reports, collection of parents’ poems, a collection of families’ stories, and several photo galleries.
Contact: FAS Community Resource Centre
Contact: FAS-CRC, 4710 E. 29th St. #7, Tucson AZ 85711.

FASD and the Justice System
fasdjustice.on.ca/
This site is designed for justice system professionals and others who want to understand more about FASD. It provides information and resources about Fetal Alcohol Spectrum Disorder (FASD), including background information, case law, legal resources and strategies for effective intervention.

VIDEOS

Fetal Alcohol Syndrome and the Criminal Justice System - Understanding the Offender with FAS 2000. Asante Centre, Vancouver, BC
Set of 3 videos Talking With Victor 43 min, A Judge's Perspective 56 min, and Mistakes I Have Made 28 min. Based on the publication ‘FAS and the Criminal Justice System by Conry and Fast, this series of videos explores the unique considerations facing individuals with FAS that come in contact with the criminal justice system such as: The implications of FASD in the Canadian Charter of Rights and Freedoms; The concept of “Not Criminally Responsible by Reason of a Mental Disorder; The tendency for clients with FASD to be impressionable, suggestible and easily mislead; Examples of assumptions that may seem reasonable for a typical client, but would not be appropriate for a client with FASD; and The importance of obtaining an FASD assessment.
FINDING FASD INFORMATION, WORKSHOPS AND CONFERENCES
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<table>
<thead>
<tr>
<th>FASCETS: Fetal Alcohol Syndrome Consultation, Education and Training Services</th>
<th><a href="http://www.fascets.org">www.fascets.org</a></th>
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<tr>
<td>FASD Information &amp; Consultation Service: Canadian Centre on Substance Abuse (CCSA)</td>
<td><a href="http://www.ccsa.ca">www.ccsa.ca</a></td>
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<tr>
<td>FASlink: Canadian Fetal Alcohol Syndrome Internet Information and Support Communications Link.</td>
<td><a href="http://www.acbr.com/fas/faslink.htm">www.acbr.com/fas/faslink.htm</a></td>
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<td>FASlink maintains both an extensive FAS information website and a discussion listserve. FASlink's website and the FAS InfoDisk/CD ROM (resource list for purchase) are updated regularly along with other electronic publishing projects. FASlink also publishes brochures and electronic media for distribution. Contact: FASlink, 2445 Old Lakeshore Road, Bright's Grove, ON N0N 1C0; Phone (519) 869-8026 or Email: <a href="mailto:FASlink@acbr.com">FASlink@acbr.com</a></td>
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<tr>
<td>Fetal Alcohol Spectrum Disorders (FASD) Center for Excellence Website. US Department of Health and Human Services Substance Abuse and Mental Health Services Administration (SAMHSA)</td>
<td><a href="http://www.fascenter.samhsa.gov">www.fascenter.samhsa.gov</a></td>
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<tr>
<td>SAMHSA is a US Federal initiative devoted to preventing and treating FASD. The website provides information and resources about FASD. The site offers information on training, technical assistance and materials you can use to raise awareness about FASD. The website provides many resources including a searchable online FASD Resource library; events calendar; and resource list of what experts recommend as a starting point for caregivers and parents to begin understanding FASD. Contact: SAMHSA FASD Center for Excellence, 1700 Research Boulevard, Suite 400, Rockville, MD 20850; Phone 1-866-786-7327 or Email: <a href="mailto:fascenter@samhsa.gov">fascenter@samhsa.gov</a></td>
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<tr>
<td>Fetal Alcohol and Drug Unit Department of Psychiatry and Behavioral Sciences, University of Washington School of Medicine</td>
<td><a href="http://www.depts.washington.edu/fadu">www.depts.washington.edu/fadu</a></td>
</tr>
<tr>
<td>A source of technical and academic material, most of it taken from research undertaken or supervised by the psychology professor, and FASD researcher, Dr. Ann Streissguth at University of Washington Faculty of Medicine in Seattle. Fetal Alcohol And Drug Unit, University of Washing School of Medicine,180 Nickerson St., Suite 309, Seattle, WA 98109; Phone (206) 543-7155.</td>
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<tr>
<td>National Organization on Fetal Alcohol Syndrome (NOFAS)</td>
<td><a href="http://www.nofas.org">www.nofas.org</a></td>
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<td>NOFAS is a national US nonprofit organization that addresses alcohol use during pregnancy and improving the quality of life those individuals and families affected by FASD. The website hosts numerous health, educational, and advocacy resources on FASD, including a national directory of services and links to affiliated programs and services of NOFAS online. Contact: NOFAS 900 17th Street, NW, Suite 910, Washington, DC 20006; Phone (202) 785-4585.</td>
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<tr>
<td>Project FACTS: Fetal Alcohol Consultation and Training Services</td>
<td><a href="http://www.fasalaska.com">www.fasalaska.com</a></td>
</tr>
<tr>
<td>This website provides information on FASD, with a focus on intervention techniques for educators. The site has handouts to download on the following: 8 Magic Keys: Developing Successful Interventions for Students with FAS, Links to Other FAS Sites (home schooling, family, and sites on resources in Alaska, US, and International), Social/Behavioral Challenges/Schedule, Biological Basis of FAS, Common Misinterpretations, Developmental Characteristics and FAS Frequently Asked Questions. Contact: FACTS, PO Box 1092, Homer, Alaska 99603; Phone (907) 235-2544 or Email: <a href="mailto:debevensen@alaska.net">debevensen@alaska.net</a></td>
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