

Fetal Alcohol Syndrome



A NEW WAY TO SUPPORT FAMILIES

Missouri Developmental Disability Resource Center/Family-to-Family Health Information Center is housed within Missouri's University Center for Excellence in Developmental Disabilities Education, Research and Services (UCEDD) at the University of Missouri-Kansas City, Institute for Human Development.

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Welcome to the Missouri Developmental Disability Resource Center (MODDRC). You are receiving this letter with an enclosed packet of information because a request was made by you (or someone on your behalf) to the MODDRC.

We have compiled information from a number of sources and have included them in this packet, which is divided into the following sections:

- **Overview of a specific disability, special health care need, or other major topic**
- **Current practices**
- **Personal Stories**
- **Family support, advocacy and services**
- **Missouri Service Systems**

The MODDRC, which has now expanded to include Missouri's Family-to-Family Health Information Center, seeks to inform and connect individuals with disabilities or special health care needs and/or their families to peer support. We also provide opportunities for leadership development and volunteerism. When contacting the MODDRC, you are connecting to staff that have first-hand knowledge about disability related issues because they have the experience of living with the disability, either as an individual, parent or family member.

Thank you for using the MODDRC. This packet of information is one of the many ways that the MODDRC can support you in your journey with disability. We hope you will connect with us again.



Overview

The purpose of this section is to help you gain a better understanding of a specific disability or special health care need. It is intended to provide a basic explanation of the disability and possible causes and characteristics.

If you would like more in-depth information on this topic, other topics of information or if it is not the topic you requested, please feel free to contact us again.



Overview: Fetal Alcohol Syndrome (FAS)

When a pregnant woman drinks a glass of wine, her baby does too. The same is true for any other alcohol that passes mom's lips. But many people believe that a drink every once in a while during pregnancy or even a night or two of heavy drinking is no big deal. Is this true? No.

Fetal Alcohol Syndrome (FAS) is the leading known cause of congenital disability (a disability that begins at or before birth) in the United States. It can be prevented 100% of the time, by a mother choosing to not drink alcohol at all during her pregnancy. But when a baby is born with FAS, it's very unlikely that his or her mother knew what was happening inside her own body.

She might not have known yet she was pregnant, or may have been given wrong information by others about small amounts of alcohol being okay during pregnancy. She might have needed more help to stop drinking, in the case of a serious problem with alcohol dependency.

Whatever the reason, the alcohol the mother drank passed easily to her developing baby. Unfortunately, it ended up in an even higher concentration in the bloodstream of her child, changing a life forever.

Every woman and each pregnancy is different. While one baby may be born without signs of exposure to small amounts of alcohol, another one will suffer from its harmful effects. The only safe option is to avoid alcohol completely during pregnancy.

When is "a little" too much?

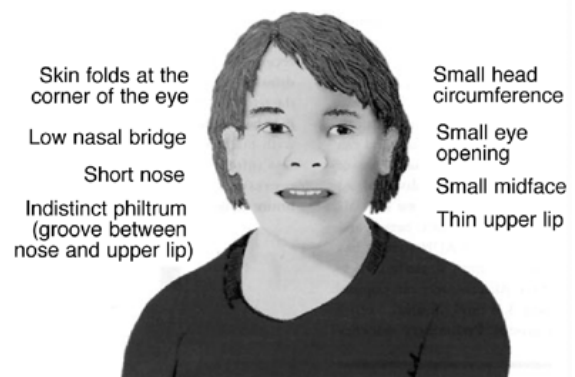
Research shows that "as little as two drinks in early pregnancy or four drinks all at once (a binge episode) later in pregnancy can kill developing brain cells."¹ But sometimes the real strength of alcohol is hidden or masked by sweet flavors in

the drink. Take, for example, the very popular drink called Long Island Iced Tea. One of these actually contains about the same amount of liquor as four to five drinks. One alcoholic iced tea plus one developing baby equals one very bad combination. This means that the idea that only heavy drinkers have children affected by alcohol just isn't true.

What to look for:

If you're concerned that a child you know and love may be experiencing problems as the result of prenatal alcohol exposure, check to see if any of these signs are present:

- Limbs, hands or feet with unusual shape
- Small head
- Low birth weight and slow growth rate
- Heart, liver, or kidney problems



- FAS facial features, such as small eye openings, smooth or missing philtrum (groove between the lips and nose), thin upper lip (see above)
- Poor coordination
- Developmental delays
- Short attention span, hyperactivity, nervousness, inability to control own behavior, anxiety

¹ (National Organization on Fetal Alcohol Syndrome, 2010)

- Sleep problems
- Vision or hearing problems
- Problems with friendships and relating to groups of people

If you notice any of these signs, take your concerns to a doctor for further help and information.

What are the effects?

Children with fetal alcohol syndrome can be affected in many different ways and in various amounts, from mild to severe. For this reason, the syndrome is sometimes referred to as a “spectrum” disability and is often called Fetal Alcohol Spectrum Disorder (FASD) by professionals and parents.

According to the National Institute on Alcohol Abuse and Alcoholism², persons affected by FAS/FASD can have difficulty with:

Verbal learning – memory for language; some children with FAS/FASD learn fewer words and at a slower pace

Visual-Spatial Learning – memory of where objects are placed in relation to each other; for example, knowing where to put things back into their proper place

Attention – a common difficulty for those with FAS/FASD; unlike kids with ADHD, children with FAS are usually able to focus and maintain attention. However, they have trouble shifting attention from one task to another.

Reaction Time – children’s brains, when affected by FAS/FASD, often process information more slowly, which can impact intelligence and learning speed

Executive Functioning – problems with planning, organizing, and changing to new problem solving strategies when needed

Children with FAS do not “outgrow” the effects of pre-natal alcohol exposure. They become adults with the same difficulties in learning, memory, attention, and problem solving, along with emotional and behavioral challenges. However, there are many things that can be done to improve the lives of persons with FAS/FASD (see Current Practices section).

Learning about Fetal Alcohol Syndrome can be confusing. Don’t be afraid to ask questions of your doctors, other families who have gone through it too, and our staff here at the Missouri Developmental Disability Resource Center/Family-to-Family Health Information Center. We’re here to help.



Works Cited

National Institute on Alcohol Abuse and Alcoholism. (2000, December). *Alcohol Alert No. 50*. Retrieved April 28, 2010, from NIAAA/National Institutes of Health: <http://pubs.niaaa.nih.gov/publications/aa50.htm>

National Organization on Fetal Alcohol Syndrome. (2010). Retrieved April 28, 2010, from National Organization on Fetal Alcohol Syndrome: <http://www.nofas.org/educator>

² (National Institute on Alcohol Abuse and Alcoholism, 2000)



Current Practices

The purpose of this section is to provide you with the most current techniques and procedures for supporting people with developmental disabilities or special health care needs. These could include such things as:

- Information on therapies
- Medical treatment
- Accommodations
- Interventions

If you would like more information on current practices, please feel free to contact us again.



On the following pages, you will find more information on Fetal Alcohol Syndrome (FAS)/ Fetal Alcohol Spectrum Disorders (FASD) from sources the MODDRC regards as respected and trustworthy. All information has been reprinted with permission and is for educational purposes only. For more information regarding your personal situation, please consult your team of medical professionals.



Treatments (Fetal Alcohol Spectrum Disorders - FASDs)

CDC has provided the information on this page because it may be of interest to you. CDC does not necessarily endorse the views or information presented. CDC cannot answer personal medical questions. Please talk to your healthcare professional about specific questions concerning appropriate care, treatment, or other medical advice.

No two people with an FASD are exactly alike. FASDs can include physical or intellectual disabilities, as well as problems with behavior and learning. These symptoms can range from mild to severe. Treatment services for people with FASDs should be different for each person depending on the symptoms.

Early Intervention Services

There is no cure for FASDs, but research shows that early intervention treatment services can improve a child's development. Early intervention services help children from birth to 3 years of age (36 months) learn important skills. Services include therapy to help the child talk, walk, and interact with others. Therefore, it is important to talk to your child's doctor as soon as possible if you think your child has an FASD or other developmental problem.

Even if your child has not received a diagnosis, he or she might qualify for early intervention treatment services. The Individuals with Disabilities Education Act says that children

younger than 3 years of age who are at risk of having developmental delays may be eligible for services. The early intervention system in your state will help you have your child evaluated and provide services if your child qualifies.

In addition, treatment for particular symptoms, such as speech therapy for language delays, often does not need to wait for a formal diagnosis.

Protective Factors

Studies have shown that some protective factors can help reduce the effects of FASDs and help people with these conditions reach their full potential.¹ Protective factors include:

Early diagnosis

A child who is diagnosed at a young age can be placed in appropriate educational classes and get the social services needed to help the child and his or her family. Early diagnosis also helps families and school staff to understand why the child might act or react differently from other children sometimes.



Involvement in special education and social services

Children who receive special education geared towards their specific needs and learning style are more likely to reach their full potential. Children with FASDs have a wide range of behaviors and challenges that might need to be addressed. Special education programs can better meet each child's needs. In addition, families of children with FASDs who receive social services, such as counseling or respite care have more positive experiences than families who do not receive such services.

Loving, nurturing, and stable home environment

Children with FASDs can be more sensitive than other children to disruptions, changes in lifestyle or routines, and harmful relationships. Therefore, having a loving, stable home life is very important for a child with an FASD. In addition, community and family support can help prevent secondary conditions, such as criminal behavior, unemployment, and incomplete education.

Absence of violence

People with FASDs who live in stable, non-abusive households or who do not become involved in youth violence are much less likely to develop secondary conditions than children who have been exposed to violence in their lives. Children with FASDs need to be taught other ways of showing their anger or frustration.



Types of Treatments

Many types of treatments are available for people with FASDs. They can generally be broken down into five categories:

- Medical Care
- Medication
- Behavior and Education Therapy
- Parent Training
- Alternative Approaches

Medical Care

People with FASDs have the same health and medical needs as people without FASDs. Like everyone else, they need well-baby care, vaccinations, good nutrition, exercise, hygiene, and basic medical care. But, for people with FASDs, concerns specific to the disorder must also be monitored and addressed either by a current doctor or through referral to a specialist. The types of treatments needed will be different for each person and depend upon the person's symptoms.

Types of medical specialists might include:

- Pediatrician
- Primary care provider
- Dysmorphologist
- Otolaryngologist
- Audiologist
- Immunologist
- Neurologist
- Mental health professionals (child psychiatrist and psychologist, school psychologist, behavior management specialist)
- Ophthalmologist
- Plastic surgeon
- Endocrinologist
- Gastroenterologist
- Nutritionist
- Geneticist
- Speech-language pathologist
- Occupational therapist
- Physical therapist

Medication

No medications have been approved specifically to treat FASDs. But, several medications can help improve some of the symptoms of FASDs. For example, medication might help manage high energy levels, inability to focus, or depression.

Following are some examples of medications used to treat FASD symptoms:

Stimulants

This type of medication is used to treat symptoms such as hyperactivity, problems paying attention, and poor impulse control, as well as other behavior issues.

Antidepressants

This type of medication is used to treat symptoms such as sad mood, loss of interest, sleep problems, school disruption, negativity, irritability, aggression, and anti-social behaviors.

Neuroleptics

This type of medication is used to treat symptoms such as aggression, anxiety, and certain other behavior problems.

Anti-anxiety drugs

This type of medication is used to treat symptoms of anxiety.

Medications can affect each child differently. One medication might work well for one child, but not for another. To find the right treatment, the doctor might try different medications and doses. It is important to work with your child's doctor to find the treatment plan that works best for your child.

Behavior and Education Therapy

Behavior and education therapy can be an important part of treatment for children with FASDs. Although there are many different types of therapy for children with developmental disabilities, only a few have been scientifically tested specifically for children with FASDs.

Following are behavior and education therapies that have been shown to be effective for some children with FASDs:

Friendship training

Many children with FASDs have a hard time making friends, keeping friends, and socializing with others. Friendship training teaches children with FASDs how to interact with friends, how to enter a group of children already playing, how to arrange and handle in-home play dates, and how to avoid and work out conflicts. A research study found that this type of training could significantly improve children's social skills and reduce problem behaviors.²

Specialized math tutoring

A research study found that special teaching methods and tools can help improve math knowledge and skills in children with FASDs.³

Executive functioning training

This type of training teaches behavioral awareness and self-control and improves executive functioning skills, such as memory, cause and effect, reasoning, planning, and problem solving.



Parent-child interaction therapy

This type of therapy aims to improve parent-child relationships, create a positive discipline program, and reduce behavior problems in children with FASDs. Parents learn new skills from a coach. A research study found significant decrease in parent distress and child behavior problems.

Parenting and behavior management training

The behavior and learning problems that affect children with FASDs can lead to high levels of stress for the children's parents. This training can improve caregiver comfort, meet family needs, and reduce child problem behaviors.

Parent Training

Children with FASDs might not respond to the usual parenting practices. Parent training has been successful in educating parents about their child's disability and about ways to teach their child many skills and help them cope with their FASD-related symptoms. Parent training can be done in groups or with individual families. Such programs are offered by therapists or in special classes.

Although each child is unique, the following parenting tips can be helpful:⁴

- Concentrate on your child's strengths and talents
- Accept your child's limitations
- Be consistent with everything (discipline, school, behaviors)
- Use concrete language and examples
- Use stable routines that do not change daily
- Keep it simple
- Be specific—say exactly what you mean
- Structure your child's world to provide a foundation for daily living
- Use visual aides, music, and hands-on activities to help your child learn
- Use positive reinforcement often (praise, incentives)
- Supervise: friends, visits, routines
- Repeat, repeat, repeat

Families might need support from a family counselor or therapist. Parents might also benefit from local support groups, in which parents of children with FASDs can discuss concerns, ask questions, and find encouragement.

Alternative Approaches

With any disability, injury, or medical condition, many untested therapies become known and are promoted by informal networks. These therapies are referred to as alternative treatments. Before starting such a treatment, check it out carefully, and talk to your child's doctor. Your child's doctor will help you weigh the risks and benefits of these therapies.

Some of the alternative treatments used for people with FASDs include:

- Biofeedback
- Auditory training
- Relaxation therapy, visual imagery, and meditation (especially for sleep problems and anxiety)
- Creative art therapy
- Yoga and exercise
- Acupuncture and acupressure
- Massage, Reiki, and energy healing
- Vitamins, herbal supplements, and homeopathy
- Animal-assisted therapy

References

1. Streissguth, A.P., Barr, H.M., Kogan, J. & Bookstein, F. L., Understanding the occurrence of secondary disabilities in clients with fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE). Final report to the Centers for Disease Control and Prevention (CDC). Seattle: University of Washington, Fetal Alcohol & Drug Unit; August 1996. Tech. Rep. No. 96-06.
2. O'Connor, M.J., Frankel, F., Paley, B., Schonfeld, A.M., Carpenter, E., Laugeson E.A., et al. (2007). A controlled social skills training for children with fetal alcohol spectrum disorders. *Journal of Consulting & Clinical Psychology*, 74(4),639–648.
3. Kable, J. A., Coles, C. D., & Taddeo, E. (2007). Socio-cognitive habilitation using the math interactive learning experience program for alcohol-affected children. *Alcoholism: Clinical & Experimental Research*, 31(8), 1425–1434.
4. Mitchell, K. T. (2002). *Fetal alcohol syndrome: Practical suggestions and support for families and caregivers*. Washington, DC: National Organization on Fetal Alcohol Syndrome.

This information is provided courtesy of the Centers for Disease Control and Prevention.
Find the full article by visiting the CDC at: <http://www.cdc.gov/ncbddd/fasd>





Personal Stories

The purpose of this section is to provide you with the perspective of parents, family members and those living with the disability or special health care need. These stories give you insight of what life was like growing up and what life looks like now, as well as some of the joys and challenges that were experienced.

Written personal stories are one way of connecting to others who have similar experiences. Another way of connecting with others is through the Sharing Our Strengths peer support network. This service of the MODDRC provides you with an individualized match specific to what you want. This may include being matched to mentors with a similar disability experience, a mentor located in a similar part of the state or around a specific issue. If you are interested in being matched or in becoming a mentor for someone else, please contact us.



BRAVO ZULU!

By JAHc, mother of a son with a Fetal Alcohol Spectrum Disorder

Bravo Zulu is a term given to some military personnel by superior officers, using either flag or voice to signal approval of the accomplishment of a task—it's one of the ways the US Military says "job well done." Now, as an official "Military Mom" (honest, I have a hat that says that, even!) I want to take the opportunity to say "Bravo Zulu" to my son, J. and take a moment to tell you how J. has gotten to this point in his life.

When J. entered my life in March 1987, he was 4 days old, a squirmy, vocal little guy, looking for a Mom to provide a life that could not be provided by the young woman who gave birth to him. With great joy, I entered into parenthood with quite a little teacher. He was a boisterous, tempestuous, loving and demanding child that wanted consistency in his world, but created anything but that in the wake he left behind as a small "human tornado." The pediatrician talked of "Attention Deficit-Hyperactivity Disorder" and by age 6, I placed him on Ritalin, due to safety issues. He was an escape artist, and his favorite thing was to go AWOL from the classroom, missing once for almost an hour.

As his young life progressed, I noticed other things; near illegible handwriting, a consistent inability to firmly establish handedness, receptive language issues, behaviors that did not communicate what he was truly trying to express, and an increasing level of frustration with life. So much of life just didn't make sense to him or fit into his idea of the world. I asked his school for testing to look for a disability, beginning in 4th grade. By 5th grade we had a 504 plan, based on his diagnosis of ADD/ADHD, but nothing else.

Then, in 1999, the summer between 5th and 6th grades, I took J. to a local Children's Hospital where they had an ADD/ADHD Clinic, out of sheer frustration. There were things that seemed to be more than attention issues, and I wanted answers. We received many of those answers on that first visit, and, life began to change for both

of us, from that point on. While we were there, the doctor pointed out many subtle physical characteristics that indicated that J. had a mild form of Fetal Alcohol Syndrome; what she referred to as Fetal Alcohol Effect, in addition to ADD/ADHD. This opened the door to testing during the school year that revealed that he also had a learning disability called dysgraphia--difficulty in expressing thoughts in writing.

Once we found what was happening, life began to improve for J. He began to get needed assistance in special education, and we both began to focus on his strengths. At his IEP to begin transition, just before his 14th birthday, the IEP team began to talk of the future. What career did J. see for himself? After talking about so many options related to things he loved and his need learn by "hands on" methods, J. simply said "I think I just want to be in the military."

After doing some exploring of a possible ROTC program in our school district, I happened upon the US Naval Sea Cadet Corps, with a flight squadron in our area. In April 1999, J. joined the Sea Cadets and rose from the ranks of recruit to the position of Lead Cadet Petty Officer by September of his sophomore year. By 2001, J. decided to remove himself from all medication related to his ADD/ADHD, in preparation to join the military. And, on July 28, 2004, he successfully passed the ASVAB (Armed Services Vocational Aptitude Battery) and became a participant in the one of the US Military's Delayed Entry Program—preparing himself to join "the service" upon graduation in May 2005.

Just after high school graduation, J. departed for the US Military and took his basic training. During basic training, J. was chosen for the one of the elite U.S. Military honor guards. Each branch of the US military provides the current sitting President with a military honor guard, and each branch houses their honor guard members at bases around the Washington DC area. Each elite



group is responsible for government ceremonial activities in Washington DC and all over the world. They are at the disposal of the sitting president 24/7 to attend to ceremonial responsibilities upon command, which can include Pentagon Functions, the visits of foreign heads of state, honor guard responsibilities at the funerals of US dignitaries, White House activities, and Presidential Inaugurations. This group also bears the awesome responsibility as honor guards for the burial of their fallen military comrades at Arlington National Cemetery.

J. served for almost 3 years in Washington DC. J. His activities there during this time included the visit of Queen Elizabeth of Great Britain, the change of Command for the US Joint Chiefs of Staff, Ceremonial Color Guard at weekly summer music performances of the branch Band, doorman at the US Military Ball, various parades, and wreath laying ceremonies by visiting dignitaries at the Tomb of the Unknowns. However, if you asked J about his time with this group, he would tell you that his most honorable activity while there was serving on the “firing

team” that provided 21-gun salutes for funeral ceremonies at Arlington National Cemetery.

J. is now going to school with the military to learn a trade and skill to use during the remainder of his military service. He re-enlisted for an additional time period to secure this schooling, and he hopes it will lead to further opportunities for travel and adventure. He called a few days ago, bemoaning his advancing age. Given the fact that he is now only 22 years old, I asked him why he was worried about getting old. He said, “Mom, I have my first service strip for my uniform sleeve; that means I have been in 4 whole years!” I smiled at his concern, and secretly hoped that this would be the first service stripe of many for his sleeve.

Sometimes, it is hard to imagine that this small bundle of energy and mayhem has grown into such a fine young man. Bravo Zulu, my son, for a “job well done” for these first 22 years of life. Remember that I love you, I miss you, and I am so proud of you!





Family Support, Advocacy and Services

The purpose of this section is to provide you with a listing of organizations specifically designed to meet the support needs of individuals with developmental disabilities or special health care needs and their families. This listing includes parent organizations, support groups or other advocacy organizations.

Support for Families

Sharing Our Strengths (SOS) Peer Support Network

215 W. Pershing Road, 6th floor
 Kansas City, MO 64108
 Toll free: 800-444-0821
 Web: <http://www.sharingourstrengths.com>

SOS is a statewide support network of parents, family members, individuals with developmental disabilities or special health care needs, and professionals who are matched with peer mentors to share experiences, offer emotional support and to network with others. You can request an individual parent to parent or peer support match with another parent or individual who has experienced similar circumstances.

Midwest Regional Fetal Alcohol Syndrome Training Center

Department of Family and Community Medicine
 Saint Louis University School of Medicine
 1402 South Grand Blvd.
 St. Louis, Missouri 63104
 Phone: 314-977-8480
 Website: <http://medschool.slu.edu/mrfastc>

Missouri Fetal Alcohol Syndrome Rural Awareness and Prevention Project (MOFASRAPP)

Website: <http://www.fascenter.samhsa.gov/initiatives/states/missouri.cfm>

Missouri Parents Act (MPACT)

8301 State Line Rd., Suite 204
 Kansas City, MO 64114
 Phone: 816-531-7070
 Toll free: 800-743-7634

National Organization on Fetal Alcohol Syndrome (NOFAS)

1200 Eton Court, NW
 Third Floor
 Washington, D.C. 20007
 Phone: 202- 785 8570
 Toll free: 800- 66 NOFAS
 Email: information@nofas.org
 Web: <http://www.nofas.org>



Support for Families, continued

Fetal Alcohol Spectrum Disorders Center for Excellence

Substance Abuse and Mental Health Services Administration (SAMHSA)

2101 Gaither Road, Suite 600

Rockville, MD 20850

Toll free: 866-STOPFAS (786-7327)

Web: <http://www.fasdcenter.samhsa.gov>

Email: mrfastc@slu.edu

The FAS Family Resource Institute

PO Box 2525

Lynnwood, WA 98036

Web: <http://www.fetalalcoholsyndrome.org>

FAS Community Resource Center

Website: <http://www.come-over.to/FASCRC>





Missouri Service Systems

The purpose of this section is to provide you with a listing of agencies focused on areas such as educational, medical care or social services to individuals with developmental disabilities or special health care needs. This includes listings such as state or local agencies, hospitals, clinics or education systems.



Missouri Service System Contacts

First Steps

Phone: 573-522-8762

Toll free: 866-583-2392

Email: webreplies@desse.mo.gov

First Steps is the Missouri statewide program for children, ages 0-3, who show signs of possible developmental delay or disability or are diagnosed as such. The program provides “early intervention” to help at-risk infants and toddlers gain important developmental skills, like crawling, playing, talking and eating. First Steps brings families together with early intervention specialists to learn new ways to encourage and support their child’s development within their daily activities.

Regional Offices, Division of Developmental Disabilities Missouri Department of Mental Health

Toll free information: 800-207-9329

Email: ddmail@dmh.mo.gov

Web: <http://www.dmh.mo.gov/dd>

You must apply through one of 11 regional offices to gain access to many state services, including funding through HCBS (Home and Community-Based) waiver programs. To find the regional office for your area, use the toll free number listed above or visit: <http://www.missouri.networkofcare.org> and click on Developmental Disabilities.

