



Utah Parent Center

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e-Journal

Issue No.7, September 2012

FETAL ALCOHOL SPECTRUM DISORDERS

Introduction

Welcome to the Utah Parent Center e-Journal on **Fetal Alcohol Spectrum Disorders (FASD)**. This topical e-journal is part of a series published by the Utah Parent Center (UPC). It is the Utah Parent Center's hope that this information will be a valuable resource for both parents and professionals.

FASD is the leading known cause of birth defects and intellectual disabilities. FASD is a term to describe a pattern of birth defects found in children of mothers who drank alcohol during pregnancy. The effects may include physical and intellectual disabilities as well as problems with behavior and learning disabilities. Know that FASD is 100% preventable when pregnant women abstain from alcohol.

Each year in the United States, an estimated 40,000 babies are born with an FASD. (Centers for Disease Control and Prevention, 2010.) The National Institute of Health, U.S. Department of Health and Human Services reports 0.5 to 3.0 children out of 1,000 are reported as having FASD. In addition, recent retrospective analyses of hospital admissions data indicate that under-reporting of alcohol misuse or harm by women may further disguise true prevalence rates (Morleo et al., 2011).

The cost factor of raising a child with an FASD is significant. Amendah and colleagues (2011) found that, for a child with identified FAS, incurred health costs were nine times higher than for children without an FASD. Lupton and colleagues (2004) have estimated the lifetime cost of caring for a person with FAS to be at least \$2 million, and the overall annual cost of FASD to the U.S. healthcare system to be more than \$6 billion.

In this issue you will find information to help you and your child or youth with Fetal Alcohol Spectrum Disorder including information on FAS, diagnosis, services to help an individual with FAS, parent stories, FAS prevention during pregnancy and much more! Electronic copies of this e-Journal, fact sheets, and materials on related topics are available on or through the UPC's website at www.utahparentcenter.org.

The **Utah Parent Center** has been serving Utah families of children, youth, and young adults with all disabilities since before 1983. We provide free resources such as publications, workshops, and individualized assistance to help families make decisions about education, support services, vocational training, employment, and other services for their child and family.



*Fetal Alcohol Spectrum Disorder (FASD) is **100% preventable** if a woman does not drink alcohol during pregnancy. There is no safe amount of alcohol to drink while pregnant. There is also no safe time during pregnancy to drink and no safe kind of alcohol.*

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What is Fetal Alcohol Spectrum Disorder (FASD)?

Fetal Alcohol Spectrum Disorder (FASD) is the name given to a group of conditions that a person can have if that person's mother drank alcohol during pregnancy. These effects can range from mild to severe and affect each person in different ways and can include physical, intellectual, behavioral, and learning disabilities that remain throughout an individual's lifetime. Often a person has a mix of these problems.

Fetal alcohol spectrum disorders (FASD) are a group of conditions that can occur in a person whose mother drank alcohol during pregnancy. These effects can include physical problems and problem with behavior and learning. Often, a person with an FASD has a mix of these problems.

Types of FASDs

- **Fetal Alcohol Spectrum (FAS):** FAS represents the severe end of the FASD spectrum. People with FAS might have abnormal facial features, growth problems and central nervous system problems. They can also have problems with memory, attention, communication, vision or hearing.
- **Alcohol-Related Neurodevelopmental Disorder (ARND):** People with ARND might have intellectual disabilities and problems with behavior and learning. They might do poorly in school and have difficulties with math, memory, attention, judgment and poor impulse control.
- **Alcohol-Related Birth Defects (ARBD):** People with ARBD might have problems with the heart, kidneys, bones, hearing, or they might have a mix of more than one symptom.

Physical signs of FASDs can include:

Each individual with FASD will have unique physical, educational, social and medical needs which may include:

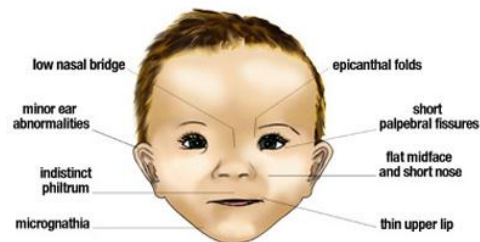
(1) A specific pattern of three abnormal facial features including a smooth ridge between the nose and upper lip (smooth philtrum); thin upper lip; and a short distance between the inner and outer corners of the eyes, giving the eyes a wide spaced appearance.

(2) Problems with growth. Children with FASD may have problems with height; weight or both that are lower than normal. For some children with FASD, growth problems resolve themselves early in life.

(3) Problems with the central nervous system. The central nervous system is composed of the brain and spinal cord. It controls all the workings of the body. When something goes wrong with a part of the nervous system, a person can have trouble moving, speaking, learning, behavior, memory, senses or social skills.

Physically you may see a smaller-than-normal head size or significant changes in the structure of the brain.

FETAL ALCOHOL SYNDROME



Neurologically there can be problems with the nervous system that include poor coordination, poor muscle control and problems with moving.

Functionally, the person's ability may be well below what's expected for his or her age, schooling or circumstances. The individual may have an intellectual disability, developmental delays or problems with learning such as a learning disability. They may also have problems in other areas which include:

- (A) Executive functioning deficits. These deficits involve the thinking processes that help a person manage tasks. Such deficits include poor organization and planning, lack of inhibition, difficulty grasping cause and effect, difficulty trying things in a new way, difficulty following multistep directions, poor judgment and the inability to apply knowledge to new situations.
- (B) Motor functioning delays. These delays affect how a person controls his or her muscles. Examples may include delay in walking (gross motor skills), difficulty writing or drawing (fine motor skills), clumsiness, balance problems, tremors, difficulty coordinating hands and fingers (dexterity), and poor sucking in babies.
- (C) Behavior, attention problems and hyperactivity. An infant with FASD may be irritable or fussy and cry a lot for no apparent reason. As the child grows you may see a child who has one or more of the following problems: overly active, inattentive, difficulty completing tasks, difficulty moving from one activity to another, over-stimulated and or hard to calm down, unable to comprehend danger or verbal warnings, problems with bonding, prone to melt downs and noncompliance, unable to comprehend danger, problems with sleep, and difficulty responding appropriately to common parenting practices (understanding cause-and-effect discipline). The parent may report that their child's behavior is inconsistent and changes from day to day.
- (D) Problems with social skills. A child with lack of social skills exhibits inappropriate social interactions, shows difficulty reading facial expressions and social cues, may prefer younger children as friends, be immature, and have difficulty communicating about his/her feelings.
- (E) Other problems with sensory issues including taste, touch, sound and smell.

How Can The Health Effects of FASD Be Addressed?

An early diagnosis; appropriate medical care; involvement in early intervention and special education services; along with a loving, nurturing, and stable home environment free of violence can greatly improve the health outcomes for individuals with FASD. Persons with FASD tend to have problems in multiple areas and services need to be individualized to meet the needs of each child or youth with FASD. Remember parents or caregivers are important! Providers should keep parents or caregivers informed about medical and school services provided. Providers need to explain his/her treatment plan in steps or a format that is easy to follow. The plan may include frequent follow up visits. Communication is vital when a team of providers is involved! Make sure each member of the team receives all current and appropriate information about the individual with FASD.

1 Streissguth, A.P., Bookstein, F.L., Barr, H.M., Sampson, P.D., O'Malley, K., Young, J.K. Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Developmental and Behavioral Pediatrics*. 2004;5(4):228-238.

ii 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), August, 1996, Seattle: University of Washington, Fetal Alcohol & Drug Unit, Tech. Rep. No. 96-06, (1996).

Adapted from:

- ✧ Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities. *Facts about FASDs*
- ✧ Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities, *FASD Diagnosis*. <http://www.cdc.gov/ncbddd/fas>.
- ✧ U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration (SAMSA), Center for Substance Abuse and Prevention. *The Physical Effects of Fetal Alcohol Spectrum Disorders*

If You're Concerned

Talk with Your Child's Doctor

As a parent, you know your child best. If your child is not meeting the milestones for his or her age, or if you think there may be a problem with the way your child plays, learns, speaks, or acts, talk to your child's doctor at the next visit.

[Click here to view Utah's Baby Watch Early Intervention Developmental Milestones.](#)

Developmental Screening

The American Academy of Pediatrics recommends that children be screened for general development using standardized, validated tools at 9, 18 and 24 or 30 months and for autism at 18 and 24 months or whenever a parent or provider has a concern. Ask your child's doctor about your child's developmental screening.

Easter Seals, through support from CVS Caremark Charitable Trust, provides parents with FREE access to the Ages and Stages Questionnaires®, Third Edition, one of many general developmental screening tools. [Click here to learn more and take the questionnaire.](#)

Contact Your Local Early Intervention Program

Baby Watch is Utah's network of early intervention service providers for children from birth to three. [Click here to find your local early intervention provider.](#) Your early intervention provider will meet with you to determine whether your child is eligible. Your child may be determined to be eligible in one of two ways:

1. An evaluation of your child's development shows that there is a significant developmental delay.
2. Your child has a medical diagnosis that is expected to lead to a developmental delay.

The above information was gathered from *Baby Watch Early Intervention*, www.utahbabywatch.org; *CDC Learn the Signs. Act Early.*, www.cdc.gov/ncbddd/actearly/index.html; *Easter Seals*, www.easterseals.com

Cognitive Changes May Be Only Sign of Fetal Alcohol Exposure

Distinct facial features not seen in many cases, National Institute of Health study finds

Most children exposed to high levels of alcohol in the womb do not develop the distinct facial features seen in fetal alcohol Spectrum, but instead show signs of abnormal intellectual or behavioral development, according to a study by researchers at the National Institutes of Health and researchers in Chile.

These abnormalities of the nervous system involved language delays, hyperactivity, attention deficits or intellectual delays. The researchers used the term “functional neurologic impairment” to describe these abnormalities. The study authors documented an abnormality in one of these areas in about 44 percent of children whose mothers drank four or more drinks per day during pregnancy. In contrast, abnormal facial features were present in about 17 percent of alcohol exposed children.

"Our concern is that in the absence of the distinctive facial features, health care providers evaluating children with any of these functional neurological impairments might miss their history of fetal alcohol exposure," said Devon Kuehn, M.D., of the Epidemiology Branch of the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), the NIH institute involved in the study. "As a result, children might not be referred for appropriate treatment and services."

Dr. Kuehn conducted the study with NICHD colleagues Tonia C. Carter, Ph.D., Mary R. Conley and Jim Mills, M.D, as well as researchers at the National Heart, Lung and Blood Institute, the National Capital Consortium, in Bethesda, Md., and the University of Chile in Santiago.

Their findings appear online in *Alcoholism: Clinical and Experimental Research*.

The research was conducted as part of a long-term study of heavy drinking in pregnancy known as the NICHD-University of Chile Alcohol in Pregnancy Study. To conduct the study, the researchers asked over 9000 women at a community health clinic in Santiago, Chile about their alcohol use during pregnancy. They found 101 pregnant women, who had four or more drinks per day during their pregnancies and matched them with 101 women having similar characteristics but who consumed no alcohol when they were pregnant. After these women gave birth, the researchers evaluated the infants' health and conducted regular assessments of their physical, intellectual and emotional development through age 8.

The researchers documented differences in the rate of children affected in the following areas:

	Alcohol exposed	Unexposed
Abnormal facial features	17 percent	1 percent
Delayed growth	27 percent	27 percent
Cognitive delays (including intellectual)	35 percent	6 percent
Language delays	42 percent	24 percent
Hyperactivity	27 percent	2 percent

Reprinted from U.S. Department of Health and Human Services, National Institute of Health, Eunice Kennedy Shriver National Institute of Child Health and Human Development. NIH News (July 2012). <http://www.nih.gov/news/health/jul2012/nichd-23.htm>

A Parent's Story

By Terra Daniel

Briar was born on September 4, 2005. From the moment she was placed in our arms we knew she was ours. She seemed perfect in every way and had these huge, beautiful eyes that seemed to take in everything around her. She had her daddy, older sister, Téa, and I wrapped around her finger from the beginning.

As she grew older we started noticing that she wasn't as quick to do all that her older sister had done at the same age. Physically she was perfect – people would often stop me at the store to comment on her beauty. At 11 months we could tell she was delayed both physically and mentally and we started trying to figure out what was wrong.

One day, my husband said, "I wonder if Briar has Fetal Alcohol Spectrum Disorder." It was a word I had rarely heard and one that he was also unfamiliar with. We knew her birth mom had consumed alcohol but thought it was at an occasional party and had never pursued it any further. We pulled out Nicole's health history. On the forms she had written down that she drank alcohol daily for the first 5 months of gestation. It was an answer to our prayers. We will be eternally grateful that Nicole not only had the unconditional love to place Briar with our family but that she had the courage to be honest in her health history. Without her admission, we would not have been able to get a diagnosis for Briar or know what it was that was causing her to struggle in life. At just under a year, Briar was diagnosed with FASD and we started to learn about her invisible disability.

On the outside she looks like any other 5 year old but inside she is more like a 3 year old. She started walking at 22 months and after years of physical therapy she can now run and climb but is still learning how to jump. We are constantly working on her fine motor and gross motor skills – something we took for granted with Téa. She loves to play outside and every curb she finds to balance on or flower to pull petals off of has become a tool that helps in her development.

She has absolutely no understanding of cause and effect, whatsoever. When she gets frustrated and resorts to hitting or biting Téa, she doesn't understand why we get upset. It doesn't hurt her to do the biting or hitting so why does it hurt Téa? The girls recently had to go from a shared bed to bunk beds because Briar couldn't understand why she couldn't stay up and play when it was time to go to bed. If Téa would roll over to sleep, Briar thought it was a game and would jump on her, Téa would ignore her actions which would result in more hitting and biting to get Téa's attention. Recently we were eating at a local restaurant and my husband threw a piece of popcorn into the girl's mouth to see if they could catch it. Days later, we are still trying to help Briar understand that throwing food at the table is not appropriate.

Her speech is delayed but is improving with the help of a private speech therapist and daily "Mommy and Briar time" where we work on various speech concepts. We were walking down to the park the other day and she exclaimed, "Look! Big, blue car!" We all clapped and cheered at her huge accomplishment. Not only had she said the words audibly but she had been able to complete a thought process of seeing the car, processing the size and color of the car and then saying the thought out loud.

On the outside we look like any other family but take a trip to the grocery store or spend a few days with us and you will see that we have a set of unique challenges. We have really good days and we also have really bad days. The smallest things will set Briar off and when that happens it is a complete melt down, not just a tantrum that goes away after a few minutes. Too many noises, too many people, a change in a normal routine are all things that may or may not cause a meltdown. There usually are not any signs or warnings that a meltdown is about to occur.

When she is experiencing an overload, she will usually start crying, screaming, lie down on the ground and curl up as if by making herself smaller, it will all go away. As her mother, I see the confusion in her eyes and my heart breaks. The only way to calm her down is to pick her up, carry her to a quiet place and hold her in our arms and talk to her until she can see that she is okay.

You would think that after experiencing an average of 10 melt-downs a week, we would be stronger both emotionally and physically to pick her up and carry on. In reality, every time she “melts” something inside of me dies and I wish for a Fairy Godmother to come and take us away – away from the judgmental glares of other people in the store, the innocent comments of other children wondering “why she doesn’t talk like she should” and the feelings of inadequacy that I feel as her own mother.

Any chance at a successful meal time calls for all electronics to be shut off in hopes that Briar will be able to concentrate on her food without any distractions. She usually begins eating about the time we are all finishing. She is very possessive and has her own chair at the table and at the kitchen bar. If anyone uses one of the chairs at any time of the day it can cause a meltdown. She has her spot in bed and she is the only one who can lie in that specific spot. She sleeps in a pull up and nothing else because the feel of fabric against the sheets is too much to handle. In the morning, we have a routine we follow before going to school. If we deter from that routine, Briar will go to the usual next step and wait until we fall back into the correct order. If we push going about it a different way, she will have a meltdown.

Another commonality with FASD is known as the “Swiss cheese brain”. Some things are understood immediately while others fall through the holes. Some lessons are retained one day, even for weeks at a time and then can slip through the holes the next. Last year Briar could count from 1 to 5 and then she woke up one day this summer and couldn’t remember how to count at all. We are back to working on how to count to 5. For 20 months, we worked on saying her name every day, all day. One day she woke up and said, “My name Briar.” Tears sprang to our eyes as we heard our 4 year old daughter say her name for the first time and use it in a sentence! For 3 years, we have worked on potty training. This past summer, she understood it and completely grasped the concept. She has been in “big girl underwear” for two months now but has had a few days where she woke up and had no recollection of what it felt like to use the bathroom or why we need to keep our underwear dry. The next day, she was back to using the bathroom as if she had been potty trained for years.

While raising a child with FASD has its struggles, we have chosen as a family to not use it as an excuse or allow it to limit us in any way. Briar loves to go to the pool and slide down the water slide over and over and over again. She loves to play at the park, ride her bike, play with her friends and dance class is always a highlight in the week. We go out to eat, knowing that Briar will be unable to focus on her food but will love to see the activity going on around her. Briar loves to take our dog, Coco, for walks and if the walk outside isn’t long enough; we have learned to have her walk Coco around the kitchen until she is ready to let go.

People living with FASD face similar, yet very different struggles. There isn't a text book answer for what Briar's future looks like. We had to learn to stop stressing about what the future may hold and live in the moment that today offers.

Briar is now 5 years old and still has us all wrapped around her finger. We have been asked a few different times if we could go back if we would do things differently. There is absolutely nothing we would change. We have no doubt that God sent Briar to us because we were meant to be her parents. Briar has taught us patience, compassion and the importance of celebrating even the smallest of successes. Téa and Briar share a bond that is uniquely different, than any other sisters we have known. Briar knows she is safe and the world is ok when Téa is by her side. Téa knows that she is an instrumental part in showing Briar the way and guiding her throughout life. They are best friends. Briar is Cruz's little mommy, always making sure he is happy. Cruz loves to wrestle and follow Briar around as if he is her personal bodyguard. She loves to laugh and has a love for life that is an inspiration to all around her.

FASD was not part of our vocabulary until Briar came along. FASD is a disability that is 100% preventable and that is why we feel so passionate about sharing our story. We want others to know that there is hope and that, though limited, resources are available to anyone who may be affected by FASD. Prevention of FASD is extremely important but not nearly enough federal money or awareness is going towards intervention for the children, already affected that we are taking care of now.

We hope that FASD becomes a common household name so that everyone can become educated on the effects of alcohol use while pregnant. Loving a child with special needs changes the lives of everyone involved. We hope that by raising awareness, the public will become better educated, more compassionate and understanding when they interact with those affected by FASD. Briar will live with brain damage for the rest of her life. If her story helps one woman understand the effects her drinking may cause, resulting in a healthy child who may have otherwise been born with FASD, then our story was worth sharing.

GETTING HELP

An early diagnosis, appropriate services, and a stable home can greatly improve the health outcomes for individuals with Fetal Alcohol Spectrum Disorder. No two people with FASD are exactly alike and symptoms can range from mild to severe. Generally, children with FASD are at increased risk for chronic physical, developmental, behavioral or emotional conditions and require health and related services of a type or amount beyond that required by children generally. Treatment services for people with FASDs should be different for each person depending on their symptoms. Look at multiple services and supports for help. Services may include medical care, early intervention or school services and training for parents.

Medical Care

An early diagnosis is important. Because most people with FASD have no visible signs of alcohol exposure, the child's problems may be wrongly blamed on poor parenting or other disabilities. Early diagnosis and interventions contribute to positive long-term outcomes. Accurate diagnoses can:

- Help the person receive appropriate services.
- Aid communication among clinicians, caregivers, educators, and families.
- Provide better self-awareness and understanding by family members.

Pediatricians are the first professional to see the child and hear the concerns of parents. Pediatricians are in a unique and central position to identify developmental concerns early and refer children at risk for further evaluation and treatment. You will need a referral from your pediatrician for evaluation and diagnosis.

FASD is not a particular disorder but refers to several conditions including a diagnosis of Fetal Alcohol Spectrum, Alcohol-Related Neurodevelopmental Disorder and Alcohol-Related Birth Defects. An expert trained to assess birth defects and FASD can make a diagnosis including a geneticist or neuropsychologist. A Neuropsychologist is a licensed psychologist with additional specialized training in “brain behavior relationships.” Tests usually include a complete physical (which includes height, weight, vision, hearing, cardiogram, etc.), evaluation of the face, and an IQ test (WISC, Woodcock Johnson, WAIS). Occupational therapy, speech, neurologic and psychiatric evaluations can be used.

For diagnoses and treatment in Utah you contact the following:

- **Children’s with Special Health Care Needs**, Utah Department of Health
Phone: 801-584-8284 to toll free at 800-829-8200
Website: <http://www.health.utah.gov/cshcn/>
- **Cottonwood Treatment Center**
Phone: 801-433-2920
Website: <http://www.cottonwoodtreatment.com/fasd.htm>
- **Mary K. Hales, PhD.**, Clinical Neuropsychologist
Email: mary.hales@neurodynamics.biz
- **University of Utah – Division of Medical Genetics**
Phone: 801-581-8943
Website: <http://healthcare.utah.edu/pediatrics/Genetics/>

Individuals with FASD have problems in multiple areas and can benefit from a medical home model. A medical home is a partnership formed between the parents, child, and doctor. The doctor treats you as a partner and shares information about your child’s care. The doctor’s office coordinates care, talks to the different specialists that your child sees, organizes services, tests, medications, information about community resources and makes referrals when you need them. Ask your pediatrician if he/she uses a medical home approach. For more information about a medical home contact Utah Family Voices at 801-631-1609 or Toll Free 800-468-1160.

How Do I prepare?

It will help to record your child’s history and behavior and make copies of written reports. Include a list of all providers, services provided, and date of services provided. Bring documents and photos of your child at various ages. Areas to include:

- History of prenatal alcohol exposure
- Child’s growth pattern
- Physical characteristics, such as atypical facial features
- Medical history, such as illnesses, surgeries, and vision or hearing problems
- Signs of central nervous system damage such as behavior problems, memory or learning problems or poor impulse control

When a team of providers is involved, make sure each receives all current and appropriate information about the individual. For help with keeping track of medical information download the Collaborative Care Notebook from the Utah Medical Home Portal at <http://www.medicalhomeportal.org/living-with-child/caring-for-children-with-chronic-conditions/managing-and-coordinating-care/care-notebook>

Early Intervention Services

If your baby or child has developmental delays you may want to consider Early Intervention Services. Early intervention can identify and respond to concerns about a baby's or toddler's development by providing supports that will minimize potential effects of the child's developmental delays and maximize healthy development. Baby Watch Early Intervention Program services may begin at any time between birth and age three; however, when early intervention is needed, the earlier it is provided, the better the outcome for the child and family. For referral and a list of Early Intervention Programs go to www.UtahBabyWatch.org or call 1-800-961-4226.

Early intervention can provide the following:

- **A Multidisciplinary Team Meets with the Child and Family** to evaluate the child's developmental strengths and needs. Results are shared with the family in their native language and in writing.
- **When a Child Is found Eligible**, the family works with their service coordinator to choose what they want their child to work on and the goals for their family. Together with their early intervention team, they develop a plan of services called the Individualized Family Support Plan (IFSP) and supports to help reach those goals.
- **Baby Watch Early Intervention Staff Coach the Family** on ways to teach their child new skills. Family members and other caregivers use these techniques during regular activities throughout the day.
- **Children Leave the Baby Watch Early Intervention Program** when they no longer need early intervention services or when they reach age 3. At 3, a child may qualify for **special education preschool** or be referred to other community programs.

Parents can receive support and training about the Early Intervention Process and developing the IFSP by contacting the Utah Parent Center at 801-272-1051.

School Services

For some children, growing up can be very hard to do! When a child is having trouble in school, whether it is academic problems such as difficulty reading or doing math or having trouble with their behavior it's important to find out why. The child may have a disability. Under the law, the Individuals with Disability Act (IDEA) provides for the following:

- **Free Appropriate Public Education (FAPE):** The right to FAPE means special education and related services are available to eligible children with disabilities age 3 to 22 and are provided at no cost to the parents. The specially designed educational programs and services reflect the child's individual education needs, and are provided in conformity with the Individualized Educational Program (IEP).

- **Evaluation:** To determine eligibility, an appropriate evaluation gathers information. The evaluation needs to be in “all areas of suspected disability.” This evaluation identifies the student’s strengths and educational needs.
- **Individualized Education Plan (IEP):** If a child qualifies an IEP is written. The IEP is a legally binding, written document that outlines the special education program, services and related services based on the individual child’s educational needs.
- **Parent and student participation in decision making:** Parents be given the opportunity to play a central role in the planning and decision making process regarding their child’s education. Parents must have the opportunity to participate in the meetings regarding identification, evaluation, educational placement and the provision of FAPE to the student.
- **Procedural due process:** The guarantee of procedural due process means that there are safeguards designed to protect the rights of the parents and their children with disabilities, as well as to give families and schools a mechanism for resolving disputes.

For more information see “Parents As Partners in the IEP Process” at http://www.utahparentcenter.org/wp-content/uploads/2011/08/IEP_Parent_Handbook.pdf or call UPC at 801-272-1051.

Parent Training

Children with FASDs might not respond to the usual parenting practices. Parent training can increase parent’s success by educating parents about his/her child’s disability, ways to teach their child many skills and help them cope, and providing information on service systems parents need to access for his/her child with FASD. Parents can also benefit from local support groups, in which parents of children with FASDs can discuss concerns, ask questions, and find encouragement. Families might also need support from a family counselor or therapist.

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

- Concentrate on your child’s strengths and talents
- Accept your child’s limitations
- Be consistent with discipline, school and behaviors
- Focus on positive behavior supports often (praise, incentives)
- Use stable routines that do not change daily
- Keep it simple
- Be specific--say exactly what you mean
- Model for the child what you want him/her to do
- Use visual aids, music and hands-on activities
- Supervise and simplify visits to stores, routines, visits from family and friends

For parent training and support refer to:

Utah Parent Center

Phone: 801-272-1051
Toll Free 800.468.1160
Website:
<http://www.utahparentcenter.org>

Utah Family Voices

Phone: 801-272-1068
Toll Free: 1-800-468-1160
Website:
www.medhomeportal.org

Utah Fetal Alcohol Coalition

Website:
<http://www.fetalalcohol.org>

A Parent's Story

UNDERSTANDING SENSORY ISSUES

By: Chris H Stuart

There were times when my daughter's behavior was termed unprecedented, meaning without cause, just a sudden unpredictable negative action such as yelling at me or a sudden slug to my shoulder displaying angry disrespectful behavior.

My daughter now age 27 received a diagnosis of Fetal Alcohol Effects at age 16. It would have been so helpful to receive an early diagnosis and begin to understand her sensory issues at an early age. Finally we were able to begin to understand her behavior by reading about sensory integration issues that may accompany FASD. It was most helpful when my daughter began reading about it. She was not aware that the way she took in information was different from the way others could acquire information.

Through an audiologist and an occupational therapist trained in sensory integration, we were able to learn that she had an auditory discrimination deficit equaling a 60% hearing loss. She also could hear secondary noise that others tune out as primary auditory input. Therefore someone turning a page or tapping a pencil from the back row, even though she was seated on the front row, would over-ride the teacher's voice. We learned that she did a great deal of lip reading so when a teacher turned to write on the board and continued with the lecture she was not able to connect the message on the board with what was being said. We learned that she had no peripheral vision and her eyes were not able to look directly straight ahead without first bouncing to several unwanted locations before arriving at the destined location such as the board at the front of the classroom making copying work next to impossible.

Unprecedented behavior began to disappear. Instead of yelling or giving me an angry slug in the shoulder she was able to say, "Mom, remember when you file your nails? I can't hear what dad is saying. She was able to develop peripheral vision through motion therapy. A well trained OT was able to learn which pitches within normal voice range and identify pitches she was hypersensitive to. Her auditory sensory issues were diminished by 15% through music and motion therapy at Sensory Dynamics in West Jordan, Utah. Since that time I've learned there are other motion therapy locations available.

Though challenged by sensory integration issues, frustration can be replaced with understanding through identification of sensory processing. That is when we begin to build on strengths and assist areas of need.



Preparing Youth and Young Adults with FASD to Living Independently

With good transition planning and the use of supports and services adults with Fetal Alcohol Spectrum Disorders (FASD) can be successful in adulthood. Most adults with 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

CAN PEOPLE WITH AN FASD LIVE INDEPENDENTLY?

A supportive community is important for everyone, but it is essential for people with 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 FASD should start planning early for the transition to adulthood, when eligibility for school services will end.

Most adults with FASD will need help to meet the routine demands of work, home and living in the community. Areas where assistance may be important include employment, soft job skills, further education and training, independent living skills such as money management, grocery shopping, cooking, etc.; and access to medical services.

Many individuals with FASD 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.²
- The box shows the percentages that require help with other daily tasks.

-
- | | |
|--------------------------------|------------------------------------|
| • Getting social services, 70% | • Staying out of trouble, 47% |
| • Getting medical care, 66% | • Structuring leisure time, 47% |
| • Having relationships, 56% | • Keeping clean, 36% |
| • Shopping, 52% | • Using public transportation, 24% |
| • Cooking meals, 49% | |

HOW CAN YOUTH BECOME SUCCESSFUL ADULTS?

School Services

Planning for a career should begin in school. If a student is on an Individualized Education Plan (IEP) transition planning should begin no later than age 16 and earlier if needed. If the student is on a Section 504 Plan, transition planning takes place with the Student Educational Occupational Plan (SEOP). Transition services refer to a coordinated set of activities for a student designed to assist students with disabilities as they move from school into the adult world. Post school outcomes should be set in employment, further education or training, and independent living. The coordinated set of activities is based on the individual student's needs. The student's strengths, preferences and interests should be taken into account. The activities include courses of instruction, related services, community experiences, the development of employment and other post school adult living objectives, and if appropriate, the acquisition of daily living skills and a functional vocational evaluation. For more information on transition services see the UPC Website, "*Transition to Adult Life – 'From 'No Where' to 'Know Where'*" and the *IEP Handbook* at <http://www.utahparentcenter.org/publications/handbooks/>.

Employment Services

Appropriate training and assistance can help youth and adults with an FASD find and hold jobs.

- The Utah State Office of Rehabilitation (USOR) mission is to assist eligible individuals in obtaining employment and increasing their independence. Rehabilitation Services include counseling and guidance, assessment and evaluation for services, training and education for a job, job placement, and follow up services. Offices are located throughout the State of Utah. For services see <http://www.usor.utah.gov/division-of-rehabilitation-services>.
- The Utah Department of Workforce Services (DWS) provides accessible employment related services and support **services** responsive to the needs of employers, job seekers, and the community. DWS provides workshops on resume writing, job searching and technology, job interviewing, and networking. You can look up careers, availability in Utah and the average wage. For information see <http://jobs.utah.gov/>.

Further Education or Training

Once a teen leaves high school he/she might want to consider further training or education to help them with his/her career. Vocational Rehabilitation can provide on-the-job training, job coaching and supported employment. For further education on a particular career the youth can look into Utah's Centers for Applied Technology (UCAT) or a college or university. If the student struggles because of his/her disability he/she can seek accommodations and supports through the UCAT Student Center, ADA Services or on college campuses, Disability

Resource Centers. For further information go to <http://www.utah.gov/education/colleges.html>.

Medical or other Supports

"The physician's prime responsibility is the medical management of the young person's disease, but the outcome of this medical intervention is irrelevant unless the young person acquires the required skills to manage the disease and his/her life." [Ansell: 1998] When a youth turns age 18 he or she becomes the responsible adult when dealing with adult services or medical concerns. To be able to navigate the medical system he/she must learn to manage health conditions; access needed services and resources; move from a pediatrician to an adult provider, be able to discuss his/her disability and access health care coverage. Parents and health care providers can start early to empower youth with information and resources to proactively manage their care and to plan for the future. For more information go to the Utah Medical Home Portal at <http://www.medicalhomeportal.org/>.

If a young adult with FASD is not covered by health insurance he/she may want to consider Medicaid or the Primary Care Network (PCN). Medicaid is a federal program, administered by individual states, that covers the cost of medical care. To qualify for Medicaid benefits, income and assets must be below a certain level. For more information on Medicaid go to http://health.utah.gov/medicaid/provhtml/general_info.html. The Primary Care Network (PCN) is a health plan offered by the Utah Department of Health. It covers services administered by a primary care provider. Enrollment for PCN opens once a year. For further information go to <http://www.health.utah.gov/pcn/>.

People with FASD 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. For more information see <http://ssa.gov>.

Youth and young adults with FASD can become successful adults with the support of parents, educators and service providers. Start early on preparing your youth to live independently in his/her community! For further information or referral to services you can contact the Utah Parent Center at 801-272-1051.

ⁱ U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Substance Abuse Prevention, SAMSA, Fetal Alcohol Spectrum Disorders Center for Excellence, *Independent Living for People with Fetal Alcohol Spectrum Disorders*. http://www.fasdcenter.samhsa.gov/documents/WYNKIndLiving_6_colorJA_new.pdf

ⁱⁱ Streissguth, A., and Kanter, J., eds. 1997. *The Challenge of Fetal Alcohol Spectrum: Overcoming Secondary Disabilities*. Seattle: University of Washington Press.

Adopting and Fostering Children with Fetal Alcohol Spectrum Disorders

Parenting has been called the toughest but most fulfilling job in the world. Parenting children with special needs, such as fetal alcohol spectrum disorders (FASD), brings its own set of challenges.

Many parents of children with FASD are adoptive or foster parents. Some knew about FASD when they welcomed their children into their family, while others did not. In any case, information is the key to raising children with FASD.

Learning about FASD can help parents understand how their children are affected, which parenting strategies work best, and how to get services and support. For people who want to adopt or foster a child with an FASD, knowing the facts can help them make an informed decision. A child with FASD is likely to need an evaluation and services throughout his or her life and may never be able to live independently.

There is little information available about FASD and adoption or foster care. One study of children in foster care in Washington State revealed a rate of FASD 10 to 15 times higher than in the general population, suggesting that children in foster care are more likely to have an FASD.³ Estimates of international adoptions vary by country. In Russian orphanages, the rate of FASD alone has been estimated at 1 to 10 per 100.ⁱ

Despite the challenges, children with FASD have a number of strengths. For example, they tend to be caring, creative, determined, and eager to please. They also respond well to structure, consistency, concrete communication, and close supervision. With a supportive home, an early diagnosis, and appropriate services, many children with FASD can avoid secondary disabilities and reach their full potential.ⁱⁱ

Gathering Information

Many children who have an FASD lack an accurate diagnosis and their problems may not be clear. Prospective parents may request a copy of a child's complete medical and family history. However, because records may not tell the whole story, they may also ask specific questions about:

- Possible prenatal exposure to alcohol or drugs
- The physical and mental health of the mother and any siblings

- The developmental history of the child, including possible delays
- Independent evaluations from a physician

Most States require adoption and foster care agencies to share information with prospective parents about the health and social history of the child and birth parents. Some States require more information sharing than others, but few specifically address alcohol.ⁱⁱⁱ Full investigation and disclosure is best for everyone so that placements are successful, parents are prepared, and children get the help they need.

CONCLUSION

Parenting offers many rewards, despite its hurdles. Those who choose to become a parent or caregiver to a child with an FASD experience great joy along with the challenges. The child can benefit from a stable, loving home with parents and caregivers who understand his or her needs. Ultimately, adoptive and foster parents can change the outlook for individuals with an FASD, one day at a time.

Duplicated from *“Adopting and Fostering Children with Fetal Alcohol Spectrum Disorders,”* U.S. Department of Health and Human Services, Substance Abuse and Mental Health Service Administration, Center for Substance Abuse Prevention, www.samhsa.gov

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^{iv} U.S. Department of Health and Human Services. Administration for Children and Families, National Adoption Information Clearinghouse. 2003 Adoption State Statutes-at-a-Glance. Collection of Family Information About Adopted Persons, Birth Parents and Adoptive Parents, <http://noic.acf.hhs.gov/general/lega/statues/collection.pdf>

Tips for Adopting or Fostering Children Who are Prenatally to Alcohol or Other Drugs

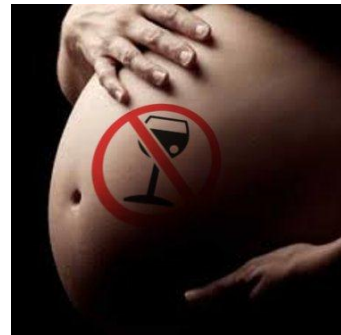
1. Work with informed professionals in quality adoption agencies.
2. Explore your feelings about alcohol and drug abuse, particularly among pregnant women.

3. Discuss the child's background with your social worker so that you have a realistic picture of the birth parents' substance use and related lifestyle.
4. Ask for written summaries of the child's diagnoses, medical complications, treatment services, and necessary follow-up care.
5. Ask for information on services and resources to meet the child's needs, including eligibility for adoption subsidies and Medicaid.
6. Find out how to reduce the impact of the child's biological risks by providing a nurturing, responsive, and healthy care giving environment.
7. Recognize that you must be prepared for and able to tolerate the uncertainties that are part of adopting a child prenatally exposed to drugs or alcohol.
8. Resist negative stereotypes of children prenatally exposed to drugs or alcohol, which ignore the individuality of each child and the role of a healthy environment.
9. Recognize the importance of timely identification of problems and early intervention

Adapted from Edelstein, S. 1995. *Children With Prenatal Alcohol and/or Other Drug Exposure: Weighing the Risks of Adoption*. Washington, DC: CWLA Press.

When You Are Pregnant

Approximately 1 in 8 women each year drink alcohol while pregnant, according to a 15 year study by the Centers for Disease Control and Prevention. The study also found that 1 out of every 50 pregnant women engaged in binge drinking each year. Any alcohol use was defined as at least one drink of an alcoholic beverage in the past 30 days and binge drinking was defined as having five or more drinks on at least one occasion in the past 30 days. Alcohol is one of the most widely abused substances during pregnancy, and its effects on fetal development and damage to a developing fetus have been well researched. Every time a pregnant woman has a drink, her unborn child has one, too. Alcohol passes easily through the placenta from the mother's bloodstream into the baby's blood – and put's her fetus at risk of having a fetal alcohol disorder. The blood alcohol level of the unborn baby becomes equal to or greater than the blood alcohol level of the mother. Because the unborn baby cannot break down alcohol the way an adult can, its BAC remains high for a longer period of time.



Since 2005 the U.S. Surgeon General has stated that “it is now clear that no amount of alcohol during pregnancy can be considered safe.” Based on the current, best science available we now know the following:

- Alcohol consumed during pregnancy increases the risk of alcohol related birth defects.
- There is no known safe time to drink alcohol during pregnancy. Alcohol can damage a fetus at any stage of pregnancy. Damage can occur in the earliest weeks of pregnancy, even before a woman knows that she is pregnant.
- The cognitive deficits and behavioral problems resulting from prenatal alcohol exposure are lifelong.
- Alcohol-related birth defects are 100% preventable.

Drug Abuse and Pregnancy

More than 5 percent of the 4 million women who gave birth in the United States in 1992 used illegal drugs while they were pregnant, according to the National Institute on Drug Abuse (NIDA) survey of drug use among pregnant women. Prescription substance abuse during pregnancy has tripled according to the National Institute of Health.

Similar to alcohol use, use of other substances can have significant effects on the developing fetus. For example, cocaine or marijuana use during pregnancy may result in premature birth, low birth weight, decreased head circumference or miscarriage. Prenatal exposure to marijuana has been associated with difficulties with brain functioning. Even if there are no noticeable effects in the children at birth, the impact of prenatal substance use often become evident later in their lives. Children who were exposed to cocaine prenatally can have difficulty focusing their attention, be more irritable, and have more behavioral problems. Prenatal exposure to methamphetamine can cause a wide range of problems including birth defects, fetal death, premature birth, low birth weight, developmental disorders, behaviors, learning disabilities and hypersensitivity to touch in newborns. There has been an increase of mothers taking prescription drugs, including painkillers like Oxycontin and Vicodin, and anti-anxiety drugs like Xanax during pregnancy. Medications during pregnancy can be dangerous to the baby

Consider the following . . . nearly half of all pregnancies are unplanned and many women do not know they are pregnant for several weeks during which time they may drink alcohol or abuse substances.

For these reasons:

- A woman who is considering becoming pregnant should abstain from alcohol. Use the motto “not one drop.”
- A pregnant woman who has already consumed alcohol during her pregnancy should stop in order to minimize further risk.
- Recognizing that nearly half of all births in the United States are unplanned, women of childbearing age should consult their physician and take steps to reduce the possibility of prenatal alcohol exposure.

- Women who use alcohol or illicit drugs may find it difficult or seemingly impossible to stop, even when they are pregnant. Moreover, pregnancy can be stressful and uncomfortable. Don't avoid seeking treatment or adequate prenatal care because of substance abuse problems.
- Health professionals should inquire routinely about alcohol consumption by women of childbearing age, inform them of the risks of alcohol consumption during pregnancy, and advise them not to drink *one drop* of alcoholic beverages during pregnancy.
- ¹ Streissguth, A.P., Bookstein, F.L., Barr, H.M., Sampson, P.D., O'Malley, K., Young, J.K. Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Developmental and Behavioral Pediatrics*. 2004;5(4):228-238.
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NIDA Survey Provides First National Data on Drug Use During Pregnancy, (Vol. Volume 10, Number 1

January/February 1995), U.S. Department of Health and Human Services, The National Institute on Drug Abuse (NIDA) is part of the National Institutes of Health (NIH) http://archives.drugabuse.gov/NIDA_Notes/NNVol10N1/NIDASurvey.html

FASD Resources

FASD ONLINE RESOURCES

- ✧ **Centers for Disease Control and Prevention (CDC) Fetal Alcohol Syndrome** - Facts; questions and answers; treatment options; data and statistics; research; articles; outreach materials; links; and more. <http://www.cdc.gov/ncbddd/fasd/index.html>
- ✧ **FASCETS** - The Fetal Alcohol Syndrome Consultation, Education and Training Services, Inc., is a non-profit organization that has resources, articles, books (Trying Differently Rather Than Harder), and more. <http://www.fascets.org>
- ✧ **FAS Diagnostic & Prevention Network (FAS DPN)** - Washington state network of clinics with information, training, professional articles, diagnostic codes, links, and more on FAS. <http://depts.washington.edu/fasdpn/>
- ✧ **March of Dimes** - Information about preventing birth defects and having healthy babies. <http://www.marchofdimes.com>
- ✧ **National Institute for Alcohol Abuse and Alcoholism (NIAAA)** - News and events; publications; research; clinical trials; links; and more. <http://www.niaaa.nih.gov>
- ✧ **National Organization on Fetal Alcohol Syndrome (NOFAS)** - Sections for families, professionals, educators and others that contain information about FASD; financial and other support services; professional education and patient education materials; advocacy information and events; special education information and resources, newsletters and much more. <http://www.nofas.org>
- ✧ **SAMHSA FASD Center for Excellence** - FASD information, publications, training, FAQ's, links and more from the National Center <http://www.fasdcenter.samhsa.gov>
- ✧ **Utah Fetal Alcohol Coalition** – FASD information, publications, training and events, local resources Utah Resources. <http://utahfetalalcohol.org>

UTAH RESOURCES

- ✧ **211 Information and Referral Center** - Find local community services online or dial 211 to talk to an operator. <http://www.uw.org/211>
- ✧ **Allies With Families** - Empowering families with voice, access and ownership. They offer real life experience, practical resources and training for parents as advocates. For more information, call 801-433-2595 or toll-free 877-477-0764. <http://www.allieswithfamilies.org>
- ✧ **Baby Your Baby** - Find financial help during pregnancy and information to help you have a healthy pregnancy. <http://www.babyyourbaby.org>
- ✧ **Clean Start Program** - For information, call Weber Human Services at 801-778-6811 or 801-625-3700. <http://weberhs.org/home/WHSServices.htm>
- ✧ **Children with Special Health Care Needs** - Clinics with screening and diagnostic services for children with developmental delays and chronic conditions. <http://health.utah.gov/cshcn/>

- ✧ **Davis Family Advocate Program** - Provides case management, outreach, and referrals. Call 801-776-0054 or after hours 801-773-7060.
<http://www.medicalhomeportal.org/resources/services/provider/12672>
- ✧ **Disability Law Center** - Helps to enforce and strengthen laws that protect the opportunities, choices and legal rights of people with disabilities in Utah. For more information, call 801-363-1347 or toll-free 800-662-9080.
<http://disabilitylawcenter.org>
- ✧ **Division of Services for People with Disability (DSPD)** - Promote opportunities and provide support for persons with disabilities to lead self-determined lives. Support includes community living, day services, supported employment services, and support for people with disabilities and their families. For information call 1-800-837-6811. <http://www.dspd.utah.gov>
- ✧ **House of Hope** - Formerly the Utah Alcoholism Foundation, this organization provides treatment and other services for women, children, and families including parenting skills education, individualized treatment, vocational training, and more.
<http://houseofhopeut.org>
- ✧ **NAMI Utah** - The National Alliance on Mental Illness, Utah Chapter's mission is to ensure the dignity and improve the lives of those who live with mental illness and their families through support, education and advocacy. For more information call 801-323-9900. <http://www.namiut.org>
- ✧ **Pregnancy Risk Line** - This free, private, and easy-to-use telephone information service answers questions about medicines, drugs, chemicals, and other environmental exposures, during pregnancy and breastfeeding, that can potentially harm an embryo, fetus, or infant. For more information call 1-800-826-9662.
<http://www.babyyourbaby.org/expert-advice/pregnancy-riskline.php>
- ✧ **Treatment Providers** - The Division of Substance Abuse and Mental Health (DSAMH) in Utah has a locator map to help families find a local treatment provider.
<http://www.hsmh.utah.gov/locationsmap.htm>
- ✧ **Utah Department of Workforce Services (DWS)** - Provides accessible employment related and support services responsive to the needs of employers, job seekers, and the community. <http://jobs.utah.gov>
- ✧ **Utah Family Voices** - Provides support for families of children with disabilities and is run by parents of special needs children. Support services includes fact sheets, support groups, training, care notebooks, conferences, listserv, and more. For more information call 801-272-1051 or Toll Free at 800-468-1160.
<http://www.utahfamilyvoices.org>
- ✧ **Utah Fetal Alcohol Coalition** – FASD information, publications, training and events, local resources Utah Resources. <http://utahfetalalcohol.org>
- ✧ **Utah Newborn Safe Haven** - Provides information about the Utah law that allows the safe relinquishment of newborns by the mother to a 24 hour hospital. Also has a hotline telephone number for questions and list of local hospitals. For further information call 1-866-458-0058. <http://www.utahsafehaven.org>

- ✧ **Utah Parent Center** - Resources for parents of children with disabilities in Utah including resources about autism, working with schools and more. For more information call 801-272-1051 or Toll Free at 800-468-1160
<http://www.utahparentcenter.org>
- ✧ **Utah State Office of Education, Special Education Services** – Provides leadership and support for educators, parents, and students with disabilities receiving special education and related services throughout Utah public schools and communities.
<http://www.schools.utah.gov/sars/>
- ✧ **Utah State Office of Education, Educational Equity** – Provides information and guidance on Section 504 to educators, parents and students on Section 504 or the Rehabilitation Act of 1973
<http://www.schools.utah.gov/equity/Civil-Rights-Information/Section-504>
- ✧ **Utah State Office of Rehabilitation (USOR)** - Assists eligible individuals in obtaining employment and increasing their independence. For more information call 801-538-7530 or Toll-Free 1-800-473-7530. <http://www.usor.utah.gov>
- ✧ **Work Ability Utah** - Creates a comprehensive, consumer-responsive system of work supports that increases employment outcomes for individuals with disabilities in Utah. <http://www.workabilityutah.org>

USEFUL TOOLS

- ✧ **Drinking and Reproductive Health: A Fetal Alcohol Spectrum Disorders Prevention Tool Kit** - Continuing education for providers that provides a FASD overview, screening guidelines, FAQs, contraception information, resources, and more including a CD. From the American College of Obstetricians and Gynecologists and the CDC. <http://utahfetalalcohol.org/pdf/FASDToolkit.pdf>
- ✧ **Information for Educators** - Tools and information about fetal alcohol spectrum disorders (FASDs) for educators including a FASD Toolbox for Educators from the CDC <http://www.cdc.gov/ncbddd/fasd/educators.html>
- ✧ **FASD Resources for Police Officers** This guidebook is part of a program designed to increase your awareness of disabilities caused by pre-natal exposure to alcohol and to help you be more effective in your investigations when dealing with individuals with FASD. <http://www.asantecentre.org/Library/docs/latestfasguide.pdf>
- ✧ **Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis** - These guidelines are intended to assist physicians and allied health professionals in the timely identification, referral, and diagnosis of persons with fetal alcohol syndrome. From the CDC and National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect. http://www.cdc.gov/ncbddd/fasd/documents/FAS_guidelines_accessible.pdf
- ✧ **Fetal Alcohol Syndrome: A Parents Guide to Caring for a Child Diagnosed with FAS** - A 40-page document with an overview of FAS, early intervention information, school issues information, IEP helpful hints, and more.
- ✧ **Medical Information Card** - This card, with information about FAS and legal rights, can be carried by a person with FASD and given to police, from the [University of Washington Fetal Alcohol and Drug Unit](http://www.utahfetalalcohol.org/pdf/MIfPsmall.pdf)<http://www.utahfetalalcohol.org/pdf/MIfPsmall.pdf>

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Utah Parent Center

{ If your child has special needs,
so do you! } *We can help!*

www.utahparentcenter.org

1-800-468-1160

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Email: upcinfo@utahparentcenter.org • Website: www.utahparentcenter.org

Our Mission: To help parents help their children with disabilities to live included, productive lives as members of the community. We accomplish this through the provision of information, training, and peer support.

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