

Fetal Alcohol Spectrum Disorders (FASDs) and Fetal Alcohol Syndrome (FAS) at a Glance

Alcohol, when ingested by a pregnant woman, can produce a wide array of complications in the growing fetus. Fetal Alcohol Spectrum Disorders (FASDs) is an umbrella term that includes several diagnoses that result from prenatal alcohol exposure. Although not strictly genetic, we felt that it would be helpful to include this common condition caused by exposure during pregnancy. FASDs include a wide variety of physical, intellectual, behavioral, and developmental effects seen in people who were exposed to alcohol before they were born. These disabilities vary from very mild to very severe. Variability depends on many things including amount of alcohol, timing of exposure, etc.

The National Organization on Fetal Alcohol Syndrome (NOFAS) states that 1 in 100 infants born each year are affected by FASDs.

FASD includes Fetal Alcohol Syndrome (FAS). FAS is defined by specific differences in growth, facial features, and central nervous system functioning *as well as* a documented prenatal history of alcohol consumption. The specific physical findings are what distinguish FAS from FASDs.

On these pages, we will use the term FASDs to represent findings for both conditions.



Meet Tori on page 15.

1. Medical / Dietary Needs

The list of possible medical problems in FASDs can be extensive. However, each individual usually has only some of these problems. Also, the severity of any one of these medical problems varies widely between individuals. Therefore, it is important to ask the parents about the medical issues in their child.

No special diet is required for FASDs, although a well-balanced diet is important.

School age children with FASDs may have annual doctor and specialist visits to monitor medical conditions. Be aware of potential seizure activity, and heart, skeletal, vision, hearing, kidney, liver, and dental issues.

- Routine management of middle ear infections and monitoring of hearing should be undertaken

Physical characteristics and/or symptoms:

Not all people with FASDs have all of these characteristics.

Fetal Alcohol Spectrum Disorders (FASDs) are often diagnosed based on the complete set of characteristics in an individual. The effects of FASDs can vary in their presentation over the course of an individual's lifespan. The characteristics that may be seen in individuals with FASDs at different times in their lives may include:

Growth Deficiency

- In height
- In weight
- In both height and weight
- Small size until puberty when "catch up" growth is common

Specific Facial Characteristics (These are often most notable in Fetal Alcohol Syndrome)

- Smooth philtrum (The philtrum are the two vertical ridges between the nose and mouth.)
- Short palpebral fissures (Palpebral fissures are the openings for the eye between the eyelids.)
- Thin upper lip
- Flat midface
- Short upturned nose
- Underdevelopment of the upper ear

Central Nervous System Dysfunction

- Microcephaly (small brain size)
- Tremors
- Seizures
- Hyperactivity
- Attention deficits
- Impulsivity
- Distractibility

- Difficulty with abstraction
- Challenges with
 - Gross Motor
 - Fine Motor
 - Sensory integration
 - Memory
 - Processing information
- Learning disabilities
- Developmental delays
- Intellectual disabilities

Other Physical Effects

- Heart defects
- Skeletal defects
 - Fused bones in arms, fingers, hands, and toes
- Vision and hearing problems
- Kidney and liver defects
- Dental abnormalities

What you can do

- A yearly check-up and studies as needed should occur in the child's Medical Home.
- Be aware of any changes in behavior or mood that seem out of line with the situation and notify the parents.
- Be aware of any physical changes or medical issues that might arise.
- It is important to be aware of any academic changes. Contact parents when any differences are noticed.

2. Education Supports

What you need to know

Children with FASD usually show some degree of language disability or delayed language development. They often have significant problems in communicating regardless of whether or not their general development is delayed. This difficulty with language affects social communication and academic learning.

Students with FASDs may have trouble understanding higher order language and have difficulty conveying their message. Many times, children with FASDs have a hard time differentiating between talking and communicating.

Individuals with FASDs may have many learning challenges.

- They often have higher rates of learning disabilities and problematic classroom behaviors.
- Some individuals with FASDs have low IQ (intellectual disability), but many individuals will have normal or above average IQs.
- An individual's challenges are often more severe than what would be predicted by their cognitive abilities.
- They often have better performance in reading and language, and poorer ability in math.

Individuals with FASDs often have strengths which can help them overcome their challenges.

- It is important to remember that not every individual with FASDs will have the same strengths and weaknesses. The effects are very individualized and specific to each person.

Challenges can occur in many obvious and subtle areas of development.

General overview of potential areas of difficulty

- Cognitive
- Executive functioning
- Behavioral impairments
- Verbal and spatial learning
- Planning
- Working memory
- Cognitive flexibility
- Inhibition
- Problems solving
- Reading
- Spelling and math skills
- Discrepancy between high verbal skills and inability to communicate effectively

Specific areas of difficulty that may occur

- **Visual and Auditory processing**
 - Individuals may not respond to traditional teaching methods
 - They may act out when frustrated or lose control with sensory overload
- **Language**
 - Skills often appear much greater than the child's actual ability to communicate effectively
- **Executive Skills**
 - Executive skills (sometimes referred to as executive functions) are those processes which allow an individual to manage themselves and their resources in order to achieve a goal.
 - These are high level cognitive functions that allow individuals to organize their behavior through planning and organizing
 - Individuals need to be able to sustain attention, persist to complete a task, manage emotions, and monitor thoughts to work efficiently
 - Executive skills have been defined as the directive capacities of the mind, which cue the use of other mental abilities
 - These skills are controlled by the frontal lobes of the brain. The brain damage caused by prenatal alcohol exposure can affect the frontal lobes of the brain, which in turn causes executive dysfunction.
- **Inhibition Difficulties**
 - Inhibition is the ability to stop you from responding to distractions and to think before acting
 - It also includes the ability to resist the urge to say something, or the ability to delay gratification in the present for more important, long-term goals
 - Signs of inhibition difficulties
 - Easily distracted
 - Impulsive
 - Interrupts
 - Chooses smaller, immediate reward over a larger, delayed reward
 - Gives up quickly on difficult or challenging tasks
 - Begins tasks without having listened to or read all the instructions
 - Answers questions quickly and then changes their answers
 - Talks back
 - Difficulty waiting for their turn
- **Flexibility**
 - Flexibility is the ability to move smoothly from one situation or task to another and the ability to respond appropriately to the new situation or task

- Signs of flexibility challenges
 - Persists in one approach to a situation/problem
 - Unable to explore multiple approaches to a problem or task
 - Difficulty with open-ended questions or tasks
 - Becomes easily frustrated with changes in plans, routines, or situations
 - Younger children may exhibit temper tantrums when faced with a change of situation or task
 - Difficulty adjusting when the directions for a task *change* during the task
- **Emotional control**
 - Emotional control refers to the individual's ability to manage their emotions
 - It is important to be able to control emotions so that rational thoughts and actions can be used to approach situations and tasks
 - Signs of emotional difficulties
 - Exhibits inappropriate reactions to situations/tasks
 - Over-reacts to situations/tasks
 - Easily frustrated when tasks become challenging
 - Displays emotions that may be inappropriate for the situation
 - Makes negative statements about the situation/task
 - Anxious at a level inconsistent with the situation/task
 - Slow to recover from disappointments
 - May exhibit tantrums, mood changes, or outbursts of temper
- **Initiation**
 - Initiation is an individual's ability to begin a task or activity independently
 - Initiation also involves the ability to generate ideas, responses, or problem-solving strategies
 - Signs of the initiation difficulties
 - Difficulty getting started with tasks
 - Needs reminders to get started on tasks
 - Slow to move from completed task/activity to the next task/activity
 - May need to be reminded of schedule
 - Waits for another member of a group to initiate group activities
- **Working memory**
 - Working memory is necessary for an individual to hold information in their memory while completing a task or activity
 - Signs of working memory difficulties
 - Unable to follow directions

Strengths of individuals with FASDs

- Highly Verbal
- Visual learners
- Artistic
- Musical
- Mechanical
- Athletic
- Friendly
- Generous
- Outgoing
- Affectionate
- Determined
- Willing
- Helpful

Characteristics in elementary school aged children with FASDs

- Attention difficulties
- Hyperactivity
- Language difficulties
 - Delayed development of language or difficulties with expressive and/or receptive language
- Learning disabilities
- Intellectual disabilities
- Memory difficulties
- Impulsivity
 - May result in lying, stealing, or defiant acts
- Poor judgment
- Short attention span, poor coordination
- Difficulty with both fine and gross motor skills
- Social difficulties
 - May include immaturity
 - Difficulty making choices
 - Being overly friendly and/or being easily influenced

Characteristics in adolescents and young adults with FASDs

- Difficulties with abstractions
- Difficulty understanding or anticipating consequences

- Low academic achievement
- Trouble keeping up with school
- Low self-esteem
- Memory difficulties
- More pronounced impulsivity
 - Lying
 - Stealing
 - Defiant acts
 - Poor judgment
 - Poor impulse control
 - Cannot distinguish between public and private behaviors
 - Must be reminded of concepts on a daily basis
- Social difficulties
 - Immaturity
 - Difficulty making choices
 - Overly friendly
 - Easily influenced
 - Low self-esteem from recognizing that they are different from their peers.

What you can do

Tips for working with children with FASD

- Offer clear, concise, and simple directions
- Modify assignments as needed
- Break down assignments into small pieces
- Use repetition, practice
- Use literal terms and be concrete
- Directly teach figurative language. High exposure to this type of language can improve understanding
- Be consistent
- Transitions are hard. Use cues!
- Simple environment with few distractions (1:1 or small groups)
- Be specific and give directions step by step
- Supervise. Individuals can be naïve, gullible, and lack social skills
- Learn how to tell when child is getting frustrated
- Often lack ability to make logical decision
 - Must be taught how to make reasonable choices and be given opportunities to practice

- Work on cognitive therapy around executive functioning (planning/organizing/completing) can help students stay on task and focused on the goal at hand
- Routine
 - Keep family and school routines as consistent as possible
 - If the routine or schedule changes, remind the child about changes

FAS and Educational strategies:

<http://www.psychiatry.emory.edu/PROGRAMS/GADrug/Edfas.htm>.

3. Behavioral and Sensory Support

What you need to know

The effects of FASD can include mental and behavioral effects. Individuals may have FASD or FAS as well as other diagnoses (i.e. autism, depression). It is important to diagnosis all conditions an individual has and treat each appropriately.

- Individuals may also be diagnosed with
 - ADHD
 - ODD
 - Anxiety

Additional issues

Individuals may also have:

- Judgment problems
 - Failure to learn from experience or develop a logical approach to problems
- Lack of safety awareness
 - Lack of impulse control
 - Lack of behavioral inhibition
 - Poor judgment
 - Difficulty generalizing skills across contexts

Having FASDs can also cause individuals to have psychosocial stress. Individuals with FASDs often lack social skills. Making friends and maintaining friendships is challenging.

Social difficulties

Individuals with FASDs may have difficulty socially with:

- Listening
- Asking for help
- Waiting their turn and sharing
- Understanding social cues
- Processing social information
- Communicating in social contexts
- Following directions
- Participating in treatment that requires receptive language skills like group therapy
- Processing info and applying info
- Using reward systems because time is abstract

Behavioral and Sensory Issues in Adolescence

This is a time of physical and emotional change. Behavioral and mental health problems stemming from pre-natal alcohol exposure can become more pronounced. Depression and anxiety are common as is alcohol and drug use.

Vocational and transitional services are important during adolescence. Adolescents must be given instructions as well as lifestyle support early on. Individuals with FASDs need help with life skills such as:

- Basic maturity
- Observational learning
- Punctuality

Other issues that may arise:

- Anxiety and depression
- Victimization
- Lying, stealing or antisocial behavior
- Sexual behavior also becomes an issue at this age
 - Individuals with FASD are often unaware of the boundaries for appropriate interaction, the subtle social cues, and impulse issues

Behavioral and sensory issues in adulthood

- Many daily obstacles can occur in general living:
 - Affordable and appropriate housing
 - Transportation

- Employment and money handling

What you can do

To address attention problems

- Medication may be helpful
- Keep the child's environment as simple as possible, and structure time with brief activities
- Provide activities that are short and fun

To address social problems

- Teach basic rules of social behavior
- Model, rehearse, and practice and provide feedback
- Pair the child with another who is one or two years younger
- Teach safety rules and skills
- Need help with daily skills and life skills
- Help them learn community based skills
- Learn how to tell when child is getting frustrated and help out early
- Tell the child about what will happen if he or she has acceptable behavior or inappropriate behavior at school
- Let child know when he or she has acceptable behavior
- Teach self-talk to help child develop self-control. Use specific, short phrases such as "stop and think."
- Repeat everything you say and give the child many chances to do what you ask
- Be patient
- Give directions one-step at a time. Wait for the child to do the first step in the directions before telling the child the second step
- Be sure child understands rules, and be firm and consistent with them
- If easily frustrated or tantrums occur:
 - Remove the child from the situation and use calming techniques such as sitting in a rocker or playing quiet music
 - Consider a functional behavioral assessment if issues impact quality of life

To address issues in adolescence

- Anxiety and depression:
 - Medication and or counseling may be helpful

- Find out what activities are meaningful to the child and help them join in. For example, encourage child to participate in sports, clubs or other structured activities
- Victimization
 - Monitor the activities of the child and discuss dealing with strangers
- Lying, stealing, or antisocial behavior
 - Family counseling may be helpful
 - Set simple and consistent rules with immediate consequences
- Sexual behavior may also become an issue at this age
 - Individuals with FASD are often unaware of the boundaries for appropriate interaction, the subtle social cues, and impulse issues
 - Close supervision and open lines of communication are important

To address issues in adulthood

- Housing
 - Finding appropriate housing for adults affected by FAS/FASDs is extremely challenging
 - Contact your state's department of disabilities to pursue funding if appropriate
- Poor peer or social relations
 - Encourage/help the person develop meaningful friendships and relationships
 - e.g., enroll in classes or social clubs with other adults
- Mental health issues
 - Provide structure, routine and plenty of interesting and meaningful activities
 - Investigate medication options and counseling if needed
- Handling money
 - Many adults need the support of their family to handle financial matters
- Difficulty obtaining or keeping jobs
 - Investigate trade schools
 - Job training programs or job coaches
 - Be sure to select jobs that offer structured, routine activities that won't cause overload or stress

The Fetal Alcohol Spectrum Disorders Handbook

- <http://www.usd.edu/medical-school/center-for-disabilities/fetal-alcohol-spectrum-disorders-handbook.cfm>

4. Physical Activity, Trips, Events

What you need to know

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- Any change in routine may produce anxiety, fears, and/or worry. Crowds and loud noises may be overwhelming to some individuals.
 - If the event is in a public place, the child may be more apt to interact with strangers so monitoring is important.
- If you live in New England (USA) and qualify, Northeast Passage offers Therapeutic Recreation and Adaptive Sports programming (www.nepassage.org).

What you can do

- Provide supports PRIOR to any new event or trip to help familiarize with the upcoming change. This could be a story about the event, photos, etc.
- Provide any supports that help them with sensory overload (iPod, ear phones, etc.).
- Because some children are overly friendly and familiar with strangers, a one-on-one aide on field trips may be required.

5. Absences and Fatigue

What you need to know

- Absences should not be a major factor for school aged children.

What you can do

- Contact parents if changes are noticed.

6. Emergency Planning

What you need to know

- Develop an emergency plan if necessary, depending on the needs of individual children.

7. Resources

Emory Maternal Substance Abuse and Child Development

<http://www.psychiatry.emory.edu/PROGRAMS/GADrug/Edfas.htm>

This website offers helpful strategies for students with FASD, such as how to best give instructions, how to arrange the environment, and how to help with transition. This was developed at the Maternal Substance Abuse and Child Development Project through Emory University School of Medicine (<http://www.emory.edu/msacd/>).

You may also find these interesting:

- FAS and Social Skills
(<http://www.emory.edu/msacd/news/FAS%20and%20Social%20Skills.html>)
- FAS and Heart Defects
(<http://www.emory.edu/msacd/news/FAS%20and%20Heart%20Defects.html>)

Fetal Alcohol Spectrum Disorders International (FASD)

<https://fasdunited.org/>.

FASD United supports individuals and families living with FASD through referrals, advocacy, training, information dissemination, and a wide range of diverse initiatives and resources.

FASD Center for Excellence

www.fasdcenter.samhsa.gov/

The FASD Center for Excellence is a Federal initiative devoted to preventing and treating FASD. The website provides information and resources about FASD, including materials to promote awareness.

Centers for Disease Control and Prevention (CDC)

<https://www.cdc.gov/ncbddd/fasd/facts.html>

Includes Basics about FASDs from the CDC

American Academy of Pediatrics (AAP)

<https://www.aap.org/en/patient-care/fetal-alcohol-spectrum-disorders/>

Overview of FASDs from the AAP

Medline Plus

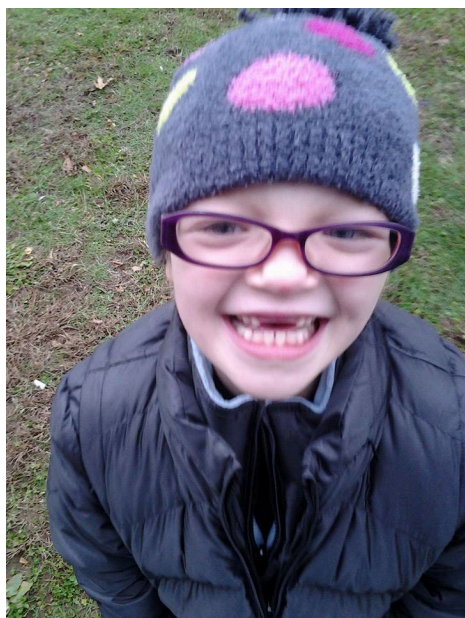
<https://medlineplus.gov/fetalalcoholspectrumdisorders.html>

Consumer-friendly information about human genetics from the U.S. National Library of Medicine

8. Meet a Child with FASD

Tori, Candy Crush Pro!

GEMSS would like to thank Tori and her mother for their generosity in sharing this story with us. You have made the site come to life with the addition of your thoughts and feelings. Thank you so much!



Tori is a child who loves people and gives warm hugs instantly! Sometimes this happens to people she might not know. She lives in a small New Hampshire (USA) town and was adopted by her parents. Her family originally fostered another child and when that child eventually left, they wanted to do more. They agreed to temporarily provide respite for Tori. Her mother Michele says, “From the very beginning, we knew she was a keeper!”

Her tiny frame supports a big ball of energy. “She is a very sweet, adorable girl who has one volume- loud” says Michele. Tori is also very talented with Candy Crush. At a recent hospital stay, the doctors were coming to Tori with their iPads and smart phones to have Tori help them beat the Candy Crush levels that were getting them stuck.

Tori can read well but has difficulty with comprehension. She has a Dynavox Maestro to help with communication and to help her imitate the words and talk more. “Tori calls everyone her friend,” says Michele. She has friends at school and her teachers help facilitate friendships and connections. “Tori can be loud and physical and may climb on people – she doesn’t have a concept of physical boundaries.” Michele says that they go to community events and family gatherings but if Tori gets overwhelmed, they just leave a little early.

Tori was diagnosed with Fetal Alcohol Syndrome after making her new home with her family. She had the facial features of FAS, her birth mother was noted to have been drinking during her pregnancy, and she also had the behavioral characteristics of FAS. Other conditions, such as Fragile x syndrome and Smith Magenis syndrome, were ruled out with genetic testing.

Tori goes to public school and is in regular classes in second grade. She receives academic support in reading and math as well as PT, OT, and Speech therapy, behavioral and guidance supports. “She is impulsive and needs one-on-one support to keep her safe,” Michele states. This “always eyes on”



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approach is necessary because she sometimes eats non-food items (pica) and has no concept of safety. Tori has also been diagnosed with epilepsy, autism, reactive attachment disorder, hearing loss, vision impairment, sensory processing disorder, post-traumatic stress disorder, and attention deficit hyperactivity disorder.

Michele and her husband Chris have big hopes and dreams for Tori. She has made huge progress in just a few short years and continues to thrive. Their goal is to help her succeed in school, make a meaningful contribution to her community, and be happy and healthy. Michele, who works at an elementary school, advises parents to “be patient, even if you have to repeat something 1000 times to get through to your child.”

Her advice to teachers and school nurses is to:

- Collaborate with parents. You’re more likely to be successful if you work together as team.
- Adapt all aspects of learning or the daily schedule, if needed. For example, if the lunch room is too loud/over-stimulating, find a quieter place for the child to eat.
- Do your research so you know about each child’s specific condition, challenges, and needs.