

Navigating Fetal Alcohol Spectrum Disorders (FASD)

A Guide for Parents and Families



Table of Contents

Section I:	Introduction
Section II:	Overview of Prenatal Alcohol Exposure
Section III:	Understanding Fetal Alcohol Spectrum Disorders (FASD) <ul style="list-style-type: none">% <i>Disorders Under the Umbrella of FASD, Explained</i>% <i>Presentation Across the Lifespan</i>% <i>Primary Verses Secondary Characteristics</i>% <i>The Importance of Protective Factors</i>
Section IV:	Diagnosis on the Spectrum <ul style="list-style-type: none">% <i>Purpose and Process</i>
Section V:	Intervention and Support <ul style="list-style-type: none">% <i>Strategies for Addressing Behaviors</i>% <i>Navigating FASD and the School System</i>% <i>Helping Siblings Understand FASD</i>% <i>FASD Education and Support Groups</i>
Section VI:	FASD Resources <ul style="list-style-type: none">% <i>Media</i>% <i>Websites</i>
Section VII:	Prevention and Risk Reduction
Section VIII:	References

Please note: Proof Alliance NC acknowledges that not every person who can become pregnant identifies as a woman. Although we try to use gender-neutral language as often as possible, much of the current research available currently refers only to “women” when discussing the ability to become pregnant. When citing this research, we refer to the language used in the study. In these cases, “woman” refers to someone who was assigned female at birth.

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Introduction

Learning that your child may have fetal alcohol spectrum disorders (FASD) can cause a range of emotions. You may feel disappointment, a sense of loss, angry or overwhelmed. On the other hand, you may also feel relieved that you are now on the path to understanding why your child has challenges with learning and/or behavior. If your child is diagnosed as having an FASD, you may be asking, “What do we do now?”

We’ve developed this guide as a tool for parents and families seeking diagnosis and/or interventions for children with FASD. The guide provides a brief overview of fetal alcohol spectrum disorders, an overview of the diagnostic process, as well as resources that include interventions and strategies that can help you, and your family navigate this disorder.

The information included comes from providers who have worked with individuals and families navigating FASD, along with a synthesis of research and guidebooks encountered during their work. We’ve done our best to document these in the reference section at the end of the guide but would like to note up front that we’ve drawn heavily from the work of Diane Malbin, Dr. Ira Chasnoff, Chandra Zieff, Dr. Rochelle Schwartz-Bloom and our partner organization, [Proof Alliance](#). This guide should be considered a resource for families seeking help, and not a definite text on FASD.



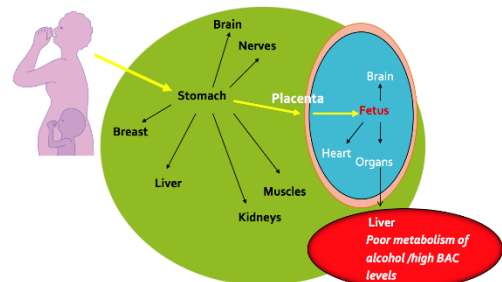
Overview of Prenatal Alcohol Exposure

The Centers for Disease Control and Prevention (CDC) estimates the more than 3 million people in the United States are at risk for having an alcohol exposed pregnancy. About half of all pregnancies are unplanned, and most people don't know they are pregnant until they are 4-6 weeks into the pregnancy.

This means that a person may be drinking and exposing the developing fetus to alcohol without even knowing it. Prenatal alcohol exposure is harmful because alcohol is toxic to the developing embryo or fetus and is classified as a teratogen. *“A teratogen is defined as any agent, substance or occurrence which can induce abnormalities of development in the developing embryo or fetus”.*

Prenatal exposure to teratogens can cause:

- Premature Birth
- Brain Injury
- Pre and Postnatal Growth Restriction
- Physical Malformations
- Sudden Infant Death Syndrome (SIDS)
- Cognitive and Behavioral Problems



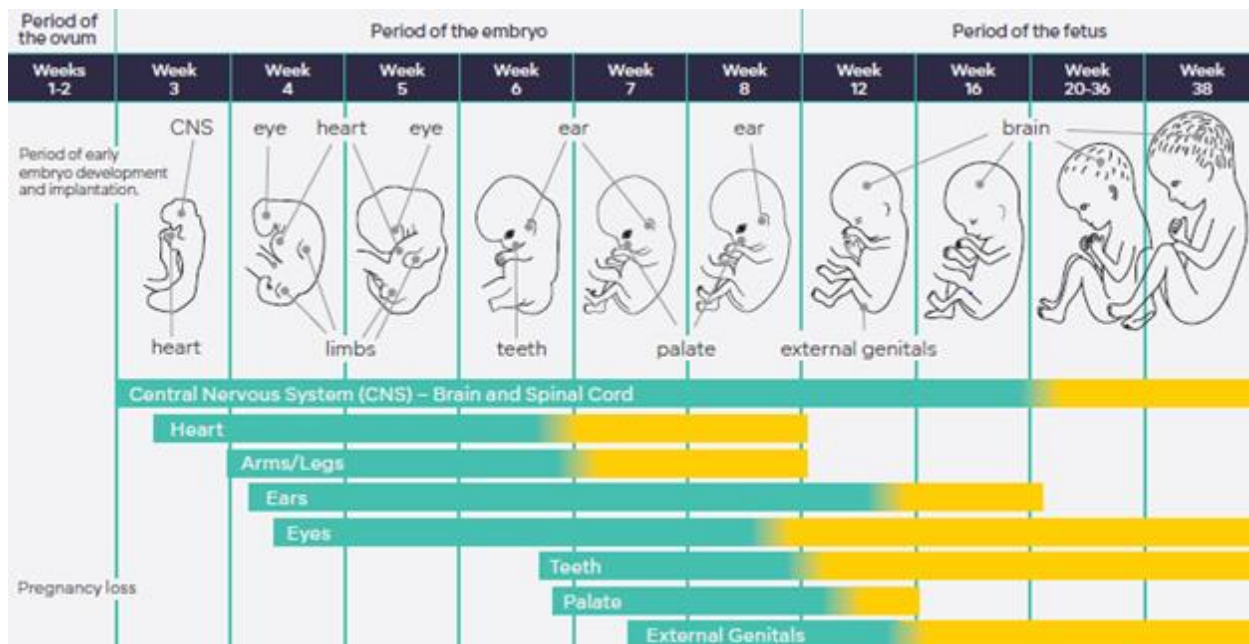
When a pregnant person ingests alcohol, the alcohol enters the stomach and continues throughout the digestive tract. All the while, alcohol is **'absorbed'** into the blood vascular system and is easily distributed throughout all parts of the person's body, including to the developing fetus.

This exposure can kill cells that help parts of the fetus develop, such as the brain, heart, face, limbs, kidneys and/or other organs. The death of these cells impact development and can result in birth defects. Alcohol can also limit the amount of nutrients and oxygen the fetus receives and affects how the fetus grows.

Once the placenta is fully formed and functioning, alcohol is then delivered directly to the fetus via the umbilical cord. Since the fetus does not have the enzyme needed to breakdown the alcohol, the blood alcohol concentrations (BAC) in the fetus' system are almost equal to that of pregnant person's BAC.

The brain is the organ that is most affected by prenatal alcohol exposure. In most cases, the brain will not look different, but the alcohol can damage parts of the brain that cannot be seen. Alcohol affects parts of the brain that gives us our memory, self-control, coordination and judgement. An individual that was exposed to alcohol during pregnancy may still have brain injury even though they may not have any of the facial features that are so often associated with the medical diagnosis of Fetal Alcohol Syndrome (FAS).

We know that the amount of alcohol, duration and timing of exposure combined with other factors such as maternal age, number of pregnancies, maternal nutrition and genetics play a role in how the developing fetus will be impacted. Alcohol exposure can affect the developing fetus during every trimester of pregnancy and these affects are listed below the fetal development chart.



This chart shows vulnerability of the fetus to defects throughout 38 weeks of pregnancy. Teal represents the period of development when major defects in bodily structure can occur. Yellow represents the period of development when major functional defects and minor structural defects can occur. Since it is difficult to know exactly when conception occurs, health care providers calculate a due date 40 weeks from the start of a person's last known menstrual cycle.

Chart Adapted from Moore (1993), FASD United (2009) and the Centers for Disease Control (2018).

Drinking alcohol up to the 13th week of pregnancy can cause:

- % Brain injury;
- % Problems with the heart, liver and kidneys;
- % Miscarriage;
- % Facial malformations.

Drinking alcohol between weeks 14 and 26 can cause:

- % Brain injury;
- % Miscarriage;
- % Damaged muscles, skin, teeth, glands and bones.

Drinking alcohol between weeks 27 and 40 can cause:

- % Brain injury;
- % Lung damage
- % Low birth weight;
- % Premature delivery.

To prevent fetal alcohol spectrum disorders, please help us educate people of childbearing age (15-44 yrs.) about the importance of abstaining from alcohol use if one is pregnant, trying to become pregnant, or is sexually active and not using an effective method of birth control.

For additional prevention information, go to www.ProofAllianceNC.org or call 1.919.215.4738.

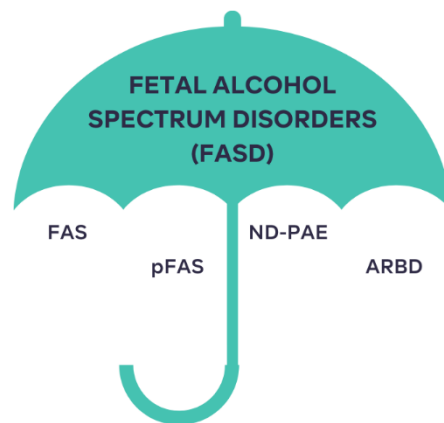
Understanding Fetal Alcohol Spectrum Disorders (FASD)

Fetal alcohol spectrum disorders (FASD) is an umbrella term used to describe the range of effects that can occur in an individual who was prenatally exposed to alcohol. FASD is not a clinical diagnosis, rather a term that includes a group of developmental disorders resulting from prenatal alcohol exposure.

These conditions may include physical, mental, behavioral and/or learning disabilities with possible lifelong implications and can affect each individual differently. Recent studies that included a site in North Carolina, show that an estimated 1 in 20 school age children have an FASD.

There are many terms under the umbrella of FASD, some may include:

- % Fetal Alcohol Syndrome (FAS),
- % Partial Fetal Alcohol Syndrome (pFAS),
- % Neurobehavioral Disorder (ND-PAE),
- % Alcohol Related Birth Defects (ARBD)



While FAS is the most well-known of these disorders, it accounts for only 10% of all cases of FASD. It is important to remember that an individual can be affected by prenatal alcohol exposure and not meet the criteria for Fetal Alcohol Syndrome (FAS); but fall somewhere on the spectrum.

Fetal Alcohol Syndrome (FAS) is characterized by:

- Growth deficiency
(height or weight < 10th percentile).
- A unique cluster of minor facial anomalies
(small eyes, smooth philtrum, thin upper lip).
- Severe central nervous system (CNS) abnormalities
(structural, neurological, and/or functional abnormalities).
- Prenatal alcohol exposure
(confirmed or unknown).

Partial Fetal Alcohol Syndrome (pFAS) is a diagnostic classification for patients who present with:

- Most, but not all, of the growth deficiency and/or facial features of FAS.
- Severe CNS abnormalities
(structural, neurological, and/or functional abnormalities).
- Prenatal alcohol exposure *(confirmed).*

Neurobehavioral Disorder/Alcohol Exposed (ND/AE) is a diagnostic outcome classification for patients who present with:

- Moderate central nervous system dysfunction.
- Prenatal alcohol exposure *(confirmed).*

Neurobehavioral Disorder-Prenatal Alcohol Exposed (ND-PAE) is a diagnostic outcome classification recently introduced by the DSM-5. It is characterized by issues with:

- Thinking and memory

- Behavior issues
- Trouble with day-to-day living

Alcohol Related Birth Defects (ARBD) describes the physical effects linked to prenatal alcohol exposure, including heart, skeletal, kidney, ear and eye malformations in the absence of apparent neurobehavioral or brain disorders.

Static Encephalopathy/Alcohol Exposed (SE /AE) is a diagnostic classification is for individuals who present with:

- Severe CNS abnormalities which include: structural, neurological and/or severe functional abnormalities
- Prenatal alcohol exposure (confirmed).

FASD FACTS

- % FASD is the leading known cause of intellectual disability
- % FASD affects 1 in 20 children
- % Approximately 25% of people with an FASD also have some form of severe intellectual disability.
- % Annually, FASD costs up to \$6 billion in direct and indirect costs.
- % For one individual with FAS, the lifetime cost is at least \$2 million.
- % Not all individuals with an FASD have specific facial features, but many have an invisible brain injury.

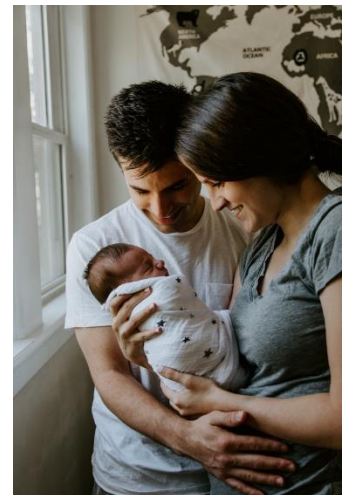
Presentation of FASD Across the Lifespan

Individuals with FASD are part of virtually every community. Because many of the effects are brain-related rather than physical, FASD is often referred to as an “invisible disability,” with its effects not always obvious or easily distinguishable from developmentally appropriate behaviors. As noted earlier, approximately 1 in 20 school age children have FASD. Further, many of the issues associated with FASD overlap with other diagnoses, such as ADHD.

That said, the following are some issues that commonly present at different developmental stages and can be used as a starting point for identification.

NEWBORN (birth to 9 months) – possible issues:

- Small in height and weight
- Small head size
- Low muscle tone (*floppy*)
- Poor sleep patterns
- Difficult to soothe
- Feeding problems/poor suck
- Poor bonding with caregivers
- Sensory issues (*over or under responsive*)
- Difficulty adapting to new things/situations



TODDLER (9 months to 4 years) – possible issues:

- Head banging
- Problems with fine motor or gross motor development
- Language delays
- Poor coordination and balance
- Memory problems
- Hyperactivity
- Developmental delays
- Cognitive impairment (*intellectual disability*)
- Sensory issues



EARLY SCHOOL AGE (4 - 12 years) – possible issues:

- Learning disabilities
- Poor social skills (*turn-taking, conversation*)
- Short attention span
- Executive functioning deficits
- Impulsivity
- Frequent tantrums
- Lower IQ
- Slow task completion
- Poor risk assessment (*fearlessness*)



ADOLESCENCE INTO ADULTHOOD – possible issues:

- Poor judgment and impulsivity
- Defiant and uncooperative
- Can't predict consequences
- No “stranger danger”
- Alcohol and drug use
- Difficulty telling time, and keeping appointments
- Poor money management
- Talk the talk, but not walk the walk



Primary vs Secondary Characteristics of FASD

Primary Characteristics

Primary characteristics are the effects that an individual is born with, as a result of prenatal alcohol exposure.

Some primary characteristics may include:

- Poor executive functioning skills
(*impulse-control, planning, organizational skills, task-shifting, working memory*)
- Impaired ability in reading, spelling and arithmetic.
- Lower level of adaptive functioning or everyday life skills

Some primary characteristics continued:

- Impaired cognitive functioning
- Developmental delays
- Brain injury that can result in intellectual disability or borderline intellectual functioning
- Characteristic facial features: thin upper lip, smooth philtrum, small palpebral fissures (*eye openings*); *only found in about 10% of people with an FASD*
- Small head circumference
- Shorter-than-average height and slow growth
- Low body weight

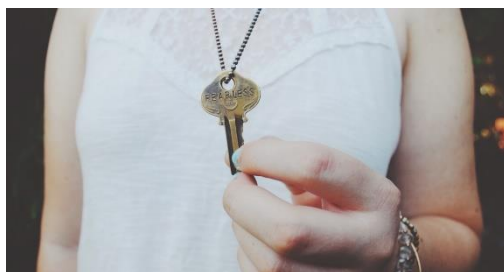
Secondary Characteristics

When people with an FASD are not properly identified and supported, “secondary characteristics” may appear. Secondary characteristics can emerge over time when expectations, environments, and supports do not properly match the person’s specific needs. The main secondary characteristics that have been identified include: mental health issues, disrupted school experience, involvement with the justice system, hospitalization, alcohol and drug use and inappropriate sexual behaviors. Secondary characteristics can be improved or avoided with early intervention and appropriate supportive services. Additionally, there are protective factors that can make a significant difference in improving outcomes.

The Importance of Protective Factors

While individuals born with a brain-based disability, such as FASD are at a higher risk for experiencing the secondary characteristics mentioned above, it isn’t a foregone conclusion. The key to helping these individuals avoid secondary characteristics and achieve their full potential is to put protective factors in place.

Some of the key protective factors for individuals with FASD are:



- Early diagnosis (before age 6)
- Early intervention and applied strategies
- Stable and nurturing home environment
- Absence of exposure to violence
- Few changes in caretaking placements
- Eligibility for social and educational services

Diagnosis on the Spectrum

PURPOSE and PROCESS

Could it be FASD?

Fetal alcohol spectrum disorders (FASD) can be mistaken for other developmental disorders or mental health conditions. Individuals can have multiple diagnosis. To learn if it could be FASD, review the [FASD indicator checklist](#) created by Proof Alliance, our collaborating organization.

Diagnosis is Important

Most individuals who have FASD have no visible signs of alcohol exposure because FASD is a brain-based disability. An accurate diagnosis can help you and your child get the services and support needed to have successful and fulfilling lives.

Accurate Diagnosis Can Help:

- Identify and refer the individual for appropriate services;
- Align understanding and aid communication among caregivers, educators, clinicians, families and the individual with an FASD;
- Help the individual and their families better understand their unique combination of strengths and impairments

Diagnostic Criteria for Fetal Alcohol Syndrome

While there are variations among current published guidelines on FASD diagnostics (*4 Digit Code, Hoyme et al, CDC, Canadian*), the core criteria remain the same. Professionals diagnosing Fetal Alcohol Syndrome typically look for evidence in four different areas:

- **Growth Deficiency:** Individuals with FAS are often growth deficient. Two key indices for growth are height and weight adjusted for age.

- **Facial Phenotype:** The facial features often found in individuals with gestational alcohol exposure include small palpebral fissures, in association with a smooth philtrum, and thin vermillion border of the upper lip.
- **Central Nervous System (CNS) Abnormalities:** These include physiological evidence of brain abnormalities, such as seizures, microcephaly, or other anatomical abnormalities; and learning, behavioral, and/or adaptive differences, such as struggles with attention, memory, executive functioning, sensory processing, cognition, language, etc.
- **Prenatal Alcohol Exposure:** To the extent possible, a history of prenatal exposure is collected, including frequency and severity.

Diagnosing on the Spectrum

There is no single test to diagnose an individual who was prenatally exposed to alcohol and while there are different methods for diagnosing, the process usually requires multiple evaluations by different developmental specialists. The types of professionals involved with an FASD clinic include physicians (*clinical geneticists or developmental pediatricians*), psychologists, speech language pathologists, occupational therapists and clinic social workers.

An interdisciplinary assessment for FASD will involve the following steps:

- % **Comprehensive History**
Medical record review, interview with family prior to appointment
- % **Standardized Testing and Consultations**
Administered by Occupational Therapist, Speech Therapist, Neuropsychologist and Genetic Counselors
- % **Physical Examination**
Administered by the Geneticist/Developmental Pediatrician
- % **Behavioral Observations**
Come from parents, teachers, as well as pre and in clinic observations

Diagnosing in North Carolina

Currently, there are three entities that diagnose on the spectrum. Atrium Health-Levine Children's Hospital Developmental and Behavioral Clinic, Mission Hospital's Fullerton Genetics and I2I FASD Services, LLC. A referral from the patient's primary care provider is required for an appointment. In addition to a referral from your child's provider, some clinics may require certain evaluation results prior to accepting the referral. We recommend you reach out to the clinic before initiating the referral, as well as determining cost and accepted insurance. Contact information for clinics can be found on Proof Alliance NC's website, [getting a diagnosis](#).



Next Steps

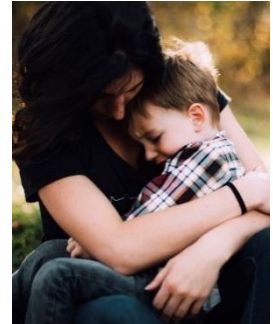
Getting and FASD diagnosis is not about labeling a child. It is rather an opportunity for your child and family to get the services and support needed to be successful.

- Share the diagnosis with your child's school to assist with the development of an Individualized Education Program (IEP).
- Share this information with your child's healthcare providers to receive more appropriate medical and mental health services.
- Contact your county's local management entity/managed care organizations, about available services and supports. Click [here](#), to find your local provider.
- Reach out to FASD informed parent organizations for support

FASD Intervention and Support

Strategies for Addressing Behavior

Too often, individuals with FASD are perceived as acting defiant, not listening, or not following the rules on purpose. This can lead to harsh and unfair judgment, feelings of shame, anxiety and “treatment” that focuses on increasing consequences and discipline, leading to frustration for all involved.



We recommend a different approach. Instead of blaming the person for their behaviors, remember that they have a brain injury caused by prenatal alcohol exposure. Instead of thinking they won't do something, it's possible that they can't do it, at least not in the specific way they're being asked.

Fetal alcohol spectrum disorders are an invisible, brain-based disability with behavioral symptoms.

When we view FASD in this correct context, we can then shift our intervention paradigm away from blame and consequences, and towards understanding and problem solving:

From:

Won't.....

IS the problem.....

Doesn't work.....

Acts immature.....

Doesn't try.....

To:

Can't

HAS a problem

Has trouble starting

Is dysmature

Tired of failing

A critical step in this improved intervention paradigm is to begin by considering an individual's strengths. While no two people with FASD are the same, **common strengths of individuals with FASD may include:**

- Learn by doing, by being shown and/or by relationship
- Learn through consistency, continuity and relevance
- Able to participate in problem solving with appropriate support
- Often have a strong long-term visual memory
- Can be highly verbal
- Creative
- Determined
- Multi-modal learners

An important step in addressing the needs of an individual with FASD involves questioning behavioral interventions based on consequences and rewards.

Prenatal alcohol exposure can impact connectivity between regions of the brain, making it difficult to draw on memory while problem solving, and rendering this type of intervention ineffective. Ask yourself: will an individual who can't access information in the moment about future rewards or consequences be able to use that to modify their behavior? Probably not.

Instead, try to examine the environment and expectations in which a person is struggling. Is there a mismatch between expectations and abilities?

A simple example of this would be giving verbal directions. If your child struggles to follow verbal directions, it's possible that this behavior isn't defiance, but rather a struggle with working memory or auditory processing. Using effective communication techniques can help improve the fit between abilities and expectations. In this case, a picture chart or set of written instructions may improve follow through.

Another critical step in crafting interventions is to remember to work with developmental age, not chronological age or physical appearance and to set reasonable expectations that match his/her functional abilities.

For example, if an individual is chronologically 16 years old but functions closer to 6 or 7 years old, try changing communication and teaching techniques (*along with expectations*) to match more closely with the younger developmental age. Frustrated parents are often able to find effective interventions by asking themselves, “How would I address this with a younger child?”

Here are some guidelines on successful FASD behavior interventions

- % Identify the brain-based tasks inherent in the task or expectations that person is struggling to understand or do (*i.e. abstract thinking, good memory, fast auditory pace*)
- % Work backwards from secondary characteristics (*i.e. anger, anxiety, disruptive behavior*) to discover the primary characteristics (*i.e. poor memory, trouble initiating*) preventing someone from success in task completion
- % Consider the person’s developmental skill level in relationship to the task or expectation
- % Identify applicable strengths (*i.e. visual learning, determination, desire to succeed*)
- % Create accommodation that allows person to harness strengths in order to complete task or meet expectation

For an example, consider John, a lively thirteen year-old boy with an FASD, who struggles to follow directions at the community pool. Traditionally, his behavior would met with responses such as time-outs, consequences, or perhaps even being prohibited from the pool in the future. Using the steps above, we can identify some brain-based tasks needed to behave appropriately at the pool.

Surely, to follow the rules, one has to know the rules, and often pool rules are written on long, text-heavy lists that are only displayed at the entrance to the pool. John would need good reading comprehension and working memory skills to know these rules.

Additionally, the pool can be very stimulating, think of the water, the noise, sun, heat, smells, and all the other children. If John has any sensory processing struggles, this is likely to be a tough environment for him. Finally, consider his developmental age. John may have been born thirteen years ago, but when it comes to the pool, his skills may be closer to an eight or nine year old.

Now that we've established developmental age and gaps between John's skill and the environment, let's consider his strengths. John has a strong visual memory, and is very relational, he loves his friends and family! Using all this information, new interventions come to mind other than consequences. Perhaps the family could make a picture book of pool rules and keep it close by for periodic review. Consider assigning John a buddy to follow at the pool, since he is so focused on others. Finally, rather than time outs as punishments, short sensory breaks away from the chaos may help him find calm and remember what's expected of him.

Navigating FASD and the School System



One of the most critical interventions for an individual with FASD is to ensure that they receive the proper academic supports. Most often, this is achieved through the creation of an IEP (Individualized Education Plan) or 504 plan.

These written plans, outlining needed services and accommodations, are designed collaboratively between students, parents, teachers, and school administrators. Individuals with FASD should be recognized as having a brain-based disability and are entitled to have their educational needs accommodated.

While each individual with FASD is different and will have unique learning needs, some common challenges include:

- Difficulty with information processing and memory
- Attention difficulties
- Difficulty with abstract thought and conceptual thinking
- Math difficulties – especially with computational math
- Reading and writing difficulties – especially reading comprehension and organization of writing
- Problems with executive functioning

Additionally, there are some common characteristics of classroom environments that give students with FASD the best chance for success. As with interventions, it's important to remember that we're most successful when we focus our effort on modifying the environment, and not the individual.

Characteristics of FASD Informed Classrooms:

- Calm, ordered and organized
- Auditory and visual distractions are minimized
- Classroom space is defined, and often labeled with pictures, photos or words
- Students have access to quiet corners or “offices” within classroom
- Students’ desks are placed strategically away from distractions

Five teaching strategies have been identified as effective for students with FASD. These include: **structured environment, consistent, routine, brief presentations, variety and repetition.**

Teachers creating a **structured environment** should focus on teaching and holding students accountable to a few simple rules, rather than a more extensive list. They should simplify notebooks and class materials and try to streamline organizational strategies across subjects and classrooms. It's also critical to keep communication between school and home open.

Students with FASD do best with a **consistent routine**. This may include assigned seats and posting and reviewing a daily schedule. These students will also benefit from help with transitions.

It's critical to keep **presentations brief and simple**. This can be accomplished through simple language, concrete concepts, familiar vocabulary, and accompanying lectures with hand gestures, facial expressions, or references to posters/visuals in the classroom. Multi-step directions should be broken down into smaller chunks, often with only one direction given at a time.

Variety helps students with FASD to find their best learning modalities. Teachers incorporate variety through technology, multi-sensory learning, hands on activities and relating teaching to real life experiences.

Say it over and over again: **repetition** is key. Teachers should reteach and reinforce learn concepts. Practice, practice, and practice. It also helps to teach steps in the same sequence.

In addition to these classroom strategies, parents of a student with an FASD may work with their school counselor and special education department to see if their child needs services and accommodations such as:

- Speech and Occupational Therapy
- Specialized reading instruction
- Smaller class sizes or small group learning within classroom
- Multi-modal instruction, including multi-sensory and activity-based learning
- Direct (One on One) Instruction
- Separate quiet spaces for test-taking or self-directed work
- Organization and study skill support
- Visual aides to reinforce classroom rules and expectations

The social worker, or parent navigator, involved in FASD diagnoses can help families to navigate the process of establishing special education services.

Helping Siblings Understand FASD

Often, parents who bring their child to the multi-disciplinary clinic for diagnosis will ask for help in dealing with siblings. They wonder what to tell siblings about their brother or sister's disability, how to deal with a number of complicated issues (*such as conflict arising from challenging behaviors*), and questions of fairness related to changing expectations to meet each child's ability level.



To start, parents should always be advised to trust their gut judgement and parenting philosophy when dealing with sibling issues. However, here are some ideas for talking to siblings about FASD:

- *Use the language of “invisible” physical disability to explain their sibling’s diagnosis and remind them that their sibling didn’t choose to have this condition.*
- *If appropriate, explain the mechanisms of prenatal alcohol exposure in an age-appropriate manner. Let siblings know “when a woman drinks alcohol when she is pregnant, the baby might have a harder time learning, remembering, and paying attention as they grow up and go to school.”*
- *Explain to them that everyone’s brain works differently and that when their sibling’s brain was developing, the alcohol changed how their brain works.*
- *Remind them that their sibling’s behavior is not their fault, and that it’s normal to sometimes feel angry, frustrated, jealous or embarrassed.*
- *Give them tools to help them manage and regulate their emotions.*
- *Help them focus on their sibling’s strengths, and all the wonderful things they can do together!*
- *Let them know that learning how to support a sibling with FASD can give them unique opportunities, such as: learning how to understand and deal with problems, practicing loyalty and family pride and becoming more capable of handling differences in people.*

EDUCATION PROGRAMS

The Aware Program is one of the only evidence-based programs that helps adolescents and young adults with FASD or other intellectual disabilities develop skills to regulate their feelings, make healthier choices, and avoid risky behaviors such as using alcohol or other drugs. The Aware Program enhances adolescents' abilities to regulate their emotions and make healthy decisions.

<http://awareprogramsonline.com/>

The Comprehensive Guide for Pre-K - Educators is designed for every educator (*e.g., teachers, special education teachers, resource specialists, speech and language specialists, school nurses, psychologists and occupational therapists*) who works with K-8 elementary and middle school level students. The guide addresses the impact of prenatal exposure to alcohol and how it affects the K-8 grade student.

https://sites.duke.edu/fasd/files/2016/04/FASD_Guide.pdf

Do2Learn website contains educational resources for special needs children like schedule boards, aids for teaching math and a "FASD Toolbox" for teachers.

<http://www.do2learn.com/>

The FASD Website of the government of Alberta, Canada that has workbooks and manuals about teaching to students with FASD available to download.

<http://fasd.alberta.ca/>

The Wrightslaw Website for reliable information about special education law, education law, and advocacy for children with disabilities.

<https://www.wrightslaw.com/>

Website for the National Technical Assistance Center on Positive Behavioral Interventions and Supports (PBIS) was established to address the behavioral and discipline systems needed for successful learning and social development of students. The Center provides capacity-building information and technical support about behavioral systems to assist states and districts in the design of effective schools.

<https://www.pbis.org/>

SUPPORT FOR FAMILIES in North Carolina

NCFASD Informed is the lead organization in North Carolina for guidance for families navigating FASD. Please visit their website for more information.



<https://ncfasdinformed.org/>

Creating a Family

Creating a Family is a support and training nonprofit for foster, adoptive, and kinship families. Their mission is to strengthen foster, adoptive, and kinship families and the professionals who support them by creating expert-based, trauma-informed resources, community support, and training. They have several styles of training for those parenting kids with prenatal substance exposure, including 1-hour self-paced online courses and a full-service 3-session interactive training for parents that will teach them research-based strategies for kids from birth to young adulthood. <https://creatingafamily.org/>



FASD Hope is a NC based podcast for people whose lives have been touched by Fetal Alcohol Spectrum Disorders (FASD). Their podcast is about awareness, information, inspiration and building an FASD informed community.



To listen to their podcast, go to <https://fasdhope.podbean.com/>

I2I FASD Services, LLC

Elizabeth (Liz) Redhead Kriston is an FASD informed, board certified Speech-Language Pathologist. Her expertise includes a Master of Science in the area of communication sciences, a 25-year career working with individuals from birth through high school, parenting an individual with an FASD, and compiling well over 100 hours of training in the area of FASD.



Using her first-hand knowledge in concert with her educational and professional background, Liz founded I2I FASD Services, LLC. The services offered include ND-PAE diagnosis (children and adults), consultative or therapeutic support for families and individuals, and education for professionals or community members.

For more information, please visit [I2I FASD Services](#)

Nurture Nature Family Consulting

Specializes in [Families Moving Forward \(FMF\)](#), an evidence-based intervention to help families raising children who are affected by prenatal alcohol exposure, with or without a fetal alcohol spectrum disorder (FASD) diagnosis. The FMF program combines a positive behavior support (PBS) approach with motivational interviewing (MI) and cognitive behavioral therapy (CBT) to help parents change their own knowledge and attitudes about PAE and FASDs, leading to improvements in their child's behavior.

To learn more, contact [Nurture Nature Family Consulting](#).

ADDITIONAL SUPPORT Organizations

FASD United Family Navigator

The FASD United Family Navigator program provides individuals living with fetal alcohol spectrum disorders (FASD), their family members, caregivers and supporters with expert, confidential support, and referrals.



A FASD Family Navigator can be reached from 9am-10pm Eastern Time, Monday through Friday via phone at 202-785-4585

Virtual Support Groups

Proof Alliance NC cannot recommend a specific online support group. However, The FASD Collaborative Project has created a list of support groups for birthmothers, self-advocates and caregivers in the FASD Community.

<https://www.fasdcollaborative.com/>

Section VI

FASD Resources

For Crisis and Immediate Assistance: Find help for a mental health and substance use crisis in your county here: <http://crisissolutionsnc.org/>

STATE RESOURCES

Children with Special Health Care Needs Hotline

1916 Mail Service Center

Raleigh, NC 27699-1916

Toll Free: (800) 737-3028

Email: CYSHCN.Helpline@dhhs.nc.gov

Disability Rights North Carolina

3724 National Drive, Suite 100

Raleigh, NC 27612

Phone: (919) 856-2195 / Toll Free: (877) 235-4210

TTY: (888) 268-5535 / Fax: (919) 856-2244

www.disabilityrightsnc.org

info@disabilityrightsnc.org

Families' Information Resources Support and Technology (F.I.R.S.T.)

PO Box 802, Asheville, NC 28802

Phone: (828) 277-1315

Fax: 828-277-1321

Toll-Free: (877) 633-3178

<http://www.firstwnc.org>

Family Support Network of North Carolina

University of North Carolina, CB #7340

Chapel Hill, NC 27599-7340

Toll Free: (800) 852-0042

cdr@med.unc.edu

www.fsnnnc.org

North Carolina Council on Developmental Disabilities

3125 Poplarwood Court; Suite 200

Raleigh, NC 27604

info@nccdd.org

Phone: (919) 850-2901

<https://nccdd.org/>

North Carolina Collaborative for Children, Youth and Families

Governor's Institute

1121 Situs Ct. Ct. Unit 320

Raleigh, NC 27606

<https://nccollaborative.org/about-us/>

NCDHHS

Division of Mental Health, Developmental Disabilities and Substance Abuse
Services

Advocacy and Customer Service Section:

Phone: (919) 733-7011

<https://www.ncdhhs.gov/divisions/mhddsas>

North Carolina Infant-Toddler Program (NC ITP)

Early Intervention Services/CDSAs

1916 Mail Service Center

Raleigh, NC 27699-1916

Phone: (919) 707-5520

<https://bearly.nc.gov/>

The Arc of North Carolina

353 East Six Forks Rd., Suite 320

Raleigh, NC 27609

(919) 782-4632

(800) 662-8706

<https://arcnc.org/>

UNC Carolina Institute for Developmental Disabilities

<http://www.cidd.unc.edu/>

Media: DVDs and Web Videos

“Moment to Moment: Teens Growing Up with FASD” (DVD)

Written and produced by Gabe Chasnoff, this touching film explores the lives of four adolescents with FASD and the effects that prenatal alcohol exposure has had and continues to have on their journeys to finding independence, fulfillment, and understanding the world around them.

<https://www.ntiupstream.com/>

“Recovering Hope: Mothers Speak Out about Fetal Alcohol Spectrum Disorders”

(Available on YouTube and FASD United)

Mothers speak about their own discovery of how their substance use disorder/addiction impacted their birth children.

“An Ounce of Prevention” (DVD)

Short, contemporary DVD engages students in a setting with which they can relate while teaching about the serious realities of Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorder. Designed for use in high school parenting classes, health classes and other venues appropriate for discussion of preventing alcohol-related birth defects. Includes a fact sheet, background information on FAS and FASD, and a student assessment. 17 minutes.

<https://store.realityworks.com/products/dvd---an-ounce-of-prevention>

Additional videos can be found on the FASD United (formerly NOFAS) website:

<https://fasdunited.org/tools-for-parents-and-caregivers/>

<https://www.nofas.org/video/>

Recommendations from Families and Providers

BOOKS:

Chancer: How One Good Boy Saved Another- a memoir

- By Donnie Kanter Winokur (<http://thechancerchronicles.com/books/>)

Fantastic Antone Grows Up

- By Judith Kleinfeld with Barbara Morse and Siobhan Wescott

Fantastic Antone Succeeds

- By Judith Kleinfeld and Siobhan Wescott

Fetal Alcohol Spectrum Disorders: Trying Differently Rather Than Harder

- By Diane Malbin, MSW

Fetal Alcohol Spectrum Disorders: Understanding Mental Health

- By Ellen Rodger and Rosie Gowsell

Fetal Alcohol Syndrome: A Guide for Families and Communities

- By Ann Streissguth, PhD - University of Washington

The Broken Cord

- By Michael Dorris

The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities

- By Ann Streissguth, Ph D-University of Washington

Living with FASD

- By Sara Graefe

**Power Parenting for Children with ADD/ADHD:
A Practical Guide for Managing Difficult Behaviors**

- By Grad L. Flick

Smart but Scattered: Executive Functioning Resources

- By Peg Dawson, EdD, and Richard Guare, PhD.

The Out-of-Sync Child: Recognizing and Coping with Sensory Processing Disorder

- By Carol Stock Kranowitz, M.A.

WEBSITES:

Circles concept for safe touch and relationships with kids with poor boundaries/stranger discrimination:

http://www.ascd.org/ASCD/pdf/journals/ed_lead/el_199109_walker-hirsch.pdf

Conscious discipline: strategies for parents, teachers, other caregivers based on promoting self-regulation instead of consequences

<https://consciousdiscipline.com/about/becky-bailey/>

Groden network: relaxation training for all age groups (based on ASD needs)

<https://grodennetwork.org/>

Fact Sheets and Strategy Guides

<https://www.proofalliance.org/article/fact-sheets-and-strategy-guides/>

RESOURCES:

FASD Diagnosis

- <https://nccd.cdc.gov/FASD/>
- <https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/fetal-alcohol-spectrum-disorders-toolkit/Pages/default.aspx>
- www.fascets.org/
- <https://nfrf.ucla.edu/SEEDS>
- <https://pubs.niaaa.nih.gov/publications/arh341/64-75.htm>
- <https://www.proofalliance.org/>
- <https://osepideasthatwork.org/sites/default/files/IDEAsIssBrief-FASD-508.pdf>

Early Intervention

- *Going the Extra Mile: Improving Math and Behavior in Alcohol Affected Kids*
<http://msacd.emory.edu/Research/MILE.html>
- *Responding to the Challenge of Early Intervention for FASD*
<https://depts.washington.edu/fasdpn/pdfs/olson2007.pdf>
- Early Intervention for Children with Fetal Alcohol Spectrum Disorders
<http://www.child-encyclopedia.com/fetal-alcohol-spectrum-disorders-fasd/according-experts/early-intervention-children-fetal-alcohol>
- *Fetal Alcohol Spectrum Disorders (FASD) - Impact on Children and Families*
<https://www.continued.com/early-childhood-education/articles/fetal-alcohol-spectrum-disorders-fasd-22994-22994>
- Theraplay
<http://www.theraplay.org/index.php/articles-about-theraplay/82-theraplay-with-special-populations/70-article-theraplay-and-fetal-alcohol-syndrome>
- FASD Treatments
<http://www.cdc.gov/ncbddd/fasd/treatments.html>

NATIONAL WEBSITES:

American Academy of Pediatrics FASD Toolkit

<https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/fetal-alcohol-spectrum-disorders-toolkit/Pages/default.aspx>

Collaborative for Alcohol-Free Pregnancy

<https://nccd.cdc.gov/FASD/>

Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CIFASD)

<https://cifasd.org/>

FASD United, formerly known as the National Organization on Fetal Alcohol Syndrome (NOFAS)

<http://fasdunited.org/>

Fetal Alcohol Syndrome Consultation, Education and Training Services

<http://www.fascets.org/>

Fetal Alcohol Disorders Society

<http://www.faslink.org/index.htm>

Fetal Alcohol Diagnostic and Prevention Network, University of Washington

<http://depts.washington.edu/fasdnpn/>

Fetal Alcohol Syndrome Support, Training, Advocacy and Resources

<http://www.come-over.to/fasstar/>

MotherToBaby: Medications and More During Pregnancy and Breastfeeding

<https://mothertobaby.org/>

Proof Alliance

<https://www.proofalliance.org/>

The Centers for Disease Control and Prevention (CDC): FASD

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

The FASD Collaborative Project

<https://www.fasdcollaborative.com/>

Prevention and Risk Reduction

Why is prevention essential?

- FASD is prevalent, but preventable.
- In NC, an estimated 8,628 babies are born alcohol-exposed each year.
- The effects of prenatal alcohol exposure can be severe, lifelong and challenging for both the person impacted and their support systems.
- Our systems of care have a very limited ability to effectively support people with FASD.
- Preventing alcohol-exposed pregnancies is a cost-effective public health response.
- Sharing accurate public health information about prevention empowers people to make safer alcohol choices that can benefit them during pregnancy and throughout their lives.
- Alcohol (mis)use is often overlooked as one of the biggest factors contributing to health conditions in our nation.
- Prevention campaigns can increase awareness about alcohol misuse and help create effective, non-stigmatizing programs and policies that address these behaviors and prevent alcohol-related issues.

In the United States, 1 in 7 (13.5%) pregnancies are exposed to alcohol.

This number is likely an underestimate. A different CDC study (2020) found that 19.6% of pregnant women in their first trimester had at least one drink in the past 30 days. 10.5% had engaged in binge drinking.

While it is possible that conception had not occurred during each of the drinking episodes, this data suggests that the rates of alcohol-exposed pregnancies are likely higher than 1 in 7.

Alcohol use any time during pregnancy, even before a person knows they are pregnant can cause injury to the developing brain, impacting an individual for a

lifetime. To have the healthiest pregnancy possible, a person should abstain from using any form of alcohol. This includes liquor, wine, wine spritzers, wine coolers, alcopops, beer, craft beer, light beer and even non-alcoholic beers which may include low levels of alcohol.



How Can You Help?

Schedule an FASD Training for your community!

[Proof Alliance NC](#) provides trainings free of charge to organizations, schools and the general population across the state. Trainings can be delivered in-person or virtually, with sessions running from one to two hours. Proof Alliance NC's primary focus is prevention, but we also offer presentations that focus on strategies for providers in a variety of settings.

The modules are prevention focused (for the general population, college students, high school students, or middle school students), and include both prevention and support strategies (for service providers, educators, substance use treatment professionals and an FASD overview for Guardian Ad Litem/Court Advocates. FASD@arcnc.org

For Partners, Family, and Friends:

It's important to have a conversation about alcohol use even before a woman reaches childbearing age. Many people are unaware of the consequences of drinking alcohol during pregnancy.

Some people have received misinformation and believe that wine and beer are not as harmful as hard liquor, or they may think that there are certain times during the pregnancy that it's safe to drink. In some cases, a person may be struggling with an alcohol-use disorder and may need additional support and possibly treatment. Behavior change is a difficult process, but support can make a difference and determine the success of recovery.

If you know someone who is pregnant and needs support and possible treatment, please refer them to the [NC Alcohol and Drug Council](https://www.ncadcc.org/) @ 1-800-688-4232.

Everyone plays a role in preventing FASD:

- If you can become pregnant, talk with your care provider about preventing an alcohol-exposed pregnancy.
- Support the pregnant people in your life to have an alcohol-free pregnancy:
 - Be supportive and refrain from judgement and shaming.
 - Assist in planning strategies on how to stop drinking.
 - Do things that are enjoyable together that do not involve alcohol.
 - Encourage the use of mocktails and other non-alcoholic beverages.
 - Encourage them to follow up with their health care provider.

Community Efforts to Prevent FASD:

Prevention starts by educating others about the dangers of alcohol use during pregnancy and about FASD.

- Raise awareness in schools and in your community.
- Participate and support local and state efforts surrounding FASD.
- Help educate medical and allied health professions.
- Promote FASD Awareness Day/Month (September 9).
- Be an advocate for change as it relates to alcohol policies in our state and your community.

For Health Care Professionals:

- Take every opportunity to have conversations with all patients about alcohol use before and during pregnancy.
- Ask routinely at every medical appointment.
- Ask at appointments in various systems.
- Ask in a nonjudgmental manner.
- Use effective screening tools.
- Ask about possible prenatal exposure.
- Imbed questions about alcohol use in general health questions (*e.g., wearing seat belts, taking vitamins, stress management, tobacco use, etc.*).

Research shows that brief interventions can help reduce alcohol use among individuals of childbearing age, whether pregnant or non-pregnant. Please view the following sites to help you identify resources that can help you have these conversations with individuals.

<https://www.cdc.gov/ncbddd/fasd/alcohol-screening.html>
<https://nccd.cdc.gov/FASD/>

Additional information on the prevention of alcohol exposed pregnancies and fetal alcohol spectrum disorders can be found at www.proofalliance.org

Substance Use Prevention

- www.cdc.gov/ncbddd/fasd
- <https://www.proofalliance.org/>
- <https://fasdprevention.files.wordpress.com/2017/11/substance-using-individuals-with-fasd-service-providers-perspectives-report-web.pdf>
- <https://www.samhsa.gov/resource/ebp/tip-58-addressing-fetal-alcohol-spectrum-disorders-fasd>
- <http://journals.sfu.ca/fpcfr/index.php/FPCFR/article/view/204/32>
- <https://www.cdc.gov/violenceprevention/acestudy/index.html>
- <https://fasdunited.org/>

References

Astley S, (2004) Diagnostic Guide for Fetal Alcohol Spectrum Disorders: The 4-Digit Diagnostic Code. Seattle, Washington. University of Washington Press.

Astley S, (2011). Diagnosing Fetal Alcohol Spectrum Disorders (FASD). Prenatal alcohol use and Fetal Alcohol Spectrum Disorders: Diagnosis, assessment and new directions in research and multimodal treatment (pp. 3-29). Oak Park, IL: Bentham Science Publishers. Accessed July 1, 2012 at <http://depts.washington.edu/fasdpn/htmls/literature.htm>

Behnke M, (2013) Prenatal Substance Abuse; Short and Long-term Effects on the Exposed Fetus. PEDIATRICS Volume 131, Number 3, March 2013

Coons K, (2013) Determinants of Drinking During Pregnancy and Lifespan Outcomes for Individuals with Fetal Alcohol Spectrum Disorders. JoDD, Volume 19, Number 3, 2013

Hagan J, (2016) Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure. American Academy of Pediatrics Volume 138, Issue 4, October 2016

Hoyme E, et al. (2016) Updated clinical Guidelines for Diagnosing Fetal Alcohol Spectrum Disorders. PEDIATRICS Volume 138, Number 2, August 2016.

Malbin D, (1993) Fetal Alcohol Syndrome and Fetal Alcohol Effects: Strategies for Professionals. Center City, Minnesota: Hazelden Educational Materials.

Malbin D, (2002) Trying Differently Rather Than Trying Harder. Portland, OR. FASCETS.

May P, (2018) Prevalence of Fetal Alcohol Spectrum Disorders in 4 US Communities. JAMA 2018; 319(5): 474-482

Streissguth AP, (1997) Fetal Alcohol Syndrome: A Guide for Families and Communities. Baltimore, Maryland: Paul H. Brookes Publishing

Streissguth AP, Kanter J, (1997) The Challenges of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities. Seattle, Washington: University of Washington Press.

Tan C, et al. (2015) Alcohol Use and Binge Drinking Among Women of Childbearing Age – United States, 2011-2013. MMWR, 64(37); 1042-1046, September 2015.

Zieff C, Schwartz-Bloom, R, (2008) Understanding Fetal Alcohol Spectrum Disorders (FASD): A Comprehensive Guide for Educators. Durham, NC. Duke University Press.

10 England LJ, Bennett C, Denny CH, et al. Alcohol use and co-use of other substances among pregnant females aged 12–44 Years — United States, 2015–2018. MMWR Morb Mortal Wkly Rep. 2020;69:1009–1014.