

Service, Support and Success

The Direct Support Workers Newsletter

Something is Different Here:
**Promoting Awareness of
an Invisible Disorder**



By: Robin VanEerden and Anna Erb

The goal of this article is to shine a spotlight on Fetal Alcohol Spectrum Disorders (FASD). September 9, 2014 is International Fetal Alcohol Spectrum Disorder Awareness Day, and the purpose of this day is to raise awareness of FASD and its impact on individuals and families who struggle with the disorder. The ninth day of the ninth month of the year was chosen to remember that, during the nine months of pregnancy, a woman should abstain from alcohol. The only known cause of FASD is maternal drinking while pregnant.

This article is intended for direct support professionals, and it begins with the authors' "aha moments" – our personal stories of learning about FASD. We then provide basic information about FASD, review recommended support strategies, and provide suggestions about where to find additional resources. It would be impossible to review the complexities of all individual experiences, research, and recommendations related to FASD within this newsletter, so we encourage you to seek out additional training and information about FASD.

Anna's Aha Moment

As a direct support professional, previous program specialist and current behavior specialist, I strive to positively impact people with special needs and to help them become vibrant members of their communities. I have successfully provided that support through advocacy, system change, training, and individual intervention. That is, until about 2008 when I met Mike¹. He was full of life but consistently struggled with impulsivity, destructive behavior, and the consequences of poor decision making. It felt as if all of the textbook techniques and tools that I possessed were ineffective in assisting Mike. It felt like nothing worked. As I researched ways to support him, I came across three letters: F-A-S. This became a turning point in the personal and professional support I provided Mike, as well as the effect it would have on my future career.

I was aware that drinking alcohol while pregnant could affect an unborn child, yet I was unfamiliar with the diagnosis of Fetal Alcohol Syndrome (FAS) and the term Fetal Alcohol Spectrum Disorder (FASD). As I began to research the neurological effects of prenatal alcohol exposure, its behavioral manifestations, and the effective intervention techniques for working with persons living with FAS, it was as if a light bulb went off. The supports I had been providing were not only inadequate and ineffective, but also potentially counterproductive to Mike's actual needs.

¹ Name changed to protect identity

This prompted me to review the history and case files of several other clients who exhibited similar characteristics, such as difficulties meeting their personal goals and trouble managing various aspects of daily life. Buried in the old case notes, evaluations, and assessments of several clients were diagnoses of FAS, partial fetal alcohol syndrome (pFAS), fetal alcohol effects (FAE) or a notation of reports indicating maternal drinking while pregnant. While these individuals and their support teams continue to identify and manage challenges, they are able to equip themselves with better support tools and a deeper understanding of the reason behind many of the challenging behaviors being exhibited. This is not to say that, after learning about FASD, an individual and their support team face no challenges. At times it still feels as if every two steps forward comes with one step back, and that success can be hard to see. But to quote Dr. Susan Doctor (2013), "There is hope in the interventions."

Robin's Aha Moment

I have worked in the human services field for almost 36 years. During this time, I have had incredible opportunities to develop and oversee support for people with intellectual disabilities and co-occurring mental health diagnoses. As my career progressed, I began to notice a certain pattern of people who "slipped through the cracks." I saw people with severe emotional dysregulation become involved in the legal system, be admitted to inpatient psychiatric hospitalizations, and access countless emergency rooms. Even with a solid focus on person-centered planning, it felt as if nothing would lead to an improved quality of life.

Three years ago, I took a position as a Clinical Director for my home state. Part of my position as a Clinical Director is to identify statewide trends and gaps in services. As part of this process, I began to assess individuals with challenging behaviors who resided in prisons and community residential placements. Within the first six months, I became aware that seven out of the 10 people with the most significant struggles had a diagnosis of Fetal Alcohol Spectrum Disorder or a presentation that was consistent with FASD!

As I began to thoroughly investigate FASD, the findings and research astonished me. Many of the challenging behaviors I was seeing were the result of a poor fit between a neurological (brain-based) condition, the surrounding environment, and available supports. I also learned that many people living with the effects of FASD are not identified, diagnosed or they are misdiagnosed. The knowledge that I gained from research and from the experts in the field led me to begin to report my findings. I found many people in prison were not criminals, but had problems interacting with their environment. There were people in inpatient psychiatric units who were not receiving appropriate medications or supports. Others may appear to present with a mental illness but, in some cases, the underlying condition of FASD better explained their challenges.

Since these discoveries, I have been passionately working to identify and appropriately support individuals, families, and teams who are impacted by this often “invisible disability.” Through understanding and awareness, supports need to be tailored for “a better fit.” Behavior support plans must be “FASD friendly” with concrete language and strategies. Therapies must be carefully chosen and targeted to individual strengths. For example, art, music or movement therapies are often more effective than talk-based therapies.

For me, this has been a learning process. I have had the great opportunity to connect and work with individual, parent, clinical, and research experts on FASD. I have seen how education, training, and appropriate support strategies have the power to improve quality of life. My personal story has led me to continue to develop appropriate individualized supports and spread the word of “0-4-9” prevention – zero alcohol for nine months.

What is Fetal Alcohol Spectrum Disorder?

Fetal Alcohol Spectrum Disorder (FASD) is a non-diagnostic umbrella term used to describe a group of diagnoses related to prenatal alcohol exposure. This group includes Fetal Alcohol Syndrome (FAS), Partial Fetal Alcohol Syndrome (pFAS), and Alcohol Related Neurodevelopmental Disorder (ARND) (CDC, 2004). Fetal Alcohol Syndrome is a medical diagnosis, and it is the only syndrome under the FASD umbrella that can be diagnosed without confirmed maternal drinking (Streissguth, 2007). Alcohol puts the developing fetus at risk due to the interference of developing cells within the central nervous system.

FASD is the leading preventable cause of intellectual disabilities. While influenced by maternal nutrition, timing, frequency, and amount of alcohol exposure, FASD can happen to any fetus that comes into contact with alcohol while in utero. The only known cause of FASD is maternal drinking while pregnant. FASD affects almost one out of 100 newborns in the United States each year (Paley, 2009) making these disorders more common than new diagnoses of autism spectrum disorder (CDC, 2010). The effects of this brain-based physical disorder are life-long (from birth to death) and are influenced by access to appropriate services and supports. With appropriate supports, more positive life outcomes are possible. There are many children and adults who are living with the effects of FASD, but many have not been formally diagnosed or identified. This does not change the fact that their day-to-day lives may be impacted.

What are some of the symptoms of FASD?

Some people have specific characteristic facial features or physical symptoms due to FASD such as hearing impairments and visual impairments. However, most of the primary symptoms of FASD are invisible and are related to neurological (brain based) changes (Substance Abuse and Mental Health Services Administration, 2014) and to the neuroendocrine system (hormones that regulate mood, emotions, immune system, etc.) (Uban, et al., 2011). These primary symptoms include challenges with:

- executive function (planning, switching between tasks, reasoning)
- understanding and foreseeing consequences; not foreseeing danger
- memory
- applying knowledge in different environments (generalization)
- recalling information
- regulating emotion
- being biologically unable to calm down once emotionally escalated (altered stress response)
- making connections between cause and effect
- learning from mistakes
- confabulation (telling made up or misinterpreted memories about oneself or the world, without a conscious intention to deceive).
- attention
- coordination
- identifying hunger
- sleeping disturbances
- cognitive abilities and below average IQs.

These symptoms can be made better or worse through support strategies, life experiences, social situations, and access to appropriate services. When symptoms, poor supports, and stressful social situations combine, they can lead to common but not inherent characteristics. These characteristics can include problems with (Substance Abuse and Mental Health Services Administration, 2014):

- impulsivity
- disobedience
- lack of stranger awareness
- not understanding social situations and social cues
- enjoying talking though the act of talking is often more important than what is being said
- talking about unrealistic subjects
- poor judgment
- waking up in the morning

Added together, these symptoms and characteristics can put a person with FASD at a greater risk for (Substance Abuse and Mental Health Services Administration, 2014):

- school failure
- homelessness
- employment difficulties
- substance abuse issues
- incarceration
- psychiatric confinement

What does this mean?

Due to the effects of alcohol on the developing brain and the influence of social factors, those with FASD may have specific strengths and deficits. A person may be able to read a book but be unable to tell you about what they have just read. One day they can remember how to complete a task and then the next day they can't. Most are incredibly friendly and caring, though they may lack important social skills. They may desire to go to an event, but at the last minute run away because they were overwhelmed by transitions due to environmental change. A person might not be able to manage money or balance a checkbook, but can create beautiful artwork.

Token economies and reward systems are often ineffective interventions for persons with FASD. This is because of the difficulty with connecting cause and effect over a period of time. Due to cognitive and auditory processing issues, even a simple conversation could be overstimulating. The combination of an altered stress response and ineffective coping skills could cause overwhelming emotions. These uncontrolled emotions might lead to property destruction, elopement, and other potentially dangerous behaviors.

What about strengths?

Many people with FASD have great strengths. Some of these common strengths include being:

- friendly and cheerful
- likeable
- determined
- creative
- hard working
- approval seeking
- fun

These strengths need to be harnessed and nurtured in order to promote happy and healthy lives.

Why is all of this information important?

Persons living with the effects of FASD will experience some level of symptoms across their lifetime. In order to effectively support persons with FASD, strategies and supports must be FASD-informed and person-centered. This is because common behavioral interventions, medication regimens, and psychiatric supports are often not effective for people with FASD.

Since FASD is a medical and neurological issue, best practices call for a complete medical assessment, psychiatric evaluation, neuropsychological assessment, and an informed, comprehensive support plan. All strategies selected must be proactive instead of reactive.

What can we as support people do?

- If you are working with someone with FASD or a suspected FASD, educate yourself. Become FASD informed and provide FASD-informed supports. Look closely and through the perspective of FASD.
- Provide the external executive function (coach, guide, suggest options).
- Identify strengths.
- Make sure other associated medical issues are researched and addressed as these may change over the lifespan.

How can I provide FASD informed supports?

- Educate the entire team on FASD. This includes: law enforcement, primary care physicians, therapists, direct care professionals, and hospital staff.
- Partner with community services to ensure that people and their needs are understood.
- Make sure support plans are FASD informed, strength based, and trauma informed.
- Request assessments that may identify which area of the brain may have been effected (i.e. neuropsychological evaluation).
- Make sure that your expectations for people match their ability.
- Work with a prescribing psychiatrist who is FASD informed and understands the mental health diagnoses that may co-exist with FASD.
- Accept that sometimes people can't do a task, it is not that they won't (and sometimes they can one day and not the next).
- Look at how to make a person's routine more structured and predictable.
- Investigate and address sensory issues such as problems with auditory processing and visual deficits, and then implement effective strategies (i.e., sensory integration evaluation by an occupational therapist trained in sensory integration).
- Assess the environment for potential sensory issues: Is it too cluttered, loud, or crowded?
- Use labels, color codes, visual schedules and other organizational tools.
- Use role play and modeling to teach new skills and to review acquired skills.
- Assist the person to develop healthy friendships and community supports.
- Encourage physical exercise.
- Write things down, draw pictures, do not rely on verbal communication!
- Support persons must role play appropriate social skills and healthy choices.
- Use a coaching or mentorship model.
- Develop a Wellness Recovery Action Plan (Copeland Center, Mary Ellen Copeland).
- Develop a crisis plan.
- Develop safety plans as necessary.
- Clearly explain expectations before, during, and after activities.
- Plan for breaks and rest periods before someone experiences emotional dysregulation.
- Use auditory cues according to developmental skill level including texting, phone reminders, egg timers, and other electronic reminders.
- Provide appropriate instruction regarding dating, sexuality, and sexually appropriate behaviors.
- Match strategies with personal strengths and personal motivation.

In Conclusion:

Fetal Alcohol Spectrum Disorders are prevalent yet, by providing appropriate intervention, people can lead more successful, productive, and happy lives.

This brain-based disability is invisible unless the person has physical features that can be identified. A small percentage of people who actually have an FASD have the all the accompanying facial features (Substance Abuse and Mental Health Services Administration, 2014). Persons are not always diagnosed with an intellectual disability, but may have severe deficits in social, communication, and vocational/educational domains. FASD does not have a socio-economic or cultural boundary. While influenced by maternal nutrition, timing, frequency, and amount of alcohol exposure, FASD can happen to any fetus that comes into contact with alcohol while in utero.

It is important to learn to identify and understand the presentation of people with FASD. Referral to the proper community physicians including primary care physicians, psychologists, and neuropsychologists is important for the journey towards appropriate supports. It is also a social responsibility to not judge and to spread the message of “0-4-9” as a preventative measure. Zero alcohol for nine months.

While those with FASD may have deficits, they have many wonderful skills and strengths. These need to be identified to create life goals which foster self-esteem and increase motivation. Strategies and services must be friendly to people with an FASD. When strategies are not FASD friendly, problems can be made worse causing frustration, low self-image, and high stress. **If working with someone with an FASD, it is your responsibility to learn as much as possible, implement appropriate supports, and pass information on to others.**

About the authors:

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Anna Erb is a social worker who supports adults with intellectual and developmental disabilities. She is completing her Doctorate in Clinical Social Work at The University of Pennsylvania. Her dissertation explores the life experiences of adults with FASD.

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