

# Fetal Alcohol Spectrum Disorders: One Minute to Midnight

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**Abstract:** This reflection focuses on my experiences as a social worker working with individuals with fetal alcohol spectrum disorders (FASDs) and their families for almost 40 years. The first child I met with fetal alcohol syndrome was a three-year-old who stole my heart with his boundless energy and big smile. Ever since I met “Darren” and a group of advocates who shared my interest in this disorder, we have sought to raise awareness about the leading preventable cause of intellectual and developmental disabilities in the United States. I feel an urgency to share what I have learned from individuals with FASDs and family members about what it’s like to live with an FASD with helping professionals who are encountering children and adults who have FASDs but who are going unrecognized. As a nation, it is time to address the impact of prenatal exposure to alcohol on individuals, families, and communities.

**Keywords:** fetal alcohol spectrum disorders, social work practice, advocacy, policy

## Introduction

I was once referred to as a “rogue advocate” by a program director: She did not appreciate that I represented a mutual client who’d been denied needed accommodations. That label became my personal badge of honor. I have tried to set a high bar when it comes to campaigning for the civil and human rights of the people I have been so honored to partner with as an advocate. One of my greatest frustrations has been that in almost 40 years of advocacy work alongside individuals with fetal alcohol spectrum disorders (FASDs), families, and colleagues, there remains minimal recognition of the leading preventable cause of intellectual and neurodevelopmental disability: prenatal alcohol exposure (Williams & Smith, 2015). When I think about these years, I often think of “Darren.”

The first memory I have of Darren is the joy with which he flew across the room: arms stretched out in the air, glasses with thick lenses askew and frames too big for his small face and head as he carried his thin three-year-old body across the office. He was constantly in motion, laughing, flitting, and whirling. Darren had fetal alcohol syndrome, the only category of the spectrum that can be medically diagnosed (Hoyme et al., 2016). I was in my first few weeks of my social work internship at a large urban child welfare agency in one of the poorest cities in the United States and had been assigned to follow up with Darren and his placement with a family member. I soon found there were no support services specifically for FASDs I could recommend.

In my early career years, I became simultaneously aware of the *prevalence* of FASDs and the *lack* of recognition and support services for families and individuals with them. FASDs describe a range of conditions that impact learning, behavior, and physical health due to prenatal exposure to alcohol (Warren & Foudin, 2001). FASDs include fetal alcohol syndrome, partial fetal alcohol syndrome, alcohol-related neurodevelopmental disorder, and alcohol-related birth defects. In spite of the most recent prevalence studies that find up to 1 in 20 elementary school-aged children have been prenatally exposed to alcohol and consequently have an FASD

(May et al., 2018), we have no national policies or funding to facilitate much-needed coordination and collaboration between the multiple systems that would provide services to them. Children with FASDs grow into adults who will have co-existing developmental and mental health needs for their lifetimes—but too often they end up in jails and prisons. This is because we do not recognize that their crimes are directly related to the poor decision-making skills, lack of executive functioning abilities, and vulnerability to peer pressure caused by prenatal exposure (Brintell et al., 2019; Fast & Conry, 2009).

### **Understanding FASDs**

According to May et al. (2018), FASDs affect elementary school-age children in the United States at rates of 1 in 100 (1.1%) to 1 in 20 (5%) using conservative estimating and 1 in 31 (3.1%) to 1 in 9 (9.9%) using a weighted approach. These rates are higher overall than children at age 8 years diagnosed with autism spectrum disorders (ASDs), which currently have an overall prevalence rate of 1 in 54 (1.85%) (Maenner et al., 2020). Despite the higher prevalence of FASDs, there is a much larger support and advocacy network for those living with ASDs, resulting in more awareness, screening, and support services as outlined in the Combatting Autism Act of 2006, known today as the Autism Collaboration, Accountability, Research, Education and Support (CARES) Act of 2019 (2019). Conversely, individuals with FASDs are rarely evaluated for the disorder even when part of a high-risk group such as child welfare where between 6% and 16.9% of children and youth were found to have an FASD based on a meta-analysis of international, active ascertainment studies that pooled prevalence rates (Lange et al., 2017). The under-recognition of FASDs is illustrated by a study of 156 foster care and adopted children where 80.1% had missed being diagnosed with the effects of prenatal alcohol exposure and another 6.4% had been misdiagnosed (Chasnoff et al., 2015).

Adoptive parents report a persistent lack of knowledge of FASDs throughout systems that are supposed to support children and adults with disabilities, including education and developmental disabilities services systems (Petrenko et al., 2014). Only fetal alcohol syndrome (FAS) and partial fetal alcohol syndrome (PFAS) are diagnosable because of the unique facial features (small eye opening, flat philtrum, thin upper lip) solely associated with prenatal alcohol exposure (Astley et al., 2002). A diagnosis of FAS requires all three of the facial features as well as growth delays and central nervous system impairments. PFAS requires two of the three facial features and growth delays or brain morphogenesis or neuro-developmental problems (Warren & Foudin, 2001). However, for those who do not have the facial features that cinch a clinical diagnosis, neurodevelopmental and behavioral disabilities associated with FAS may be present (Mattson, et al., 2019). The two other categories of FASDs, alcohol-related neurodevelopmental disorder (ARND) and alcohol-related birth defects (ARBD), require confirmation of maternal alcohol use during pregnancy, which is often difficult to ascertain (Hoyme et al., 2016). ARND is a term used to delineate the impact of prenatal alcohol exposure on neurological development and the consequent impairments in cognitive and behavioral functioning, motor skills, executive function, memory, emotional regulation, and adaptive skills (Flak et al., 2014; Kable et al., 2016; Mattson et al., 2019). ARBD describes the physical conditions, including problems with the heart, kidneys, bones, sight, and hearing, along with immune system disorders that arise with prenatal alcohol exposure (Bodnar et al., 2016; Warren & Foudin, 2001). The DSM-5 has added

a category named neurodevelopmental disability associated with prenatal alcohol exposure (ND-PAE) which requires confirmation of prenatal exposure to alcohol with impaired cognitive functioning, self-regulation, and adaptive functioning which cause significant distress or impairment in social, academic, occupational, and other areas of functioning (American Psychiatric Association, 2013). This will provide an avenue for diagnosis of ARND if criteria are blended between ARND and ND-PAE and it moves from “proposed” to “accepted” as a clinical category in the DSM-5 (Hoyme et al., 2016).

In my experience, individuals who have no diagnosis or a misdiagnosis are most at risk because they are not recognized as having a developmental disability, which can lead to greater trouble with the law, being labeled as mentally ill, receiving no or inappropriate services, or ending up homeless or trafficked as they enter adolescence and young adulthood (Reid, 2018; Streissguth et al., 2004). However, we do not have solid research that says how many people with FASDs make up the population of people who are homeless, who are being trafficked, who are incarcerated, or who end up dead—as did one of the youth with FAS I knew, in a drug deal gone bad. Children and young people who are involved in child welfare services or juvenile justice systems and who are homeless should always receive screening and diagnostic services for FASDs, but this rarely happens. Consequently, we have a difficult time putting numbers to these populations who are more at risk for prenatal exposure to alcohol and the consequent cognitive, behavioral, social, physical, and emotional disabilities.

### **FASDs and Youth in the Child Welfare System: A Hidden Population**

At the time I met Darren, FAS had been identified only 15 years earlier by French physicians who noticed a similarity in the facial features and behaviors of children born to alcoholic mothers (Lemoine et al., 1968). It was then written about by a group of American doctors (Jones et al., 1973), some of whom are still researching FASDs almost 50 years later. Their work continues to focus on the impact of prenatal exposure to alcohol on neurological and behavioral development and raise public awareness of this disorder that touches everyone’s lives—even if we as a society largely remain uneducated about and unaware of those among us who have been prenatally exposed to alcohol. Other than a federal advisory (Centers for Disease Control and Prevention [CDC], 2005), there is still no national effort to prevent FASD and support affected individuals and their families as we do with other recognized developmental disabilities.

Darren was assigned to me during my internship because I had volunteer and work experience with children and adults with developmental disabilities. Darren had been taken from his mother because of neglect due to her use of drugs and alcohol. Darren did have a diagnosis of FAS, which was clear from his small head, facial features, tiny body, and neurodevelopmental issues that included ADHD, cognitive impairment, and problems with language. He had been placed in several foster care homes, but he never stayed long partly due to his need for constant supervision. At one point when there was no foster home available, I had to take him to a large children’s home with his clothes and a couple of toys in a garbage bag. He cried and clung to me as if his heart would break!

Even if you can get a diagnosis, which is rare, and while services and supports do exist for

children and adults with developmental disabilities across the United States, FASDs are often not seen as disorders that confer automatic eligibility for those services (Petrenko et al., 2014). The prevalence of FASDs in our population is higher than the rate of ASDs; yet, few states and organizations have implemented programs to consistently identify and support children, youth, and adults who are living with a developmental disability that so heavily impacts their daily lives (Kodituwakku, 2007, 2009, 2010). The Substance Abuse and Mental Health Services Administration (SAMHSA) once funded a Center for Excellence on Fetal Alcohol Spectrum Disorders which gathered state FASDs coordinators and worked towards prevention and intervention, but the Center was dissolved several years ago with no single agency to replace it (National Organization on Fetal Alcohol Syndrome, 2020).

One thing Darren taught me was that having FAS did not mean all learning and growing stopped, even though ARND is also referred to as *static encephalopathy*—having an impaired brain that doesn't change. There were no known interventions or informed services at this time in the mid-1980s, so treatment focused on individual areas of concern such as increasing attention or improving fine motor control. One day I went to pick up Darren from one of his multiple foster care placements for an appointment. He was staying with a long-time foster mother who had taken care of many children. Frankly, I was a bit intimidated by her years of experience. I carefully held Darren's hand as we walked across the street to my small car and put Darren in the front seat, fastened his seatbelt (no car seats back in those days), and locked and shut the door. I looked up and thought I saw his foster mother in the window and gave a cheery wave good-bye—then at that moment I realized I had locked my keys in the car with Darren! I told Darren to lift up the button for the car lock. He tried, straining against the seatbelt, to grab the slim button and pull it up. Finally, I told him to slip under the seatbelt, and success! He was able to grab the button and pull it up! I looked up and saw the curtains fluttering a bit in the window and thought to myself how fortunate I was that Darren was able to follow directions and was so persistent in his good-natured way. Darren had quite a severe cognitive impairment, but his willingness to keep trying and to listen would serve him well. I am fortunate to have had such good teachers in the children, youth, and adults who have shared themselves and their experiences with me over the years. Darren was one of my great teachers and this experience with him was one of many reminders that continue to this day: to never assume that someone labeled with a disability is unable.

Alcohol use and abuse is a huge social and health problem, and it is the third leading cause of preventable death in the United States (Mokdad et al., 2004), with alcohol-impaired driving accidents accounting for almost a third of driving fatalities (National Highway Traffic Safety Administration, 2015). Over 26 percent of adults reported at least one episode of binge drinking in the past month—drinking more than five drinks within two hours for males and four for females (SAMHSA, 2018). Data from the Behavioral Risk Factor Surveillance System indicates that 11.5 percent of pregnant women (1 in 8) drink during pregnancy, with 3.9 percent reporting binge drinking during the past 30 days (Denny et al., 2019).

Children, youth, and adults with FASD are in all arenas where social workers and other helping professionals provide services, but for the most part we are ignorant of a major reason for the memory problems, out-of-control behavior, and what we label as oppositional defiant disorder

until 18 (when these new adults are now viewed as purposely obstinate, aggressive, and manipulative). Behaviors that are difficult for parents and child welfare workers to understand will often land these children in long-term residential placements to be raised by three shifts of people paid minimum wage. While I am sure for the most part these workers do their best, numbers of sexual, emotional, and physical abuse endured by children and youths in these situations are high—and often, after 18, they are set free to experience more of the same (Fong & Cardoso, 2010; Williams & Frederick, 2009). From my own experiences with transitioning adolescents from child welfare systems and looking at the research literature, these older adolescents who are involved in child welfare systems—and homeless youth—are very vulnerable to human and sex trafficking; yet, there is little research that identifies the levels of intellectual, developmental, and learning disabilities in these populations (Lightfoot et al., 2011; O’Brien et al., 2017; Reid, 2018). The U.S. Department of State in the Trafficking in Persons Report (2019) finds that children and adults with disabilities are consistently used in labor and sex trafficking across the globe.

At the time of placement, Darren’s older sister had just turned 18 and was newly married. She wanted to care for Darren and to keep him in their family. It was clear she loved him very much. They were approved as a foster placement with the intention that, if things went well, the young couple would adopt Darren. Darren, his sister, and her new husband lived in an apartment above her husband’s grandmother’s place.

Between 2005 and 2008, as a social worker for a local advocacy agency, I was allowed to define my role in partnership with youth in transition from child welfare services, their families, caseworkers, teachers, and community organizations to try to prevent these young people, most who had unidentified FASDs and other developmental disabilities, from falling off the proverbial cliff and landing in jail or prison or experiencing sex trafficking, violence, or homelessness as they aged out of child welfare care. Our agency had been helping youth aging out all along, but too often we were approached within a few months of a young person exiting care, too late to help get needed benefits such as Social Security or adult developmental disability and employment services, too late to find that “one adult who [was] crazy about [them]” (Greenson et al., 2010, p. 576) and get safe housing in place. These emerging adults between the ages of 16 and 21 allowed me into their lives and shared the difficulties they encountered in trying to stay housed, finish school, maintain employment, keep out of trouble with the law, and be in supportive relationships on a day-to-day basis.

One older teen I worked with, “Thomas,” had turned 19 recently and had a history of educational and mental health labels (ADHD, learning disabilities, oppositional defiant disorder, and depression). Thomas had been bounced between relative homes and foster care since the age of eight. He had spent time in residential treatment because of aggressive behavior; after he told me about his background, I was convinced he was reacting out of his traumatic history and because of being prenatally exposed to alcohol, which we soon confirmed with a diagnostic assessment and a statement from a family member that his mother had episodes of binge drinking during her pregnancy with him. Thomas’s history of being uncooperative reached me before I met him. However, the young man I met was not at all like his reputation. He wanted to do the right thing for his girlfriend who was living with her parents, get a job, get married, and find them their own

home. He knew he had a disability and told me that he “must just be stupid” as his last teacher had said he could only read at a first-grade level. We talked a lot about why he might have difficulty learning to read and that it didn’t make him stupid, but he might need to learn differently and figure out what he did well that could lead him to a job.

Our local child welfare office understood that in order to stop transitioning adolescents from falling off that proverbial cliff, we needed to identify those at most risk and connect them to the supports, services, and relationships available in the community before exiting the child welfare system. Our community had a monthly wrap-around meeting where social workers and service providers from across the county gathered to discuss the needs of transitioning adolescents to identify and secure those connections. Volunteers from our local FASDs diagnostic clinic were willing to meet me anywhere to do the evaluation, especially one nurse practitioner who would go to a home, office, or local neutral place depending on the adolescent’s need to feel safe and bring her equipment to do the facial feature measurements for the FASDs diagnostic evaluations. Our local homeless shelter for youth worked with the local housing authority to get priority for a couple of subsidized apartments for aging-out youth. I handled the Social Security disability benefits applications and represented them in their appeals and stepped into the role of social worker if they aged out of child welfare before qualifying for adult developmental disabilities services. Child welfare workers helped youth apply for Medicaid, food stamps, and employment services and identified adults who would act as mentors.

As the fill-in social worker, if one of these emerging adults called and said they needed a ride to get to a doctor’s appointment or a job interview, I was there—knowing that having the skills to figure out which bus at what time would arrive by the right hour might be too many things to consider at once. It was a waste of time to assume that this young person was being lazy (as I heard a few times) or was perfectly capable of getting there themselves. Maybe so, but individuals with FASDs struggle with short-term memory and executive functioning, which means they can have the skills but still be incapable of following through without support.

I started meeting with Thomas and he couch-surfed for some months while we worked on getting his FASD diagnosis, getting his application in for Social Security disability benefits, finding housing, and applying for adult developmental disability services based on his FASD through our local community mental health agency. Unfortunately, while he was still without services or a home, he stole a car with an underage teen and 30 seconds later pulled out in front of a police car. I had lost touch with Thomas for a couple of weeks and it finally dawned on me to contact the local jail. When I called and described him, the officer told me they had to put him in solitary because he wouldn’t stop crying and the police were afraid of what other inmates might do to him. His theft of the auto at the suggestion of a 15-year-old and pulling out in front of a police car to try to get away was classic FASD behavior, as executive functioning and consequential thinking are two areas that are typically affected and lead to involvement in the criminal justice system.

Darren’s family placement didn’t work out with his sister. I think she was just too young to handle this very impulsive and energetic child—she clearly loved him, but he was going to need a lot of support throughout his life. She had difficulties organizing Darren’s appointments and

getting him to scheduled visits. I wondered if she too had been prenatally exposed to alcohol, as memory issues are a major component of ARND. I knew she wanted the best for Darren but was struggling to be his mother when she was still emerging from adolescence and in a new marriage. One day she told me something that she knew would get him removed from her care: She had spanked him with a belt. Darren didn't have any marks, and the way his sister said it—almost in a whisper—made me think she may not have hit him but could not think of another way to let him go. She still needed an adult in her life to guide her, and while she and her husband had his grandmother, there was no adult willing to step forward and co-parent this young child with her.

It's hard to absorb that all the work over the 40 years since prenatal alcohol exposure was understood to be harmful has moved us what seems like only an inch in a mile. Most of the parents I have known involved in advocacy work are adoptive parents of children from the U.S. and Indian child welfare systems or Eastern Europe. Some of these parents who mentored me have died, and the rest are in their 70s and 80s still fighting and worrying what will become of their now-adult child with an FASD. These parents fought so long and hard for the services their children have needed and still need as adults; FASDs are life-long, and many of those affected need some support, more or less, to stay on track with paying the bills, showing up to work, and taking medications. Education, community mental health, and child welfare systems have been reluctant to systematically identify children with FASDs. Stigma is real, and women and men get mixed messages from health professionals and everyone else about drinking and pregnancy. Alcohol consumption is interwoven into our culture. We drink to celebrate and to mourn the dead, to relax, to deal with bad and good news, to come down from a stressful day, and to self-medicate anxiety and depression. What we do know, however, is that FASDs are 100 percent preventable if a woman abstains from drinking alcohol during pregnancy (CDC, n.d.).

While Thomas was on probation for the auto theft, he had to appear in court regularly, do community service, and follow up with his application for adult developmental disabilities services as part of his jail diversion plan. He had been fortunate to get in front of a judge who understood the many obstacles that adolescents transitioning out of foster care face. However, Thomas could not keep all his appointments straight. We tried a calendar, which worked until he lost it. So, for a while I called him the day before and the morning of his appointments to make sure he remembered. When Thomas was accepted for adult developmental disabilities services, his new social worker took over with the reminder calls. This social worker understood that this young man had a developmental disability and needed person-centered, individualized supports and services in order to get done what needed to be done.

### **Looking Forward: Prevention, Intervention, and Supports**

In all my years of practice, I have never met a mother who wanted to harm her baby by drinking alcohol. I met Darren's mom once. According to the file, she had severe drug and alcohol addiction issues. She thanked me for tracking her down to tell her the date of the termination hearing. I still hear of pregnant women being told it is okay to have a drink occasionally by their physicians. When I do trainings with social workers and other professionals I stress we cannot blame nor shame women who take the brunt of the stigma of having "damaged" their children.

When I have talked to mothers who drank during pregnancy, I have found multiple points of concern: Many women were not educated about the impact of drinking on a developing fetus, others did not know they were pregnant for months (and so did not know to stop drinking), some were given vague advice (told it was okay to drink “once in a while,” to “just not over-do it,” or to only have “one drink a week” without discussing size), or were in abusive relationships (where drinking is expected). Women who drink during pregnancy come from all racial, ethnic, and age groups and socioeconomic classes (Caetano et al., 2006). As noted by the American Academy of Pediatrics (n.d.-b) in their guide on screening for prenatal alcohol exposure, most children who have been alcohol exposed go unrecognized and undiagnosed despite having severe disabilities in cognitive, social, behavioral, and adaptive functioning. If you have financial and other resources, you probably do not come to the attention of child welfare services as you can pay for private therapists and schools for your child. Many women and children are not coming to our attention if one in eight women drink during pregnancy (Denny et al., 2019) and one in 20 to one in 50 children have an FASD (May et al., 2018).

When I worked with adolescents transitioning out of foster care, I interviewed a few mothers who were still in touch with their older children in order to find out about the youths’ prenatal exposure to alcohol. I remember two mothers who wanted to talk to me because they knew their children had disabilities and wanted to get them help. As we chatted, I asked them if they remembered drinking when pregnant. One mother told me she had not known she was pregnant with her son until she was about five months along and up to that point would “go out with [her] girls on Friday nights for a few drinks.” Another woman told me she was so stressed by her abusive relationship and trying to figure out what she was going to do she didn’t realize she was pregnant for months. No woman I have ever met decided they were going to drink to hurt their baby. Many struggle with addiction and have little access to intervention and supportive services. Because we tend to be reactive and not proactive about prevention of prenatally exposed pregnancies, we are not preparing women and men to understand how to plan for pregnancy where drinking is knowingly and intentionally stopped before attempting reproduction.

It was infrequent that I was able to meet with biological mothers when I worked with teens; most were not involved because they’d had their rights terminated, died, or had broken relationships with their families. All the mothers I assisted where an FASD was diagnosed had adopted their children, were kin providing care, or were foster parents. That is quite telling but supports what we know anecdotally: Because of the stigma and blame these women experience, we do not often identify children with FASDs in biological families. Instead, diagnoses are made when a child is already removed.

Given the seriousness of the effects of prenatal alcohol exposure, we need an intensive education program that is universal throughout our education, public health, and alcohol sales systems so that everyone knows about the dangers of prenatal alcohol exposure from an early age. There are many avenues to educate the public, but what is needed is a coordinated, intentional effort to get the word out and to ensure that health professionals are leading the campaign. The CDC funds the Fetal Alcohol Spectrum Disorders Prevention program through a funded initiative of the American College of Obstetricians and Gynecologists, which trains physicians to talk to their



patients about avoiding alcohol during pregnancy (ACOG, n.d.). An effective evidence-based prevention model for pregnant women struggling with alcohol use is the Screening, Brief Intervention, and Referral to Treatment (SBIRT) which is cost-effective and efficient to provide (Shogren et al., 2017). However, almost half of all pregnancies (45%) in the United States are unplanned (Finer & Zolna, 2016). We don't talk about alcohol use and we certainly don't discuss having sex in the United States as part of any national conversation in our educational and health systems. Meanwhile, people are drinking and having sex, often at the same time, as they do tend to go together! Is it any wonder that we have so many alcohol-exposed babies being born? We need a full-fledged national campaign such as was done with smoking led by a national health care center with regular public messaging.

Individuals with FASDs who have solid support from families, friends, and services can live full and productive lives (Streissguth et al., 1996). Prenatal exposure to alcohol affects each person differently depending on the timing and frequency of exposure as well as other environmental and maternal factors (Mattson, et al., 2019). We know that there are several factors that can support children and adults to avoid the secondary disabilities associated with FASDs. In a groundbreaking study of 415 children and adults with FASDs, Streissguth and colleagues (2004) identified the primary and secondary disabilities and the risk and protective factors. The primary disabilities identified in this study were a lower IQ and a lower level of adaptive behavior skills functioning. Secondary disabilities are defined as conditions and situations that could be avoided or lessened with awareness and appropriate supports and services (Streissguth et al., 2004). In this study the following secondary disabilities were found:

- Disrupted school experience (61%)
- Trouble with the law (60%)
- Confinement (50%, for mental health or substance use problems or incarceration for a crime)
- Inappropriate sexual behavior (49%)
- Alcohol/drug problems (35%)

Protective factors for the secondary disabilities included:

- Living in a stable home
  - Being diagnosed before age six years
  - Not having experienced violence against oneself
  - Being eligible for developmental disabilities services
  - Having basic needs met
- (Streissguth et al., 2004)

There are several evidence-based interventions being researched and implemented such as Families Moving Forward, which now has a solid base of evidence behind it for families with children who have FASDs (Olson et al., 2009). Social skills programs have been shown to benefit children by increasing relationship-building skills and decreasing behavior problems (O'Connor et al., 2006). An interactive learning program to increase math skills has been found to raise math scores significantly by over one standard deviation in four math outcome areas

(Kable et al., 2007). Another program that uses a neurocognitive therapeutic intervention has been shown to improve executive functioning and emotional problem-solving in children with FAS and ARND (Wells et al., 2012). We need more of these kinds of evidence-based programs that can be used by families and their children; those issues (executive functioning and emotional dysregulation) can, in particular, cause families to exist in a state of chaos trying to support their children's needs but lacking the information and services to do so. Also lacking are specific FASDs-informed, evidence-based programs for older adolescents in transition from child welfare and other systems and from adolescence to emerging adulthood. Given the high rate of FASDs in child welfare systems, we must develop specific and person-centered transition processes that include a "hand-off" of adolescents to a family or adult mentor and the appropriate developmental disabilities system for continued social work and other interventions.

To those of you in the field wondering why this child, teenager, young adult is acting so weird and not responding to applied behavior analysis therapy, cognitive behavioral therapy, reasoning, guilt, ADHD meds, etc., here is what I have learned from individuals with FASDs, their families, colleagues, and researchers over the past near-40 years since I met Darren. These actions can be taken in your daily professional practice and can make a profound difference in the lives of individuals with FASDs and their families. We can and must immediately weave being FASDs-informed into our professional lens when we encounter children and adults who just don't seem to "fit" the typical behavioral and developmental matrix we use. We can and must, then, do the following:

- *Find out if there was prenatal alcohol exposure.* Search for children, youth, and adults who have a history of involvement in child welfare services, juvenile justice, or criminal justice systems; have ever been homeless; or have been trafficked. If the mother is unavailable because the child is in foster care or adopted, ask someone who knew the mother during her pregnancy about her alcohol consumption in terms of amounts and frequency. Check the child's birth records and medical records. Note that as the children get older, mothers will relay their drinking history more accurately (Hannigan et al., 2010).
- *Consider screening and diagnosis.* Refer the child, youth, or adult to their physician or neurodevelopmental specialist who can use the American Academy of Pediatrics guidelines to complete the Flow Diagram for Evaluation, a screening tool to identify potential FASDs (AAP, n.d.-a) and then find a resource to do the actual diagnostic evaluation if the screen is positive. Go to the National Organization on Fetal Alcohol Syndrome for a list of state resources ([www.nofas.org](http://www.nofas.org)). Follow up with the family, youth, or adult to make sure they were able to make the connection.
- *Use your information.* If you do not have access to a diagnostic evaluation but know that the child was exposed prenatally to alcohol, treat the family and the child as if they have an FASD. Become informed about FASDs and share your knowledge with the family.

- *Match mentors.* Relationship building is so important. If you are working with youth and young adults who are detached from adult support, work with them to identify someone who might step into the role of a mentor and help them connect with that person. Explain to the mentor what the young person may need help with given their disability.
- *Be aware of transition times.* Pay attention to the big life moments of youth with FASDs and put into place needed supports and services as they transition into young adulthood at age 18, such as Social Security disability benefits, Medicaid, adult developmental disabilities services, relationships with at least one or two adults who can act as mentors, and a go-to person for talking out problems and celebrating the successes.
- *Stay educated.* Educate yourself and your colleagues on FASDs, evidence-based treatments, and brain-based supports for families living with a child who has an FASD. SAMSHA (2014) has a Treatment Improvement Protocol (TIP 58): Addressing Fetal Alcohol Spectrum Disorders guide which can be ordered for free. Advocate for your agency to use the evidence-based practices described above.
- *Join NOFAS.* Consider joining the National Organization on Fetal Alcohol Syndrome and your local affiliate. Advocate in your state with your local NOFAS affiliate for increased awareness, education, diagnostic services, prevention programs, and supports and services for individuals with FASDs and their families across the lifespan. Visit their website for lots of great information.
- *Search locally.* Find out what your state and local area provides in terms of diagnostic evaluations, services, supports, and education. There are national speakers who will come to your state for a reasonable rate who have extensive experience and education in working with children and adults with FASDs. Contact me and I will send you their information.
- *Get involved.* The Advancing FASD Research, Prevention and Services Act was introduced in November 2019 by Senators Lisa Murkowski (R-Alaska) and Amy Klobuchar (D-Minn.) to amend the Public Health Service Act to include \$42 million for research and services grants. Get your senators to sign on to this much-needed legislation and the beginning of a national program that addresses FASDs.

Eventually, a new adoption agency stepped up to find a home for Darren; they seemed to understand that he was going to need a family who would be there for the long haul and remain in his life even with his multiple health and support needs. The adoption agency found such a family and Darren joined them as a third sibling with a mother, father, brother, and sister, all of whom had a very calm and soothing presence. And just as Streissguth and colleagues (2004) find that a stable home is one of the most protective factors against poor outcomes, Darren became calm—still energetic, but learning to control some of those impulses that as he grew older would

not be seen as *cute* but instead *criminal*.

As for Thomas, he and his girlfriend moved in together and went through several different temporary living situations until they landed in a small trailer home. They both received Supplemental Security Income (SSI) based on their disabilities. They had a baby who was soon taken into care by Child Protective Services who felt the trailer home was unsafe for a newborn. Eventually a family friend adopted the baby. Thomas and his girlfriend soon broke up and, the last I heard, he was struggling to maintain a part-time job. I think we failed Thomas and his family in that for all the services they received, none could cross over and help a couple with developmental disabilities be the parents they wanted to be while living in poverty.

We need to sound the alarm about this disorder and the costs to our communities, families, and individual lives. The patchwork of prevention and intervention services is not adequate. We all can play a role in ensuring that families and children with FASDs get what is needed to ensure maximum quality of life, including early diagnosis, evidence-based interventions, supports and services identified by families such as respite care, and supportive connections with other families. We can step up to ensure that young adults who are transitioning from child welfare services and school programs are assisted with moving to adult services. We can connect them with adults for supportive and mentoring relationships before they are left on their own to try and navigate being an adult at age 18, 19, or 20. What is needed is a national effort to focus our attention on a disorder that, despite its prevalence, is not recognized for its drastic consequences for individuals, families, and communities in financial and human costs.

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