

FASD Video Series Transcript: Stigma

Narrator: Stories of FASD Stigma.

Fetal alcohol spectrum disorders (FASDs) are a group of conditions that can occur in a person who is exposed to alcohol before birth. FASDs can have lifelong effects, including problems with behavior and learning, as well as physical problems.

It is estimated that up to 1 in 20 U.S. school-aged children may have FASDs.

Despite the prevalence of FASDs, many individuals and families struggle to obtain diagnoses and support from the healthcare community.

This video shares the real-life experiences and recommendations of individuals with FASDs and their families. These are the things they most want healthcare providers to know.

Rachel: I think stigma is huge. For the doctors we work with, her primary pediatrician, her psychiatrist. They honestly were well-intentioned, and they thought they were doing us of a favor by minimizing the probability. And instead, it did an unintentional harm, that the sooner we had known, the sooner we could have started looking at interventions and supports that were appropriate for her, the less she would've suffered as a child.

Debbie: I've also felt stigma in healthcare settings and very judged by things that they've said to me that I was a not a good parent, that I should be a better parent, take a parenting class, or do anything that does not work for a brain-based disability. So, healthcare people and providers, and even therapists through the years, point fingers at you and try to push it back on you when we need to work collectively.

Emily: For me, as someone who is pregnant, I get asked nearly every visit, "Are you drinking? Are you smoking?" All of these things. And I personally am not offended by that. I have heard stories of people being almost terrified to tell their medical professional that they have an FASD and they're carrying a child, because in the back of their mind they're going, "What if this is used against me? What if they try to take my child away from me? What if social services get involved because I disclose this information?" To use that against anyone, against them in the sense of, "Oh, this could affect your parenting," is devastating. So, when someone discloses that information, one, it needs to be taken seriously in the sense of, we're not gonna brush it off as this means nothing. But it also needs to be taken with compassion, with understanding, with as much support as can be given in that situation. But if we can work towards mitigating that stigma within the offices, within a way that can make them understand that I'm not here to use this against you, or I don't think any less of you, or I am not going to keep this from helping me give you the best healthcare that I can, or even mental health care that I can, that is a step in the right direction.

Rachel: I think that the more that professionals could become aware of the possibility of better outcomes, knowing that FASD is involved, the more it will help combat stigma.

Debbie: For healthcare providers to address stigma, there just should be no blame. We need to just take away the blame. We don't blame people that have cancer. We don't blame their families. We don't blame people that are blind. You know, why does there need to be this stigma with an FASD? It just needs to go away. It's really wrong that we have to put a blame label on this disability, and that's what society tends to do. And we need to get away from that. And that's why FASD communities working collectively to raise awareness and do what we're doing is really important so that we can erase that stigma and work together for the better of everybody.

Emily: Self-stigma can come from the inner voices. Maybe they carry around grief, maybe they carry around guilt. Maybe it's shame and maybe they put it on themselves, or maybe it's because society told them to put it on. And sometimes when they do disclose the information of FASD or prenatal exposure to alcohol, maybe they are met with the shame that they were expecting or they're met with misunderstanding or not being heard.

Julie: When we left that day, I was the birth mom of a daughter with full fetal alcohol syndrome. I had 17 years of sobriety by that point. And I thought that I had worked my steps over and over and over. And nothing had prepared me for the level of blame, shame, guilt that I felt that day.

Emily: Carrying shame, whether that be internalized or from society, prevents so many people from receiving, first of all, that diagnosis, then proper interventions, then supports.

Rachel: Even as a parent caregiver, I still have some internalized stigma where I will use neurodivergent. I will say she is in the neurodiverse community just because still, within me, there's some stigma around saying she has FASD. And I think you using neurodivergent is wonderful and great, and I'm so grateful for that community. But I think that as a parent caregiver, I still need more courage about saying, "She has FASD," and deal with it.

Jen: When people look at Jay, even though he has the facial features, I don't think that he has received a lot of stigma based on his diagnosis. I will say, I think he receives a lot of judgment based on his behavioral symptoms. If you don't know about the facial features, or even if you do, it can still be really challenging because he doesn't have a wheelchair that says, "I have a disability," right? His is all tucked inside. So, when he acts poorly, it's harder to be able to have people differentiate that.

Annette: They develop very low self-esteem and lots of anxiety, lots of social anxiety. It's very isolating. You can't take your kids to certain places. You can't do the big groups. You can't go on the big outings. But I've heard nightmares, where you don't see parts of your families because they don't accept your children.

Rachel: Unconscious bias and how someone with FASD experiences stigma is really important. I think that a lot of people with FASD are very intuitive, and they connect with others on a very intuitive level, and they're very attuned to nonverbal signals or

subtle signals that are sent out. And so, if somebody has a bias that they themselves are not aware of, that can really affect someone with FASD.

Wyatt: To me, stigma is not being like understand. And it is really hard because for individuals with FASD, it's an invisible disability, so it's not like Down syndrome or autism, so you can't tell that you have it. So, it's really hard. And sometimes people look at me like I'm green and I'm like, "That's... It is what it is." They can look at me like I'm green if they want to.

Rebecca: We need to stop the stigma that's going on that when I tell somebody I have a fetal alcohol spectrum disorder, their response to those that don't know me is, "Oh my gosh, I'm so sorry." And to my family, if they don't know them, they look at my mom and they judge her and they said they judge her. How dare she drink during pregnancy? So, the stigma for me that they portray is that I won't amount to anything that I won't go far in my career. And to my mom, it's, how could you do that to your unborn child? They don't know her story. I'm adopted. Some of them don't know that. So, there's just the stigma needs to end, and people need to open their ears and listen.

Debbie: It was just really pervasive throughout the system that they wanted to blame me and not get to the root of what his disability was and provide any kind of plan to help me support him so he had a good life. The stigma affects people and families because, first of all, they look at us and say, "Oh, are you the birth mom?" Or, "What did you do wrong to your child?" Basically, "You shouldn't have done that." I don't owe anybody an explanation. I'm an adoptive mom, but regardless if I was a bio mom, I don't owe you an explanation. This is my child, I love this child and I'm gonna do everything I can. Can you just see that there is a need here so that this child has services and we can support his brain and that he has gifts and strengths to give to the world, and can we work collectively so that all children are served and he has the life that he can lead and share his gifts with everybody too. It's why birth moms don't share information about alcohol with doctors a lot of times. They're hesitant to share that because then a lot of times doctors will admonish them or they're afraid to come forward.

Annette: So, I just think people need to be more empathetic. Just like they are becoming with mental health and other conditions.

Emily: So, if a person with an FASD goes in and says, "You always diagnosed with this." If we can at all possible take off those preconceived notion glasses, so to speak, and to not look at that person as the paragraph that they read in their textbook, but as a unique individual that isn't just someone who came from a bad background or a bad environment, or has behavioral issues and look at them in a holistic way, in a compassionate way, as someone who needs a unique approach to healthcare, not just an FASD, that I think would be key.

Narrator: For more information, visit www.cdc.gov/fasd.