

Is there justice for people with fetal alcohol brain damage?

by Tom Robertson, Minnesota Public Radio,
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Pregnant women who drink alcohol risk giving birth to children with permanent brain damage. Studies show that as these kids become adolescents and adults, many get in trouble with the law. Experts say many people who work in the criminal justice system don't understand fetal alcohol syndrome. The system isn't designed to deal with offenders affected by the disorder. But there are some efforts to change that.

Newton Henderson, 26, has been locked up at the Stillwater state prison, east of the Twin Cities, nearly half his life. He walks into a small conference room clad in a white t-shirt and baggy prison pants.

Henderson bounced around as a kid and lived in several states. He grew up in a violent household where alcohol abuse was common. He was living on the street by age 13. In October 1997, when he was just 15 years old, Henderson found himself in serious trouble.

"I couldn't get anybody to give me a ride, so I went and I hitched a ride. And I ended up kidnapping and sexually assaulting a female and robbed them," says Henderson. "That same night I got caught, and I've been in prison ever since."

SIGNS OF FETAL ALCOHOL DAMAGE

Henderson is from a big family -- he has seven brothers and sisters. The youngest four have been diagnosed with fetal alcohol syndrome. Henderson has not been diagnosed, but his behavior is similar to his younger siblings. He's impulsive, and can be short-tempered.

Like people with fetal alcohol exposure, Henderson says he has trouble remembering and keeping track of more than a few things at a time.

"I've never been someone who can take instruction very well. I'm always thinking about other things," says Henderson. "Even though I'm doing this, I'm thinking about this, and before I even get to that, I'm thinking about something else. Unless I physically do it, it's probably not going to stick the first time, the first couple of times."

Henderson says he isn't crazy about the idea of being labeled with a fetal alcohol disorder. But he says he'd like to know, because at least it would help explain why his life has gone the way it has.

"I don't know whether or not I was a victim of fetal alcohol syndrome or not. It's obviously an option because it's affected so many of my brothers and sisters," he says. "But what I can say for sure is that it's obviously having a big impact on all our lives right now."

No one can say how many of the country's more than two million prison inmates are affected by fetal alcohol disorders. Minnesota and most other states don't screen inmates for the disorder. Some experts believe the number could be high, maybe as many as one in four. But there's no real data to back that up, since no studies have been done.

Henderson gets out of prison in two years. He's not sure if he'll try to get tested for fetal alcohol exposure. But there's a bright spot in his future. The 26-year-old is being adopted by a family from Isanti, Minnesota -- Mike and Linda Walinski. They are the same couple who adopted Newton's four fetal alcohol-affected siblings.

GETTING A NEW FAMILY

Linda Walinski says based on what she knows about Henderson and his family history, she believes the young man was likely exposed to alcohol while still in the womb. She thinks prison has done him a lot of good.

"He says, 'These have been the best years of my life. If it wasn't for this, I'd be dead,'" says Walinski. "He got to get his GED there. He is nourished there. He gets exercise there. There's clothing, there's warm shelter, sobriety. That's what they need is order, structure, routine, etc. Clearly, Newton is soaring."

Walinski says when she first contacted Newton in prison almost a decade ago, he had no connection with anyone on the outside. No one had visited him. No one cared about him. Walinski says her family will provide the support he needs to succeed when he gets out of prison.

"He's had a really long time to practice the skills of not getting in trouble, not antagonizing people, following the rules," says Walinski. "It's believed that in individuals with fetal alcohol, that repetition, repetition, repetition, millions of times, is what does help with learning."

Alcohol-exposed children often have lives filled with turmoil early on. Most end up in foster care. Studies show nearly three-quarters of them are either physically or sexually abused. Sixty percent get suspended, expelled or drop out of school.

One study at the University of Washington found that 60 percent of adolescents and adults with fetal alcohol syndrome get in trouble with the law. Ann Streissguth is professor emerita of psychology at the University of Washington and was involved in the study.

"How could anyone be normal who had that kind of a background, on top of being brain-damaged?" Streissguth says.

CAN'T PROCESS CAUSE AND EFFECT

Streissguth was part of the team that first identified fetal alcohol syndrome, or FAS, in 1973. She spent most of her career studying people affected by the disorders. Streissguth says there are some typical behavior patterns for these people.

Because of the physical damage from prenatal alcohol exposure, the thinking part of their brain doesn't work right. People with the disorder get in trouble because their brain can't process cause and effect.

That means they're unable to make good judgments. They often exhibit explosive behavior. Streissguth says they may commit crimes to impress their friends.

"These patients are often very gullible and very eager to be liked by their peers," says Streissguth. "They are very conspicuous scapegoats for all of the smarter criminals that are around. So they're the one that are going to be caught with the stolen goods. They're the ones that people are going to say, 'Oh, he's the one that pulled the trigger. We were just there.' And it happens over and over again."

Streissguth says people with FAS may run from authorities for no reason. They're unlikely to understand their legal rights. They may even admit to crimes they didn't commit.

Once they enter the court system, people with fetal alcohol damage are often confused by the proceedings. They sometimes don't show remorse and may come across looking guilty. They often aren't given a break because judges don't understand the disorder.

Also, Streissguth says national estimates suggest the vast majority of people affected by prenatal alcohol exposure have never been diagnosed.

"I think it's a foregone conclusion that mainly judges do not know that they are dealing with a person who has a fetal alcohol birth defect at the time they are dealing with them," Streissguth says. "If the defense lawyer assumes that they're competent and functional, then he won't necessarily pursue this. He'll assume the guy was thinking with a full stack of brains when he committed whatever he did."

When court officials don't fully understand the symptoms of fetal alcohol brain damage, offenders are treated just like everyone else.

AN 11-YEAR OLD OFFENDER IN COURT

That's what happened with 11-year-old Hunter. Because he's a juvenile, we will not use his last name.

One October day in 2006, Hunter and his younger brother went outside to play. It's not really clear how it started or who had the idea -- but the two boys broke into a neighbor's house and shattered everything -- windows, dishes, mirrors, knick-knacks and a big screen TV.

Hunter spent two weeks in a mental health treatment facility because when he admitted what he'd done to police, he showed no guilt or remorse.

"Still to this day, it's tough to try and get the reaction out of him that you want," says Kim, Hunter's adoptive mother. "He knows right from wrong, but he's very impulsive. The cause and effect, he just doesn't -- it's there one second. That's about how long it is there. Then it's gone, on to the next thing."

Hunter says he went a little crazy that October day. His parents say it was his fetal alcohol syndrome, coupled with a new medication, that led to the vandalism.

Darren, Hunter's father, says they noticed Hunter having mood swings on the new medication.

"We're not going to say for sure -- we knew it wasn't working and we had an appointment set," says Darren. "I just wish that appointment would have been a week before this happened."

People with FAS may run from authorities for no reason. They're unlikely to understand their legal rights. They sometimes don't show remorse and may come across looking guilty.

Hunter did change his medication and his moods are more controlled now. He went to court and his parents decided to plead guilty to avoid any costly jury trial. They just wanted to be done and move on.

The judge put Hunter on probation, and ordered him to pay \$45,000 in damages when he becomes an adult.

"It stays on his record for 10 years," Kim says. "But the insurance company can reopen it and it can stay on his record forever. He can start out his life not being able to have anything."

Kim and Darren don't tell many people Hunter has FAS, because they don't believe anyone will understand it.

"It's not an excuse, is it Hunter?" Kim asks her son. "We try and tell Hunter, 'Who has control of you?'"

"I do," Hunter answers.

Hunter sits at the family kitchen table and listens. He speaks softly and gives only one or two-word answers. He often puts his hands in his head and rocks back and forth, a sign he is frustrated.

"When you get frustrated, Hunter, what does it feel like?" asks Kim.

"It feels like I'm going to explode and I can't do anything," Hunter replies.

There are no national guidelines for how people with fetal alcohol damage should be handled in the justice system. There's been little federal funding available to study the impact. But there are some efforts inside the courts to help identify people affected by the disorder.

THE CAUSE OF A FORMER FIRST LADY

In 2006, Hennepin County's juvenile justice system got a federal grant to begin screening young offenders for fetal alcohol damage. The goal was to get kids diagnosed, set up support for their families and educate people in the courts.

Susan Carlson is a court referee in the county's juvenile court division. She says of the more than 600 young offenders who were screened, 16 percent were diagnosed with fetal alcohol exposure.

"A lot of these youth would never have gotten a diagnosis without this program," said Carlson.

Susan Carlson is the wife of former Minnesota Gov. Arne Carlson. During his administration, she led a statewide task force on the affects of fetal alcohol exposure. She founded and is currently president of the Minnesota Organization on Fetal Alcohol Syndrome.

Carlson says repeat juvenile offenders in the state are often sent to detention centers, which is a form of punishment that doesn't work well for people with fetal alcohol damage. Carlson says they're better served in specialized programs that are highly structured and supervised.

"I think we can get them out of the system, and that should be our goal," says Carlson. "It shouldn't be just to punish for something they probably wouldn't even understand why they were being punished anyway."

Carlson describes one young offender who'd been unsuccessful in five or six different placements. He was screened and diagnosed with partial FAS through the Hennepin County program. He was then placed in a Duluth group home that specializes in FAS care.

Carlson says the young man thrived. He earned a GED, held several jobs, and eventually joined the Army.

"I ran into the boy's probation officer a couple of weeks ago," says Carlson. "He was a non-believer when we started this whole process. And he was just beaming about this child, because he said the boy appeared to be headed for the correctional system. Now he's thriving. The probation officer said the young man was his most difficult kid."

The problem, Carlson says, is that there aren't many options for placement of offenders with fetal alcohol brain damage. There are only a few group homes that specialize in FAS. Some homes even refuse to take kids diagnosed with the disorder.

There are efforts in a number of states to educate police officers, court service staff, defense attorneys and judges to recognize and understand FAS and determine how to get proper help for offenders.

FIRST STEPS TOWARD TRAINING JUSTICE OFFICIALS

Mary Rogers is a researcher at Black Hills State University in South Dakota. Rogers has spent the past two years training people in the criminal justice system about how to recognize young FAS offenders.

Rogers says the justice system needs to work with other agencies to design probation or detention programs to help these kids.

Rogers says systems also need to be developed to figure out what works best for people with fetal alcohol brain damage, so they don't continue to offend over and over.

"What many people have told us over the years is that they have implemented strategies, but they have no information that shows and documents the case history -- how did this change this person's life?" said Rogers. "Were they able to change as far as their behaviors? Were they becoming more academically proficient? Nobody tracks that."

JUDGES' HANDS ARE STILL TIED

Even if judges do understand the disorder, many feel their hands are tied. They can't, for example, let a kid go who busts up a house. They have to follow sentencing guidelines.

There are two judges in South Dakota who try to tailor their orders so it's easier on the alcohol-exposed offender. One is Judge Janine Kern, who's based in Rapid City. She makes her conditions of probation a little simpler and easier to understand and follow.

Fetal alcohol syndrome is not listed as a federally recognized disability. That means states and local agencies aren't required to provide programs and services. Judge Kern says that doesn't leave her with many options. She wants policymakers to start talking about FAS as a disability.

"This is a 100 percent preventable defect," says Kern. "We need a strong prevention campaign, then we need the ability to assess those adults and children that are within the system that have it. That'll take funding. Then we need the services within the community, once we have the evaluation, to help people thrive and be successful."

Circuit Court Judge Pat Riepel, based in Sioux Falls, agrees with Kern. But she stresses sometimes she doesn't have a choice, because she still has to make a ruling based on law. Sometimes, she says, that involves separating families.

"Sometimes I have to take them from their parents just for their own safety, because they can't make good choices to keep themselves safe," says Riepel. "The parents have tried everything -- electronic monitoring, all types of house arrests -- and that doesn't work. My problem is, what do I do to keep them safe?"

Riepel says removing kids from their homes happens only after other methods have failed. Her choice is a residential treatment facility or placement with the Department of Corrections.

But once alcohol-exposed offenders become inmates, they are handled as criminals, not as people with a brain disorder.

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Part 2: Diagnosing FASD is tricky

by Cara Hetland, Minnesota Public Radio,
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St. Paul, Minn. — Fetal Alcohol Syndrome was first identified as a medical condition in 1973. Each year, 40,000 children are diagnosed with fetal alcohol spectrum disorder. That's a range of disabilities children and adults experience, depending on how often their biological mother drank and where she was in the pregnancy.

FASD is the leading known preventable cause of mental retardation and birth defects.

Despite decades of research, there are still many questions about the disorder. Children exposed to alcohol in the womb are often misdiagnosed with attention deficit disorder, hyperactivity or other cognitive disabilities. However, unlike those conditions, alcohol-exposed children don't respond to medication.



Evaluation

Dr. Eugene Hoyme spent years studying fetal alcohol syndrome at Stanford University. He's now head of pediatrics at Sanford Health in Sioux Falls, South Dakota. Hoyme travels the world developing better ways to diagnose and treat kids exposed to alcohol in the womb.

Hoyme says that alcohol exposure changes the deepest part of their brain, so their automatic neurological responses don't work properly.

"The network isn't wired correctly, and medication isn't going to help because it's the structure. But these kids do respond to different teaching techniques," says Hoyme. "The other thing is children with FAS need repetition. They don't really learn as quickly."

Dr. Hoyme helped develop the diagnostic spectrum used with alcohol-exposed children. It looks at the whole child, from physical features to cognitive thinking and motor skills. Around the country, there are several different approaches to diagnosis.

In Minnesota and the Dakotas, professionals take a team approach. It's a complex process that includes physicians, psychologists, therapists, teachers and social workers. It takes a full day to evaluate a person, and only a handful of children can be diagnosed each month.

Hoyme says he's now studying ways to diagnose children at birth. Most kids aren't diagnosed until they are around age 3 or 4. Hoyme says the earlier a child is identified with FASD, the spectrum of fetal alcohol disorders, the sooner that child can get help.

"We don't take the time, and a lot of kids are being misdiagnosed. We don't really have the tools yet, those are being developed," he says.

In Minnesota, some 50,000 people are likely affected by fetal alcohol spectrum disorders, but those victims remain largely hidden. Experts say FASD is grossly underreported because few doctors are trained to diagnose it. Just a few years ago, there were only a handful of places to go for diagnosis.

"What worries me is when he talks to himself so much. His anger -- the older he gets, the shorter his fuse, the quicker he'll fly off the handle."

- Melody Meyer, Matthew Roden's stepmother

In 1997, then first lady of Minnesota, Susan Carlson, launched an initiative to focus attention on FASD. The following year, the state Legislature provided nearly \$7 million for education and prevention. Carlson's efforts also led to the creation of more diagnostic clinics throughout the state.

Lakewood Clinic in the central Minnesota town of Staples is one of about a half-dozen FASD clinics in Minnesota. Five times a year, a team of health care professionals gathers to diagnose people suspected of having FASD. There's typically a three- to six-month waiting list, and about 75 percent of the people evaluated will be diagnosed with some form of FAS disorder.

Matthew Roden, who is 10, is one of five people in for an evaluation on this particular day. The all-day process begins with a physical exam with Dr. Sarah Israelson.

As Matthew takes some deep breaths for Dr. Israelson, he tells her about the pets he has at home on the family dairy farm and how he loves to ride his bike. He seems happy to answer the doctor's questions.

"Well, do you know why you're here?" Dr. Israelson asks.

"Yeah," says Matthew. "To check if I have fetal alcohol syndrome."



Diagnostic team

"Do you have any idea what that means?" the doctor says.

"That my mother drank when I was in her tummy," Matthew answers.

"Very good, wow. You are right on the ball," Dr. Israelson says.

Matthew has lots of problems. He's impulsive, easily distracted and frequently throws temper tantrums. He should be in fourth grade, but in some areas he still performs at a third grade level.

And Matthew wets himself, not at night, but during the daytime. For that reason, Matthew's dad and stepmother decided last fall to school him at home.

Matthew's stepmother, Melody Meyer, says FASD is all new to her. She had no idea what it was until Matthew got checked out, but she hopes a firm diagnosis will help them deal better with Matthew.

The more Meyer learns about the disease, the more she worries about the prospects for Matthew's future. "He's already acting like he's just plain lazy. I don't know how else to sum that one up, lack of motivation," Meyer says. "He'll sometimes lay down to take a nap, he'll sleep 18 hours. I guess what worries me is when he talks to himself so much. His anger -- the older he gets, the shorter his fuse, the quicker he'll fly off the handle."

At the end of the day, Matthew got his diagnosis. Because he didn't meet the growth deficiency criteria for full blown fetal alcohol syndrome, Matthew was diagnosed with partial FAS. It's a label and a condition Matthew will have to live with the rest of his life.

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Part 3: Living with FASD as an adult

by Cara Hetland, Minnesota Public Radio,
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St. Paul, Minn. — Many people assume that Fetal Alcohol Spectrum Disorders affect only children, but it's a lifetime disease. Hundreds of thousands of adults across the country are affected.

Advocates say once a child with FASD turns 18, most of the safety nets disappear and a vast new set of challenges emerge.

Hunter Sargent is one of those adults. Sargent, who is 31, says his birth mother was a hopeless alcoholic who was abusive, violent and suicidal. After he was taken away from his mother, he spent most of his childhood with his grandmother or in foster homes.

Hunter says he was an angry, sometimes violent child, slow on the draw, and prone to trouble. He needed constant supervision. His doctors, his teachers and his social workers never picked up on the idea that he might have fetal alcohol syndrome. For years, he was misdiagnosed.

"Dealing with FAS as a kid was a lot easier, because I could hand off my frustration to somebody else and they'd deal with it."
- Hunter Sargent

"As a child ... I was given a lot of different labels, everything from autistic to Down syndrome to ADHD, ADD, even cerebral palsy. Obviously, as you can see, none of that really contains (sic) to me," Sargent says.

When he was 12, Sargent says he watched a movie called "The Broken Cord," based on the book by Michael Dorris. It's the story of a young American Indian boy with fetal alcohol syndrome who was adopted off a reservation. The movie hit home with Hunter.

"I was watching this little boy's behaviors ... how he just processed things and stuff. For me it was kind of scary, because it was like I was looking at myself on TV," he says.

Hunter Sargent is American Indian. He's a member of the White Earth Band of Ojibwe. His Indian name, Eagle Cloud, is tattooed on his arm. Hunter says in Ojibwe, the name means "messenger."

Statistics show American Indian communities have been hard hit by the affects of alcohol. Indian Health Service data shows the alcoholism rate among Indians is more than 600 percent higher than the national average.

American Indians have the highest rate of fetal alcohol syndrome in the nation. According to the U.S. Department of Health, the incidence of FAS among American Indians is 30 times higher than whites, and some Indians in Minnesota believe that number could be much higher in some tribal communities.

Sargent has no job and he can't drive a car. He gets a monthly Social Security check because he's considered mentally disabled. He has poor eyesight and poor balance. He says his math skills are limited to counting on his fingers. Like many adults with fetal alcohol syndrome, Hunter can't manage his own money.

"One of the things that I've learned, because I'm very, very impulsive -- I had some huge, nasty bills when I started living on my own," Sargent says. "If I had access to my money, nine times out of 10 I'm not going to think about the rent, I'm not going to think about the phone bill, I'm not going to think about electricity."

Some studies suggest most adults with FAS will spend time in a drug treatment program, a mental hospital, or prison.

In that way, Hunter Sargent has been fortunate. He lives in a subsidized apartment in Plymouth. Hennepin County supplies him with a personal care attendant who provides help with day-to-day living, but Hunter says that help isn't always around.

"I gotta say, dealing with FAS as a kid was a lot easier, because I could hand off my frustration to somebody else and they'd deal with it," Sargent says. "Now as an adult, my support has certain hours that they work with me. But at night, if something were to arise, I have to constantly think of ways to diffuse myself from any negative or inappropriate behaviors or actions or thoughts."

Sargent's feelings toward his biological mother are a mix of rage and forgiveness. He says it's a daily struggle to keep his fetal alcohol syndrome under control, and Hunter says sometimes that's not possible.

"It's like a volcano. It's like, you know it's going to erupt. And sometimes you've gotta let it erupt. And for me, it's kind of scary when it erupts, because I never know when it's going to stop," Sargent explains.

"You can't ignore it, because it's going to erupt again, and it's going to keep erupting until you find a way to either put the lid on that volcano or catch the things that are really important to you, and try to put the things in that you'll deal with later back in that volcano, and try to remember not to overfill it and let it get that way again," Sargent says.

"Because nine times out of 10, if you lose control once, forget it. You've got to give yourself an hour or two, a few days before you can figure things out."

Sargent tries to lead a normal life the best he can. He knows his dream of one day becoming a police officer or a psychologist will never be fulfilled. He'd like to one day handle his own affairs, but he's not sure that will happen, either.

Hunter does have a girlfriend. He says someday he'd like to have children. But for now, it's all he can do to keep himself under control.

"I see my impulsivity, my anger, everything that resembles me, I see it as an inner child," Sargent says. "It's like a baby, you know. You ignore it too much it's going to cry, it's going to scream, it's going to do whatever it can to get your attention."

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Part 4: How to educate kids with FASD

by Cara Hetland, Minnesota Public Radio,
Tom Robertson, Minnesota Public Radio
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Plymouth, Minn. — Like many kids with FASD, Hunter Sargent says the schools he attended never knew what to do with him.

Advocates say most public schools in the U.S. don't know how to deal with FASD students. Until recently, colleges and universities that train teachers didn't pay much attention to FASD. There's no national model out there.

But one Minnesota school district has a unique approach. District 287 in Plymouth serves hundreds of special needs kids from 13 school districts in the Twin Cities' western suburbs.



Brad Wing and student

Three years ago, District 287 developed a program specifically for FAS kids. It serves only about a dozen students with severe behavioral problems. These kids ended up here because they couldn't make it in other schools.

There are usually only about four students in each classroom and the goals focus more on behavior than learning. Students get assignments in reading, math and social studies, but most days, not much academic work gets done.

These kids swear a lot. They get violent. It's not unusual for stuff to get broken in the classrooms. Teachers sometimes use video or board games in the classrooms, not as rewards, but as tools to keep kids calm.

On a good day, 15-year-old Robert is able to keep his cool. On this day, he's playing cribbage with his teacher. So what's it like for Robert on a bad day?

"Mmmm, you don't want to know," Robert says. "Those types of days are crazy days. I get mad and start throwing things, and I have to get sent out of the classroom. And then I get even madder and I just start messing up stuff in that classroom."



Cribbage game

Here's one of the things that makes this program different. Robert doesn't get punished for that destructive, impulsive behavior.

Brad Wing, the program's facilitator, says punitive teaching approaches don't work on these kids. They can't learn from consequences because their alcohol-affected brains can't process cause and effect.

"We can't punish that, because it's brain damage. You would not punish a student with typical mental retardation if they could not learn algebra. So then why would we expect our students that have behavioral outcomes of their brain damage to be able to control it, when the brain does not allow it?" Wing says. "We don't care about the ABCs and 123s. You cannot learn if you don't have your behavior under control."

When things get out of control, teachers sometimes use methods that work with autistic kids. They turn the lights down low, they use music or sometimes a light massage. A hard scratch on the back works to calm one student down when he acts out.

"I don't tell stories to my friends anymore, because they find it just too unbelievable that this population could really be around. It's very hidden."
- Brad Wing, FAS program facilitator

Even the school day is different here. Some kids have four physical education periods each day to burn off extra energy.

Brad Wing says the fledgling program is constantly evolving. What works for a student one day might not work the next. He says the main goal is to get students to recognize the triggers that set off their bad behavior.

He says staff need to constantly remind themselves that the behaviors they're dealing with are the result of brain damage.

According to Wing, one of the biggest challenges for the program is staff retention. Teaching these kids can be traumatic.

Wing says by December of the first year of the program, half his staff had quit. By the end of that year, half more had walked away, unable to cope.

"Every time you walk in the door you wonder what's next, what lies ahead. My teachers are in crisis mode," Wing says. "I don't tell stories to my friends anymore, because they find it just too unbelievable that this population could really be around. It's very hidden. There's no doubt about it, it's a very depressing population."

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From the parents: Raising FAS kids

by Lea Coon, Minnesota Public Radio
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Symptoms of fetal alcohol syndrome can differ from child to child, but parents and caregivers often have similar experiences raising these kids. Minnesota Public Radio gathered stories from those who care for children with FAS, stories that highlight common challenges of raising these children in a society that often doesn't understand the disorder. They also reveal how FAS kids can thrive when they're shown understanding and attentiveness.

Cindy Bosley, mother of two adopted children with FASD in Anoka, Minnesota.

The girls -- Caitlyn and her little sister Kylee -- are really good with hands-on stuff. But putting it into written form -- they don't do it.

Teachers don't see this as a result of the girls' disability, so they treat it as naughty behavior. They don't know what the effects of fetal alcohol syndrome are, and the schools don't recognize it.

Caitlyn was at a summer program run by the school district, where there was a little boy who kept on picking on her. Caitlyn would come home and tell me that this boy was teasing her. I told her she just had to ignore him.

"Teachers don't see this as a result of the girls' disability, so they treat it as naughty behavior."
- *Cindy Bosley, Anoka*

I also went to the staff and told them that Caitlyn has effects of fetal alcohol syndrome, that she can't take teasing, and it was in the best interest of everyone to keep Caitlyn and the boy separated. But the teasing continued. I went back to the staff, to ask them again to please separate the children.

By the end of week, I got a phone call saying that Caitlyn is on suspension for hitting the boy. Although I informed the staff of the problem, in the end, Caitlyn was penalized for something that could have been prevented.

The other day she said, "I wish us kids could take our birth parents to court and hold them responsible for the way I have to live my life."

She knows she has a disability and is different. People don't give the disability the regard it deserves.

I worry about the time when my daughters have to leave school or begin to take care of themselves. They have to have structure and routine.

Safety is an issue, because they lack cause-and-effect thinking. One day, I caught Caitlyn trying to touch the ceiling fan with her hand. They need complete supervision, even though they're now 13 and 11.

I want pregnant moms to know that if you drink, you give your child a lifelong disability from which the child will never recover. Your child will struggle for the rest of his or her life being different, and will have a hard time with education and life skills. There is no reversing this decision.

Jeanette Lang, former director of programs at the Fetal Alcohol Diagnostic Program in Duluth, Minnesota.

For eight years, I ran a program for diagnosing children with FASD. This is a very complicated task because you're dealing with brain damage, which is invisible.

You need an interdisciplinary team to do this, and consistency is important because any number of things could be wrong with a child with FASD. What made me most passionate about my work was that, at the time I started, the diagnostics were from an academic perspective.

No one stepped back and asked, "How do we talk to families in a way that makes sense to them, that helps them take practical action, and avoids creating "throwaway" kids?"

I worked with a kid whose mom died from alcoholism. The girl was 11 or 12, living with a single aunt. She was doing well in school. But she had no sense of hunger and no sense of pain. She didn't eat. The adoptive mom had no idea what was going on -- she was worried that she was causing the problem.

After we explained to the girl's aunt and her teacher that she wasn't eating because of damage to the region of her brain responsible for these functions, we got her on a feeding schedule in school. After this, she got her weight up. It was a remarkable success. This was about four years ago. She's now performing beautifully.

Joline Gitis, mother of Erica, a young woman with FAS. Minneapolis.

Erica came to live with us as a foster child when she was 4. We knew her mother drank during pregnancy.

But in 1984, scientific knowledge of the disease was limited and popular knowledge was virtually non-existent. When Erica was born, FAS was ruled out because she had a normal birth weight. She wasn't diagnosed with FAS until later.



Erica Gitis-Miles

So we attributed a lot of her problems to her unstable home life. She had been in about 12 foster care homes before we took her in. She was always a borderline case on various diagnostic tests, (so) without knowing what we were dealing with, we just made a series of lucky guesses.

We provided her with good day care and she learned things there. When she started first grade she could already read. We then enrolled her into a school with lots of structure, small classes, and personal attention. It was exactly the type of environment Erica needed.

She thrived, although her learning difficulties were recognized. I gave all of Erica's teachers a book titled, "Fantastic Anton Succeeds," which describes the experiences of actual families that have a member with FAS.

It was always a matter of trying to educate the educators on the nature of the problem, and work with them to help her retrieve the information they would give her in class.

We taught Erica how to advocate for herself, and talked with her about the nature of her disability. When we had a name for it, we called it by its name.

"It's incredibly frustrating to raise a child with FAS, but it is definitely not hopeless."

- Joline Gitis, Minneapolis

We told her, "Don't let the teachers tell you you're not trying. We know you're trying. Tell them you have to sit in the front row. Ask them for extra time, and for oral examinations instead of written ones."

One of the hallmarks of the disability is the inability to generalize from a particular experience, or take a general idea and come up with a particular example. But our education system is based on this type of thinking. Erica would look at the general rule, and then the example, and she couldn't connect the two.

She would get frustrated sometimes when she would see her peers glide through school while it was so hard for her. It was heartbreaking. But she toughed it out.

It took her nine years to graduate from college. I told her that if she could get through college, she'll be a pro at life. She's acquired so many adaptive skills. She now works and lives independently in Washington D.C.

She's more focused and self-sufficient than a lot of other 27-year-olds who are trying to figure out their lives. I know she's turned a corner. She said to me recently, "If I can find my way around Washington D.C., I can find my way around everywhere."

It was the first time she enunciated a connection between a specific experience to a generalized situation. It's realizations like this that make me want to say to people, don't give up on these kids.

It's incredibly frustrating to raise a child with FAS, but it is definitely not hopeless."

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