

BREAKINGBARRIERS

everybody belongs ■ everybody serves

Summer 2020 | Theme: Fetal Alcohol Spectrum Disorder

Parents of loved ones living with Fetal Alcohol Spectrum Disorder (FASD) come to grips with the realities of this unexpected, difficult, lifelong disability that was unknown two generations ago.

Finding Home amid Despair

by Enrico Di Giandomenico

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Fetal Alcohol Spectrum Disorder (FASD) may be the leading cause of developmental delay in children and adults. Individuals with this lifelong disability likely will require support throughout their entire lives. This disability happens along a spectrum, sometimes so mild that it is never recognized and sometimes resulting in behavioral, cognitive, and developmental delays. Because this disability has no cure, changes need to come from the supporting environment rather than from the individuals themselves.

I have found three areas to be most important for caregivers to focus on. The first is the difference between the individual's chronological age vs. their developmental functioning.

Typically, an individual with FASD functions at half of their chronological age until the age of 18; at which point they level off and remain consistent. As expectations are set, we need to keep this in mind.

The second area is a delay in the speed with which they process information. Once we ask them to complete a task, they need 10 to 30 seconds to process that request so that they can more effectively complete it.

The third area involves delays in executive functioning and daily adaptive living skills. Individuals with FASD can learn throughout their lifetime, but they may struggle to apply this to their day-to-day living.

From research and my work, I have found that caregivers, either family or professional, need these four things:

- *Training, training, and more training* to understand this disability and to stay on top of all the latest developments.
- *Support and coaching* by someone who understands the disability to provide caregivers with reminders and best practice ideas.

- *Respite and/or relief.* To provide stable and supportive living situations for individuals with FASD, caregivers require a few hours regularly to clear themselves of the daily stress and, at times, a weekend break to regenerate themselves for the day-to-day living requirements.
- *Grief and loss counseling.* As we come to understand this disability and learn of the limitations for our children, we may need support in accepting and adjusting our desires for the children and adults that we care for.

I want to encourage, reassure, and give hope to caregivers and those who are supporting individuals with this disability. While the road is long, difficult, and lonely at times, there is great opportunity for success for our loved ones with FASD. Given the proper environment and supports, they can have full, happy, and successfully interdependent lives.

Surrounded by Support, But Completely Alone

Editor's note: Author's name withheld upon request; all names have been changed.

Anna spent the first year of her life in an incubator at Toronto Hospital for Sick Children, with a tracheostomy tube in her throat. Her birth mother drank during her pregnancy, and then

surrendered her parental rights to the underweight and sickly baby born to her.

Kate knew she was in for a challenge when she learned this little girl weighed only 11 pounds at 18 months of age. Kate and her husband had plans to have a large family, so she felt that being loved and supported by many people would help Anna thrive.

The hospital arranged the placement, and Anna joined the loving and supportive family. It would have been hard to find a better home. Both parents were social service providers, and their children had a happy roster of family, school, and church activities. Even though Anna was the lone black child in a white neighborhood, she was accepted. She was one of the family.

Sadly, Anna's growth and development were not typical. From the start, her sucking impulse was weak, and she resisted cuddling and affection. As years passed, she seemed unwilling or unable to accept boundaries and resisted correction at every turn. Academics were a struggle, and even special education couldn't help with trustworthiness and reliability.

After years of frustration and self-blame, the family took their 13-year-old daughter to a specialist who readily detected the

prenatal alcohol damage. This was an explanation for Anna's deficits in self-control, logic, and reasoning. Unfortunately, at that time, not much help was available for children with FASD. Seven years later, much to the family's surprise, a car drove up to the house and a new "friend" of Anna's helped the petite 21-year-old pack up and leave their home to live with him in a large city.

Sometime later, Anna's tracheostomy had to be repaired on an emergency basis, rendering her unable to speak. She has never been able to hold a job and will likely collect social assistance for the rest of her life. Between her initial and secondary tracheostomies, her lengthy hospitalizations, special educational services, her own support, and that of her two fatherless children, the toll on society has been great.

For Kate's family, feelings of frustration remain. Every skill in their social services toolbox could not address the damage born in their baby girl.

When the System Fails a Child

Editor's note: Author's name withheld upon request; all names have been changed.

As their daughter fell deeper into a life of drugs and alcohol, Bev and Doug were faced with the awful prospect of seeing their two preschool-age granddaughters placed in foster care. "We'll take them," the active couple agreed. "We can give them a good life and keep them from being bounced from place to place with strangers."

This was not an easy decision for the couple as both children had challenges. The eldest child, Sarah, was described as "a handful." The baby suffered from a heart defect and other physical ailments. However, Bev knew that living with Grandma and Grandpa would be a lot better than the unstable life they had experienced so far with their mother.

The children adjusted well to the predictability of their grandparents' home. Still, Sarah's unpredictable behavior did not diminish. When Doug fell ill and died a few years later, Bev was left to raise the children alone.

As Sarah grew older, her behavioral challenges worsened. Bev reached out for support within the healthcare system and was

connected to a specialized facility in Toronto that diagnosed Sarah with alcohol-related neurological disorder. This helped Bev understand that Sarah's challenges were part of a larger constellation of prenatal brain damage caused by maternal drinking.

Counselling was arranged with a physician specialized in FASD, and Bev's hopes for her granddaughter were rekindled. Perhaps with support and medication this child could succeed. As Sarah entered puberty, her feelings of rage and defiance intensified, and she became uncontrollable. She threatened her grandmother and her sister with a knife and began bullying other children at school. After multiple police involvements and disruptions in the neighborhood, Bev knew professional intervention was required.

She contacted a regional child protection agency and reported her granddaughter's threats of suicide and her escalating violence. To Bev's surprise and utter dismay, the authorities took Sarah into custody, assuming that abuse in the home was the root of her problems. Sarah was permitted to refuse the counselling Bev had arranged for her as well as terminate the medication prescribed by the FASD specialist.

Sarah has now been in four foster homes, none of which has been able to manage her. Bev is only allowed limited access to her granddaughter. She laments the future of this vulnerable youth who needs more support than the system is offering her.

Needing a Community of Support

Editor's note: Author's name withheld upon request; all names have been changed.

The first thing Jenn said about her son Greg is, “We waited 12 years for him. He was such a healthy baby.” Seven-month-old Greg joined Jenn, her husband, and their two-year-old adopted daughter, and completed the family.

Although he adjusted well to life within the family, Greg lagged behind developmentally. School posed a great challenge for him—the academic work, making friends, and adjusting socially. He did not get along with his teachers. Greg frequently displayed bouts of rage. In addition, he was caught lying, stealing, and setting fires. Physically, he was dealing with issues as well. He underwent surgery for tremors, but it was ineffective.

The family had always been active in their church community, but Greg dropped out of the youth group in his teen years. When this happened, no one in the group reached out to him.

Jenn understood that her son's behavior was the root of the rejection he had experienced so many times before, but she was still pained by the reaction, or lack thereof, from their Christian community.

After getting married and having his own family, Greg was subsequently rejected by his wife and their two children. In addition, his own sister and her family have chosen to discontinue contact with him. As parents, Jenn and her husband have suffered from years of guilt, as well as the sting of small-town disapproval on their son's account.

Jenn is now an elderly widow. Greg is a middle-aged man. Although he successfully held a job for two years—a personal best—that job has come to an end, and he's applied for social assistance. Jenn still manages his money for him and tries to warn him about his drinking.

In the 1970s, a doctor said that Greg's actions could be the result of his mother's prenatal drinking, but no further information was available. Nothing ever came of the comment. However, Jenn has just started attending a support group for prenatal alcohol-affected families. After 47 years of parenting, she has told her family's story for the first time in public.

Editor's Note

The Heartbreak of FASD Continues

Fetal Alcohol Spectrum Disorder (FASD) is a disability that has been labeled formally since only the 1970s. This spectrum of disorders can occur in a person whose mother drank alcohol during pregnancy. Often, a person with FASD may have low body weight, hyperactivity, attention deficits, memory issues, learning disabilities, poor reasoning and judgment, impulse control, and difficulties with learning from consequences, among others. While there is no cure, today there are early intervention programs and community support systems that should be accessed for an individual's lifespan.

Soliciting articles for this issue was so difficult that we went outside our usual RCA-CRC readership to secure what's published here. One RCA shared with us about her son, adopted in the 1960s as an infant from a young, church-going mom who used alcohol during pregnancy. The son, now in his 50s, disappeared for weeks at a time growing up, caused tremendous heartache for his adoptive parents, still feels a sense of ultimate rejection by his birth mother, and remains dependent on his adoptive mother for managing his finances.

Happily, he is committed to his Christian faith and lives a faith-filled life.

Most articles in this issue tell of the hurt and pain families went through raising their children in the 1980s, when little was known about the disorder. In all cases, these families opened their hearts and their homes, adopting children they did not realize had FASD. Their experiences are heart-wrenching, and we lament with them. Sadly, some are still unable to share their stories in church or other public settings. As with all disabilities or differences, we long for our churches to become supportive communities where everybody belongs and everybody serves.

—Terry A. DeYoung

Upcoming Themes

Winter 2021—Unexpected access.

The coronavirus pandemic actually has removed barriers for some people with disabilities, allowing access to communities and spaces that were inaccessible before. If this has been your experience during our long stretch of isolation and distancing, please tell us your story (400 words) of unexpected access **by October 30.**

Awards and Past Issues

This newsletter and the Disability Concerns blog (network.crcna.org/disability), co-published by CRC and RCA Disability Concerns ministries, received two awards from the Associated Church Press this year: for the Best in Class category, the Award of Merit for *Breaking Barriers*, and in the blog category, for the Disability Concerns blog on the Network. In addition to this summer issue, find back issues of *Breaking Barriers* and editions in Español and in 한국어, plus a link for electronic subscriptions, at either the CRC website (www.crcna.org/disability) or RCA website (www.rca.org/disability).

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