Pediatric RESEARCH

INSIGHTS

Family reflections: fetal alcohol spectrum disorders

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In a way, we were lucky. Not quite 20 years had passed since Jones and Smith had named fetal alcohol syndrome and labeled it a "tragic disorder".[1] Having recently been granted custody of Andrew, my husband's grandson, we had taken him for a checkup with a savvy new pediatrician. He had noted one-and-a-half-year-old Andrew's low birth weight, and the fact that his mother was a heavy drinker. Was this a case of FAS, he wondered, and referred us to a geneticist at Toronto's respected Hospital for Sick Children. It was 1992, well before multidisciplinary teams became the gold standard for diagnosis, so it was just the three of us and the doctor. Her observations included that Andrew's head circumference was below the second percentile, the back of his skull appeared small compared with his face size, his little fingers were abnormal, and his eye openings were small. The overall conclusion was unequivocal: "Andrew clearly has a number of dysmorphic features typical of fetal alcohol syndrome."

This is where the luck came in. First, that Andrew could be readily identified as having FAS. Absent the facial characteristics—and he has other typical ones, such as a thin upper lip and a flat philtrum— and the known history of his mother's drinking, he might never have been identified, at least not for years. With that diagnosis, we could begin the unending process of intervention and advocacy.

First, though, we had to educate ourselves about FAS (the term FASD did not come along until the early 2000s; at the time the supposedly less severe variation was FAE, for fetal alcohol effects). This was not easy. The only lay book we could find on the subject —maybe the only one that existed then—was Michael Dorris's *The Broken Cord*,[2] a harrowing account of his raising his adopted son whose FAS went undiagnosed for years.

What we learned was that the damage to worry about was not external: the physical characteristics of FAS are sufficiently subtle that most children with the syndrome, including Andrew, do not even fall into the funny-looking kid category. Dorris made clear that what we were dealing with was brain damage that Andrew had sustained in the womb because his mother drank during her pregnancy. The mean IQ of those with FAS falls between 65 and 80, he wrote—though later the range was found to be much broader. (When Andrew was eventually tested, he scored 76, although we came to question that number.) Dorris also indicated that there was little anyone could do to mitigate the terrible harm that had been done: "Problems with brain cells and organization…cannot be repaired." Today, FASD, which comprises FAS, partial FAS, and alcohol-related neurodevelopmental disorder, or ARND, is recognized as the leading cause of cognitive disability in North America.[3]

When Andrew was two and a half, he was fired by his babysitter for being too rough with the other children. By four he had been diagnosed with ADHD—a very common secondary characteristic with FAS. Then the principal of his preschool gently indicated that he was not welcome back the next year—he was too disruptive. He began his public-school career, as he ended it, in a special-needs class.

Treatment in the conventional sense did not, and still does not, exist. It is a source of great resentment and frustration among parents of those with FASD that many resources and a lot of sympathy are directed toward individuals, particularly children, with autism spectrum disorder, while virtually none goes to those with FASD. Yet the incidence of ASD is lower (1% across all ages, according to Lai and Baron-Cohen[4]) than that of FASD (though 0.91% has been the commonly accepted figure for some time; more recently some researchers have cited rates between 2.3 and 6.3%[5,6]).

So treatment was strictly DIY. The first priority, because it affected his self-esteem, was addressing Andrew's poor hand–eye coordination and clumsiness, which are common FAS issues. He would frequently trip, then heartbreakingly say, "I meant to do that." Swimming, soccer, baseball, basketball, karate, and even figure skating, followed, and within a few years his coordination was in the normal range. There was math tutoring—poor math skills are another common FASD issue; a summer camp for special-needs kids; personal youth workers; "operating manuals" for teachers (avoid giving too many instructions at a time, do not expect homework to happen, concepts mastered today may have evaporated by tomorrow…).

Then, when he was 12, Andrew discovered the guitar. He practiced so much that he moved his fingers, changing chords, while he slept; there were weekly lessons, he formed a band, and

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we sent him to rock camps. Coincidentally or not, his marks, even math marks, showed a distinct uptick—he was taking applied courses, not academic, and he was still in a special-needs classroom, but he ultimately graduated from high school just a year behind his peers. To our immense pride and considerable surprise, he was accepted in a community college's music program.

Only later did I discover that there might have been a reason for this remarkable leap: the research that links musical training, neuroplasticity, and cognition. A 2010 paper by Rodrigues et al. notes that musicians exhibit positive nonmusical cognitive abilities attributed to their musical training. The authors also state that "musical practice is just one sort of training that can lead to neural and cognitive changes on human brain."[7] Research exploring this idea in relation to FASD is overdue.

Similarly, while there is currently a lot of work being done on neuroplasticity as it relates to cognition and recovery from stroke, are some of those findings transferable to the area of FASD? I believe this is another subject that needs examination.

Just as important, though—still—is improving the process of diagnosis. Only a minority of individuals with FASD exhibit the physical characteristics of FAS.[8] Everyone else's disability is entirely invisible. Particularly if the mother's alcohol use is unknown, as is often the case in an adoption, or because of a woman's pediatrician's inability to assess the situation, children are at exceptional risk due to late or missed identification. Not only will they fail to benefit from early intervention, but as they age, they will be more vulnerable to FASD's well-documented secondary disabilities: unemployment, homelessness, addiction, mental health problems, and trouble with the law.

When my kid, now 29 and styling himself Drew, was younger, my mordant wish for him was that he not end up in a maximum-security institution. Of course, he has not been "cured"—he operates at the level of an immature 18-year-old, still lives at home, drinks away his paychecks, and needs what parents in FASD circles call an external brain—mine—to manage the details of life. Then again, he is a valued employee in the restaurant kitchen where he worked since finishing high school, with breaks to attend several year-long community college music programs. In his off time, he plays guitar really well and writes his songs: "Hanging on with one hand / Feeling close to the end / When tranquility's screaming like it's burning alive / Let the healin' begin / I must be due for a win."

My own life's trajectory has also involved some hanging on with one hand. I am now widowed, but like many parents of challenged and challenging kids, my husband and I separated, in our case when Andrew was 13. I see a family therapist, alone. At 70, a constant worry is who will take over as the external brain when I die. I cry.

ADDITIONAL INFORMATION

Consent for publication I grant permission to *Pediatric Research* to use the photo I supplied of me, Lynn Cunningham, and my son, Andrew Hild.

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