

FASD ACROSS AMERICA: THE SOCIAL AND EMOTIONAL IMPACT OF FETAL ALCOHOL SPECTRUM DISORDER

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Research Goal

This study set out to understand the impact FASD has on the social and emotional life and well-being of parents and caretakers of those with FASD

Background

- Fetal Alcohol Spectrum Disorder (FASD) is a developmental disability caused by prenatal alcohol exposure (American Academy of Pediatrics 2021)
- Individuals with FASD struggle with emotional regulation and executive dysfunction (May et al. 2022)
- 1.1% to 5% of the American population have an FASD and 80% of them go undiagnosed (May et al. 2011, 2022)
- Knowledge of FASD among providers and professionals is lacking (Coons-Harding et al. 2019)
- Developmental disabilities cause caretakers to face emotional, social, and physical strain (Song, Mailick, and Greenberg 2018)

Methods

This study's participants had current or previous experience caring for individuals diagnosed with FASD or a developmental disability falling under the umbrella of FASD and were 18 years old or older. These specifications were made to reflect the disposition and perspective of caretakers dealing with the ramifications of these disorders.

I rode a bicycle from city to city stretching from coast to coast, starting in Topsail, NC and finishing in Manhattan Beach, CA. I conducted in-person semi-structured interviews with participants about their experiences, struggles, and success in caring for someone with an FASD.

Limitations

With this study in particular, none of the participants were biological parents of individuals with FASD. They were all adoptive parents. The experiences birth parents and non-birth parents have in caring for those with FASD has distinct similarities (Petrenko et al. 2014), but there is a part of the narrative that is impossible to incorporate without having their perspective.

Conclusion

Caretakers overwhelmingly struggle with providing the necessary care for those with FASD due to a lack of services and guiding resources. They are burdened with the challenges FASD presents and are left directionless while being judged for the methods they do pursue. These challenges are prevalent and still left unaddressed in the services available and highlights the poor diagnosis pathways currently in place. The expectations placed on those with FASD, and subsequently the expectations placed on their caregivers, create a standard of success that they are unable to meet.

The current infrastructure creates a narrative of success that excludes those with FASD and does not provide them with the resources to attain success by any other definition. This study further validates and emphasizes the challenges caretakers face and provides irrefutable evidence that their struggles require respect, more adequate medical care and social support, and a more appropriate standard of success.

Results

The Caretaker Experience

"I often described my parenting journey as trying to stop the freight train with my bare hands. It's ludicrous. It's coming at you. You're trying to stop it. You know it's going to crash" (Interview 5)

Caretakers face physical danger and verbal abuse in dealing with the ramifications of executive dysfunction in their children. The impaired memory of those with FASD makes it difficult for them to understand consequences and translate them to other contexts. The dangers of overstimulation and confusion in those of FASD impose a need for caretakers to be hypervigilant and ever-present in the lives of their children.

Expectation, Stigma, and Judgement

"I think society has a shoe that they want everyone to fit into. And FASD does not fit in that shoe. At all. It is way outside of the shoe. And so you get shunned, you get shamed. It's lonely. You get isolated. You lose a lot of friends." (Interview 12)

The standards for success in communities surrounding those with disability create an environment where failure is inevitable. This "failure" of those with FASD to meet these standards incurs judgement for them and their caretakers which adds to the emotional load caretakers carry.

The methods caretakers use to provide an environment that is safe and conducive to relative success are also judged and stigmatized. When parents of those with FASD provide the necessary safety and structure for their children, they are perceived as incompetent parents putting unnecessary limits on their children. They are attempting to set these children free from the challenges they face but are judged as if they are doing the opposite.

Diagnosis and Services

"The diagnosis is so important, and it also can be challenging because none of the professionals we ever went to over the years, I'd had him for thirteen years by then, not a single one had realized that was what was really going on." (Interview 13)

Obtaining a diagnosis was a unanimous roadblock across all respondents. They struggled to find providers educated and willing to diagnose. Diagnosis provides something to name, which provided relief to some participants and their children. This also gave them hope of trying to find solutions to a now clearer problem. However, once a diagnosis was obtained, the challenge to locate and provide services was vast and consistent across respondents; there is a dearth of adequate and necessary services.

Emotional Load

"It's a double-edged sword. You hope things get better. You believe things will get better. You want to put everything into getting to a better place. And then the other side of that sword is accepting that it's not going to get better." (Interview 5)

The challenges caretakers take on accrue mental burdens and emotional challenges. They are faced with tasks that seem impossible to overcome and are not able to find the aid they need, even with concentrated effort. Their response to these challenges and their mindset is indicative of the dangers and burdens they face. They have hope that they will successfully care for their children, but they are also aware of the challenges they must overcome to achieve this.

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