Parents and Caregivers

Emory University Center for Maternal Substance Abuse and Child Development



The Importance of Parents and Caregivers

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Though individuals with fetal alcohol spectrum disorder (FASD) have social, educational, cognitive, mental health and medical needs, a stable and supportive home environment, including a supportive and involved caregiver, has been found to be protective and indicative of better prognostic outcomes (Olson et al., 2009). For example, caregivers can help navigate the many systemic barriers that individuals with FASD face, involve the individual with FASD when possible, in co-creation of activities and services, as well as advocate and increase awareness in the community educators, health providers, etc) for individuals with FASD. Parents or caregivers also have an important role in many of the interventions that support individuals with FASD in improving academic socialization, behavioral performance, and regulation (e.g., Reid et al., 2022). Despite the protective nature of the caregiver role, this role can also cause significant stress and strain.

Center Highlight

Understanding the importance of caregivers, the Center for MSACD published a research article entitled "Parenting by Individuals with Fetal Alcohol Spectrum Disorders and Neurobehavioral Outcomes in their Offspring." This article states that the neurobehavioral health impairments associated with prenatal alcohol exposure are now known to persist through adulthood. However, little is known about how these impairments affect individuals' parenting abilities and the neurobehavioral health of their offspring. This study compares parents with fetal alcohol spectrum disorder (FASD) with socioeconomically-matched, nonexposed parents on measures of parenting and family support and assesses the neurobehavioral health of the children in both groups.

For more information, you can find the article listed below.

Ritfeld GJ, Wang M, Shapiro Z, Kable JA, Coles CD. Parenting by individuals with fetal alcohol spectrum disorders and neurobehavioral outcomes in their offspring. Alcohol Clin Exp Res (Hoboken). 2024 Feb;48(2):400-408. doi: 10.1111/acer.15256. Epub 2024 Jan 8. PMID: 38149361; PMCID: PMC10922647.



Resources for Parents and Caregivers

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It is evident that parents and caregivers are an essential component to healthy environments for those who are in their care. It is easy to neglect the needs of the parent and/or caregiver in these situations. Services and organizations that provide resources for parents or caregivers are vital but finding them in your area can be stressful. Below, you will find a list of resources that can provide support and resources for parents and caregivers.

FASD United | fasdunited.org

• FASD United has developed an entire tab on their website "Help and Information." There you will find a plethora of resources for families and educators including the FASD Family Navigator.

Healthy Mothers, Healthy Babies | hmhbga.org

 Healthy Mothers, Healthy Babies Coalition of Georgia has virtual classes, peer support groups, blogs and informational videos to help improve access to prenatal and preventive healthcare for women, babies and families in Georgia.

Project Healthy Grandparents | phg.lewis.gsu.edu

• Project Healthy Grandparents has been active in Clayton, DeKalb and Fulton counties for over 20 years. They specialize in assisting grandparent led households through social work, health, and early interventions services as well as providing support groups, parenting education classes and transportation. Visit their website to apply for their services.

Parent to Parent | p2pga.org

 Parent to Parent of Georgia is a parent support group that aims to support families and individuals in the state of Georgia that may be impacted by disabilities or special health care needs.

FOCUS | focus-ga.org

• FOCUS, Families of Children Under Stress, provides various services including, workshops, camps and parent support groups for families and individuals in the state of Georgia.

Caregiver Stress

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There are many scenarios in which someone might find themselves in a caregiving role, whether for a child, an aging parent, or other loved one. While each situation is unique, caregiving in general often presents challenges. Some may experience challenges related to navigating medical or therapy appointments, increased emotional strain, or difficulty finding balance with other aspects of their lives. Parents and caregivers of children with FASD specifically have reported experiencing a particularly high level of stress related to navigating the diagnostic process, accessing appropriate resources, and concern for the future (Kautz et al., 2020).

Experiencing long-term stressors has the potential to lead to burnout and can impact caregiver mental and physical health. It can also impact the caregiving relationship (Sullivan et al., 2015). Identifying and understanding causes of stress can aid in finding ways to strengthen and support caregivers to ensure their well-being and that of the person under their care.

Some stressors may be alleviated in part by access to tailored programming and resources for various aspects of the caregiving role. This might include resources for helping a caregiver better support an individual with FASD as they navigate the academic, social, cognitive, and medical areas of their life. It might also include resources to help educate, advocate, and inform others about FASD.

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FOSTERING RESILIENCE AND BOLSTERING SELF-CARE IS IMPORTANT FOR MANAGING STRESS,

Fostering resilience and bolstering self-care is important for managing stress, improving overall quality of life, preventing burnout, and supporting emotional health. Being able to communicate with, and lean on, social supports can increase resilient coping strategies (Palacio et al., 2020). For some, finding social support among others with similar experiences may be helpful. Connecting with advocacy or support groups for other caregivers, families, or individuals with FASD can help with creating a sense of community among those with shared experiences.

For some, the challenges associated with caregiving may also bring negative feelings of self, such as shame or guilt. A recent study suggests that practicing self-compassion may be associated with reduced feelings of shame and guilt among caregivers of children with FASD (Biddle, et al., 2020). Sometimes, caregivers can also benefit from the extra perspective and support of a mental health professional in caring for their own well-being. What is most important is for caregivers to utilize the strategies that work best for them.

Sources

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