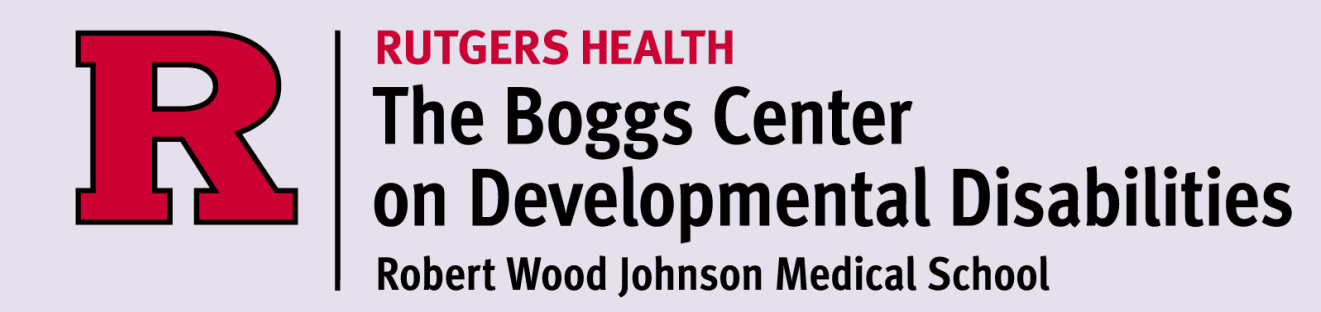


A Parent's Guide to Autism & Epilepsy: Education, Awareness, and Advocacy



Renad Amer, Rutgers Ernest Mario School of Pharmacy
Nida Bajwa, Rutgers School of Public Health
Carolyn Fox, Rutgers Robert Wood Johnson Medical School
Site Preceptor: Renata Zelvys, Family Resource Network



Host Organization

The *Family Resource Network* is a non-profit organization that strives to provide resources and support to families with disabilities as a personalized approach to care.

Affiliates: Autism Family Services of NJ
Caregivers of NJ
Epilepsy Services of NJ

Needs Assessment

- ✦ **Communication Barriers:** Information following a diagnosis can be very confusing for parents and caregivers
- ✦ **Healthcare Navigation:** Navigating healthcare systems becomes increasingly challenging when a child is diagnosed with a disability. Empowering parents and caregivers with clear and concise information can allow individuals to more effectively advocate for their children

My Child Was Recently Diagnosed with Autism

WHAT HAPPENS NEXT?



Our Project

With the intention of easing a parent's burden after their child's diagnosis, we created booklets outlining some expectations caregivers should have, and developmental changes that may occur after diagnosis. These booklets include a list of commonly used medical acronyms, advice on how to adjust the at-home environment, descriptions of various referrals a child's physician might make, personal accounts from parents of children with disabilities, and many other helpful resources.

My Child Was Recently Diagnosed with Epilepsy

WHAT HAPPENS NEXT?



Sustainability Objectives

- ✦ Utilize resources unlikely to change over time, ensuring accurate information is distributed to families
- ✦ Empower families to advocate for their child's needs by educating caregivers on the new diagnosis
- ✦ Direct families to reputable resources and organizations that provide care and support to children with additional needs
- ✦ Initiate community-building among newly diagnosed families

Acknowledgements

The EASI program appreciates the support from the Office of the Rutgers Health Chancellor, the participating schools, the Boggs Center on Developmental Disabilities at RWJMS, and the community sites that made this possible. Thank you to Renata Zelvys and the Family Resource Network staff for guiding us with our project. We are grateful to the EASI co-directors, Sarah Kelly and Maria Pellerano, for their development of insightful workshops and commitment to this program.