



Keena Fitzhugh

On this episode of the Black I/DD Podcast we talk with Keena Fitzhugh. Keena is the mother of a daughter who has a disability, and she works as a cultural liaison for the New Jersey Council for Developmental Disabilities (NJCDD).

Show notes:

- Regional Family Support Planning Councils - In accordance with the 1993 Family Support Act, the New Jersey Council on Developmental Disabilities established the Regional Family Support Planning Councils (RFSPCs). The RFSPSCs provide a venue for parents and family members of people with developmental disabilities to exchange knowledge and information about family support services.

<https://njcdd.org/the-regional-family-support-planning-councils/>

- Wheelchair Symbol Plates and Persons with a Disability Placards

<https://www.nj.gov/mvc/vehicles/disability.htm>

- What is an Nasogastric (NG) Tube

<https://www.youtube.com/watch?v=IKnKYKRfYgA>

- Early Intervention – Early intervention services are designed to address a problem or delay in development as early as possible.

<https://www.nj.gov/health/fhs/eis/for-families/when/#:~:text=The%20first%20three%20years%20of,takes%20a%20slightly%20different%20course.>

- Aging Out of the School System

[https://www.nj.gov/humanservices/ddd/individuals/transition/#:~:text=Students%20receiving%20services%20through%20school,IEP\)%20Team%20and%20transition%20coordinator.](https://www.nj.gov/humanservices/ddd/individuals/transition/#:~:text=Students%20receiving%20services%20through%20school,IEP)%20Team%20and%20transition%20coordinator.)

- The Arc of NJ – The Arc of New Jersey is the state's largest organization advocating for and serving children and adults with intellectual and developmental disabilities and their families.

<https://www.arcnj.org/>

- Calling 211 - NJ 211 is a nonprofit organization that provides the 211 Service to the residents of New Jersey. This is a valuable information and referral service that connects people in need with a variety of health and human service programs.

<https://nj211.org/about-nj-211>

- The NJ Resource Book – The 2024 NJ Resource Guide

<https://nyccbf.org/wp-content/uploads/2024/02/2024-New-Jersey-Resource-Guide-1.pdf>

- DDD - The Division of Developmental Disabilities assures the opportunity for individuals with developmental disabilities to receive quality services and supports, participate meaningfully in their communities and exercise their right to make choices.

<https://www.nj.gov/humanservices/ddd/about/division/>

<https://njcdd.org/wp-content/uploads/Accessing-Developmental-Disability-Services-in-NJ-English.pdf>

- NJ PerformCare - Through the New Jersey Children's System of Care, PerformCare connects young people and their families statewide to the care they need to be well.

<https://www.performcarenj.org/>

- Rowan University RISN Center - Provides a family-centered, continuous, comprehensive, coordinated, compassionate, and culturally-competent health care approach that is as developmentally appropriate as it is technically sophisticated.

<https://centers.rowanmedicine.com/risn/about-us/>

- Guardianship

<https://www.nj.gov/humanservices/ddd/individuals/guardianship/>

- Alternatives to Guardianship - Supported Decision-Making 101 is an easy-to-understand introduction to the concept of Supported Decision-making, an explanation of how it might work for New Jersey residents, and a brief discussion of how it fits with other alternatives to guardianship.

<https://disabilityrightsnj.org/resource/supported-decision-making/>

- Support Coordinator Agencies – List of agencies:

<https://www.nj.gov/humanservices/ddd/assets/documents/individuals/support-coordination-agencies-list.pdf>

- PPP or Personal Preference Program - The New Jersey Personal Preference Program (PPP) offers an alternative way for NJ FamilyCare Plan A members who qualify for the Personal Care Assistant (PCA) services benefit to remain in their home and active in their community, and does not require the use of a home health care agency.

https://www.nj.gov/humanservices/dmahs/clients/PPP_Fact_Sheet.pdf

<https://www.nj.gov/humanservices/dmahs/clients/njppp.html>

https://www.nj.gov/humanservices/dmahs/clients/PPP_FAQ.pdf

- Catastrophic Illness – The program will consider the purchase of a specialized, modified vehicle and any subsequent modifications that are related to the medical condition of the child at the time the expenses were incurred as an eligible expense. A one-time vehicle allowance is capped at \$7,500 for the purchase of a lease or a specialized vehicle.

https://www.nj.gov/humanservices/cicrf/literature/CICRF%20Policy_Coverage_Vehicle%20Purchase%20and%20Modification_20230104.pdf

- Disney World Disability Access Service (DAS) - Learn how this service supports Guests who, due to a developmental disability like autism or similar disorder, are unable to wait in a conventional queue for an extended period of time. Plus, find details about the registration process and usage guidelines.

<https://disneyworld.disney.go.com/guest-services/disability-access-service/>

- NJ PerformCare Family Support Services (FSS) - A coordinated system of on-going public and private supports, services, resources, and other assistance, which are designed to maintain and enhance the quality of life of a young person with an intellectual/developmental disability (I/DD) and his or her family.

<https://www.performcarenj.org/pdf/families/family-support-services-facts.pdf>

Advice: Make sure you are cared for – You cannot give what you don't have. Be assertive and you need to show up as yourself. With healthcare – Get names and titles so you can know who you are talking to about supporting your child. Use all of your resources – sign up for newsletters. Get support from a physiologist for your child's Cerebral Palsy. If you are in a hospital and need additional supports, supplies, or need to file a complaint, ask them to connect you with a social worker. Get everything in writing and take notes on your phone as you think about the things you need to do for your child. Ask for help from your community. And be open to seeing a therapist to share how you are feeling.

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