



Respite Program Case Study *Respite in the Time of COVID-19*

New Jersey Family Resource Network

Program Description

The Family Resource Network (FRN) provides direct support services to children and adults with intellectual and developmental disabilities and their family caregivers statewide in New Jersey. Originally known as the Epilepsy Foundation of New Jersey, the Family Resource Network is in its 50th year of operation and includes Epilepsy Services of NJ, Autism Family Services of NJ, and Caregivers of NJ.

The FRN roughly serves 1,800 children and adults with disabilities monthly. Services are funded by the Department of Human Services. Children's services are coordinated through the NJ Department of Children and Families, and adult services are coordinated through the Division of Developmental Disabilities (DD).

The FRN provides respite services through their voucher program, in-home services, and various out-of-home community-based options, such as an afterschool program, summer camp, and community inclusion activities and events.

Due to the COVID-19 pandemic all community-based respite services were closed March 12 at the time of the statewide shutdown. For voucher and in-home services, a phased-in approach was used to reopen due to different state agency oversight guidance and requirements for child vs. adult services. Direct Support Professionals (DSPs) were determined to be essential workers by the Governor, which allowed FRN to continue to offer voucher and in-home respite services. During the shutdown, the voucher service for children was able to continue, and in-home respite continued where possible, available, and agreed upon. Though significantly reduced, services were maintained. This occurred within 30 days of the shutdown.

Planning and Guidance for Reopening Respite Services

The Family Resource Network immediately began planning to explore pandemic resources and information, address staff financial support, and determine feasible strategies for addressing reopening in-home respite services safely for staff and families.

- **Researched information and resources** through the Centers for Disease Control and Prevention (CDC), NJ Department of Children and Families, Division of Developmental Disabilities (DD), NJ Academy of Pediatrics, FRN Health and Innovations Department (internal public health experts), and Governor Orders/Guidance.
- **To gain clarity on how to proceed, communicated on a regular basis** with the NJ Department of Human Services: Department of Children and Families and Division of DD.
- **Applied for and received a [Paycheck Protection Program \(PPP\)](#)¹ loan from the federal government** to continue to maintain DSP staff salaries and benefits.
- **Applied for free Personal Protective Equipment (PPE) with NJ organizations** such as the NJ Association for Community Providers.
- **Immediately contacted all DSP staff to discuss options** for continuing to work as PPP loan provided option to retain staff. Some staff did not continue to work. Others were repurposed and used in other services or administrative tasks.
- **Conducted extensive outreach to families** including weekly emails, social media posts, and individual phone calls to each family.
- **Identified regional Respite Coordinators** in each area of the state to assist with planning, PPE purchase and dissemination, family outreach, and service reopening protocols.
- **Developed the [FRN Guide for Use of PPE](#)**² to instruct DSPs around using masks and gloves, including how to decontaminate masks, and provided specific guidance on hand washing techniques. Also addressed other ways to stop the spread of the coronavirus, including proper sneezing and coughing etiquette, social distancing, cleaning surfaces, and when to seek medical care.
- **Identified best options for purchasing PPE**, delivering or shipping to Regional Coordinators, and disseminating to DSPs.
- **Developed COVID health screening procedures** for both families and DSPs to be conducted 24 hours prior

to service and the day of service ahead of going to the home. Questions asked included: Have you had a fever or sore throat in the last 24 hours? Have you been exposed to anyone that has COVID or is awaiting results? Have you traveled out of the country in the last 2 weeks?

- **Started tracking COVID numbers internally** including exposure, testing results, and deaths to get a better grasp of the scope of the pandemic for NJ.

COVID-19 Training and Resource Dissemination

- **Called each DSP and provided individualized orientation and training** by phone to go over service reopening procedures and protocols. Reviewed the FRN Guide for Use of PPE, safety protocols, and phone COVID screening prior to service provision for them and families. [N=60 DSPs]
- **Established FRN Connect³ through Zoom and provided free virtual training and events** for families and DSP staff during April, May and June. Topics included caregiver issues, hygiene, yoga, Zumba, fitness classes, story time and more.
- **Established Mental Health Zoom sessions** with social worker providing support for Direct Support Professionals actively supporting families in their own homes. This was to let staff know they were supported by FRN.

Reopening Procedures and Requirements

- **Regional Respite Coordinators** ensured all reopening tasks were completed, including PPE distribution, orienting and training DSPs by phone, and communicating with all families.
- **Prior to service, the regional Respite Coordinators call families** by phone to review the safety protocols, including the FRN Guide for Use of PPE, and to assess their comfort level in having someone come into their homes to provide services.
- **DSPs call and implement COVID screening procedures** by conducting calls 24 hours prior to service and the day of service before going to the home and providing any services.
- **Help families find funding for PPE** if needed through state agencies.
- **Discuss and address other family needs** such as food assistance, health insurance, and financial and housing needs. If families need additional help, they are referred to appropriate local and state programs and agencies.

Challenges and Opportunities

- **Working with two state agencies**, one focused on child services and the other on adult services, resulted in challenges regarding consistent determinations about reopening.
- **Through extensive individual family outreach** during the pandemic, staff became more connected to families, sharing their stories on social media and taking “porch” photos to capture their experiences.
- **Families and FRN administrative staff found a newfound appreciation for DSPs** who rose to each challenge in their new roles providing respite for families. Overall, the FRN only had a 15% reduction in in-home respite services.

Respite Service Continuation

- **FRN anticipates that all pandemic-related respite program changes** will remain in place for the foreseeable future.
- **Ongoing DSP/staff support** around new COVID-19 information and resources will be needed.
- **PPE supplies will be maintained** for current and future needs.
- **FRN will advocate** for DSP concerns and issues.
- **FRN will continue to apply for funding for PPE Supplies** with FEMA and other sources.

Respite Contact, Email and Phone Number

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<https://www.familyresourcenetwork.org/frn-support-services>

Website Link URLs

1. <https://www.sba.gov/funding-programs/loans/coronavirus-relief-options/paycheck-protection-program>
2. https://archrespite.org/images/COVID-19/StateResources/NJ_FRN_Protocols.pdf
3. <https://www.gotostage.com/channel/d71411af88874eae816ce4659271aa01>