

Respite Needs in the United States

Nevada Virtual Respite Summit

August 27, 2020

Jill Kagan

ARCH National Respite Network and Resource Center



Presentation Overview

- ❑ National Picture of Family Caregiving
- ❑ Respite benefits and barriers
- ❑ Federal Lifespan Respite Program
- ❑ State grantee activities and innovation
- ❑ Sustainability Strategies for Lifespan Respite
- ❑ Innovative and Exemplary Services
- ❑ Volunteer respite resources
- ❑ Respite during COVID-19



Family Caregiving in the U.S.

- ❑ 53 million adults in the U.S. are family caregivers of an adult or a child with a disability or chronic condition.
- ❑ 80% of those needing long-term services and supports live at home.

Sources: 1) *Caregiving in the U.S. 2020*. Washington, DC: National Alliance for Caregiving and AARP Public Policy Institute; 2) *Rising Demand for Long-Term Services and Supports for Elderly People*, CBO, June 2013





Family Caregiving is Lifespan!

Majority of family caregivers caring for an adult ages 18-75 (54%).

- 20% of family caregivers care for someone ages 65-74;
- 20% care for someone ages 50-64;
- 14% care for someone ages 18-49.

Nearly 14 million children have special health care needs.

Sources: Caregiving in the U.S. 2020. National Alliance for Caregiving and AARP Public Policy Institute; and US Health Resources and Services Administration, The 2017-18 National Survey of Children's Health.



Respite is...

Planned or emergency care provided to a child or adult with special needs in order to provide temporary relief to family caregivers who are caring for that child or adult.

***Lifespan Respite Care Act definition
PL 109-442***

Respite



Benefits

Access

Barriers



Respite may help --

- ❑ Reduce family caregiver stress levels, which in turn, benefits caregiver physical and emotional health
- ❑ Improve overall caregiver and family well-being
- ❑ Reduce social isolation
- ❑ Reduce hospital costs and avoid or delay more costly foster care, nursing home or other out-of-home placements
- ❑ Give care recipients a break, too!

Respite: Too Little, Too Late

- ❑ Just 14 percent of family caregivers report having used respite, though 38 percent feel it would be helpful (*2020 Caregiving in the US, NAC/AARP*).
- ❑ Of those who do, they often receive too little, too late.





Lifespan Respite ... a system of services

Lifespan Respite Definition:

Coordinated **SYSTEMS** of accessible, community-based respite services for all family caregivers regardless of age or special need.



Lifespan Respite Grant Activities

**Statewide Respite
Registries**

**Connecting
families to respite**

**Volunteer and
Faith-based
Respite**

**Consumer-
directed Respite
Voucher Programs**

**Recruiting and
Training Respite
Providers**



Sustainability Strategies

- ❑ Integrating respite into No Wrong Door, LTSS State Systems
- ❑ Forging State agency fiscal partnerships
- ❑ Engaging employers
- ❑ Expanding reach of informal services and community supports
- ❑ Documenting outcomes
- ❑ Strengthening Coalitions/Securing grassroots support
- ❑ Advocating for State funding



Innovative & Exemplary Respite Services





**Community-based
Respite**



**Pediatric Palliative
Care Homes**



Crisis Nurseries



**Volunteer and Faith-
Based Respite**



Rural Respite Models

- ❑ The Gathering (MN)
- ❑ Parent/family Co-ops (SC)
- ❑ Mobile Respite (GA, OK)
- ❑ Home Care Worker Co-ops

<https://seniors.coop/resources-2/>

Volunteer Respite Manual:

Creating Valuable Options for Family Caregivers

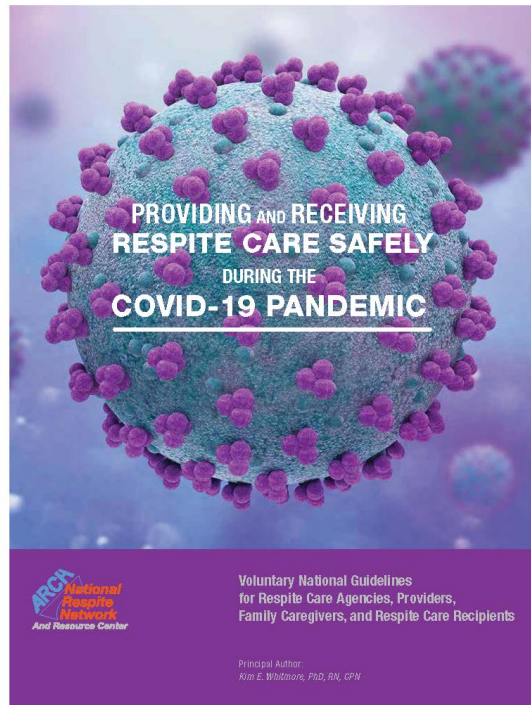


Volunteer Respite Manual: Creating Valuable Options for Family Caregivers

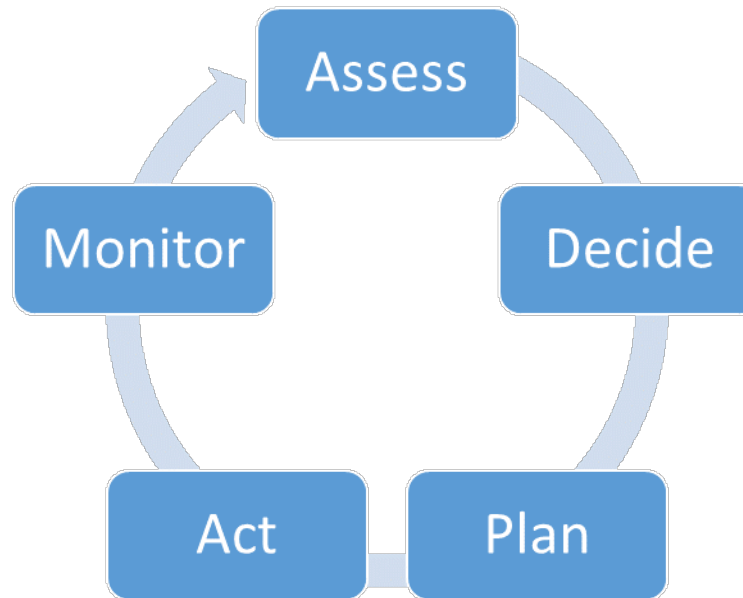
<https://archrespite.org/volunteer-respite-manual-appendices>

National Voluntary Guidelines for Providing and Using Respite Safely During the Pandemic

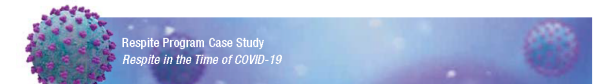
Guidelines



Decision Guides



Case Studies



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) 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 PPE²** 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

Access Resources here: <https://archrespite.org/national-respite-guidelines-for-covid-19>

For More Information



Jill Kagan
Program Director
703.256.2084

jkagan@archrespite.org

ARCH National Respite Network
and Resource Center
<http://www.archrespite.org>

Lifespan Respite Technical Assistance Center



This project was supported, in part by grant number 90LT0002, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.