

# Providing Respite

Supporting People and Families Across the Lifespan



This publication was made possible through a partnership between:



Division of  
Developmental Disabilities  
and  
Division of  
Aging Services



This publication was made possible through partnership between

The New Jersey Department of Human Services and

The New Jersey Lifespan Respite Coalition

A resource developed by:

**RUTGERS**

Robert Wood Johnson  
Medical School

**THE BOGGS CENTER**  
ON DEVELOPMENTAL DISABILITIES

In collaboration with:



New Jersey Lifespan Respite Coalition  
The Family Resource Network  
1 AAA Drive, Suite 203  
Trenton, NJ 08691

Toll Free: (800) 376-2345

<https://www.facebook.com/njlifespanrespite>

## Becoming a Respite Provider...

**Respite** provides caregivers with a short period of rest or relief by arranging alternative caregiving for the child or adult family member needing support. Providing respite is rewarding work. Becoming a respite provider offers an opportunity for those currently working as Direct Support Professionals, as well as those interested in exploring the field of direct support, to gain additional experience and work closely with families. Respite is available to individuals with support needs across the lifespan, allowing respite providers to experience working with different populations in varied settings. Most importantly, providing respite makes a positive impact in the lives of people with disabilities, seniors, and their families.



**“I’m taking care of people and changing their lives and their parent’s lives. I can see that in every phone call, in every situation that they really need this help and I think I’m very blessed to be able to do this.”** – Jeana, Respite Provider

**“Not only is this job fun, but it is also very rewarding professionally and personally.”** – James, Respite Provider



**“Barbara always smiles and is happy when I help her. She is one of the sweetest people and I feel like that’s a great reward. Being able to help someone that needs it is a good feeling.”** – Alexis, Respite Provider



## Family Caregiving Across the Lifespan

Family members frequently serve as the main supporters of children and adults with intellectual and developmental disabilities, as well as seniors, providing care that enables their loved ones to remain in their homes and communities. Nationally, an estimated 61.6 million family caregivers provide at least \$450 billion in uncompensated support services by assisting their loved ones with activities of daily living, personal care, medical therapies or treatments, advocating with numerous service systems and arranging outside services with providers.<sup>1</sup>

Across the country, about 40% of older adults over 65, and nearly three-quarters of adults with disabilities between the ages of 18 and 64, relied exclusively on care provided by family members.<sup>2</sup> In addition, roughly one-third of family caregivers provide support to two or more family members.<sup>3</sup> This is increasingly common as parents of children and adults with developmental and other disabilities may encounter the added responsibilities of caring for an aging parent.

Balancing demands for care with their other responsibilities—including employment, healthcare, and maintaining family and social relationships—is a challenge for many family caregivers. In a survey of close to 5,000 caregivers across the country, nearly half reported more caregiving responsibilities than they can handle.<sup>4</sup> In a recent survey of family caregivers across New Jersey, only 35% of respondents had a full-time job, and 44% reported providing constant care, 24 hours a day, 7 days a week.<sup>5</sup> Close to half of caregivers say they have sacrificed time they spend with other family and friends.<sup>6</sup>

Caregiving is demanding, and those with the most extensive responsibilities may be particularly vulnerable to declines in financial, health, and social well-being that can impede their ability to support family members now or themselves in the future.<sup>7</sup> Among the greatest concerns for most family caregivers are taking care of their own health, meeting financial needs, and not having enough **respite care**.<sup>8</sup>

## Defining Respite

**Respite** is a service that offers a short-term break for caregivers that regularly provide support to a child, adult, or senior family member with a disability or chronic health care need.

Respite may be **planned**, providing scheduled services to allow for intermittent breaks from caregiving, or may be available on an **emergency** basis in the case of unexpected life events that would negatively impact the individual receiving care. Emergencies could include a personal health crisis, job loss, or housing problem experienced by the caregiver.

Respite can be provided in a variety of settings, including:

- In the family's/individual's home
- In the respite provider's home
- Group homes or supervised apartments
- Existing day care centers
- Adult day programs
- Camps



# Respite Providers make a difference in the lives of, and build meaningful relationships with...

Children, Adults, and Seniors with:

- Intellectual and Developmental Disabilities
- Physical Disabilities
- Autism
- Alzheimer's Disease
- Dementia
- Chronic Health Care Needs
- Terminal Illnesses
- Mental Illness and Serious Emotional Disturbance



## Why Caregivers Use Respite

Ongoing caregiving responsibilities can be demanding for family members, potentially impacting the caregiver's health, economic stability, and relationship both within and outside of the home. The caregiving role may limit the ability to maintain employment, and younger family caregivers (under 45) that do work full-time face the greatest emotional and physical strain.<sup>9</sup>

At one point or another, many caregivers experience anxiety, physical fatigue, exhaustion, sleeplessness, back pain, headaches, stomachaches, and feelings of being overwhelmed.<sup>10,11</sup> The stress of family caregiving can affect marital quality, while support obligations may reduce the attention given to family members other than care recipient and limit the number of relationships outside of the home.<sup>12</sup>

---

*"I feel closer to my son ... because I have time to do my own thing and it helps me refill my cup with patience."*

-Family Caregiver

---

**Respite** is more than a break from providing care, and has several benefits for both the family caregiver and the care recipient.

### Respite gives family members the opportunity for:

- Rest and relaxation
- Caring for personal needs
- Social involvement
- Enjoyment and enrichment

### Respite gives care recipients the opportunity for:

- Time away from family
- Making friends and spending time with other people
- Engaging in activities of interest

## Person and Family Centered Respite Supports

Respite services are designed around the support needs and preferences of the person receiving the service. This information is described in the person's service plan and it is important that respite providers understand and are able to follow this guidance.

It is of particular importance that respite providers are aware of what is *"important to"* and *"important for"*<sup>13</sup> the people they support.

---

### *Important To*

*Addresses the things that help to create life experiences that are meaningful to the person, including:*

*Relationships  
Choices and decisions  
Activities and places to go  
Routines and pace of life  
Recognition of strengths  
Having a valued role*

---

---

### *Important For*

*Includes the supports that are necessary for:*

*Health  
Safety  
Freedom from abuse, neglect,  
and exploitation*

---

When respite providers are aware of and use this information, they are better able to provide quality support that not only meets the needs of seniors and children and adults with disabilities, but also helps to make sure the time spent with them is enjoyable and enriching.

## Core Competencies of Lifespan Respite Providers

There are key sets of core skills and knowledge direct service providers across disability and aging fields need to have. Developing these competencies is important to ensuring that the supports provided are best able to meet the needs of the person and his or her caregivers. Respite providers must be able to demonstrate competency in the following job responsibilities:

- Demonstrate *professionalism* by maintaining ethical standards and respecting the rights of the people supported and their caregivers.
- Respect and recognize the *role of the family and other caregivers* as an essential factor in the person's quality of life.
- Provide supports that are *culturally competent*.
- *Communicate* in a manner that is respectful and helps to create a supportive relationship with the person and his or her caregivers.
- Assist the person through providing supports that *maintain health and wellness*.
- Support *participant empowerment* by providing assistance needed to make informed decisions on his or her behalf.
- Provide *person-centered supports* based on the person's strengths, interests, and goals.
- *Assess and respond* to the needs of the person.
- Maintain a *safe environment*, reduce risk, and be prepared for emergencies.
- Use effective strategies to *address challenging behaviors and crisis situations*.<sup>14</sup>

## Professional Development

Respite providers participate in training activities to increase their skills and competencies as related to their role. Often training is required by the employer, but additional training may be requested and is frequently available at no cost to the employee or employer.

Educational opportunities vary based on who is being supported. Employers provide training based on provider qualifications and standards set forth by the state. In addition to meeting mandatory training requirements, respite providers may also participate in supplementary educational opportunities that are provided across the state. This may include workshops and seminars offered through:

- Provider Organizations
- University Resources - including The Boggs Center on Developmental Disabilities and Rutgers University Behavioral Health Care Behavioral Research and Training Institute
- Clinical Education Entities - including Trinitas Regional Medical Center's Statewide Clinical Outreach Program for the Elderly
- Community Colleges
- Training Consultants
- Online training - including the College of Direct Support for adult disability service providers
- Department of Labor Grants
- New Jersey Department of Human Services approved training programs - including Nurse Assistant and Personal Care Aide Certification

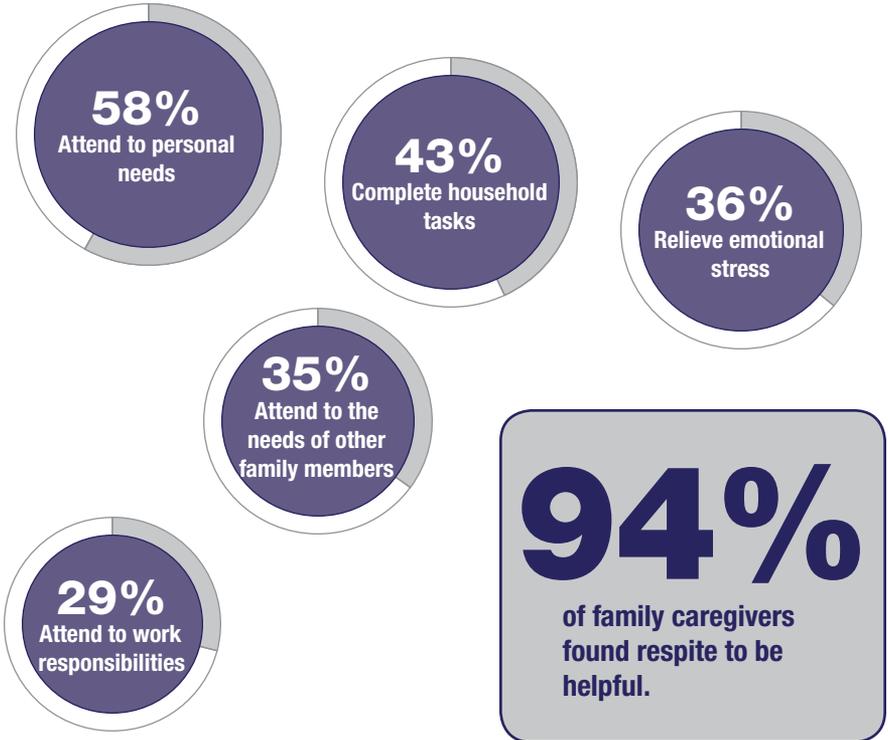
Direct support professionals and their employers are encouraged to access these resources and seek out additional opportunities to increase their skills.

## Impact of Respite

Respite provided across the lifespan can enhance health among family caregivers and those receiving care, as well as stability within the home. Family caregivers report improved physical and emotional health and reduced stress when respite is available for their loved one. Individuals receiving support also experience improved well-being, and decreased likelihood of hospitalization or out-of-home placement.<sup>15</sup> Respite services can restore stability within the home, allowing family caregivers to return to caregiving responsibilities renewed.

### Of family caregivers surveyed in New Jersey...<sup>16</sup>

Respite provided family caregivers with an opportunity to...



## What Does Respite Mean to Families?

“If I didn’t have respite I really don’t know...I would not have been able to run my business and have some freedom to be able to come and go a little bit more. It’s a huge relief to be able to just release me from some of the day to day.”



“The respite provides us with the relief not to get burned out, so that we can continue to care for him in our home where we would like him to be.”

“The gamut of options to use the respite workers originally had started with work and then it advanced to opportunities for me to go out with family or friends. In the recent past I had some surgeries that required hospitalization and the respite workers really had to pitch in and help in addition to the family.”



## To Learn More About Respite and Training Opportunities:



New Jersey Lifespan Respite Coalition  
The Family Resource Network  
1 AAA Drive, Suite 203  
Trenton, NJ 08691

Toll Free: (800) 376-2345

<https://www.facebook.com/njlifespanrespite>

**RUTGERS**

Robert Wood Johnson  
Medical School

**THE BOGGS CENTER**  
ON DEVELOPMENTAL DISABILITIES

The Boggs Center on Developmental Disabilities

Rutgers, The State University of New Jersey

335 George Street

New Brunswick, NJ 08901

732-235-9300

<http://rwjms.rutgers.edu/boggscenter/training/overview.html>

## References

- <sup>1</sup>AARP Public Policy Institute. (2011). *Valuing the Invaluable: 2011 Update, The Growing Contributions and Costs of Family Caregiving*. Washington, DC: AARP.
- <sup>2</sup>Spector, W. D., Fleishman, J. A., Pezzin, L. E., & Spillman, B. C. (2001). *The Characteristics of Long-term Care Users: AHRQ Research Report*. Rockville, MD: Agency for Health Care Research and Quality.
- <sup>3</sup>National Alliance for Caregiving & AARP. (2009). *Caregiving in the U.S. 2009*. Washington, DC: NAC and AARP.
- <sup>4</sup>Anderson, L.L., Larson, S.A., & Wuorio, A. (2011). *2010 FINDS National Survey Technical Report Part 1: Family Caregiver Survey*. Minneapolis, MN: University of Minnesota, Research and Training Center on Community Living.
- <sup>5</sup>New Jersey Department of Human Services & New Jersey Lifespan Respite Project. (2014). *New Jersey Lifespan Respite Program Survey Results*. Trenton, NJ: New Jersey Department of Human Services and New Jersey Lifespan Respite Coalition.
- <sup>6</sup>National Alliance for Caregiving & AARP. (2009). *Caregiving in the U.S. 2009*. Washington, DC: NAC and AARP.
- <sup>7</sup>National Alliance for Caregiving & AARP. (2009). *Caregiving in the U.S. 2009*. Washington, DC: NAC and AARP.
- <sup>8</sup>National Family Caregivers Association & Allsup. *NFCA/Allsup Family Caregiver Survey*. Washington, DC: National Family Caregivers Association.
- <sup>9</sup>New Jersey Department of Human Services & New Jersey Lifespan Respite Project. (2014). *New Jersey Lifespan Respite Program Survey Results*. Trenton, NJ: New Jersey Department of Human Services and New Jersey Lifespan Respite Coalition.
- <sup>10</sup>National Respite Coalition Lifespan Respite Task Force. (2009). *Benefits and Cost-Savings Due to Respite*. Annandale, VA: National Respite Coalition.
- <sup>11</sup>New Jersey Department of Human Services & New Jersey Lifespan Respite Project. (2014). *New Jersey Lifespan Respite Program Survey Results*. Trenton, NJ: New Jersey Department of Human Services and New Jersey Lifespan Respite Coalition.
- <sup>12</sup>National Alliance for Caregiving & AARP. (2009). *Caregiving in the U.S. 2009*. Washington, DC: NAC and AARP.
- <sup>13</sup>Smull, M., & Sanderson, H. (2005). *Essential Lifestyle Planning for Everyone*. Stockport, UK: Learning Community.
- <sup>14</sup>National Direct Service Workforce Resource Center, Centers for Medicare and Medicaid Services. (2013, August 6). *Core competencies for the direct workforce version 3.0*.
- <sup>15</sup>National Respite Coalition Lifespan Respite Task Force. (2009). *Benefits and Cost-Savings Due to Respite*. Annandale, VA: National Respite Coalition.
- <sup>16</sup>New Jersey Department of Human Services & New Jersey Lifespan Respite Project. (2014). *New Jersey Lifespan Respite Program Survey Results*. Trenton, NJ: New Jersey Department of Human Services and New Jersey Lifespan Respite Coalition.





Division of  
Developmental Disabilities  
and  
Division of  
Aging Services



This publication is funded through the Lifespan Respite Project which is supported in part by grant #90LR0029, from the U.S. Administration for Community Living, U.S. Department of Health and Human Services in partnership with the NJ Department of Human Services and the NJ Lifespan Respite Coalition.

## THE BOGGS CENTER ON DEVELOPMENTAL DISABILITIES

*New Jersey's University Center for Excellence in Developmental Disabilities Education, Research, and Service*

# RUTGERS

Robert Wood Johnson  
Medical School

The Boggs Center on Developmental Disabilities  
Department of Pediatrics  
Rutgers, The State University of New Jersey  
Liberty Plaza, 335 George Street  
New Brunswick, NJ 08901  
<http://rwjms.rutgers.edu/boggscenter>  
p. 732-235-9300  
f. 732-235-9330