

## ORGANIZATION NEWS

### Information/Education Page

#### Accessing Respite Care for Persons With a Disability



Respite care is a service that provides temporary care relief for family caregivers of persons with a disability. Planned breaks from care are an important way for caregivers to reduce stress and be more attentive to their own personal needs.<sup>1,2</sup> Unfortunately, respite is often underused by caregivers because they have concerns about how the services will effectively meet the needs of their loved one.<sup>3</sup> However, the well-prepared caregiver is familiar with respite service providers within their community and understands the respite benefit provided by the care recipient's insurance.

#### Types of respite care

Through a variety of care providers, respite care can take place in the home, out of the home, for portions of the day, overnight, or even for several nights. [Table 1](#) lists common types of respite providers and their advantages and disadvantages.

#### Eligibility and coverage

Respite services are often covered by insurance and health care coverage plans, such as:

- Medicare/Medicaid
- Private insurance
- Long-term care insurance
- Social Security Disability Insurance
- Veterans benefit
- Hospice benefit

For further information on specific benefits available, caregivers should contact insurance providers, hospice, or the social security office. Although the language used by these coverage groups to describe respite services can vary, common terms to use when inquiring about service may include "respite," "home-health services," "long-term care coverage," and/or "adult day care."

#### Important considerations

Before choosing a respite care provider, there are a few important questions to consider, especially when working with an institution or an agency:

1. Is the residential care facility or adult day care clean (smell free), and do the people appear well-cared for on a tour?
2. What differences do you notice in staffing and care during the day versus the evening at residential care facilities?

3. What experience does the person/group have in working with others like my loved one?
4. What charges will I be responsible for directly?
5. Are there any upfront charges that I need to know about?
6. What forms of payment are accepted and what are the billing practices?
7. Does the person in my home make me feel safe?

When working outside of agencies, for instance with independent contractors or family members, be certain to get all paid agreements in writing, including an agreed upon hourly rate, how time is calculated, expected responsibilities and duties, living/sleeping arrangements if overnight care is needed, and any pertinent house rules. Also, remain cautious and do not leave money, valuables, or personal information (ie, bank statements, receipts) out in the open.

For additional information please refer to the following resources:

- ARCH National Respite Network and Resource Center (available at: <http://Archrespite.org>)
- National Association of Area Agencies on Aging (available at: <https://www.n4a.org/>)
- Alzheimer's Association (available at: [www.alz.org](http://www.alz.org), 1-800-272-3900)
- National Alliance on Mental Illness (available at: [www.nami.org](http://www.nami.org), 1-800-950-6264)
- U.S. Department of Veteran Affairs (available at: <https://www.caregiver.va.gov/>, 1-855-260-3274)

#### Authorship

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**Table 1** Respite care provider options and their advantages and disadvantages

Provider Type/Setting	Advantages	Disadvantages
Home health care agencies	<ul style="list-style-type: none"> <li>• Have trained and licensed staff</li> <li>• Agency completes staff background checks</li> <li>• 24h/d, 7d/wk availability</li> <li>• May assist with obtaining necessary durable medical equipment for the home</li> <li>• Care recipient can remain in familiar environment</li> <li>• Available to continue with care assistance beyond respite</li> </ul>	<ul style="list-style-type: none"> <li>• Must accept and work with strangers in the home</li> <li>• Around-the-clock care can be expensive</li> </ul>
Residential care facilities (group homes, nursing homes, assisted living facilities, and specialty hospitals)	<ul style="list-style-type: none"> <li>• Have trained and licensed staff (training level can vary by setting)</li> <li>• Facility completes staff background checks</li> <li>• 24h/d, 7d/wk care</li> <li>• Nursing home and specialty hospital staff are able to manage complex and unpredictable care needs</li> <li>• Available to continue with care assistance beyond respite</li> <li>• Ideal for when the regular caregiver is traveling</li> <li>• Provides opportunities for social engagement</li> </ul>	<ul style="list-style-type: none"> <li>• Transition for person needing care may be difficult</li> <li>• Setting is more restrictive than home</li> <li>• Residential-based care can be expensive</li> </ul>
Privately hired workers	<ul style="list-style-type: none"> <li>• More flexibility in scheduling</li> <li>• May be available to continue with care assistance beyond respite period</li> <li>• Out-of-pocket costs may be less than residential care facilities and homecare agencies</li> </ul>	<ul style="list-style-type: none"> <li>• The family is responsible for training</li> <li>• The family is responsible for paying applicable taxes</li> <li>• The family is responsible for completing background checks</li> <li>• The family is responsible for supervision</li> </ul>
Adult day care centers	<ul style="list-style-type: none"> <li>• Provides sitter service and therapeutic care</li> <li>• Offers structured activities</li> <li>• Encourages social engagement</li> <li>• Transportation services often available</li> <li>• Meals usually included</li> </ul>	<ul style="list-style-type: none"> <li>• Not appropriate for care recipients with high care needs or aggressive/combatative behaviors</li> <li>• Limited hours of service</li> </ul>
Summer and/or day camp programs	<ul style="list-style-type: none"> <li>• Great opportunities for social engagement</li> <li>• Generally takes place during the summer</li> <li>• Geared toward school age children through young adult age 25y</li> <li>• Typical duration is 5d</li> <li>• Overnight options often available depending on care needs</li> <li>• Scholarships are often available</li> </ul>	<ul style="list-style-type: none"> <li>• Transition for person needing care may be difficult</li> </ul>
Unpaid volunteers (family, friends, neighbors, religious groups, and community organizations)	<ul style="list-style-type: none"> <li>• Free!</li> <li>• Best for short breaks (1–4h)</li> </ul>	<ul style="list-style-type: none"> <li>• The family is responsible for training</li> <li>• The family may be responsible for supervision and background checks depending on the organization providing volunteers</li> <li>• Medication administration or attention to personal care needs (ie, toileting assistance) may not be available</li> </ul>

## Disclaimer

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## References

1. National Academies of Sciences Engineering and Medicine. Families caring for an aging America. In: Schulz R, Eden J, editors. Washington (DC): The National Academies Press; 2016.
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3. Stirling CM, Dwan CA, McKenzie AR. Why carers use adult day respite: a mixed method case study. *BMC Health Serv Res* 2014;14:245.