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9 STEPS TO RESPITE CARE for Family Caregivers of Children and Adults with Intellectual and Developmental Disabilities

A Pathway to Get the Break You Deserve

Are you a parent or family member providing support to a child or adult with an intellectual or developmental disability? You may engage in multiple roles in supporting the independence and overall quality of life of your family member and sometimes that role includes being a caregiver.

You are called a caregiver if you provide help or support for another person due to medical, physical or mental conditions or functional limitations, whether you help full-time or as time permits. Your family member needing support may live in their own home, with you, or in a residential setting. Typically, caregivers are parents, but can include other family members, such as siblings, and friends who are providing care.

Caregivers of children and adults with intellectual and developmental disabilities (I/DD) may face additional challenges. Sometimes, individuals with disabilities have unique physical, emotional and behavioral conditions that require specialized care. For example, recent research has shown a growing incidence of early onset Alzheimer's for people with Down syndrome. In addition, individuals with I/DD may have complex medical conditions or behavioral issues that require someone with relevant experience or training to provide support. For additional respite resources for someone with I/DD who also may have a medically complex condition or for a person with Autism, see page 12.

At times you and members of your family may feel overwhelmed and stressed. You may find that your mental and physical health and well-being are impacted by all that caregiving entails. Therefore, identifying yourself as a "caregiver" is important for there are numerous resources available to help you.

▶▶▶ Tools are available to assess your respite needs: *Time for Living and Caring: Making Respite Services Work for You* at archrespite.org/images/docs/Outside_Reports/Lund_TLCRespiteBrochure_2014.pdf and to help you plan for respite: *Charting the LifeCourse: Respite* at www.lifecoursetools.com/respite.

▶▶▶ This factsheet is a guide for getting the respite care you deserve. By reading it, you will have a better understanding of the resources that are available, what you can expect, and how to select a high-quality service that best meets the needs of your family.

STEP
1

**Understanding
Respite Care**

As a parent or family caregiver of a child or adult with an intellectual or developmental disability, it is important for you to be aware of a resource called respite care. Respite services can provide a much needed break away from your caregiving responsibilities. By taking a break, you will become less stressed, better rested and renewed. Sometimes feelings of guilt or anxiety about leaving your family member may keep you from seeking respite in a timely way. Parents and families are encouraged to use respite on a regular basis to avoid feelings of guilt, exhaustion, isolation and burnout.

STEP
2

**Types of Respite
Care Available**

Respite care is offered in a variety of ways. You can receive a break for a few hours, a few days or even several weeks. Services may take place in the home, or outside the home, in a community or faith-based agency or organization, at a day care or afterschool program, in a hospital or healthcare facility, or in a residential setting. You can get a respite break through therapeutic recreation, inclusive recreation, and day and overnight camp programs. Other family members, friends or neighbors may also be available to provide informal respite opportunities.

Depending on your family needs, paid care may be provided by a community-based program, a

disability organization such as Easterseals, the Autism Society, United Cerebral Palsy, The Arc, through a home health agency, or by someone you hire on your own. Volunteer services are available in many communities. Churches, synagogues and other faith-based organizations are increasingly offering respite for people with disabilities, often utilizing volunteers from the congregation.

Services may be free or offered on a sliding scale. Some respite service organizations support people within a specific age bracket or persons with specific conditions. In some cases, emergency respite services are available.

Non-traditional or more informal respite services may allow volunteers or paid respite workers to accompany your family member to inclusive community activities. Some families build respite cooperatives coordinating caregivers to trade off providing respite services to one or more children or adults with I/DD at home or in the community.



STEP
3

**Where Do I
Find Services?**

There are several ways to find respite. Some programs are for specific populations such as children with autism or adults with intellectual disabilities, while others are provided to the general public. Below is an overview of places to contact regarding the respite services that are available in your community.

You can access respite services through formal supports and paid services, participant-directed respite, or informal supports such as inclusive community activities. Consider these options:

- registering for **case management** or service coordination services as they may provide a path to accessing respite programs or funding for respite care;
- exploring state and local **family support services** and/or funds;
- looking for **voucher** or **participant-directed respite** models; and
- finding **informal supports** that focus on family-driven and person-centered respite services.

**Respite Programs Serving
Children and Adults with Intellectual
and Developmental Disabilities (I/DD)**

- **State-Funded Developmental Disabilities Respite Programs.** Many states have dedicated funds specifically for respite and other supports for the I/DD population. Contact your state disability agency for the most recent information at www.nasdds.org/state-agencies.
- **Local Disability Agencies** provide support to caregivers and can help you find respite services and options in your community for children and adults with I/DD. Some agencies offer respite services.

- **Community-based disability organizations**, such as **Easterseals**, provide adult day, in-home, and camp programs for people with intellectual and developmental disabilities. Find services in your state at www.easterseals.com/explore-resources/for-caregivers/respite-care.html.
- **Advocacy agencies** often provide respite services through their local and state affiliates – such as **The Arc**, the **Autism Society** and **United Cerebral Palsy**. For information on how to contact them, see pages 10 to 11.
- **Inclusive community activities** offered by community centers, parks and recreation, YMCAs, arts programs, social clubs, faith-based organizations, camp programs, and others.
- The **National Family Caregiver Support Program** provides respite and other caregiver support to caregivers assisting someone 60 and older, an Alzheimer’s patient of any age, or to a grandparent or relative caregiver (age 55+) of a minor child, or to an older parent or relative caregiver (age 55+) of an adult with disabilities. Access services through your local **Area Agency on Aging (AAA)**. To find the AAA nearest you, contact the **Eldercare Locator** at eldercare.acl.gov or call 1-800-677-1116.

Finding Respite in the General Population

The following programs are available to help caregivers access respite services. Contact the organization listed for further details.

- The **Lifespan Respite Care Program** is available in some states to provide respite services. Some states provide planned and emergency respite services to persons who are unserved by other programs. Lifespan Respite programs often work closely with a State Respite Coalition partner. Depending on the state, the Lifespan Respite program or their State Respite Coalition may help you find respite providers or funding resources to help you pay for respite. For Lifespan Respite state contacts, see archrespite.org/lifespan-programs. For State Respite Coalition contacts, see archrespite.org/state-respite-coalitions.

- If your state does not have a State Lifespan Respite Program or a State Respite Coalition, you can visit the **ARCH National Respite Locator Service (NRLS)** at archrespite.org/respitelocator to find possible respite programs in your area. Many Lifespan Respite programs have also developed online respite registries. Links to state registries can be found at www.lifespanrespite.memberlodge.org/StateRegistries.
- **No Wrong Door (NWD) Systems** established jointly by the Administration for Community Living and the Centers for Medicare and Medicaid Services are working in every state to make it easier for all people needing long-term services, including respite, to get the support they need. To find a NWD partner, including **Aging and Disability Resource Centers**, near you, visit the **Eldercare Locator** eldercare.acl.gov or call 1-800-677-1116. For more information on NWD Systems, see nwd.acl.gov.
- **Home Health Agencies** may provide in-home respite. To find a home health agency, visit Caring.com at www.caring.com/local/in-home-care. If the person with I/DD is Medicaid eligible, you will have to ask the home health agency you have selected if it is a Medicaid certified provider in your state.

▶▶▶ **Consumer-Directed Respite:** Some Lifespan Respite Programs, state-funded respite programs, and Medicaid waivers, provide respite vouchers or a service budget that allow family caregivers to hire, train and pay their own respite providers. These programs are sometimes known as cash and counseling, parent or family stipend programs, or consumer or participant-directed services, but program names differ from state to state.

STEP
4

How Will I Pay for Respite?

In many cases, respite will be free, but time-limited. You may be required to pay a co-payment based on the care recipient's medical or disability status and financial information. Similarly, Medicaid respite is for caregivers of older adults or persons with specific disabilities or conditions who meet income guidelines. Medicaid respite services are delivered without charge. In addition, some volunteer and public respite programs are free for caregivers.

Possible Public Funding Sources for Respite

Medicaid: Generally, every state offers some respite assistance through various Medicaid Waivers if the person with a disability meets the eligibility requirements. To find out more about specific Medicaid waivers that pay for respite in your state, click on your state on the **ARCH US Map for Respite Funding and Caregiver Supports** at archrespite.org/respitelocator/respite-locator-service-state-information-map and scroll down to "Medicaid Waivers that Pay for Respite." Please note that there may be waiting lists for Medicaid waiver services. Sometimes respite is available for Medicaid eligible

individuals through the Medicaid State plan. Note that not every state provides this optional benefit through Medicaid. Contact your local Medicaid office by visiting medicaiddirectors.org/about/medicaid-directors for details about eligibility and providers under the Medicaid state plan.

State Funded Respite Programs: Your state may provide respite through state-funded respite, caregiver or family support programs for children and/or adults with developmental and intellectual disabilities, and special medical or health care needs. Check with your State Lifespan Respite program for more information or visit the **ARCH US Map for**

Respite Funding and Caregiver Supports at archrespite.org/respitelocator/respite-locator-service-state-information-map and scroll down to “Other Possible Public Funding Sources.”

National Family Caregiver Support Program: Funding may be available through the National Family Caregiver Support Program, which is administered through your local **Area Agency on Aging (AAA)**, if you are caring for someone over the age of 60 or someone of any age with Alzheimer’s or other dementias. If you are a grandparent age 55 or older caring for a grandchild or if you are a parent or other relative age 55 or older caring for an adult with disabilities you may also qualify for respite and other caregiver supports under this program. Visit the **Eldercare Locator** to contact your AAA about respite funding options: eldercare.acl.gov.

For additional information on federal funding sources to help you pay for respite, refer to **Federal Funding and Support Opportunities for Respite:** lifespansupport.wildapricot.org/Federal_Funding_Guide.

Private Funding Sources for Respite

Private or Self-Pay: If none of the options listed above work for you, you may choose to pay for private respite services. You can contract for services through community agencies providing respite or find a respite provider through family or friends.

Long-Term Care Insurance: In limited cases, there may be respite care coverage in some long-term care insurance policies. According to the 2017 Genworth Cost of Care Survey, typically homemakers and home

▶▶▶ **ABLE Accounts:** The ABLE Act allows qualified individuals with disabilities and their families to save and use their own funds for disability-related expenses, including respite, through tax-advantaged investment ABLE accounts. The funds in the account, and distributions made for qualified disability-related expenses, are also not factored into determining eligibility for federally funded means-test benefits, such as Supplemental Security Income (SSI) and Medicaid. The ABLE National Resource Center has more information: www.ablenrc.org/about/what-are-able-accounts.



health aide companies charge about \$15 to \$20 per hour and adult day health averages \$70 per day. Rates vary by where you live.

Cost Saving Options: Many of the community-based programs and services mentioned earlier may provide financial support by offering sliding fee scales, payment plans, scholarships, and camperships. They may also have collaborative funding through local community service organizations that will support respite service options. Be sure to ask the program or service provider about these options.

STEP 5 **How Do I Decide What's Right for Me?**

Once you have decided to use respite care, you want to make sure the service you are considering is right for your situation and family. Unfortunately, in some areas there may only be one option for respite care. If you do have a choice of services, however, use the following tips when selecting what's right for you:

Before You Contact Potential Providers

- If you have feelings of guilt or anxiety about leaving your family member, speak to another family caregiver about their respite experiences. Respite for you will mean that you will be better prepared to continue providing care.
- Plan a time to sit down with your family members to discuss the possibility of using respite services. Be sure to include your family member with I/DD in the discussion if possible. To include family members living far away, consider arranging a conference call or Skype session.
- Take time to explore respite options and decide what would work best; in-home or out-of-home care, after school care, adult day care, community respite (e.g., therapeutic or inclusive recreation programs), or overnight care in a residential or medical setting.

- Discuss how often you would like to use the respite service.
- Confirm what each family member would need to make the most of respite care. Are there activities your family member would like to do while you are getting respite? Are there important considerations that need to be addressed so that your family member is comfortable?
- Make a list of questions to ask potential providers (see ideas on page 7).
- Create a checklist of important information you think the care provider needs to know about the medical, behavioral, and daily living (toileting, feeding, and mobility) needs of the person who will receive care, including dietary, recreational and other preferences. There are guidebooks and templates to help you put this information together in the *ABCs of Respite* at archrespite.org/consumer-information.
- Explore *Charting the LifeCourse: Respite* at www.lifecoursetools.com/respite that can help family caregivers caring for individuals with disabilities across the lifespan create a plan to identify and access respite services within and outside of the formal service system in their local communities. LifeCourse materials include a respite guide, videos, tools, and resources to help you find and plan for respite.



- If respite is being provided in the home consider strategies to increase safety and avoid theft, such as placing all valuables and medication in a safe. Be sure to discuss whether the respite provider will be given a key or access to home security systems.

Contact Potential Providers

Once the family has had an initial discussion, and you have identified possible respite services or providers, ask each provider you are considering

to send you a brochure and other pertinent information in advance so you can get familiar with their services. Contact the potential providers along with your family member, when possible, and discuss your family's expectations and these questions:

- How are the respite providers selected and trained?
- Are background checks performed?
- Do the respite providers have training and/or experience with children or adults with intellectual or developmental disabilities?
- Are respite providers licensed and bonded, if required?
- What tasks can be performed by the respite provider?
- Can the respite provider administer medications, assist with medical tasks or daily living needs, if necessary?
- Will the respite provider engage in or offer activities or social and recreational services requested by the family or child or adult with I/DD?
- What hours and days are services available?
- If the provider will be driving the care recipient, do they have a valid driver's license?
- What is the eligibility process for families?
- What are the fees and how are they paid? Are any financial supports available (e.g., sliding fee scale, scholarships)?
- How are emergencies and problems handled?
- Are references available?

If you are considering respite services outside the home, request a tour for you and your family member.



When possible, visit the program or community setting more than once and observe the engagement between participants and staff. Observe for cleanliness and the types of activities available. Are there opportunities for social engagement or other activities desired by the care recipient?

If you decide to hire a private independent respite provider who is not an employee of an agency, then the questions listed above become essential. In addition, it is even more important to check references, use telephone interviews to screen providers, and conduct a background check for safety reasons. Although finding someone on your own is usually less expensive, it is more complicated. Remember, you may also be responsible for paying household employee taxes if you use one provider consistently. To find independent providers, start by asking family and friends, check with religious communities and online respite registries, and you may consider placing an ad in local newspapers or using vetted online resources.

STEP
6

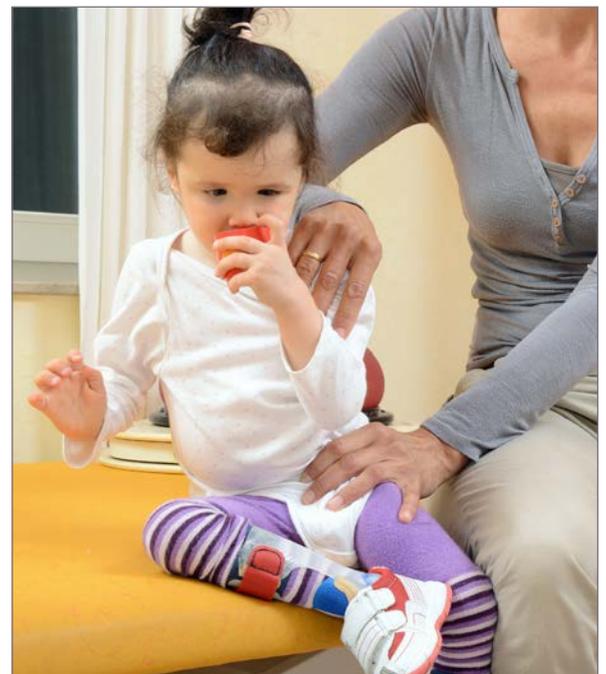
Preparing My Family Member for Respite

Respite provides a much needed break for both the caregiver and the care recipient. Some care recipients, however, may be resistant because they are uncomfortable in an unfamiliar environment or being with people who are considered “strangers.” This may be especially true for children and adults who have communication and/or behavioral issues. Allowing someone new to provide help may be outside of his or her comfort zone, and yours. Here are a few tips that may help:

- Introduce the idea of respite well in advance of when you might want to start using it. Planning is key! Set aside enough time to prepare your family member for the respite experience and enough time to plan for how it will occur.
- You, as the caregiver, have the primary responsibility for making the decision to access respite services. However, when it is possible, involving the care recipient in some aspects of respite service planning may help smooth the transition and assist in acceptance of respite care.

Ways in which the care recipient might be involved could include choosing the location of service, activities, or time frames. Providing appealing respite options with desirable activities or social opportunities may increase the care recipient’s willingness to participate.

- When talking about the respite service, use positive language and show your excitement about the opportunity.
- Try spending time with your family member in the respite setting or with the respite provider to help them feel more comfortable.
- Have the respite provider arrive early so that you can plan a smooth transition for your family member. This also provides an opportunity to share up-to-date information or any changes in the care recipient’s needs.
- Consider hiring your family member’s daytime caregiver to provide overnight respite care.
- To make the respite situation more comfortable for your family member, be sure that familiar routines and activities will be included in the respite experience.



STEP
7

Planning to Make the Most of Respite

There are several ways you can make the most of your time away from caregiving.

Use Respite Early. First, when possible, try to take a break on a regular basis beginning as soon as possible in your caregiving experience. Avoid waiting until you are overwhelmed and stressed.

Use Respite as Frequently as Possible. By getting respite at least once a week, when possible, you can restore your balance and reduce stress.

Planning is Key. You want to make sure your respite time is enjoyable. Find ways to use your time to reconnect with friends, exercise, participate in a hobby or get some much needed rest. Plan what you will do during your respite times and resist waiting until the last minute to confirm your plans.

Focus on You. Some respite initiatives might focus on activities specifically for you – through weekend retreats for families caring for family members with intellectual or developmental disabilities, respitality offered by private organizations in collaboration with hotels or other leisure providers, or caregiver education programs (see resource list on page 10). Remember, your goal with respite is to take care of yourself, while ensuring your family member is safe and secure...so plan your respite time so that it is meaningful for you.

STEP
8

Orienting Respite Providers

As mentioned earlier, it will be helpful to create a checklist for the respite provider. Make it clear to the respite provider that you, as the parent or family caregiver, are the primary point of contact.

Checklist for Information to Share with the Respite Provider

- ✓ Your contact information
- ✓ The care recipient's preferences, likes and dislikes
- ✓ Information about special diets, medications, and daily living needs (e.g., the need for toileting assistance or help with dressing)
- ✓ Overview of a typical day in the life of the care recipient
- ✓ Tips for how to deal with any difficult behaviors exhibited by the care recipient

Summarize key information in a packet so that the care provider can “grab and go” if they need to take the care recipient to the hospital. Include essential information from the above checklist and put the packet by the door for easy retrieval.

If the respite provider is qualified to perform medical tasks, administer medication, or assist with more complex activities of daily living, make sure you dedicate sufficient time before you leave to demonstrate correct and preferred approaches. You know your family member best. By sharing your expectations for how care is to be provided, you will help ensure the safety and well-being of your family member.

STEP
9

Find Out About Other Helpful Resources

Although being a caregiver is rewarding, it can also be challenging. Using respite services on a regular basis helps you be the best caregiver you can be. There are also a number of other types of services that can help. You will want to get all of the support and assistance that is available. Use the resource list below to find the most desirable, safe and appropriate respite options and other useful services.

General Respite Information: What is Respite, How to Find It, Choose It and Pay for It

ARCH National Respite Network and Resource Center

archrespite.org

The ABCs of Respite: A Consumer Guide for Family Caregivers – archrespite.org/consumer-information

ARCH Fact Sheet: Respite for Family Caregivers of Children and Adults with Intellectual and Developmental Disabilities (I/DD) – archrespite.org/images/docs/Factsheets/FS_62-Respite_I-DD-2.pdf

Charting the LifeCourse: Respite – videos, tools, and resources for respite www.lifecoursetools.com/respites

Time for Living and Caring: Making Respite Services Work for You – archrespite.org/images/docs/Outside_Reports/Lund_TLCRespiteBrochure_2014.pdf

Caregiver Resources for the General Population

Caregiver Action Network (CAN) is a non-profit organization providing education, peer support, and resources to family caregivers across the country

free of charge including a Family Caregiver Toolbox www.caregiveraction.org/family-caregiver-toolbox.

Family Care Navigator, Family Caregiver Alliance (FCA) provides caregiver resources and care recipient benefits by state at www.caregiver.org/family-care-navigator. FCA just developed a new resource *Caregiving at Home: A Guide to Community Resources, Family Caregiver Alliance* – www.caregiver.org/caregiving-home-guide-community-resources.

Specific to Family Caregivers of Children and Adults with I/DD

Autism Society

www.autism-society.org

Since 1965, the Autism Society has been the national leader in serving people with autism and their families. The Autism Society has a national network of almost 100 affiliates dedicated to providing respectful and caring services.

Easterseals

www.easterseals.com

Easterseals provides services, education, outreach, and advocacy so that people living with autism and other disabilities can live, learn, work and play in our communities. Easterseals programs include a variety of respite services for all ages, including adult day services, in-home support and services, and camping and recreation opportunities.

Family-to-Family (F2F) Health Information Centers (HIC)

www.fv-ncfpp.org/f2fhic/about_f2fhic

Family-to-Family Health Information Centers (F2F HICs) are family-staffed organizations that assist families of children and youth with special health care needs and the professionals who serve them. F2F HICs provide support, information, resources, and training around health issues. To find a F2F HIC in your state go to www.fv-ncfpp.org/f2fhic/find-a-f2f-hic.

Grandfamilies.org

www.grandfamilies.org

Grandfamilies.org serves as a national legal resource in support of grandfamilies within and outside the child welfare system. GrandFacts: State Fact Sheets for Grandparents and Other Relatives Raising Children provide state-specific data, local program resources, benefits, and legal information at www.grandfamilies.org/State-Fact-Sheets.

National Down Syndrome Society

<https://www.ndss.org>

The National Down Syndrome Society is the leading human rights organization for all individuals with Down syndrome. To find a local affiliate, visit <https://www.ndss.org/resources/local-support>.

Parent to Parent USA (P2P)

www.p2pusa.org

Parent to Parent programs across the country provide emotional and informational support to families of children who have special needs, most notably by matching parents seeking support with an experienced, trained 'Support Parent.' To find a state program, scroll down to map at www.p2pusa.org/parents.

Sibling Leadership Network

www.siblingleadership.org

The Sibling Leadership Network provides siblings of individuals with disabilities the information, support and tools to advocate with their brothers and sisters and to promote the issues important to them and their entire families. To find a state chapter, visit www.siblingleadership.org/about/sibling-leadership-network-state-chapters.

The Arc

www.thearc.org

The Arc is the largest national community-based organization advocating for and serving people with intellectual and developmental disabilities and their families. The organization encompasses all ages and

all spectrums including autism, Down syndrome, Fragile X and various other developmental disabilities. To find a local or state chapter go to www.thearc.org/find-a-chapter.

United Cerebral Palsy (UCP)

www.ucp.org

UCP educates, advocates and provides support services to ensure a life without limits for people with a spectrum of disabilities. Contact the local UCP affiliate in your area at www.ucp.org/findaffiliate.

University Centers for Excellence in Developmental Disabilities (UCEDDs)

www.aucd.org

University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs) work nationally to ensure that individuals with disabilities participate fully in their communities. All UCEDDs have active advocacy and family support initiatives, and some have programs focused on family caregivers including respite options. For more information about the UCEDD in your state go to www.aucd.org/directory/directory.cfm?program=UCEDD.

Self-Advocacy Resources

Autistic Self Advocacy Network (ASAN)

autisticadvocacy.org

The Autistic Self Advocacy Network is a 501(c) (3) nonprofit organization run by and for Autistic people. ASAN was created to serve as a national grassroots disability rights organization for the Autistic community.

National Council of Self-Advocates of The Arc (NCSA)

www.thearc.org/self-advocates

NCSA is composed of individuals with I/DD who are members of The Arc either at the local, state or national level. The Research and Training Center on Community Living (RTC) at The University of Minnesota and The Arc have partnered to

support Self-Advocacy Online at <http://www.selfadvocacyonline.org>.

S.A.B.E. Self Advocates Becoming Empowered
www.sabeusa.org/meet-sabe

S.A.B.E is a national board of regional representatives and members from every state in the U.S. whose mission is to ensure that people with disabilities are treated as equals and that they are given the same decisions, choices, rights, responsibilities, and chances to speak up to empower themselves; opportunities to make new friends; and to learn from their mistakes. S.A.B.E. was also funded to establish the first national Self Advocacy Resource and Technical Assistance Center (SARTAC) at <http://www.selfadvocacyinfo.org> which includes the Self-Advocacy Online feature where self-advocates can find local self-advocacy groups at selfadvocacyonline.org/find.

Specific to Down Syndrome and Alzheimer's Disease

Alzheimer's Disease in People with Down Syndrome – Fact Sheet 2017 – <https://www.nia.nih.gov/health/alzheimers-disease-people-down-syndrome>

Alzheimer's Disease and Down Syndrome: A Practical Guidebook for Caregivers – <https://www.ndss.org/about-down-syndrome/publications/caregiver-guide-order-form>

Specific to Other Conditions

ARCH Fact Sheet: Respite for Individuals with Autism – archrespite.org/images/docs/Factsheets/FS_58_Autism_Respite.pdf

ARCH Fact Sheet: Respite for Families Caring for Children Who Are Medically Fragile – archrespite.org/images/docs/Factsheets/FS_11-MedicallyFragile.pdf

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