

archrespite.org

9 STEPS TO RESPITE CARE for Grandfamilies

A Pathway to Get the Break You Deserve

STEP 1 Understanding Respite Care

STEP 2 Types of Respite Care Available

STEP 3 Where Do I Find Services?

STEP 4 How Will I Pay for Respite?

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

STEP 6 Preparing My Family Member for Respite

STEP 7 Planning to Make the Most of Respite

STEP 8 Orienting Respite Providers

STEP 9 Find Out About Other Helpful Resources

If you are a grandparent or other relative caring for your grandchildren, nieces, nephews or other related children, you may be considered a “grandfamily.” The relationship between grandparents and grandchildren is often a very special one. For a growing number of grandparents, grandparenting really means full-time parenting for a second family.

As a grandparent or family member providing care for your grandchild or another child in your family, you may engage in multiple roles in supporting their development and overall quality of life and that includes being a caregiver. You are called a caregiver if you provide care or support for a child in your family, whether you help full-time or as time permits. Typically, caregivers are parents, but can include other family members, such as grandparents, aunts, uncles, or siblings who are providing care.

▶▶▶ **What is respite?** Respite is a temporary break from caregiving responsibilities, from taking care of the children in your home so that you can get a break, enjoy yourself, connect with friends and other family members, take care of your health issues, recharge your batteries, or just rest.

Undertaking the full-time responsibility for raising a grandchild or other relative causes major changes in one’s life. This new role often includes physical, emotional, social, legal and financial challenges that were not present when you raised your own children. Respite, a temporary break from the ongoing responsibilities of caregiving, can provide a much needed break from these responsibilities, giving time to balance caring for your grandchildren with caring for yourself.

Grandfamilies often face unique legal and financial challenges. Most grandparent and other relative caregivers step into the parenting role without legal custody or guardianship and may lack the necessary authority to consent to medical care, access education, or obtain larger, affordable housing to accommodate the new family members. The cost of raising children is also something that can cause a tremendous burden and financial

▶▶▶ The 2018 **Children Thrive in Grandfamilies** fact sheet by Generations United provides important data on how children in the care of relatives have positive experiences compared to children in non-relative care: grandfamilies.org/Portals/0/16-Children-Thrive-in-Grandfamilies.pdf



assistance is usually very limited. In addition, if your grandchild or other relative has a disability, they may have physical, emotional and behavioral conditions that require specialized care.

At times, you and members of your family may feel overwhelmed and stressed. As an older grandparent caregiver you may be dealing with your own physical and mental health concerns. It is easy to feel socially isolated when caring for children at a time in your life when you expected to be free of these responsibilities. 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.

Sometimes the tables are turned, and your grandchildren wind up taking care of you when your health fails or you face an unexpected emergency. There is help for them at the Caregiving Youth Project run by the American Association of Caregiving Youth. Resources can be found at aacy.org/what-we-do/caregiving-youth-project.

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 Tools*** at archrespite.org/consumer-information/lifecourse-tools-for-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 grandparent or family caregiver of a child in your family, 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 grandchild or family member may keep you from seeking respite in a timely way. Grandparents and relative caregivers 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, or in a residential setting. You can get a respite break through recreation and therapeutic recreation programs, and day and overnight camp programs.

Family members, friends or neighbors may also be available to provide informal respite opportunities. Take time to talk with family and friends, as they are an important part of your support network. Let them know your needs and ask if they can provide respite care so you can get a break.

Depending on your family needs, paid care may be provided by a community-based program, a local agency serving children, a home health agency, a disability organization such as Easterseals or The Arc, 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 grandfamilies, often utilizing volunteers from the congregation. Services may be free or offered on a sliding scale. Some respite service organizations support children within a specific age bracket or with specific conditions. In some cases, emergency respite services are available.

There are many community programs that might provide respite opportunities related to your specific interests and needs. Collaborative community options are offered through community agencies or organizations such as parks and recreation, cooperative extension, area agencies on aging, disability agencies, and programs serving children and youth. Step 3 provides more suggestions for exploring how you can meet your respite needs through community programs and activities.

Non-traditional or more informal respite services may provide volunteers or paid respite workers to accompany your grandchild to recreation, community or faith-based activities. Some grandfamilies build respite cooperatives coordinating caregivers to trade off providing respite services to one or more children at home or in the community.

STEP
3

Where Do I Find Services?

There are several ways to find respite for children. Some programs are for specific populations such as young children, teens, or children with disabilities or other specific needs. Below is an overview of places to contact regarding the respite services that are available in your community.

Respite Programs Serving Grandfamilies

You can access respite services through formal supports and paid services, consumer-directed respite, or informal supports such as community activities.

Respite voucher or cash assistance options may be available from state or local public and private agencies. Keep in mind that it may take time to find the respite options that will work best for you and your family.

- **Kinship Care Navigator Programs** assist grandparents and other relative caregivers get the support they need and serve as a “one stop shop” for relatives seeking information about benefits, services, supports and programs for

▶▶▶ [Visit *grandfamilies.org/State-Fact-Sheets*](https://www.grandfamilies.org/State-Fact-Sheets) and click on the fact sheet for your state to find programs and resources to help grandfamilies.



kinship caregivers. These programs are available in many states and they may provide information on respite resources and options. To find out if your state has a program, visit State Kinship Care Contacts and Programs at childwelfare.gov/organizations/?CWIGFunctionsaction=rols:main.dspList&rolType=Custom&RS_ID=148. If a state has Kinship Care Navigator program, it will be listed here as well.

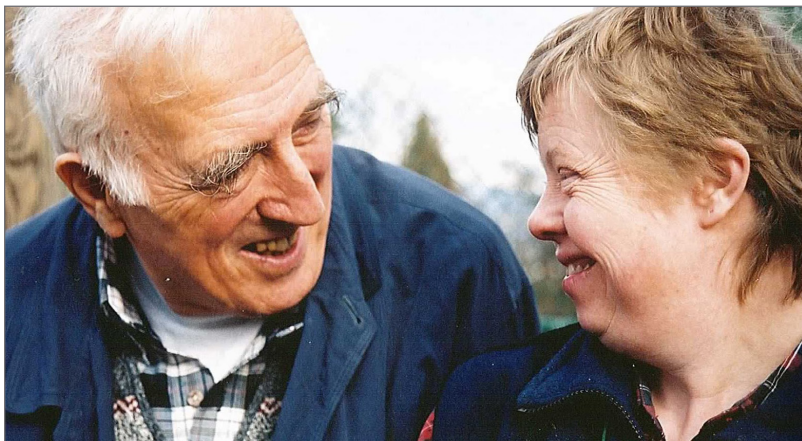
- The **Brookdale Foundation’s Relatives As Parents Program (RAPP)** provides support services, including respite opportunities, and other services in 47 states, the District of Columbia, and Puerto Rico. RAPPs support relative caregivers of all ages and may partner with community programs to provide respite or may directly offer respite opportunities such as providing child care during support group meetings so caregivers can attend. Some Area Agencies on Aging (AAAs) are part of the RAPP network and use their RAPP monies to reach relative caregivers who are under age 55, since the National Family Caregiver Program federal funds are limited to grandparents and other relatives age 55 and older. To find out if your state has RAPP services, check your state program listings at grandfamilies.org/State-Fact-Sheets.
- **Area Agencies on Aging (AAAs)** often provide respite for grandfamilies through the **National Family Caregiver Support Program (NFCSP)** or through state-funded initiatives for grandparents and relative caregivers. More information on the NFCSP and on state-funded initiatives is provided

in the next section. To find out if your local AAA provides respite services or supports, contact the Eldercare Locator at 1-800-677-1116 or eldercare.acl.gov.

- **Local Departments of Social Services** (child welfare agency) may offer “relative caregiver” services, benefits (e.g., TANF, SNAP), and other family support services. Be sure to check if you are eligible for any DSS services or benefits.
- **Respite services may be available in the private sector** in your state through community-based respite options specifically for grandfamilies, including school programs, afterschool activities, family fun nights, and day and overnight camp experiences designed for grandfamilies. There may also be **intergenerational community programs** involving family members of all ages, such as **Kinship Family Retreats**.
- **Informal supports** through neighbors and friends in your neighborhood or community might afford a respite break. Find community activities and services offered by community centers, parks and recreation, camp programs, YMCAs/YWCAs, arts and museum programs, libraries, social clubs, movie and book clubs with child care – and Big Brothers/Big Sisters, cooperative extension programs, faith-based organizations, service organizations and civic clubs, and university sponsored internships.
- **Grandfamily support groups** provide support and child care and a respite break for grandfamilies. Support groups also are a great place to ask other grandparents about local respite providers and opportunities. Check grandfamilies.org/State-Fact-Sheets for support group resources in your state.

Finding Respite for Children with Disabilities

If your grandchild has a disability or medical need, contact **disability agencies and programs** in your community. You may be able to access **case management** or **service coordination services** as



they may provide a path to accessing respite programs or funding for respite care. More information is provided below on strategies to find respite for your grandchild with a disability.

- **State-Funded Developmental Disabilities Respite Program:**

Many states have dedicated funds specifically for respite and other supports for children with intellectual and developmental disabilities. Contact your state disability agency for the most recent information at nasdds.org/state-agencies.

- **Early Intervention Services** for children under age three with certain disabilities or at-risk of disabilities are funded under Part C of the Individuals with Disabilities Education Act. While most state early intervention programs do not pay for respite, they may help you find services, especially if it is part of your Individualized Family Service Plan (IFSP). To find a local contact for your state's Part C Early Intervention Program, visit the Early Childhood Technical Assistance Center at ectacenter.org/contact/ptccoord.asp.

- **Community-based disability organizations**, such as **Easterseals**, provide child care, in-home care, and camp programs for children with disabilities. Find services in your state at easterseals.com/explore-resources/for-caregivers/respite-care.html. Other national disability and advocacy organizations 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 disability resources under Step 9.

- **Inclusive community activities** offered by schools, community centers, parks and recreation, YMCA/ YWCAs, arts programs, social clubs, faith-based organizations, camp programs, and others may afford you a break from caregiving.



Finding Respite in the General Population

These 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 lifespanspate.wildapricot.org/StateRegistries.

- **Home Care Agencies** may provide in-home respite for a child with a disability or special need. To find a home care agency, visit the National Association for Home Care & Hospice at agencylocator.nahc.org. If your grandchild 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. You can also hire privately from online home care registries, such as Rewarding Work (rewardingwork.org), CareLinx (carelinx.com) or Care.com (care.com).

STEP 4 **How Will I Pay for Respite?**

Caregivers can typically access respite opportunities through organizations and programs that receive funding to provide respite services in their local communities. Some caregivers may also find programs that provide stipends or vouchers where they receive funds to hire respite providers or purchase respite services on their own. It's important to determine the options that are available in your state and community. This section will help you explore respite funding and payment options.

In many cases, respite will be free, but time-limited. You may be required to pay a co-payment based on the child's needs and medical or disability status and financial information. Similarly, Medicaid respite is for caregivers of older adults or children or adults 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.

As discussed in Step 3 above, you should also explore informal options, such as assistance from family and friends and community activities or services that may be freely available and can provide you that much needed respite break.

Kinship Care Resources

As a grandparent or relative caregiver you may be able to apply for and receive various types of financial support through the child welfare system including public assistance, foster care payments, and adoption subsidies. This funding can help pay for informal and formal respite options for you and your family.

Grandparents and other relatives may be able to apply for public assistance for the children in their care as "**Caretaker Relatives**." The definition of "caretaker relative" varies from state to state, but generally is a category of individuals eligible for

public assistance because they are caring for a relative child who is living with them. The caregiver is not necessarily required to have legal custody of the child in their care to qualify.

Foster Care Payments may be available to relative caregivers who become licensed foster parents for the children in their care. Foster care payments are generally significantly higher than the financial support available from public assistance. However, the option to become a licensed



relative foster parent (often known as “**kinship foster care**”) is usually only available to caregivers of children who have come to the attention of the child welfare system. Children in kinship foster care are also in the legal custody of the child welfare agency, which has a host of other implications that must be carefully weighed by the family.

Adoption Assistance may be available to children who are in kinship foster care with relatives who then adopt them. Adoption assistance is available for children that the state or county determines cannot be adopted without adoption assistance. For more information go to nacac.org/help/adoption-assistance/adoption-assistance-us.

Subsidized Guardianship is another option for children who are in kinship foster care with relatives and for whom returning to their parents’ care or adoption are not viable. Many relatives, however, do choose to adopt the children in their care once they fully understand the legal, emotional and financial considerations of adoption. Most who adopt their relative children out of foster care qualify for adoption assistance payments. Some states have adoption subsidy funds to cover respite for qualifying adoptive families. Respite is generally not a formal part of an adoption subsidy agreement. These payments are often a critical source of support, but in some states, adoption or guardianship may mean the loss of access to critical services like respite. grandfamilies.org/Topics/Subsidized-Guardianship/Subsidized-Guardianship-Resources

Possible Public Funding Sources for Respite

Medicaid: If your grandchild has a disability or special medical need, they may qualify for a Medicaid home and community-based waiver. 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

▶▶▶ **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.



▶▶▶ The **Family First Prevention Services Act** was passed in February 2018 and provides federal funds that states may elect to use to help grandfamilies and kinship care families by 1) providing **prevention and support services** to families with children at risk of foster care (optional); 2) by requiring states to measure their family foster care licensing standards against model standards and improve their **licensing standards and process** to address barriers to licensing relatives who want to become licensed foster parents; and 3) by offering funds for state to establish or maintain **kinship navigator programs**. For more information read this article from **GRAND Magazine**, May/June 2018: nxtbook.com/nxtbooks/grand/20180506/index.php#/32

Medicaid office by visiting medicaiddirectors.org/about/medicaid-directors for details about eligibility and providers under the Medicaid state plan.

National Family Caregiver Support Program:

Funding may be available through the National Family Caregiver Support Program (NFCSP), which is administered through your local **Area Agency on Aging (AAA)**. Grandparent or other relatives age 55 or older caring for a grandchild may qualify for respite and other caregiver supports under this program. To find out if your local AAA provides respite services or funding options, contact the Eldercare Locator at 1-800-677-1116 or eldercare.acl.gov.

State Funded Programs for Grandfamilies:

Some states expand the eligibility for the federally funded National Family Caregiver Support Program to grandparents or relative caregivers under age 55. Your local Area Agency on Aging would have information about these programs as well.

State Funded Respite Programs for People with Disabilities:

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 check with your state disability agency.

Child Welfare/Child Abuse Prevention: Several federal programs allow states to use funds for respite for children at-risk or children with disabilities, and states do so with varying degrees.

- The **Community-Based Child Abuse Prevention Program (CBCAP)** (Title II of the Child Abuse Prevention and Treatment Act): A few states fund parenting education and support groups for kinship families, and respite and crisis nurseries for at-risk populations, through CBCAP. Respite is one of several core prevention services that are to be supported by the program. Eligible families are usually not involved with Child Protective Services. To find your state CBCAP lead agency visit: friendsnrc.org/contacts-and-assignments/state-contacts
- **Promoting Safe and Stable Families** (Title IV-B of the Social Security Act): State child welfare agencies are required to spend at least 20 percent of their funding on each of four categories of services: family support, family preservation, family reunification, and adoption promotion and supports. All of these categories permit funding for respite and/or crisis nursery services for which grandfamilies might be eligible, depending on their level of involvement with the child welfare system. For more information, contact your state child welfare agency at: childwelfare.gov/organizations

For additional information on federal funding sources to help you pay for respite, refer to **Summary Table of Federal Programs that Support Respite Care**: archrespite.org/images/Fed-Funding-Guide/Federal-Funding_Summary_Table.pdf

▶▶▶ **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-tested benefits, such as Supplemental Security Income (SSI) and Medicaid. The ABLE National Resource Center has more information: ablenrc.org/what-is-able/what-are-able-accounts

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 or home care agencies providing respite or find a respite provider through family or friends. If your grandchild has a disability, you may find services through a disability agency, such as Easterseals, The Arc or United Cerebral Palsy.

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 grandchild or 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 grandchild in the discussion if possible.
- Take time to explore respite options and decide what would work best; in-home or out-of-home care, after school care, child day care, community respite (e.g., therapeutic or inclusive recreation programs), or overnight care in a residential 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 grandchild would like to do while you are getting respite? Are there important considerations that need to be addressed so that your grandchild is comfortable?
- Make a list of questions to ask potential providers (see ideas on page 10).
- Create a checklist of important information you think the respite care provider needs to know about your grandchild, 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 Tools* at lifecoursetools.com/lifecourse-library/exploring-the-life-domains/respites. This resource can help family caregivers caring for children and adults 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 and discuss your family's expectations and these questions:

- How are the respite providers selected and trained?
- Are background checks performed?
- What type of training do the respite providers have? If needed, do the respite providers have training and/or experience with children who are separated from their parents or children with 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 receiving care?
- What hours and days are services available?
- If the provider will be driving your grandchild, 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 grandchild or 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 that your grandchild would be interested in and enjoy?

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 grandparents and the grandchildren in their care. Some children, 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 grandchildren who have recently moved into your home, or children with 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 grandchild or family member for the respite experience and enough time to plan for how it will occur.
- You, as the grandparent and family caregiver, have the primary responsibility for making the decision to access respite services. However, when it is possible, involving your grandchild in some aspects of respite service planning may help smooth the transition and assist in acceptance of respite care. Ways in which they 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 your grandchild’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 grandchild 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 of care. This also provides an opportunity to share up-to-date information or any changes in your grandchild’s needs.
- Consider hiring someone who already provides care for your grandchild or family member, such as staff from a recreation or after school program.
- To make the respite situation more comfortable for your grandchild, 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 time 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 special activities or weekend retreats for grandparents or family caregivers. Remember, your goal with respite is to take care of yourself, while ensuring your grandchild is safe and secure...so plan your respite time so that it is meaningful for you.

▶▶▶ Use this resource to help you plan for respite and make the most out of your respite break: *Time for Living and Caring: Making Respite Services Work for You* at archrespite.org/images/docs/Outside_Reports/Lund_TLCRespiteBrochure_2014.pdf



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 grandparent or family caregiver, are the primary point of contact.

Checklist for Information to Share with the Respite Provider

- ✓ Your contact information
- ✓ Your grandchild's preferences, likes and dislikes
- ✓ Information about preferences, special diets or food allergies, 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 your grandchild
- ✓ Tips for how to deal with any difficult behaviors that might be exhibited by your grandchild

Summarize key information in a packet so that the care provider can “grab and go” if they need to take your grandchild 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 grandchild or family member.

STEP
9

Find Out About Other Helpful Resources

Although being a grandparent or family 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](http://archrespite.org/consumer-information)

**Fact Sheet: Respite Services to Support
Grandfamilies** [archrespite.org/images/docs/
Factsheets/FS_45-Grandparents_Grandchildren.pdf](http://archrespite.org/images/docs/Factsheets/FS_45-Grandparents_Grandchildren.pdf)

Charting the LifeCourse Respite Tools
[lifecoursetools.com/lifecourse-library/exploring-
the-life-domains/respite](http://lifecoursetools.com/lifecourse-library/exploring-the-life-domains/respite)

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 at caregiveraction.org/family-caregiver-toolbox.

Family Caregiver Alliance provides caregiver resources and benefits by state at [caregiver.org/
connecting-caregivers/services-by-state](http://caregiver.org/connecting-caregivers/services-by-state). FCA also has the resource **Caregiving at Home: A Guide to**

Community Resources at [caregiver.org/caregiving-
home-guide-community-resources](http://caregiver.org/caregiving-home-guide-community-resources).

Specific to Grandfamilies and Relative Caregivers

Generations United

gu.org

The mission of Generations United is to improve the lives of children, youth, and older people through intergenerational collaboration, public policies, and programs for the enduring benefit of all. The National Center on Grandfamilies at Generations United promotes awareness of grandfamilies, grandparents, and other relatives raising children, and how to help meet the needs of these unique families at [gu.org/
explore-our-topics/grandfamilies](http://gu.org/explore-our-topics/grandfamilies).

►►► **Generations United** publishes an annual report that includes data on the number of children who live in grandfamilies and recommendations to help guide supportive policies and services. Each issue has a unique focus on a particular issues affecting grandfamilies. [gu.org/explore-our-topics/
grandfamilies/state-of-grandfamilies-in-america-annual-reports](http://gu.org/explore-our-topics/grandfamilies/state-of-grandfamilies-in-america-annual-reports)

GrandFacts: State Fact Sheets for Grandparents and Other Relatives Raising Children

grandfamilies.org/State-Fact-Sheets

GrandFacts provide valuable state-specific data, local program resources, benefits, and legal information.



GrandFamilies Guide

aarp.org/relationships/friends-family/info-08-2011/grandfamilies-guide-getting-started

The GrandFamilies Guide from AARP provides comprehensive information for grandparents and relative caregivers on legal issues, finances, work, housing and safety, health, education and child care, family challenges, and finding support.

Grandfamilies of America

grandfamiliesofamerica.org

Grandfamilies of America provides grandparents and relative caregivers with the necessary tools to navigate the complex government systems they encounter, as they try to provide safety and permanency for the children in their care, while at the same time protecting their family ties and heritage.

Grandparents Raising Grandchildren

raisingyourgrandchildren.com

This website is designed to help guide grandparents and other relatives (kinship parents) in their efforts to raise, parent, and educate these children and to find needed resources for the children as well as themselves.

Kinship Care Resource Kit

childrensdefense.org/wp-content/uploads/2018/08/kinship-care-resource-kit-helping-grandparents-relatives-raising-children.pdf

This resource kit from the Children's Defense Fund provides information for community and faith-based organizations and family caregivers.

Resources for Kinship Caregivers: Guides and Handbooks

childwelfare.gov/topics/outofhome/kinship/resourcesforcaregivers/guides

The Child Welfare Information Gateway provides an array of resources for grandparents and other relatives who are caring for children. The guides and handbooks provide information pertaining to financial assistance, legal assistance, health care, child care, finding support groups, trauma-informed parenting, and more. National, state, and local examples are included.

The Grandfamilies State Law and Policy Resource Center

grandfamilies.org

Grandfamilies.org is a collaboration among Generations United, The American Bar Association Center on Children and the Law, and Casey Family Programs. It serves as a national legal resource in support of grandfamilies within and outside the child welfare system.

Specific to Grandfamilies of Children with Disabilities

Autism Society

autism-society.org

The Autism Society is a national leader in serving people with autism and their families and has a national network of almost 100 affiliates dedicated to providing respectful and caring services. To find an affiliate in your state go to autism-society.org/about-the-autism-society/affiliate-network.



Easterseals

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. Programs include a variety of respite services for all ages, including in-home support and services, and camping and recreation opportunities. To find an Easterseals near you, visit easterseals.com/connect-locally.

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

familyvoices.org/ncfpp/f2fs

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 familyvoices.org/affiliates.

The Arc

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 thearc.org/find-a-chapter.

United Cerebral Palsy (UCP)

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 ucp.org/find-us.

Adapted by: Monica Uhl, M.A., Consultant

Layout: Norma McReynolds, Graphic Designer

Acknowledgements: ARCH would like to thank the following individuals for their very thoughtful and thorough review and their extremely helpful suggestions: Jaia Lent, Deputy Executive Director, Generations United, and Melinda Perez-Porter, Director, Relatives As Parents Program (RAPP), Brookdale Foundation Group. Connie Siskowski, American Association of Caregiving Youth provided important information about the Caregiving Youth Project. All of the reviewers serve on the ARCH National Advisory Committee to the 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.

This information is in the public domain. Readers are encouraged to copy and share it, but please credit the ARCH National Respite Network and Resource Center.

