

The Advocacy Ridge








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Respite Care

A Guide for Caregiving Families

How to Find Relief, Rest, and Support — Programs in Every State

Color-coded boxes tell you what is the same everywhere and what varies by state:

-  FEDERAL LAW — same in all 50 states
-  STATE VARIATIONS — laws differ; check your state
-  STRONGER STATE PROTECTIONS — some states give you more
-  ADVOCACY TIP — practical advice for parents
-  WATCH OUT — common pitfalls and risks
-  IMPORTANT NOTE — context and clarifications
-  STRATEGY — tactical guidance for due process

IMPORTANT NOTE

If you are the primary caregiver for a family member with a disability, this guide is for you. Caregiving is relentless work. It affects your health, your relationships, your ability to work, and your ability to be present. Respite — temporary, qualified care for your family member while you rest — is not a luxury. It is a necessity.

Respite is one of the most needed and least available supports for caregiving families. The programs exist. They are underfunded, often have waitlists, and many families don't know about them. This guide tells you where to look in every state.

There is no single national respite program. Respite is funded through a patchwork of Medicaid waivers, state programs, nonprofit organizations, and federal grants. The key is knowing all the doors — because if one is closed, another may be open.

ADVOCACY TIP

You do not need to be in crisis to ask for respite. The families who access respite are the ones who identified and applied for it before they needed it urgently.

Respite is not abandonment. Your family member getting quality care from a trained provider — while you recover — makes you a better caregiver.

The ARCH National Respite Locator is the single best starting point for finding respite in your area: archrespite.org/respitelocator — enter your zip code.

1. What Is Respite Care?

Respite care is temporary, qualified care provided to a person with a disability so that the primary caregiver can rest, attend to other responsibilities, or handle an emergency. Respite is about the caregiver — it acknowledges that you cannot give everything to your family member if you have nothing left.

Respite can look many different ways:

- In-home respite: A trained worker comes to your home and cares for your family member while you rest, run errands, attend appointments, or simply have time to yourself.
- Out-of-home respite: Your family member goes to a licensed respite facility, a respite host family, or a care center for a period of time — from a few hours to several days.
- Camp or recreational respite: Your family member attends a disability-inclusive camp or recreational program — providing enrichment for them and a break for you.
- Emergency/crisis respite: Unplanned care made available quickly when a family experiences a caregiving crisis — illness, family emergency, or caregiver burnout.

2. How Respite Is Funded — The Main Sources

Respite is not one program. It is funded through several different channels, and you may be eligible for more than one. Here are the main sources, from largest to smallest.

Source 1 — Medicaid Waiver Programs

If your family member is enrolled in a Medicaid HCBS waiver (see our separate Medicaid Waiver guide), respite care is almost certainly a covered service in that waiver. This is often the most substantial source of funded respite.

FEDERAL FRAMEWORK — Applies in ALL 50 States


Respite care is not mandated under IDEA. It is most commonly funded through Medicaid Home and Community-Based Services (HCBS) waivers and federal grant programs

such as the Lifespan Respite Care Act. Availability, eligibility, and amount vary significantly by state.

The amount of respite varies by waiver and by state — it may be expressed as hours per year, days per year, or a dollar amount in a self-directed budget.

If you are not enrolled in a Medicaid waiver but are on the waitlist: waiver respite is not available until you are enrolled. See the Medicaid Waiver guide for how to get on the waitlist.

IMPORTANT NOTE

 **EDGE CASE — Respite and FAPE:** In rare circumstances, an IEP team may determine that a caregiver support service — including something functionally similar to respite — is necessary for the student to receive FAPE, particularly where caregiver capacity directly affects the student's ability to access their educational program.

This is not common, is not guaranteed, and is not a substitute for Medicaid waiver or state program respite. It requires a specific, documented finding by the IEP team. If you believe this may apply to your situation, consult a qualified special education advocate or attorney.

WATCH OUT

In most states, immediate family members — parents of a minor child, spouses — cannot be paid as the waiver respite provider. However, grandparents, aunts, uncles, and other relatives CAN often be paid in many states. Ask your state DD agency about family member provider rules specifically.

Even if you're on the waiver waitlist and not yet enrolled, you may be eligible for other respite sources below. Don't wait for waiver enrollment to start looking.

Source 2 — State Lifespan Respite Programs

The federal Lifespan Respite Care Act funds grants to states to build statewide respite systems. Many states have used these grants to create respite programs that are available to families who are NOT enrolled in Medicaid waivers.

FEDERAL FRAMEWORK — Applies in ALL 50 States

Lifespan Respite Care Act (Public Law 109-442) provides federal grant funding to states for comprehensive respite care coordination.

These programs typically provide caregiver training, respite vouchers, and connections to local respite providers. Eligibility varies by state.

ARCH National Respite Network coordinates the national system: archrespite.org

STATE VARIATIONS — Laws Differ by State

California: Caregiver Resource Centers (CRCs) — statewide network providing respite and caregiver support. Find yours: caregivercalifornia.org

Texas: Texas Lifespan Respite Network — txrespite.org. Also HHSC respite through waivers.

Oregon: Oregon Lifespan Respite — oregonlifespan.org

Colorado: Colorado Lifespan Respite — cdhs.colorado.gov

Massachusetts: DDS Family Support Centers — mass.gov/dds

Pennsylvania: Family Support Program through ODP — dhs.pa.gov/odp

Illinois: Family Support Services through DHS — dhs.state.il.us

New Jersey: DDD Family Support Services — state.nj.us/humanservices/ddd

Michigan: MDHHS Caregiver Support Program — michigan.gov/mdhhs

Virginia: DBHDS Crisis Support and Respite — dbhds.virginia.gov

Minnesota: DHS Caregiver Support Program — mn.gov/dhs

Wisconsin: Family Support Program — dhs.wisconsin.gov

All states: Use the ARCH Respite Locator at archrespite.org/respitelocator — the most comprehensive tool for finding respite in your specific zip code regardless of state.

Source 3 — State DD Agency Family Support Programs

Many state DD agencies have family support programs specifically for families of people with developmental disabilities — separate from waiver enrollment. These programs sometimes include respite vouchers, caregiver stipends, or direct respite services.



ADVOCACY TIP

Contact your state DD agency and ask specifically: 'Is there a family support program that provides respite to families who are not yet enrolled in a waiver?' The answer varies by state but many states do have this — and families miss it because they don't ask.

Find your state DD agency: nasddd.org

In some states, family support funding has its own application and eligibility process completely separate from waiver enrollment. Apply for both.

Source 4 — Nonprofit Organizations

Many nonprofits provide respite directly or fund it for families. These are often the fastest-access option — no waitlist, low or no cost, though typically limited in hours.

- Easter Seals: Many local affiliates offer respite, day programs, and caregiver support. Find your affiliate: easterseals.com
- The Arc: Local Arc chapters in communities across the country offer respite and family support. thearc.org
- United Cerebral Palsy (UCP): UCP affiliates provide respite and family support in many communities. ucp.org
- Autism Speaks: Maintains a resource guide for respite and caregiver support: autismspeaks.org/resource-guide
- National Down Syndrome Society: Family support and respite resources: ndss.org
- Rare disease foundations: Many diagnosis-specific foundations fund respite. Search '[your child's diagnosis] family support' to find relevant organizations.

Source 5 — Military Families

If you are an active duty or veteran military family with a family member who has special needs, additional respite resources are available specifically for you.



FEDERAL FRAMEWORK — Applies in ALL 50 States

EFMP (Exceptional Family Member Program): Every military branch has an EFMP program that provides support services — including respite — for military families with members who have special needs. This is mandatory enrollment for qualifying family members, and services are free.

EFMP-A (Assistance): Connects families with respite, case management, and community resources at every installation.

Contact your installation's Family Support Center or EFMP coordinator to enroll and access services.



ADVOCACY TIP

Military families should register with EFMP as early as possible. Services and availability vary by installation — the EFMP coordinator at your base is the best starting point.

STOMP (Specialized Training of Military Parents): Federally funded parent training and advocacy for military families of children with disabilities: stompproject.org

Easter Seals Military and Veterans Services:
easterseals.com/our-programs/military-veterans

3. Finding Respite Right Now — Your Fastest Path

If you need respite today or soon, here are the steps in order of speed.

STEP 1 — Use the ARCH Respite Locator

Go to archrespite.org/respitelocator and enter your zip code. This is the most comprehensive national database of respite providers. It covers funded programs, nonprofit programs, and private providers in every state.

STEP 2 — Call 211

Dial 2-1-1 from any phone (in most states). This is the national social services helpline that connects callers with local resources including respite, caregiver support, and disability services. Available 24/7 in most areas.

STEP 3 — Contact your state DD agency

Ask: 'What respite resources are available for our family right now?' and 'Is there a family support program separate from the waiver waitlist?' Get the answer in writing. nasdds.org has the directory.

STEP 4 — Contact your local Arc or Easter Seals chapter

These organizations have community-level knowledge of what respite is actually available in your area, including programs that aren't well publicized. thearc.org and easterseals.com both have affiliate finders.

STEP 5 — If you are in crisis

If caregiving has become unsafe or you are at a breaking point, tell your state DD agency or your child's pediatrician immediately and use the word 'crisis.' Some states have emergency respite programs triggered by that specific word. You can also call 211 and say you are a caregiver in crisis.



ADVOCACY TIP

If someone tells you "there's no respite available," that usually means: not through that program, not right now, or not without further advocacy. There is almost always another door.

Keep asking. Try: 'What would need to be true for my family to qualify?' 'Is there a waitlist I can get on?' 'Is there a different program or fund?' 'Can you refer me to anyone else?' Every no is directional — it tells you which door to try next.

The ARCH National Respite Locator covers programs that aren't well-publicized: archrespite.org/respitelocator. Your state's P&A organization can help if you've been wrongly denied: ndrn.org

4. Employer-Assisted Respite and Other Overlooked Sources

Many families don't know about these additional sources. Not all will apply, but it's worth checking each one.

- **Employer Employee Assistance Programs (EAPs):** Many employers offer EAPs that include caregiver support, referrals, and sometimes direct financial assistance for respite. Check with your HR department — this resource is free and often completely unknown to employees.
- **Faith communities:** Many churches, mosques, synagogues, and faith-based organizations run respite programs or can organize volunteer respite for families in their community. Ask directly — many congregations want to help but don't know a family needs it.
- **University programs:** Some universities with programs in special education, occupational therapy, social work, or applied behavior analysis run supervised student practicum programs that include respite. Contact your nearest university's special education or ABA department.
- **Parent-to-parent respite exchanges:** Some communities have informal networks where families of children with similar disabilities take turns providing respite for each other. SPAN (Special Needs Advocacy Network) and local parent groups can connect you: span-parent-advocacy.org
- **PACE programs:** Programs of All-Inclusive Care for the Elderly (PACE) sometimes extend to younger adults with significant disabilities in some states. Ask your state Medicaid agency if PACE is available for your family member.

5. Links — Respite Resources

WATCH OUT

Respite funding is one of the first things cut during state budget shortfalls. Programs that exist today may have reduced hours or frozen enrollment next year. Apply for everything, use what you can, and always maintain a backup plan.

Private-pay respite can be expensive. However, for families with an ABLE account (see our Financial Planning guide), respite is a qualified disability expense that can be paid from ABLE funds without affecting SSI or Medicaid.

Resource	Where to Go
ARCH Respite Locator — find respite in your zip code	archrespite.org/respitelocator
ARCH National Respite Network	archrespite.org

Resource	Where to Go
2-1-1 Social services helpline	211.org or dial 2-1-1
Find your state DD agency	nasdds.org
Easter Seals affiliate finder	easterseals.com
The Arc chapter finder	thearc.org
Autism Speaks resource guide	autismspeaks.org/resource-guide
STOMP (military families)	stompproject.org
Texas Lifespan Respite Network	txrespite.org
Oregon Lifespan Respite	oregonlifespan.org
California Caregiver Resource Centers	caregivercalifornia.org
Free legal help if waiver services cut (P&As)	ndrn.org
ABLE accounts (pay for respite from savings)	ablenrc.org — see our Financial Planning guide
Medicaid waiver programs	See our Medicaid Waiver Programs guide

Need Advocacy Support?

The Advocacy Ridge is brought to you by experienced non-attorney special education advocates who work with families across multiple states.

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