Publicly Funded Respite Options for Caregivers in North Carolina

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NC DEPARTMENT OF **HEALTH AND HUMAN SERVICES**

Division of Aging and Adult Services

This document was originally developed in 2017 by a workgroup of the Lifespan Respite State Advisory Team to address one of the recommendations in the *North Carolina Lifespan Respite Strategic Plan: 2015-2020*. Subject matter experts from each publicly funded respite option included in the document reviewed their information and provided input before the document was finalized. The document was reviewed and updated by subject matter experts during July and August 2021.

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Publicly Funded Respite Options for Caregivers in North Carolina

What is respite?

Respite is defined as a break, an interval of rest or relief, from doing something that is difficult or challenging. For caregivers, respite provides a break from the ongoing responsibilities of providing care for a loved one, while at the same time ensuring that the loved one is receiving the care and attention he or she needs. The North Carolina Lifespan Respite State Advisory Team has endorsed the following definition:

Respite is a break for unpaid caregivers who provide ongoing care for an individual of any age who needs help, care, or supervision due to disability, chronic condition, or other special needs. Respite is intended to provide relief to the caregiver.

What are the benefits of respite?

While many find caregiving to be a rewarding experience, it may also lead to stress and strain and make it difficult for caregivers to carry out their other responsibilities. Quality respite care can offer many benefits, including:

- Giving caregivers time to:
 - o run errands such as shopping, banking, getting a haircut, or going to the doctor.
 - o spend time with family/friends, participate in community activities, or just relax.
- Reducing stress.
- Supporting family stability and preserving caregiver-care recipient relationships.
- Reducing caregiver burnout and delaying costly out-of-home placements.
- Preventing potential abuse and neglect.
- Providing care recipients with a break from their usual caregivers and an opportunity to interact socially with other caregivers or with peers in a group setting.
- Promoting health and well-being for both caregivers and care recipients.

Where is respite provided, and who provides it?

Respite services range from informal to formal and may be provided in a variety of different settings by different individuals. Respite care can be provided at home by:

- A friend.
- A neighbor.
- Another family member.
- A volunteer from a faith-based community or other community organization.
- A paid worker from an agency.

Respite may also be provided in a group care setting, such as a respite center, an adult day care/day health center or in a residential facility. Day or overnight camps and community caregivers' day out programs also provide group respite options.

How do you pay for respite services?

Many programs which provide respite receive public funding for their services and offer respite at no cost to the caregivers of eligible individuals. Some charge fees on a sliding scale based on a family's income. Other programs may be operated by faith communities or other non-profit organizations which receive funding from donations or other sources and train volunteers to provide respite. Many programs use a combination of funding sources to support their services.

Some programs offer consumer-directed respite by awarding respite vouchers to family caregivers. These vouchers can be used by families to purchase in-home or out-of-home respite services from providers of their choosing, including friends, family, agency workers, day care programs, or residential facilities.

This guide provides information about state and federal funding sources that may be available to cover the cost of respite or help you pay for respite if you or the individual you are caring for meet eligibility requirements. These services are organized into two sections:

- Publicly funded respite services for caregivers of children (pages 5-17)
- Publicly funded respite services for caregivers of adults (pages 19-43)

For each funding source, you will find a brief description as well as information about:

- Eligibility.
- Additional information about the program funded by that source.
- Cost to individuals or their caregivers.
- How to apply.
- Limits or barriers to using this funding source.
- How to get more information.
- What organization manages/administers the program.

If you or your care recipient do not meet the eligibility requirements for these publicly funded respite services, please note that many providers of these services accept private pay. See the section below for agencies that might be able to help you find private pay or volunteer respite services in your area.

How do you find respite services?

In addition to the contact information provided in this guide, you may also find the following to be helpful resources on respite options in your community:

- NC Lifespan Respite Project Voucher Program
- Area Agencies on Aging
- County Departments of Social Services
- Local Management Entities/Managed Care Organizations
- Private organizations such as <u>local chapters of The Arc</u>, <u>Easter Seals/UCP</u>, <u>National Multiple Sclerosis Society</u>, <u>Family Support Network of North Carolina</u>, <u>ALS Association</u>, <u>Alzheimer's Association</u>, <u>Dementia Alliance of North Carolina</u>, <u>First In Families</u>, <u>Autism Society of North Carolina</u>, <u>local chapters of NAMI</u>, <u>Brain Injury Association of NC</u>, and other disability- or aging-specific organizations.
- Faith communities

Where can I get more information about respite?

Check out the <u>ABC's of Respite: A Consumer Guide for Family Caregivers</u>, published by the ARCH National Respite Network and Resource Center.

Publicly Funded Respite Options for Caregivers of Children

Respite for Caregivers of Children with Complex Medical Conditions (birth the	rough 20)
Community Alternatives Program for Children (CAP/C)	page 7
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Respite for Caregivers of Children of All Ages with Special Needs	
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Community Alternatives Program for Children (CAP/C)

The Community Alternatives Program for Children (CAP/C) is a program for children zero through age 20 who have medically complex conditions and are at risk for having to live in a facility. CAP/C provides a variety of in-home support services to help these children stay at home with their families.

Respite services funded through CAP/C, which can be provided at home or in a facility, offer short-term relief to the primary unpaid caregiver by taking over the tasks of that person for a limited time. CAP/C respite services are available only to individuals who have been approved to participate in CAP/C.

CAP Consumer Direction is an option that allows a CAP/C beneficiary or designated representative to direct his or her care needs in a home and community-based setting. Consumer-direction offers the beneficiary choice and control over the types of services received, when and where the services are provided, and who provides the services.

Eligibility for CAP/C

Children between the ages of 0 and 20 years old who meet all the following criteria for a medically complex condition:

- A chronic physical primary diagnosis or condition
- A serious ongoing illness requiring prolonged or multiple hospitalizations, ongoing medical treatments, nursing interventions, or any combination of these that must be provided by a registered nurse or a medical doctor
- A need for life-sustaining devices or hands-on assistance to compensate for loss of bodily function or prevent deterioration

The child must also:

- Live in a private residence (children currently in a hospital or nursing facility may apply if they want to live at home).
- Meet a nursing facility level of care.
- Be at risk for institutionalization.
- Be eligible for Medicaid under the CAP/C waiver criteria.
- Be able to be cared for safely at home within the program's financial limitations.
- Have an emergency back-up and disaster recovery plan to maintain health, safety, and well-being.
- Have family members who are willing to actively participate in the child's care and care planning.

Additional information about the respite services under CAP/C

- Respite can be provided on a regularly scheduled or as-needed basis.
- Respite care can be provided in the child's home or in a facility licensed to provide the level of care needed by the individual.
- Respite time can be used for school days off, sick days or adverse weather days.
- Up to 720 hours per year can be used for respite. Families may use as much or as little of their approved respite time as they choose within the respite annual planning

period, provided they do not exceed their approved allotment by the end of the fiscal year.

Cost

 No cost to family. The costs of services are covered by Medicaid when the individual is approved to participate in CAP/C.

How to apply

There are many ways to apply for CAP/C services, including, but not limited to, the following:

- Contact a <u>CAP/C case management agency</u> in your county, your <u>county department of social services</u> or an in-home aide agency directly.
- Contact the Division of Health Benefits directly to complete a referral.
- If enrolled in a managed care plan, contact the assigned health plan.

Hospital staff, the child's medical provider, or a school nurse or counselor may also make a referral.

Limitations/barriers to use

- Respite funded through CAP/C is available only to CAP/C participants.
- The respite provider is not permitted to provide care for other family members.
- Once the annual (July through June) allotment of respite is used, there are no more hours available until the next year.
- Any respite hours not used at the end of the year are lost.

For more information

- Contact a <u>CAP/C case management agency.</u>
- Go to NC CAP/C webpage.
- Call NC Medicaid at 1-888-245-0179.

Program management/administration

NC Medicaid

Community-Based Child Abuse Prevention Respite Programs

The NC Division of Social Services (DSS) provides funding for 8 community-based programs which provide short-term respite to families with children ranging from birth to 18. These services are available in Alamance, Alleghany, Buncombe, Davie, Forsyth, Guilford, New Hanover, Orange, Stokes, Surry, Wake, Wayne, Wilkes, and Yadkin Counties.

Respite is defined as short-term care provided in the absence of a caregiver 1) to children in danger of or who have experienced child abuse and/or neglect or 2) to children with disabilities. The goal is to promote family well-being and enable the family to stay together and the children to remain in their home communities.

Eligibility for Community-Based Child Abuse Prevention Programs

Child from birth to 18 who:

- Is at risk of abuse or neglect due to poverty, domestic violence, substance abuse, young parental age, mental health concerns, and parental or child disabilities, etc.
- Does *not* have an open DSS case

Additional information about respite in Community-Based Child Abuse Prevention Programs

- Short-term care is provided within or outside of the child's home.
- Respite services vary from one agency to another and include crisis intervention, overnight respite, voucher-based respite, center-based care, and support groups for parents/caregivers and children.

Cost

No cost to families

How to apply

Access through the agency that is providing the service, including:

Caring for Children – Amy Hobson, amy.hobson@caring4children.org or 828-777-5715
Children's Center of Surry - Robin Beeson, robin@surrychildren.com or 336-386-9144
Coastal Horizons Center - Brianne Winterton, bwinterton@coastalhorizons.org or 910-392-7408
Exchange Club Alamance – Sarah Black, sarahblack@exchangefcp.org or 336-227-5601
Parenting Path- Elizabeth Miller- elizabeth.miller@parentingpath.org or 336-748-9028
Wake Human Services - Jason Mahoney, jason.mahoney@wakegov.com or 919-212-7238
Wayne Uplift - Shari Wooten, wuradvshelter@bellsouth.net or 919-736-1313
Youth Focus - Esther Ngo, engo@youthfocus.org or 336-375-1332

Limitations/barriers to use

There are only 8 sites across the state where these services are provided.

For more information

Contact Wendy Clewis, Program Consultant, at <u>wendy.clewis@dhhs.nc.gov</u> or 910-527-7254

Program management/administration

NC Division of Social Services, Child Welfare Services Section

Lifespan Respite Project

The purpose of the NC Lifespan Respite Project is to implement a statewide system of coordinated, community-based respite care for family caregivers of individuals of any age who need help, care, or supervision due to disability, chronic condition, or other special needs. The project has developed a statewide respite voucher program that reimburses eligible family caregivers for up to \$500 in respite care services each year the project is funded.

Eligibility for Lifespan Respite Voucher Program

Unpaid caregiver, age 18 or older, who is a North Carolina resident and provides care for a child or adult of any age with special needs, and who meets any of the following criteria:

- Is not eligible for any other respite services
- Has been approved for those services and is on a waiting list
- Has exhausted all available respite resources and is unable to pay privately

Priority is given to caregivers who have the greatest social and economic needs, have not had a recent respite break, and have no other ongoing publicly funded in-home assistance or other respite care, including adult day care. Applications not meeting these criteria will be considered if there are emergency or extenuating circumstances.

Additional information about respite through the Lifespan Respite Project

- Eligible families will be awarded up to \$500 annually in the form of a respite voucher.
- Respite is reimbursement-based.
- Caregivers can use voucher funds to purchase either in-home or out-of-home care or a combination. In-home care can be provided by a private individual or a licensed agency worker. Out-of-home respite includes residential facilities, adult day care, afterschool programs, day or overnight camps, and a variety of other options.

Cost

No cost to caregiver but reimbursement limited to the amount of voucher award

How to apply

- Families must be referred to the program by a referring agency.
- The referring agency verifies eligibility and screens for other potential respite resources.
- The referring agency completes the online application on behalf of the family caregiver. The application can be found on the website of the High Country Area Agency on Aging.

Limitations/barriers to use

- Voucher must be used for respite within 90 days of issue.
- Award is reimbursement-based. Family pays for the respite and is then reimbursed.

For more information

• Contact the Caregiver Coordinator at High Country Area Agency on Aging: lifespan@hccog.org or 828-264-3592.

Program management/administration

- NC Division of Aging and Adult Services
- High Country Area Agency on Aging

Family Caregiver Support Program

The National Family Caregiver Support Program provides grants to states to fund a range of supports that help unpaid family and unpaid informal caregivers care for their loved ones at home. Respite care is one of the services funded through this program.

Eligibility for Family Caregiver Support Program

Adult family members or other informal caregivers age 18 and older providing care to:

- Individuals 60 years of age and older with functional limitations or need for substantial supervision
- Individuals of any age with Alzheimer's disease or related dementias

Older relative caregivers include:

- A relative or parent who is 55 years of age of older, living with and raising an adult child (age 19-59) with a disability.
- A relative caregiver (that is not a parent) who is 55 years of age or older, living with and raising a relative child age 18 or under.

Additional information about respite through the Family Caregiver Support Program

- Respite services for caregivers of adults may be provided at home or in an adult day care or residential setting.
- Respite services for older relative caregivers caring for children may be provided at home, in a day care or residential setting, or in a structured day or overnight camp.

Cost

No cost to families, but voluntary contributions accepted

How to apply

 Contact your local <u>Area Agency on Aging</u> (AAA) and ask to speak with the Family Caregiver Support Specialist.

Limitations/barriers to use

- Each AAA has a set annual respite cap ranging from \$500 to \$2,000 per year per caregiver.
- The services that are available vary from county to county.

For more information

 Contact your local <u>Area Agency on Aging</u> (AAA) and ask to speak with the Family Caregiver Support Specialist.

Program management/administration

- NC Division of Aging and Adult Services
- Area Agencies on Aging

First In Families

First In Families of North Carolina is a family support program that serves individuals of all ages with developmental disabilities or traumatic brain injury and their families. Local chapters of First In Families work in partnership with families to find resources or services to meet the needs that the families have identified. The organization meets individual and family requests for support and assistance in various ways, including providing support to help families fund short-term respite services.

Eligibility for First In Families

- The family must have a family member with a developmental disability or delay, who is at risk of the same, or who has a traumatic brain injury
- Family income after taxes must be \$65,000 or less.
- The family/individual must live in a private home, not a licensed facility.

Additional information about First In Families

- First In Families of NC and its local Chapters define "family" very broadly. Any group of people who live together and consider themselves family are defined as family. Also, any eligible adult who lives on his/her own, with or without housemates, is considered a family.
- First In Families services all 100 counties in North Carolina.

Cost

No cost to families for the services

How to apply

- Call the state office of First In Families at 919-251-8368 to find contact information for local chapters, or go to http://fifnc.org/programs/chapters.html.
- Contact the local chapter to request an application for financial assistance.

Limitations/barriers to use

- Assistance is available only one time per year.
- Families must have or find their own respite providers. First In Families does not provide
 respite services but does provide funding to help families purchase short-term respite
 services.

For more information

Call the state office of First In Families at 919-251-8368 or go to http://www.fifnc.org/.

Program management/administration

First In Families of North Carolina and local chapters

Innovations Waiver

The NC Innovations Wavier is a resource for funding an array of services and supports for individuals with intellectual and other related developmental disabilities who are at risk for institutional care in an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF-IID). The NC Innovations Waiver is designed to promote choice, control, and community engagement.

Respite services available through the Innovations Waiver are designed to provide support and relief to the primary caregiver from the responsibility and stress of caring for the individual. The service enables the primary caregiver to participate in planned or emergency events and to have planned time for him/herself and/or other family members. **Respite services funded** through the Innovations Waiver are available only to individuals who have been approved to participate in the Waiver.

NC Innovations respite may be used to provide temporary relief to individuals who reside in licensed and unlicensed Alternative Family Living situations. This service enables the individual to receive periodic support and relief from the primary caregiver(s) at his/her choice.

The NC Innovations Waiver also offers Individual and Family-Directed Service options for self-directed care.

Eligibility for Innovations Waiver Services

Individuals with intellectual and developmental disabilities who are Medicaid eligible and meet all the following criteria:

- Live in an ICF-IID facility and wish to leave, or are at high risk of being placed in an ICF-IID facility
- Choose to participate in NC Innovations rather than live in an institution
- Need NC Innovations services, as specified in their person-centered Individual Support Plan, and must use at least one Innovations service other than respite monthly
- Can have their needs for health, safety and well-being met within the waiver cost limit
- Meet the requirements of ICF-IID level of care, which means:
 - Needing active treatment
 - Having a diagnosis of intellectual disability or closely related condition
 - Having a condition that is manifested before age 22 and is likely to continue indefinitely
 - Having substantial limitations in three or more of the following:
 - ✓ Self-care
 - ✓ Understanding/use of language
 - ✓ Learning
 - ✓ Mobility
 - ✓ Self-direction
 - ✓ Capacity for independent living

Additional Information about respite through the Innovations Waiver

 Respite may include in and out-of-home services, including overnight and weekend care and care during family emergencies.

- Respite includes transportation from the individual's residence to points of travel in the community (except for travel to/from school settings for individuals eligible for services through the Individuals with Disabilities Education Act).
- Respite may be used during school hours for sickness or injury, or when a student is suspended or expelled.
- The primary caregiver is defined as the person principally responsible for the individual's care and supervision and must maintain his/her primary residence at the same address as the individual.
- NC Innovations Respite may be used to provide temporary relief to individuals who live in licensed and unlicensed Alternative Family Living situations.
- NC Innovations Out-of-Home Crisis Services may be used as a planned respite stay for individuals who are unable to access regular respite due to the nature of their behaviors.

Cost

• No cost to participants. Medicaid covers the costs of services for individuals approved to participate in the Innovations Waiver.

How to apply

Contact your <u>Local Management Entity/Managed Care Organization (LME-MCO)</u>.

Limitations/barriers to use

- The limited number of waiver slots results in extremely long waiting lists for NC Innovations Waiver services. It could take many years before a slot becomes available to a person on the waiting list.
- For individuals who are eligible for services under the Individuals with Disabilities Education Act (IDEA), respite does not include transportation to/from school settings.
- Respite care cannot be provided by any person who resides in the individual's primary residence.
- Respite services are provided only for the NC Innovations participant. Other family members, such as siblings, may not receive care from the respite provider.
- Respite may not be used for individuals who are living alone or with a roommate.
- Staff sleep time is not reimbursable.
- The cost of 24 hours of respite care cannot exceed the per diem rate for the average community ICF-IID facility.

For more information

Contact your <u>Local Management Entity/Managed Care Organization (LME-MCO)</u>.

Program management/administration

- NC Division of Health Benefits
- LMEs-MCOs

Medicaid (b)(3) Respite Services

Medicaid (b)(3) services are additional supports for individuals who have Medicaid beyond the services specified in the Medicaid state plan. Medicaid (b)(3) services focus on helping individuals remain in their homes and communities and avoid hospitalization or living in an institution.

(b)(3) respite services provide periodic support and relief to the primary caregiver/s from the responsibility and stress of caring for children ages 3 to 21 with mental health, developmental disabilities, or substance use/addiction needs, and for adults age 21 and over with developmental disabilities.

Eligibility for Medicaid (b)(3) Respite Services

Individual who:

- Has Medicaid
- Is a child age 3 to 21 with mental health, intellectual/developmental disabilities, or substance use/addiction service needs, or an adult age 21 and over with intellectual/developmental disabilities
- Lives in non-licensed setting with an unpaid caregiver

The primary caregiver must maintain his/her primary residence at the same address as the individual.

Additional information about Medicaid (b)(3) Respite Services

- Respite may be used during school hours for sickness or injury.
- Respite may include in and out-of-home services, including overnight and weekend care
 or care based on a family emergency.
- Respite may be provided in an individual or group setting.

Cost

No cost to participants

How to apply

The individual or legally responsible person can:

- Request this service directly from a provider.
- Call the <u>Local Management Entity/Managed Care Organization (LME-MCO)</u> and ask to speak with an Access Coordinator who can provide basic information about Medicaid (b)(3) services and link the individual to a provider.

Limitations/barriers to use

- Medicaid (b)(3) services are subject to funding availability.
- Individuals on the Innovations Waiver are not eligible for (b)(3) Respite services.
- Medicaid (b)(3) respite is consistent with the NC Innovations waiver program definitions and limitations.
- Respite may not be provided by family members or anyone who lives in the individual's primary place of residence.
- Respite services are provided only for the individual, not for siblings or other family members needing care.
- Respite may not be used for individuals who are living alone or with a roommate.

- Staff sleep time is not reimbursable.
- For individuals who are eligible for educational services under the Individuals with Disabilities Education Act, respite does not include transportation to/from school settings.
- A maximum of 16 hours of respite can be provided in a 24-hour period. No more than 384 hours, or 24 days, of respite can be provided to an individual in a calendar year unless there is specific authorization for exceeding the limit.
- Individual respite cannot be provided for more than 10 consecutive days.

For more information

• Contact your Local Management Entity/Managed Care Organization (LME-MCO).

Program management/administration

- NC Division of Health Benefits
- LMEs-MCOs

<u>State-Funded Respite Services for Individuals with Mental Health,</u> Intellectual/Developmental Disabilities or Substance Use Disorders

Local Management Entities/Managed Care Organizations (LME-MCOs) have specifically allocated state funding available for services for individuals with mental health, intellectual and developmental disabilities and substance use disorders who are un-/underinsured. Respite services for caregivers of individuals in these disability groups *may* be covered, depending on the location.

Eligibility for State-Funded Services

Individuals who:

- Have a mental health or substance use diagnosis or a condition that may be defined as a developmental disability
- Meet level of care criteria specified in the applicable service definition

Additional information about State-Funded Respite Services

- State-funded respite services may be provided on either a planned or emergency basis and may include weekend care, emergency care, or continuous care up to 30 days.
- These services may be provided in a variety of locations, including homes and facilities.

Cost

- Eligibility for state-funded respite care for individuals with intellectual/developmental disabilities is *not* based on income.
- The service is provided at no cost to the individual or family. The provision of services is contingent upon funds availability.

How to access

Contact your <u>Local Management Entity/Managed Care Organization (LME-MCO)</u>.

Limitations/barriers to use

- Options for respite services may vary by county and from one LME-MCO to another.
- State-funded services depend on availability of funds; there may be a waiting list for some services.

For more information

Contact your Local Management Entity/Managed Care Organization (LME-MCO).

Program management/administration

LMEs-MCOs

Publicly Funded Respite Options for Caregivers of Adults

Respite for Caregivers of Older Adults (older adults defined as 60 +)
Family Caregiver Support Program page 21
Respite services for older adults funded through the Home and Community Care Block Grant (The Home and Community Care Block Grant [HCCBG] funds a range of services primarily for at-risk adults age 60 and over. Local groups make the decisions about what HCCBG-funded services are most needed by older adults in their county, how much of the county's HCCBG funding will be allocated to these services, and which agencies will provide the services. There are other funding sources included in this document that may support these service options for individuals under age 60.)
In-Home Aide Respite
Respite for Caregivers of Adults with Alzheimer's Disease and Related Dementias (all ages)
Community Alternatives Program for Disabled Adults (CAP/DA)page 27
Family Caregiver Support Program page 21
Project C.A.R.E. (Caregiver Alternatives to Running on Empty) page 29
Respite for Caregivers of Older Adults or Adults with Disabilities.
Community Alternatives Program for Disabled Adults (CAP/DA)page 27 (age 18+)
Family Caregiver Support Program page 21
PACEProgram of All-Inclusive Care for the Elderlypage 30 (age 55+)
State/County Special Assistance In-Home Program for Adults
Respite for Caregivers of Veterans
VA Respite Program page 32
VA Program of Comprehensive Assistance to Family Caregivers page 33
Respite for Caregivers of Adults of All Ages
Lifespan Respite Projectpage 34

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Respite for Caregivers of Adults with Intellectual/Developmental D	isabilities (I/DD)
Family Caregiver Support Program	page 21
First In Families(also includes caregivers of adults with traumatic brain injury)	page 35
Innovations Waiver	page 36
Lifespan Respite Project	page 34
Medicaid (b)(3) Respite	page 38
State-Funded Respite	page 40
Respite for Caregivers of Adults with I/DD <u>and</u> Mental Illness or Ch	allenging Behaviors
NC START (age 18+)	page 41
Respite for Caregivers of Individuals in Hospice Care	
Medicare and Medicaid Hospice Benefit	page 43

Family Caregiver Support Program

The National Family Caregiver Support Program provides grants to states to fund a range of supports that help unpaid family and unpaid informal caregivers care for their loved ones at home. Respite care is one of the services funded through this program.

Eligibility for Family Caregiver Support Program

Adult family members or other informal caregivers age 18 and older providing care to:

- Individuals 60 years of age and older with functional limitations or need for substantial supervision
- Individuals of any age with Alzheimer's disease or related dementias

Older relative caregivers include:

- A relative or parent who is 55 years of age of older, living with and raising an adult child (age 19-59) with a disability.
- A relative caregiver (that is not a parent) who is 55 years of age or older, living with and raising a relative child age 18 or under.

Additional information about respite through the Family Caregiver Support Program

- Respite services for caregivers of adults may be provided at home or in an adult day care or residential setting.
- Respite services for older relative caregivers caring for children may be provided at home, in a day care or residential setting, or in a structured day or overnight camp.

Cost

No cost to families, but voluntary contributions accepted

How to apply

 Contact your local <u>Area Agency on Aging</u> (AAA) and ask to speak with the Family Caregiver Support Specialist.

Limitations/barriers to use

- Each AAA has a set annual respite cap ranging from \$500 to \$2,000 per year per caregiver.
- The services that are available vary from county to county.

For more information

 Contact your local <u>Area Agency on Aging</u> (AAA) and ask to speak with the Family Caregiver Support Specialist.

Program management/administration

- NC Division of Aging and Adult Services
- Area Agencies on Aging

In-Home Aide Respite (funded through Home and Community Care Block Grant)

In-Home Aide Services assist the individual and/or family with essential home management and/or personal care tasks to help them remain at home and function effectively there for as long as possible. In-Home Aide Services also may be used to provide respite for the primary caregiver. Respite is defined as a component of In-Home Aide Services which provides needed relief to the primary caregivers of eligible individuals.

Eligibility for In-Home Aide Respite

Adults age 60 or older who meet all the following criteria:

- Live at home
- Have home management and/or personal care needs and require help with these tasks to remain at home
- Have a primary caregiver who needs relief
- Require constant supervision
- Cannot be left alone either because of memory impairment, physical immobility, or other problems that render them unsafe alone

Additional information about In-Home Aide Respite

- In-Home Aide Respite Care Services may be provided to an individual in his/her own home or in the home of the primary caregiver.
- In-Home Aide Services are available at four levels of complexity and in two areas of specialization: Home Management and Personal Care.
- Respite Care may consist of any level of home management or personal care tasks.

Cost

No cost to caregivers, but voluntary contributions accepted

How to apply

• Contact your local <u>Area Agency on Aging</u> to find out if In-Home Aide Respite Services are available in your area.

Limitations/barriers to use

- The type and level of In-Home Aide Services vary from county to county.
- Not all counties include the respite care component.

For more information

- Contact Lorrie Roth (<u>lorrie.roth@dhhs.nc.gov</u> or 919-855-4986), Glenda Artis (<u>glenda.artis@dhhs.nc.gov</u> or 919-855-3412) or Mary Jo Littlewood (<u>maryjo.littlewood@dhhs.nc.gov</u> or 919-855-3420).
- Go to the Division of Aging and Adult Services web page on <u>In-Home Aides</u>.

Program management/administration:

- NC Division of Aging and Adult Services
- Area Agencies on Aging

Group Respite (funded through Home and Community Care Block Grant)

Group respite provides temporary relief to family members and other unpaid primary caregivers caring for an individual with physical and/or cognitive limitations living at home. The care is provided in a safe setting where caregivers can bring their care recipients who do not require hands-on care while in attendance at the program. Group respite programs offer participants opportunities for socialization and activities and can also provide information about resources.

Eligibility for Group Respite

Adults age 60 and older who:

- Need supervision
- Have a caregiver
- Can communicate (although not necessarily verbalize) personal needs
- Have either of the following:
 - Physical conditions that are medically stable and do not require hands-on personal care assistance or intervention while at the program
 - Cognitive impairment or behaviors which can be managed through redirection, distraction, and reassurance

Additional information about Group Respite

• The program operates on a scheduled basis for a minimum of one day a week for at least three continuous hours. The program may be open for up to six continuous hours per day but for no more than four days a week.

Cost

No cost to caregivers, but voluntary contributions accepted

How to apply

• Contact your local Area Agency on Aging to see if this service is funded in your region.

Limitations/barriers to use

- No hands-on personal care (e.g., assistance with toileting or feeding) may be provided to participants during group respite.
- HCCBG-funded Group Respite is not widely available throughout the state.

For more information

- Contact your local <u>Area Agency on Aging</u>.
- Contact Heather Carter, the statewide Program Consultant for this service, at heather.carter@dhhs.nc.gov or 919-855-3416.

Program management/administration

- NC Division of Aging and Adult Services
- Area Agencies on Aging

Institutional Respite (funded through Home and Community Care Block Grant)

Institutional Respite Care is temporary placement in an institutional setting of an individual who requires constant care and/or supervision out of his/her home to provide the primary, unpaid caregiver temporary relief from caregiving responsibilities.

Eligibility for Institutional Respite

Adults age 60 and older who:

- Have an unpaid caregiver
- Require constant supervision
- Cannot be left alone either because of memory impairment, physical immobility, or other problems that render them unsafe alone

Additional information about Institutional Respite

Institutional Respite Care Service may be provided in the following locations only:

- Certified Adult Day/Health Care Facility
- Licensed Domiciliary Care Facility (such as family care home or assisted living facility)
- Licensed Nursing Facility
- Licensed hospital

Cost

- No cost to caregivers
- Voluntary contributions accepted

How to apply

 Contact your local <u>Area Agency on Aging</u> to see if this service is funded in the region where you live.

Limitations/barriers to use

• HCCBG-funded Institutional Respite is not widely available throughout the state.

For more information

- Contact your local <u>Area Agency on Aging</u>.
- Contact Heather Carter, the statewide Program Consultant for this service, at heather.carter@dhhs.nc.gov or 919-855-3416.

Program management/administration

- NC Division of Aging and Adult Services
- Area Agencies on Aging

Adult Day Care/Adult Day Health Services

(funded through Home and Community Care Block Grant)

Adult Day Care/Adult Day Health services are provided in a community group setting during the day for adults with cognitive and/or physical impairments who require supervision. These services promote social, physical, and emotional well-being and offer a variety of activities designed to meet the needs of each participant. One of the purposes of Adult Day Services is to support primary caregivers by providing respite and/or the ability to work.

Eligibility for HCCBG-Funded Adult Day Care/Day Health Services*

Adults who:

- Are age 60 and older
- Have cognitive and/or physical impairments which prohibit them from living independently in the community without supportive services
- Require supervision
- Are not able to perform at least two activities of daily living (eating dressing, toileting, bathing, mobility) without substantial assistance, including verbal reminding, physical cueing, or supervision, OR due to a cognitive or other mental impairment, require substantial supervision because they behave in a manner that poses a serious health or safety hazard to themselves or others

In addition to the requirements listed above, eligibility for Adult Day Health Services requires one of the following during hours of attendance at the day health program:

- Monitoring of a medical condition
- Provision of assistance with or supervision of activities of daily living
- Administration of medication, special feedings, or provision of other treatment or services related to health care needs

Additional Information about Adult Day Care/Day Health Services

- Transportation is an optional service the provider may choose to offer to participants.
- Medical examinations are required for admission and every year thereafter for participants to attend the program.
- The program includes a nutritious mid-day meal that meets 1/3 of an adult's daily nutritional requirement and two snacks per day.

Cost

No cost to participants for HCCBG-funded services, but voluntary contributions accepted

How to apply

- Go to <u>NC Adult Day Care/Adult Day Health Programs</u> to see whether there is a certified adult day care/adult day health program in your area.
- Contact your Area Agency on Aging or county department of social services.

Limitations/barriers to use

- Adult Day Care/Adult Day Health Services are not available in every county.
- Not all persons interested in the service will be eligible for HCCBG-funded attendance.
 See note below.

For more information

Contact any of the following:

- Your county department of social services
- Your Area Agency on Aging
- Heather Carter (<u>heather.carter@dhhs.nc.gov</u> or 919-855-3416) or Glenda Artis (<u>glenda.artis@dhhs.nc.gov</u> or 919-855-3412) at the NC Division of Aging and Adult Services.

Program management/administration

- NC Division of Aging and Adult Services
- County departments of social services
- Local departments of health for programs providing health services

*In addition to HCCBG funding for adult day care/day health services for adults 60 and older, there are other public funding sources for adult day services that may support individuals 18 and over. These include the State Adult Day Care Fund, the Veteran's Administration, the Community Alternatives Program for Disabled Adults (CAP-DA) and the Innovations Waiver.

Community Alternatives Program for Disabled Adults

The Community Alternatives Program for Disabled Adults (CAP/DA) provides an array of home and community-based services to older adults or adults with disabilities who are risk for institutionalization but want to remain at home. Services which can be provided through CAP/DA include both institutional and non-institutional respite. **Respite services funded through CAP/DA are available only for individuals who have been approved to participate in CAP/DA.**

CAP Consumer Direction is an option that allows an individual or designated representative to direct his or her care needs in a home and community-based setting. Consumer-direction offers the beneficiary choice and control over the types of services received, when and where the services are provided, and who provides the services.

Eligibility for CAP/DA

Adults who meet all the following criteria:

- Are 18 years of age and older
- Are eligible for Medicaid in the categories of Aged, Blind, or Disabled
- Live in a private residence (may be living in facility at time of application and screening, but must be discharged to a private residence before receiving services)
- Require nursing facility level of care
- Are at risk of institutionalization within 30 calendar days
- Choose CAP/DA services instead of institutional care
- Require long-term support at a level typically provided in an institution such as a nursing facility
- Can have their health, safety and well-being maintained at home with CAP/DA services
- Need services directly related to a documented medical diagnosis and identified medical care need to avoid institutionalization

CAP Consumer Direction is an option for individuals who:

- Understand the rights and responsibilities of directing one's own care.
- Are willing and able to assume the responsibilities of self-directed care or select a representative who is willing and able to direct the individual's care.
- Have an emergency back-up plan.

Additional information about respite through CAP/DA

- Institutional respite care is provided in a certified nursing facility or a hospital.
- Non-institutional respite services are provided in the individual's home by a personal care aide working through a licensed homecare agency.
- Adults who participate in CAP Consumer-Direction can hire respite workers who are not working through a licensed homecare agency, within the requirements of the Consumer- Direction program.
- There are some CAP/DA slots in each area designated for individuals with Alzheimer's disease or related dementias.

Cost

• No cost to individual or caregiver. Medicaid covers the costs of services for individuals who are approved to participate in CAP/DA.

How to apply

• Contact the <u>CAP/DA Lead Agency</u> in your county.

Limitations/barriers to use

• The combined use of both Institutional Respite Care and Non-Institutional Respite Care cannot exceed 30 calendar days, or 720 hours, in one fiscal year.

For more information

• Contact the <u>CAP/DA Lead Agency</u> in your county.

Program management/administration

• NC Division of Health Benefits

Project C.A.R.E. (Caregiver Alternatives to Running on Empty)

Project C.A.R.E. is a state-funded, dementia-specific support for caregivers of persons with Alzheimer's disease or related dementia (ADRD). The program uses a care consultation model providing caregiving and dementia specific education, information and referral services, and care consultation (caregiver assessment and care planning). Respite care vouchers may be awarded to eligible care consultation clients dependent upon available funding.

Eligibility for Project C.A.R.E. Care Consultation and Respite

- Caregiver must be unpaid primary caregiver, age 18 years or older, who can benefit from care consultation.
- Care recipient has been diagnosed with ADRD by a health care provider.
- Priority will be given to those who are underserved and with the greatest social and economic needs and who have not received respite from any other source of funding.
- Individuals who are on a waiting list for Medicaid-funded respite services may be eligible during their waiting period.

Additional information about respite through Project C.A.R.E.

Vouchers may be available for care consultation clients who need financial assistance to pay for the respite.

- Families can receive up to three \$500 respite vouchers per year in conjunction with care consultation.
- Respite is reimbursement-based and time-limited (generally must be used within 90 days of award).
- Respite can be provided in-home, in adult day care or group respite program, or in a facility.
- Family-centered approach allows families to choose provider best suited to their situation.

Cost

No cost to caregivers, but reimbursement limited by the amount of voucher award

How to apply

• Contact a regional Project C.A.R.E. Family Consultant. To find the Family Consultant for your region, go to https://www.ncdhhs.gov/assistance/adult-services/project-care.

Limitations/barriers to use

- Respite funding availability may fluctuate.
- Funding cannot duplicate or replace existing supports through other funding sources.

For more information

- Call Dawn Oakey Gartman, Project C.A.R.E. State Director, at 919-855-3462.
- Contact Caregiver Navigator at 844-728-0191 (toll free) or <u>DHHS.caregiver@dhhs.nc.gov</u>.

Program management/administration

NC Division of Aging and Adult Services

Program of All-Inclusive Care for the Elderly (PACE)

PACE programs provide comprehensive care for older adults who are at a nursing home level of care but wish to remain in their own homes and communities. PACE participants receive all their care through the program, including medical care, needed therapies, home care aide services, adult day care, prescription medications, facility-based services when necessary, and other needed services. Respite services also are available for PACE participants.

Eligibility for PACE

- Be age 55 or over
- Meet the state's nursing home level of care criteria
- Be able to live safely in the community at the time of enrollment
- Live in an approved PACE service area

Additional information about respite services through PACE

• Respite may be provided in the individual's home or in a facility.

Cost

- Most PACE participants have both Medicare and Medicaid, which together cover the cost of all services.
- The PACE program will help individuals complete applications for Medicaid.
- Individuals who do not qualify for Medicaid may be able to enroll by paying part or all the cost privately.
- Participants may be fully and personally liable for the cost of unauthorized or out-of-PACE program agreement services.

How to apply

Contact the PACE organization in your area at the following link:
 NC PACE Organizations - Service Areas and Contacts

Limitations/barriers to use

• The individual must live in an approved service area served by a PACE organization. Not all parts of the state are covered.

For more information

Contact the PACE organization in your area at the following link:
 NC PACE Organizations - Service Areas and Contacts

Program management/administration

NC Medicaid/Division of Health Benefits

State/County Special Assistance In-Home Program for Adults

The Special Assistance In-Home Program offers ongoing case management and monthly cash payments to help individuals live at home safely. The program can help with living expenses such as food, shelter, clothing and other daily necessities. Special Assistance In-Home funding can also be used to pay for respite care.

Eligibility for State/County Special Assistance In-Home Program

Adults who meet the following eligibility criteria:

- Are age 65 or older, or who are age 18 through 64 and have been determined to be disabled according to Social Security disability standards
- Can have their health, safety, and well-being maintained at home with appropriate services
- Need adult care home level of care but want to live at home
- Are a US citizen or qualified alien and a resident of NC
- Have Medicaid categorically needy eligibility established
- Meet income and asset eligibility requirements
- Meet all other Special Assistance eligibility requirements

Additional information about State/County Special Assistance In-Home Program

- Assistance payments are provided monthly.
- The social work case manager conducts a comprehensive assessment and works with the individual to determine what is needed. The economic assessment and plan of care, agreed upon by the individual, states how the monthly payment will be used.
- The social work case manager closely monitors the needs of the individual, including the effective use of the Special Assistance In-Home payment.

Cost

No cost to participants

How to apply

Apply at your <u>county department of social services</u>.

Limitations/barriers to use

Some counties may have a waiting list for the Special Assistance In-Home Program.

For more information

Contact your <u>county department of social services</u>.

Program management/administration

The State/County Special Assistance In-Home Program is supervised by the NC Division of Aging and Adult Services. The county departments of social services administer the program.

VA Respite Program

The VA Respite Program is part of the Veterans Health Administration Standard Medical Benefits Package. All enrolled Veterans are eligible if they meet the clinical need for the service. Family caregivers of eligible Veterans can receive up to 30 days of respite care per year.

Eligibility for VA Respite Program

The Veteran:

- Has a diagnosed chronic disabling illness or condition.
- Lives at home and requires substantial assistance in Activities of Daily Living.
- Has a Caregiver who needs temporary or intermittent relief from ongoing care tasks.

The Veteran must also meet the eligibility criteria for nursing home and long-term care, as well as the following clinical criteria:

- Dependence in 3 or more ADLS or significant cognitive impairment
- Two or more of the following conditions:
 - o Dependence in 3 or more Instrumental Activities of Daily Living
 - Recent discharge from a nursing home
 - Age 75 years or older
 - Identified as a high utilizer of medical services
 - Clinical depression

Additional information about the VA Respite Program

- Respite care can be offered in a variety of settings, including at home or through temporary placement at a VA Community Living Center, a VA-contracted Community Residential Care Facility, or an Adult Day Health Care Center. In-home respite services are provided through a VA-approved contract agency.
- Respite Care can be used in combination with other Home and Community Services.

Cost

• A copay may be charged based on VA service-connected disability status and financial information.

How to apply

 Veterans/caregivers should contact their Patient-Aligned Care Team (PACT) or Social Worker to request respite.

Limitations/barriers to use

- Veterans must have an established primary care provider at the VA to be eligible.
- Available services may vary by location.

For more information

• Contact the Veteran's VA Social Worker.

Program management/administration

• US Department of Veterans Affairs

VA Program of Comprehensive Assistance to Family Caregivers

The VA Program of Comprehensive Assistance to Family Caregivers (PCAFC) offers enhanced support for family caregivers of eligible Veterans who are seriously injured. Eligible Family Caregivers may qualify to receive a monthly stipend as well as other resources and benefits. If enrolled in PCAFC, they are eligible for respite services above and beyond what is available through the standard VA Respite Program.

Eligibility for PCAFC

- Veterans may be eligible for this program if they sustained or aggravated a serious injury (including serious illness) in the line of duty on or before May 7, 1975 or on or after September 11, 2001 and meet both of the following criteria:
 - Have a single or combined service disability rating of 70%
 - o Require in-person personal care services for a minimum of 6 consecutive months
- Family Caregivers must:
 - Be at least 18 years of age.
 - Be a member of the Veteran's immediate or extended family or stepfamily, or someone who will live with the Veteran full time if designated as Family Caregiver.
 - Be assessed by the VA as able to complete caregiver education and training.
 - o Complete caregiver training and demonstrate needed care competencies.
 - Have no determination of abuse or neglect of the eligible caregiver.

Additional information about respite through PCAFC

Eligible family caregivers are eligible for at least 30 days of respite per year.

Cost

There is no cost for respite through this program.

How to apply

- Both the caregiver and the Veteran need to apply together to determine eligibility.
 - Download <u>VA Form 10-10CG</u>. Submit the application and any supporting documents by mail as directed on the form, OR
 - Bring your completed form to the Caregiver Support Coordinator at your local Veterans Affairs Medical Center. To find the name of your Caregiver Support Coordinator, call the Caregiver Support Line at 855-260-3274 or go to the VA Caregiver Support Coordinator Directory.

Limitations/barriers to use

Respite services through PCAFC are available only to enrolled Family Caregivers.

For more information

Contact your local Caregiver Support Coordinator. See contact information above.

Program management/administration

US Department of Veterans Affairs

Lifespan Respite Project

The purpose of the NC Lifespan Respite Project is to implement a statewide system of coordinated, community-based respite care for family caregivers of individuals of any age who need help, care or supervision due to disability, chronic condition, or other special needs. The project has developed a statewide respite voucher program that reimburses eligible family caregivers for up to \$500 in respite care services each year the project is funded.

Eligibility for Lifespan Respite Voucher Program

Unpaid caregiver, age 18 or older, who is a North Carolina resident and provides care for a child or adult of any age with special needs, and who meets any of the following criteria:

- Is not eligible for any other respite services
- Has been approved for those services and is on a waiting list
- Has exhausted all available respite resources and is unable to pay privately

Priority is given to caregivers who have the greatest social and economic needs, have not had a recent respite break, and have no other ongoing publicly funded in-home assistance or other respite care, including adult day care. Applications not meeting these criteria will be considered if there are emergency or extenuating circumstances.

Additional information about respite through the Lifespan Respite Project

- Eligible families will be awarded up to \$500 annually in the form of a respite voucher.
- Respite is reimbursement-based.
- Caregivers can use voucher funds to purchase either in-home or out-of-home care or a
 combination. In-home care can be provided by a private individual or a licensed agency
 worker. Out-of-home respite includes residential facilities, adult day care, afterschool
 programs, day or overnight camps, and a variety of other options.

Cost

No cost to caregiver, but reimbursement limited to the amount of voucher award

How to apply

- Families must be referred to the program by a referring agency.
- The referring agency verifies eligibility and screens for other potential respite resources.
- The referring agency completes the online application on behalf of the family caregiver. The application can be found on the website of the High Country Area Agency on Aging.

Limitations/barriers to use

- Voucher must be used for respite within 90 days of issue.
- Award is reimbursement-based. Family pays for the respite and is then reimbursed.

For more information

• Contact the Caregiver Coordinator at High Country Area Agency on Aging: lifespan@hccog.org or 828-264-3592

Program management/administration

- NC Division of Aging and Adult Services
- High Country Area Agency on Aging

INFORMATION LAST UPDATED: AUGUST 2021

First In Families

First In Families of North Carolina is a family support program that serves individuals of all ages with developmental disabilities or traumatic brain injury and their families. Local chapters of First In Families work in partnership with families to find resources or services to meet the needs that the families have identified. The organization meets individual and family requests for support and assistance in various ways, including providing support to help families fund short term respite services.

Eligibility for First In Families

- The family must have a family member with a developmental disability or delay, who is at risk of the same, or who has a traumatic brain injury.
- Family income after taxes must be \$65,000 or less.
- The family/individual must live in a private home, not a licensed facility.

Additional information about First In Families

- First In Families of NC and its local Chapters define "family" very broadly. Any group of people who live together and consider themselves family are defined as family. Also, any eligible adult who lives on his/her own, with or without housemates, is considered a family.
- First In Families services all 100 counties in North Carolina.

Cost

No cost to families for the services

How to apply

 Call the state office of First In Families at 919-251-8368 to find contact information for local chapters, or go to http://fifnc.org/programs/chapters.html. Contact the local chapter to request an application for financial assistance.

Limitations/barriers to use

- Assistance is available only one time per year.
- Families must have or find their own respite providers. First In Families does not provide respite services but does provide funding to help families purchase short-term respite services.

For more information

Call the state office of First In Families at 919-251-8368 or go to http://www.fifnc.org/.

Program management/administration

• First In Families of North Carolina and local chapters.

Innovations Waiver

The NC Innovations Wavier is a resource for funding an array of services and supports for individuals with intellectual and other related developmental disabilities who are at risk for institutional care in an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF-IID). The NC Innovations Waiver is designed to promote choice, control and community engagement.

Respite services available through the Innovations Waiver are designed to provide support and relief to the primary caregiver from the responsibility and stress of caring for the individual. The service enables the primary caregiver to participate in planned or emergency events and to have planned time for him/herself and/or other family members. **Respite services funded** through the Innovations Waiver are available only to individuals who have been approved to participate in the Waiver.

NC Innovations respite may be used to provide temporary relief to individuals who reside in licensed and unlicensed Alternative Family Living situations. This service enables the individual to receive periodic support and relief from the primary caregiver(s) at his/her choice.

The NC Innovations Waiver also offers Individual and Family-Directed Service options for self-directed care.

Eligibility for Innovations Waiver Services

Individuals with intellectual and developmental disabilities who are Medicaid eligible and meet all the following criteria:

- Live in an ICF-IID facility and wish to leave, or are at high risk of being placed in an ICF-IID facility
- Choose to participate in NC Innovations rather than live in an institution
- Need NC Innovations services, as specified in their person-centered Individual Support Plan, and must use at least one Innovations service other than respite monthly
- Can have their needs for health, safety and well-being met within the waiver cost limit
- Meet the requirements of ICF-IID level of care, which means:
 - Needing active treatment
 - Having a diagnosis of intellectual disability or closely related condition
 - Having a condition that is manifested before age 22 and is likely to continue indefinitely
 - Having substantial limitations in three or more of the following:
 - ✓ Self-care
 - ✓ Understanding/use of language
 - ✓ Learning
 - ✓ Mobility
 - ✓ Self-direction
 - ✓ Capacity for independent living

Additional information about respite through the Innovations Waiver

 Respite may include in and out-of-home services, including overnight and weekend care and care during family emergencies.

- Respite includes transportation from the individual's residence to points of travel in the community (except for travel to/from school settings for individuals eligible for services through the Individuals with Disabilities Education Act).
- Respite may be used during school hours for sickness or injury, or when a student is suspended or expelled.
- The primary caregiver is defined as the person principally responsible for the individual's
 care and supervision and must maintain his/her primary residence at the same address
 as the individual.
- NC Innovations Respite may be used to provide temporary relief to individuals who live in licensed and unlicensed Alternative Family Living situations.
- NC Innovations Out-of-Home Crisis Services may be used as a planned respite stay for individuals who are unable to access regular respite due to the nature of their behaviors.

Cost

• No cost to participants. Medicaid covers the costs of services for individuals approved to participate in the Innovations Waiver.

How to apply

Contact your <u>Local Management Entity/Managed Care Organization (LME-MCO)</u>.

Limitations/barriers to use

- The limited number of waiver slots results in extremely long waiting lists for NC Innovations Waiver services. It could take many years before a slot becomes available to a person on the waiting list.
- For individuals who are eligible for services under the Individuals with Disabilities Education Act (IDEA), respite does not include transportation to/from school settings.
- Respite care cannot be provided by any person who resides in the individual's primary residence.
- Respite services are provided only for the NC Innovations participant. Other family members, such as siblings, may not receive care from the respite provider.
- Respite may not be used for individuals who are living alone or with a roommate.
- Staff sleep time is not reimbursable.
- The cost of 24 hours of respite care cannot exceed the per diem rate for the average community ICF-IID facility.

For more information

Contact your <u>Local Management Entity/Managed Care Organization (LME-MCO)</u>.

Program management/administration

- NC Division of Health Benefits
- LMEs-MCOs

Medicaid (b)(3) Respite Services

Medicaid (b)(3) services are additional supports for individuals who have Medicaid beyond the services specified in the Medicaid state plan. Medicaid (b)(3) services focus on helping individuals remain in their homes and communities and avoid hospitalization or living in an institution.

(b)(3) respite services provide periodic support and relief to the primary caregiver/s from the responsibility and stress of caring for children ages 3 to 21 with mental health, developmental disabilities, or substance use/addiction needs, and for adults age 21 and over with developmental disabilities.

Eligibility for Medicaid (b)(3) Respite Services

Individual who:

- Has Medicaid
- Is a child age 3 to 21 with mental health, intellectual/developmental disabilities, or substance use/addiction service needs, or an adult age 21 and over with intellectual/developmental disabilities
- Lives in non-licensed setting with an unpaid caregiver

The primary caregiver must maintain his/her primary residence at the same address as the individual.

Additional information about Medicaid (b)(3) Respite Services

- Respite may be used during school hours for sickness or injury.
- Respite may include in and out-of-home services, including overnight and weekend care
 or care based on a family emergency.
- Respite may be provided in an individual or group setting.

Cost

No cost to participants

How to apply

The individual or legally responsible person can:

- Request this service directly from a provider.
- Call the <u>Local Management Entity/Managed Care Organization (LME-MCO)</u> and ask to speak with an Access Coordinator who can provide basic information about Medicaid (b)(3) services and link the individual to a provider.

Limitations/barriers to use

- Medicaid (b)(3) services are subject to funding availability.
- Individuals on the Innovations Waiver are not eligible for (b)(3) Respite services.
- Medicaid (b)(3) respite is consistent with the NC Innovations waiver program definitions and limitations.
- Respite may not be provided by family members or anyone who lives in the individual's primary place of residence.
- Respite services are provided only for the individual, not for siblings or other family members needing care.
- Respite may not be used for individuals who are living alone or with a roommate.

- Staff sleep time is not reimbursable.
- For individuals who are eligible for educational services under the Individuals with Disabilities Education Act, respite does not include transportation to/from school settings.
- A maximum of 16 hours of respite can be provided in a 24-hour period. No more than 384 hours, or 24 days, of respite can be provided to an individual in a calendar year unless there is specific authorization for exceeding the limit.
- Individual respite cannot be provided for more than 10 consecutive days.

For more information

• Contact your Local Management Entity/Managed Care Organization (LME-MCO).

Program management/administration

- NC Division of Health Benefits
- LMEs-MCOs

<u>State-Funded Respite Services for Individuals with Mental Health,</u> Intellectual/Developmental Disabilities or Substance Use Disorders

Local Management Entities/Managed Care Organizations (LME-MCOs) have specifically allocated state funding available for services for individuals with mental health, intellectual and developmental disabilities and substance use disorders who are un-/underinsured. Respite services for caregivers of individuals in these disability groups *may* be covered, depending on the location.

Eligibility for State-Funded Services

Individuals who:

- Have a mental health or substance use diagnosis or have a condition that may be defined as a developmental disability
- Meet level of care criteria specified in the applicable service definition.

Additional information about State-Funded Respite Services

- State-funded respite services may be provided on either a planned or emergency basis and may include weekend care, emergency care, or continuous care up to 30 days.
- These services may be provided in a variety of locations, including homes and facilities.

Cost

- Eligibility for state-funded respite care for individuals with intellectual/developmental disabilities is *not* based on income.
- The service is provided at no cost to the individual or family. The provision of services is contingent upon funds availability.

How to access

Contact your <u>Local Management Entity/Managed Care Organization (LME-MCO)</u>.

Limitations/barriers to use

- Options for respite services may vary by county and from one LME-MCO to another.
- State-funded services depend on availability of funds; there may be a waiting list for some services.

For more information

• Contact your Local Management Entity/Managed Care Organization (LME-MCO).

Program management/administration

LMEs-MCOs

NC START Respite

North Carolina Systemic, Therapeutic Assessment, Resources and Treatment (NC START) is a statewide community crisis support program for individuals ages 6 and above with intellectual/developmental disability and co-occurring complex behavioral and/or mental health needs. Crisis prevention and intervention services are provided through crisis response, clinical consultation, training, and respite.

Eligibility for NC START

Respite services are facility-based and provided only for adults age 18 and over who are actively receiving NC START services. The individual must have a documented I/DD diagnosis prior to age 21, a co-occurring MH diagnosis and /or complex behavioral needs.

Additional information about the program and its therapeutic respite services

- There are three NC START teams statewide, one team for each region of the state (East, Central and West). Each region has one clinical team and one Resource Center for crisis respite and planned respite.
- Respite for adults is provided at the Resource Centers.
- Planned and crisis therapeutic respite is available in the Resource Centers for adults living in licensed and unlicensed residential settings. The individual must be a current START recipient and have a residential placement to return to.
- Respite is not provided for children in the resource centers; children receive therapeutic
 coaching in their homes. Therapeutic coaching includes training and support for the
 individual and family, and the family must remain in the home for this service.

Cost

 No cost to the individual or family. If the individuals receive Innovations Waiver funding, services could be provided through waiver funding as well.

How to access services

- Referrals to NC START can be made by anyone known to the individual with an understanding of the individual's status and treatment, support and behavioral history, and the applicable consent for referral.
- Referrals for adults not experiencing crises and referrals for adults in crisis may be made at any time of day or night to the NC START numbers listed below:

o NC START West: 888-974-2937

NC START Central: 919-865-8730 or 800-662-7119, x 8730

o NC START East: 888-962-3782

- All referrals for children during business hours should be made to the Local Management Entity/Managed Care Organization (LME-MCO) access line. For children in crisis after business hours, contact the LME-MCO crisis line.
 - All child referrals in the Eastern region are made by contacting NC START East directly at 888-962-3782.

Vaya Health

Phone: 828-225-2785 Crisis Line: 800-849-6127 Cardinal Innovations Phone: 704-939-7700 Crisis Line: 800-939-5911

Partners Behavioral Health Phone: 704-884-2501 Crisis Line: 888-235-4673

Alliance Behavioral Health **Phone**: 919-651-8401 **Crisis Line**: 800-510-9132

Sandhills Center **Phone**: 910-673-9111 **Crisis Line**: 800-256-2452

Trillium Health Resources Phone: 866-998-2597 Crisis Line: 877-685-2415

Eastpointe

Phone: 800-913-6109 **Crisis Line**: 800-913-610

Limitations/barriers to use

- There may be a wait list to access NC START services.
- Each NC START region has one 4-bed Resource Center for a total of 12 therapeutic respite beds statewide. Each Resource Center has 2 beds for planned respite and 2 beds for emergency respite.
- Emergency and planned respite in the Resource Centers is for individuals actively enrolled in NC START.

Program management/administration

• There is oversight and monitoring at the State level (NC Division of Mental Health, Developmental Disabilities and Substance Abuse Services) and the LME-MCO.

For additional information

 Contact your <u>Local Management Entity/Managed Care Organization (LME-MCO)</u>, the <u>NC Division of Mental Health/Developmental Disabilities/Substance Abuse Services</u>, or the applicable NC START team (see above).

Medicare and Medicaid Hospice Benefit

Caregivers of individuals who are in hospice and eligible for Medicare or Medicaid are eligible for respite under the Medicare or Medicaid Hospice Benefit. Under the Hospice Benefit, respite is defined as temporary care provided in a nursing home, hospice inpatient facility, or hospital so that a family member or friend who is the patient's caregiver can take some time off.

Eligibility for the Medicare or Medicaid Hospice Benefit

Individuals who have Medicare Part A (hospital insurance) or Medicaid and who:

- Are terminally ill (expected to live 6 months or less) as certified by a hospice doctor and regular doctor
- Accept palliative care for comfort instead of care to cure terminal illness
- Sign a statement electing hospice care instead of other Medicare- or Medicaid-covered treatments for their terminal illness and related conditions
- Get care from a Medicare- or Medicaid-certified hospice

Additional information about the Medicare or Medicaid Hospice Respite Level of Care

- The hospice provider must arrange the respite stay, not the individual or family.
- The individual may stay up to 5 days each time he/she gets respite care.
- The individual may get respite care more than once, but only on an occasional basis.
- This level of care includes room and board costs.

Cost

• There may be a small copayment for a respite stay.

How to access

• To access respite services through the Medicare or Medicaid Hospice Benefit, talk with the hospice team managing the individual's care.

Limitations/barriers to use

- There may be a small copayment for the respite stay.
- See section above on Additional information about the Medicare or Medicaid Hospice Benefit.

For additional information

• Check with the individual's doctor, call the Association for Home and Hospice Care of NC at 919-848-3450, or go to http://www.homeandhospicecare.org/.

Program management/administration:

Centers for Medicare & Medicaid Services/US Department of Health and Human Services