

# Caring for Senior Citizens with Intellectual and/or Developmental Disabilities

In New Jersey, the Department of Human Services and its Division of Aging Services administer programs directly and distribute federal and state funds to Area Agencies on Aging for local service provision. The Division of Aging Services administers federal and state-funded services and supports and makes it easier for seniors and caregivers to live in the community as long as possible with independence, dignity and choice. Area Agencies on Aging (also known as AAAs, County Offices on Aging, Senior Services, Intergenerational Services and/or Veteran and Disability Services) are located in each county to develop comprehensive coordinated systems of community-based services for persons aged 60 and older and their caregivers. AAAs can also serve as Aging and Disability Resource Connections (ADRCs).

## What are long term services and support for senior citizens with disabilities?

### Managed Long Term Services and Supports (MLTSS)

MLTSS refers to the delivery of long-term services and support through New Jersey Medicaid's NJ FamilyCare managed care program. MLTSS is designed to expand home and community-based services, promote community inclusion and ensure quality and efficiency. MLTSS uses NJ FamilyCare managed care organizations (also known as HMOs or health plans) to coordinate all services. MLTSS provides comprehensive services and supports, whether at home, in an assisted living facility, in community residential services, or in a nursing home.

### What does MLTSS cover?

Managed Long Term Services and Supports (MLTSS) includes:

- Access to all NJ FamilyCare Plan A Benefits
- Care Management
- Home and Vehicle Modifications
- Home Delivered Meals
- Respite
- Personal Emergency Response Systems
- Mental Health and Addiction Services
- Assisted Living
- Community Residential Services
- Nursing Home Care

### How is Nursing Home Care covered in MLTSS?

Any individual with NJ FamilyCare entering a nursing facility (NF) or special care nursing facility (SCNF) for the first time will have their acute and primary health care managed by the NJ

FamilyCare Managed Care Organizations (MCOs). Short-term Rehabilitation stay in a NF/SCNF is a NJ FamilyCare Plan A benefit.

Once the individual has completed rehabilitation, the MCO will screen their member to evaluate if they meet the MLTSS criteria. If the MLTSS criteria are met and the individual requires long-term custodial care in the nursing facility or community, a clinical assessment for MLTSS will be conducted by the MCOs and a determination of clinical eligibility will be made through the Division of Aging Services (DoAS).

Any individual who is pending or newly eligible for NJ FamilyCare Plan A and is living in, or requesting placement, in a NF/SCNF will be referred to the DoAS Office of Community Options (OCCO) for MLTSS clinical eligibility assessment. If the individual is approved both financially and clinically for Medicaid, the individual will be enrolled in MLTSS and in an MCO. NF/SCNF residents who were considered custodial care on Medicaid prior to July 1, 2014 will remain NJ FamilyCare fee-for-service for the duration of their stay.

**Individuals must meet Medicaid eligibility in order to qualify for MLTSS.**

### **Program of All Inclusive Care for the Elderly (PACE)**

Provides frail individuals, age 55 and older, comprehensive medical and social services coordinated and provided by a team of professionals in a community-based center and in their homes, helping program participants delay or avoid long-term nursing home care. To participate in PACE, an individual must:

- Be 55 years of age or older
- Require nursing home level of care but be able to live safely in the community at time of enrollment with the services of PACE
- Reside in the service area of a PACE organization

Participants can leave a PACE program at any time. Six PACE agencies are currently operating in New Jersey and you must live in their coverage area to participate.

### **Jersey Assistance for Community Caregiving (JACC)**

JACC is a program that provides in-home services to seniors, age 60 and over, who require a nursing facility level of care but wish to remain in their homes. JACC includes an array of services designed to supplement the assistance given by the individual's existing network of family caregivers. Qualified individuals may have the opportunity to hire their own eligible family, friends, or neighbors to provide the care they need. Services available through JACC include the following:

- Care management
- Personal care assistance
- Caregiver relief (respite)
- Home modifications
- Special medical equipment and supplies
- Chore services
- Personal emergency response system
- Home delivered meal services
- Social adult day care

- Medical adult day care
- Transportation

Individuals eligible for this program must:

- Require a nursing facility level of care, but wish to remain at home
- Not participate in other services that provide this type of care
- Meet financial guidelines for income and assets:
  - Countable monthly income that is no more than 365% of the Federal Poverty Level (\$3,881 for individuals and \$5,244 for a couple in 2021) and
  - Countable resources at or below \$40,000 for an individual or \$60,000 for a couple

JACC has a co-pay based on an individual's income.

### **Statewide Respite Care Program**

This program offers services to individuals needing care so as to provide a break ("respite") to unpaid caregivers. Services can include adult day care, home care, companion services, campership, or a short stay in a facility. There is even a caregiver directed option, which allows the caregiver to pay for/be reimbursed for services or items that make caregiving easier.

Individuals eligible for this program must:

- Live in the community and require daily, basic care that is currently being provided by unpaid caregivers such as a spouse, family members or friends
- Not participate in other services that provide this type of care
- Meet financial guidelines for income and assets

There may be a co-pay based on an individual's income.

### **Alzheimer's Adult Day Services Program (AADSP)**

This program offers financial assistance, based on the person's income, toward attending one of the programs participating day services centers.

Individuals eligible for this program must:

- Have a qualifying diagnosis that includes permanent and progressive dementia
- Live in the community and require daily, basic care that is currently being provided by unpaid caregivers such as a spouse, family members or friends
- Not participate in other services that provide this type of care
- Meet financial guidelines for income and assets

There may be a co-pay based on income.

### **Older Americans Act Funded Programs**

This Division of Aging Services administers programs funded through the Older Americans Act. Services vary depending on the county of residence and consist of things like: home delivered meals, congregate nutrition programs, information and assistance, and

screening for benefits. Some counties may have light home repair services or “handyman” services available. Eligibility for these programs is not based on income. Most programs are for individuals in need, age 60 and older, but some services are also available to caregivers of any age and to grandparents age 55 or older. To learn what services your county has available, call your County AAA/ADRC.

## **Housing Options for Senior Citizens with Disabilities**

- Independent Living: For seniors who are able to live on their own, but want the security and convenience of community living.
- Boarding Homes: Facilities that provide lodging, meals, and/or services for a fee.
- Residential Health Care Facilities (RHCF): Long term care alternative that provides residents with a home-like atmosphere and assistance in getting health services.
- Continuing Care Retirement Community (CCRC): Provides housing, services, health care, including nursing home care, to people of retirement age.
- Assisted Living: A coordinated array of supportive personnel and health services, available 24 hours a day, to residents who need these services, including those who require formal long-term care.
- Adult Family Care (AFC): Community option in which up to three people receive room, board, and other supportive health and social services in the home of another, unrelated person.
- Nursing Home and Long Term Care: Housing option for seniors who need help completing activities of daily living such as washing, dressing, and feeding.

For more information, please refer to this [page](#) by NJ DoAS and our tab on \*housing\*.

## **Office of the Public Guardian for Elderly Adults (OPG)**

The OPG is appointed guardian by the New Jersey Superior Court when there is no willing or appropriate family or friend to become the guardian of an incapacitated person 60 years of age or older. The OPG is usually appointed plenary guardian of both person and property. In this capacity, OPG addresses all the medical and property issues of the ward.

## **Protecting the Rights of Elders**

Sometimes the frailty and dependence of seniors and individuals with disabilities can make them targets for abuse, neglect or exploitation. There are programs to help, whether the individual is living in the community or is residing in a nursing home or other long-term care institution.

Adult Protective Services (APS) is a program that helps state residents, aged 18 or older, who lack the capacity to understand their circumstances and cannot protect themselves. Trained workers from APS programs in each county respond to requests for help by making a personal visit and finding ways to reduce the risk of harm. APS workers make every effort to help individuals remain in their homes.

APS investigates all complaints of suspected abuse, neglect, and/or exploitation of adults. A complaint to APS generates a thorough assessment, which includes a private face-to-face

interview with the potentially at-risk adult to determine if intervention is warranted. All information generated by the investigation is confidential. A report of suspected abuse may be made to the Division of Aging Services' Information and Referral toll-free number or to the APS office in the county where the individual lives.

## End-of-Life Care

If you are facing a life-threatening health crisis, you and your caregiver must make many important medical, legal and practical decisions. Being informed about your choices can help ease some of the burden.

Hospice is an approach to end-of-life care that focuses on providing comfort and dignity to patients at the end of life. The goals of hospice are achieved through various efforts, including pain and symptom management, caring for the patient in the patient's home, and delivering care through a network of caregivers. Hospice is also very focused on the family of the patient, and offers emotional and psychological support to family members, both before and after the patient dies.

### Hospice care resources

- The **New Jersey Hospice and Palliative Care Organization** at [www.njhospice.org/](http://www.njhospice.org/) is a nonprofit organization that promotes hospice and palliative care in New Jersey, including education and advocacy, technical assistance, support, and information for professionals, families, and friends.
- The **Center to Advance Palliative Care** is a national organization dedicated to increasing the availability of quality palliative care services. Visit its website at [www.getpalliativecare.org](http://www.getpalliativecare.org).
- **National Association for Home Care and Hospice** is a trade association that represents home care agencies, hospices, and home care aide organizations. It also offers a user-friendly tool on its website to locate agencies in your area that provide hospice. Go to [www.nahcagencylocator.com/](http://www.nahcagencylocator.com/).
- The **NJ Home Care Association**, a nonprofit organization which has hospice and home care resources available to the public. Visit their website at [www.homecarenj.org/](http://www.homecarenj.org/).

### Additional End of Life Resources

- **Americans for Better Care of the Dying** at [www.caringcommunity.org/helpful-resources/models-research/americans-for-better-care-of-the-dying/](http://www.caringcommunity.org/helpful-resources/models-research/americans-for-better-care-of-the-dying/) is dedicated to ensuring good end-of-life care. The organization focuses on improved pain management, better financial reimbursement systems, enhancing continuity of care, support for family caregivers, and changes in public policy.
- **The National Cancer Institute (NCI)** has a helpful fact sheet on its website at [www.cancer.gov/cancertopics/factsheet/Support/end-of-life-care](http://www.cancer.gov/cancertopics/factsheet/Support/end-of-life-care) titled "End of Life Questions and Answers."

## End of Life Planning

When planning for the future of a loved one with an intellectual and developmental disability, many parents and guardians think about establishing their own will and creating a special needs trust. However, planning for a loved one's end of life isn't often included in their plans.

End-of-life planning can include:

- Advance Health Care Directive
- End-Of-Life Housing
- Estate Planning
- Funeral Planning
- Obituary and Death Notice

### **Expressing Wishes for the Future**

The Letter of Intent (LOI) outlines information on daily needs, supports, and legal and financial matters of a person with an intellectual or developmental disability (I/DD). The LOI should communicate the family and person's intentions for the future. It serves as a good resource during times of transition.

### **Estate Planning & Writing a Will**

A will is a legal document that states who will receive your property when you die, who will oversee your estate (paying taxes, distributing assets), and, if you have children under 18 and/or adult dependent children, who will raise and care for them. If you don't create one, the courts will make these decisions for you.

Resources

- Planned Lifetime Assistance Network of NJ: <https://plannj.org>
- Checklist: Documents to organize and share:  
<https://www.everplans.com/articles/checklist-documents-to-organize-and-share>

### **Advance Health Care Directive**

An Advance Health Care Directive, also called an Advance Directive, is a legal document stating how a person would like to be treated at the end of their life.

New Jersey has two kinds of Advance Directives:

1. Proxy Directive (Durable Power of Attorney for Healthcare) - who can advocate for your care when you may not be able to
2. Instruction Directive (Living Will) - stating the types of medical treatments you do and do not want at the end of your life

It is your decision whether to have either directives or just one of them.

For an individual that has a guardian:

- If a person with I/DD has a legal guardian, then that person will make all health care decisions, including all end-of-life decisions. However, guardians should plan ahead and have a secondary plan in place in the event of their passing.

For individuals without a guardian:

- An Advanced Directive should be established.

### **Other Options:**

#### [Practitioner Orders for Life-Sustaining Treatment \(POLST\)](#)

This form, signed by a patient's attending physician or advanced practice nurse, provides instructions for health care personnel to follow for a range of life-prolonging interventions. This form becomes part of a patient's medical records, following the patient from one healthcare setting to another, including hospital, nursing home or hospice.

### **Funeral Planning**

When planning a funeral or memorial service, there are many aspects of the service that you can plan and personalize, from your final resting place to readings and songs to participants.

#### [Irrevocable Agreements](#)

In New Jersey, irrevocable agreements are required when creating a prepaid funeral account for SSI/Medicaid applicants and recipients. Irrevocable means that the trust fund moneys are NOT REFUNDABLE. Only individuals prepaying their funerals in order to qualify for SSI, Medicaid, or General Assistance may establish irrevocable arrangements, which must be used for funeral and burial purposes. Irrevocable prepaid funeral agreements cannot, by law, be canceled or refunded (although consumers may change funeral homes).

#### [Public Assistance Funerals](#)

The State of New Jersey can help a family in need pay for a funeral through the Department of Human Services (DHS). Apply for "public assistance" funeral funds by calling your county board of social services in the county in which the deceased resided at the time of their death.

### **Bereavement**

As our society continues to explore how to deal with death, we are also learning and understanding more about grieving. A number of organizations and agencies provide bereavement services and support groups to help you through this difficult time.

- **AARP** at [www.aarp.org](http://www.aarp.org) provides extensive information about end-of-life issues on its website, as well as links to resources about specific issues of law, grief, and loss. For helpful resources, click on "Home & Family."
- An "**After-Death Checklist for Survivors**" is available from the Austin Memorial and Burial Information Society, an affiliate of the national Funeral Consumer Alliance (FCA), which provides a comprehensive list of decisions to be made and tasks to be done when a death occurs. The following website will link you directly to this

document:[www.fcaambis.org/wp-content/uploads/2010/06/After-Death-Checklist-for-Survivors-05-20-11.pdf](http://www.fcaambis.org/wp-content/uploads/2010/06/After-Death-Checklist-for-Survivors-05-20-11.pdf).

- The **Funeral Consumers Alliance of Princeton**, at [www.fcaprinceton.org/](http://www.fcaprinceton.org/), is the local affiliate of FCA, a nonprofit organization that protects consumers' rights to choose meaningful, dignified, affordable funerals. Additionally, FCA's website at [www.funerals.org](http://www.funerals.org) offers many educational resources.
- **Griefnet** at [www.griefnet.org](http://www.griefnet.org) provides access to 50 e-mail support groups and websites. The support groups are organized by the relationship the caregiver had to the deceased, including a group for adult children of elderly parents.

## Important **Contacts** & Resources

- Contact The Arc of NJ for further assistance:
- Aging & Disability Resource Connection/Area Agency on Aging (ADRC/AAA):  
<https://www.state.nj.us/humanservices/doas/home/saaaa.html>
- DoAS Services & Support list: <https://www.state.nj.us/humanservices/doas/services/>
- Advance care Planning Go Bag:  
<https://www.thearcfamilyinstitute.org/resources/end-of-life-go-bag.html>