



# Caregivers:

*Unsung heroes who  
play a **VITAL** role  
in mental health care!*

The work of family members who are caring for a loved one with a mental health condition is too often unacknowledged.

According to the New York State Office for the Aging (SOFA), about three million people in the state are providing care for a family member at any given time.

Individual caregivers provide critical assistance with daily activities - helping people manage the functional impairments that often accompany persistent mental illness, substance use, and other chronic conditions, including Alzheimer's Disease, the most common form of dementia.

Family caregivers must handle the non-stop demand of providing care 24 hours a day, seven days a week. Caregiving can be physically grueling and emotionally exhausting, with caregivers feeling isolated, leaving them at high risk of depression and stress-related physical problems.

Despite these hardships, many caregivers will enthusiastically say that they find the experience incredibly rewarding.

"Caregiving is the ultimate act of love," wrote journalist Marlo Sollitto in a June 2017 article for AgingCare.com "6 Reasons to Appreciate Your Job As a Caregiver."

"Caregiving changes your perspective on life," Sollitto wrote. "They may be few and far between, but when special moments come along, they make your heart sing. A moment of recognition from a loved one with dementia, a heartfelt 'thank you' from someone who is usually ornery, a long-lost family story and a shared laugh are all treasures for caregivers to cherish."

This edition of *OMH News* is dedicated to the unsung heroes of mental health care and the unselfish work they do.

We welcome your comments at: [omhnews@omh.ny.gov](mailto:omhnews@omh.ny.gov)

# Companionship: Finding family in unexpected places



One morning in 1942, five-year-old **Rhoda Merlin** and her three-year-old sister, **Grace** boarded a big, yellow bus in front of their home in New York City — and never came back.

With both children diagnosed with mental illness and a home life already difficult because of a failing marriage, their mother did what was considered common practice at the time and sought care for the sisters at an institution — at what was then called the “Wassaic State School for Mental Defectives” in Dutchess County.

## From place to place

Rhoda spent the next nine years of her life at Wassaic. Sadly, her sister was not with her long, dying there within a few, short years. Rhoda’s mother visited regularly for a time, but the visits eventually became further apart and then stopped all together.

Alone as a teenager, Rhoda felt that she was forgotten by her family. “Nobody came for me,” Rhoda said, “And for years I didn’t know where any of them were.”

During the next 50 years, Rhoda was cared for by several different families in the Kingston area. She found employment as an elevator operator at Wassaic, and worked in the facility’s laundry department. For 30 years, she worked at the former Kingston ARC Work Center, retiring just a few years ago.

Then seven years ago, her case came to the attention of **Susan Neilson**, a provider in OMH’s Family Care Program.

“When I was asked to work in family care, I was reluctant,” Neilson said. “I thought: ‘Who would want a stranger living in their homes?’ But the more I learned about it, I was intrigued. As it turned out, it was the best decision I could have ever made. I love doing this type of work.”

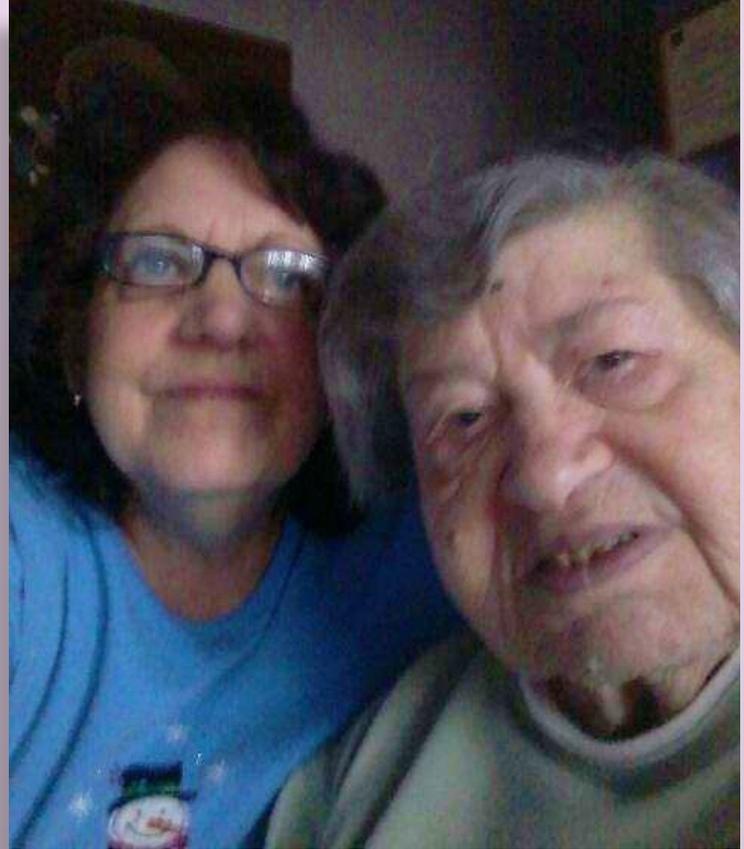
## A new home

Neilson welcomed Rhoda into her home on the day before Thanksgiving, “just in time to have a real meal with a real caring, family,” Neilson said. Since then, the two have grown close, with Neilson’s own family recently helping Rhoda celebrate her 80th birthday.

During the day from Monday through Thursday, Rhoda goes to River Valley Adult Day Care in Poughkeepsie. On Fridays, she’s part of a social club in Kingston that offers games, music, and entertainment. “Given Rhoda’s age, I’ve asked her on some days if she’s tired and would prefer to stay home,” Neilson said. “But she always wants to go out!”

Neilson has been working over the years to help Rhoda rediscover her past. They learned that Rhoda’s mother had married four times. They traveled to the cemetery at Wassaic and found Grace’s grave marker, overgrown with weeds. Neilson has been trying to obtain legal identification for Rhoda, but she has still not been able to locate her birth certificate.

As it turned out, some other people were also trying to learn about Rhoda’s past: Her cousins in New York City.



*Susan Neilson and Rhoda Merlin*



*Wassaic State School in 1930.*

*Museum of disABILITY History*

## A new family

Believing that Rhoda had died, the family was conducting research and tracked her through Social Security. In turn, Social Security contacted the Rockland County Psychiatric Center, which told them Rhoda was living in Neilson's home.

"The family was delighted to discover that Rhoda was actually alive," Neilson said. "And Rhoda was just as excited to learn that she had a family. They couldn't wait to meet each other." A teary, yet happy, reunion was held at Neilson's house soon after. "I learned that I not only have cousins," Rhoda said. "I have half-sisters and nieces and nephews." She learned she also had a brother who had unfortunately died several years before.

Each month, the family comes up from New York City to have dinner with Rhoda at a local restaurant and bring her gifts. One cousin bought a headstone for Grace's grave and calls Rhoda frequently. "You should see how Rhoda's eyes light up when I tell her that her cousin is on the phone!" Neilson said.

Neilson is glad that she's had an opportunity to be a part of this reunion and considers herself fortunate to have been a part of Rhoda's life.

"It's been wonderful to have Rhoda live with us," Neilson said. "She's so full of love. It's not like she's a resident. She's a part of my family." OMH



*Rhoda, enjoying life in Neilson's home.*

## Matchmaking: Finding the right Family Care fit



Family Care Program operators work carefully to match the personalities of clients and providers.

"We always want the match to be a good one," said **Sarah Reich, RN**, Family Care Coordinator for Rochester Psychiatric Center (RPC), which serves 66 individuals who are diagnosed with mental illness living in 43 homes in Genesee, Livingston, Monroe, Orleans, and Wyoming counties. The program provides a variety of personal assistance services, ranging from helping those who are dependent on aides for activities of daily living to those able to drive and work.

"We start by focusing on screening," Reich said. "We find out what the client's needs are and whether they have mutual interests. Then we give them an opportunity to meet. The client can see the house in which they would live. The next step would be an overnight visit or a long-stay visit, to see if they're a good fit."

Clients can opt out at any time if they feel it's not right. As the client and provider get into a routine during the next few weeks, the RPC Family Care team follows up with weekly meetings for the first month, biweekly for the next month, and then monthly meetings after that.

Family Care Program providers are required to take 30 hours of training in their first year, then 15 hours per year. "One of our training programs is 'Hearing Voices,' through which trainees try to focus on a series of tasks while hearing distressing voices over headphones," Reich said. "It helps to give them an understanding of what many of their clients are experiencing and encourages them to have patience."

The RPC program has had several success stories. One client with anxiety disorder, who had a 20-year history of hoarding, now has a clean living space and works at a local YMCA. Another client from Jamaica, who had been in the program for 10 years, now has a green card and is working at a local children's museum and volunteering to work with children at City Court. She's used the money she's earned to fly home to visit her children. OMH



*Participants in one of Rochester Psychiatric Center's Family Care programs. From left: Caregivers **Yvette** and **John Settles**; and residents **Carmen DeLeón**, **Kevin Hanley**, **Barbara Bennett**, and **Richard Greco**.*

# Family Care: Sharing homes, contributing to recovery



For someone recovering from a serious mental illness, the support of a family or caring community can make all the difference.

The OMH **Family Care Program** is designed to help connect individuals who are in recovery with support, guidance, and companionship, placing up to three people in homes in residential neighborhoods. Family Care providers, in turn, receive training, support, and financial reimbursement for their services.

## 24-hour residential services

Family Care is the oldest and most cost-efficient residential program offered by OMH. It provides 24-hour residential services in small family settings that carefully match each residents' needs and providers' skills to offer individually tailored supervision.

Its participants are people from all social, financial, ethnic, and educational backgrounds who don't have a supportive, therapeutic living environment in the community. They may have a history of institutionalization.

Before placement into the Family Care Program, participants' mental health needs are evaluated through several interviews and screening. Every effort is made to match the person with a home that best meets their needs in terms of location, household composition, compatibility with the provider, and community availability of needed services.

Additional training and Medicaid funds are available to Family Care providers who are willing to perform individual, hands-on services for residents. Eligibility for personal care services require that a substantial portion of a client's personal and physical care be provided by another person, but have medical needs that are not severe enough to warrant admission to a health-related facility.

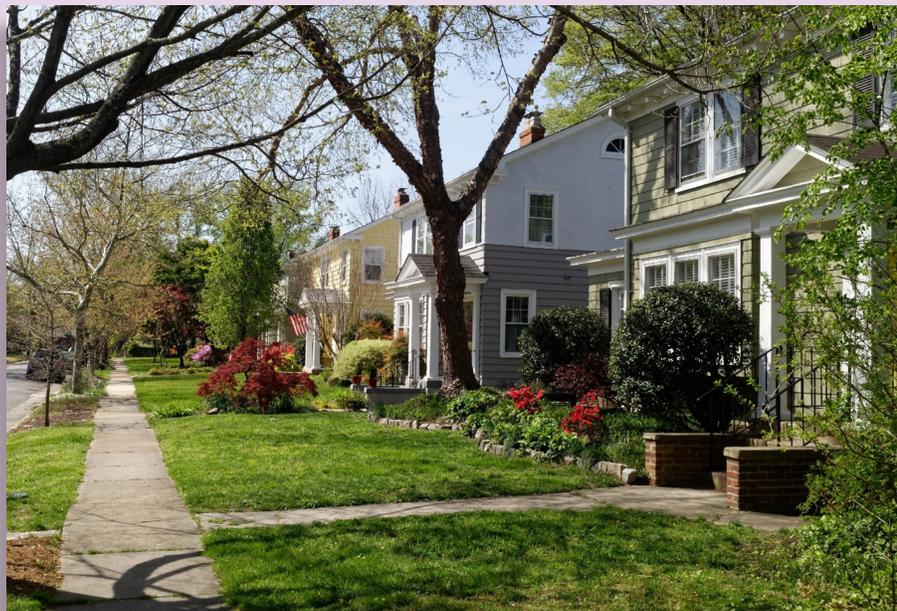
## Who can be a Family Caregiver?

Anyone with the motivation and desire can be a provider. Experience working with individuals with mental illness isn't necessary. Applicants must be at least 21 years of age. They can be married or single, men or women, owners or renters.

The most important requirement is a family's willingness to provide the caring, secure, and understanding environment that an individual living in Family Care needs. A Family Care home provides an extended, supportive family for residents, helping them to develop meaningful relationships with and become productive and active members of their communities.

OMH screens and evaluates all applicants for their interest and ability to provide Family Care services. Applicants' homes are also evaluated for safety, space, and utility.

The program sponsor – either a psychiatric center or community-based mental health program – is responsible for training providers, securing emergency support services, and monitoring the home for compliance with OMH policy and procedures.



## Who is Family Care for?

- Individuals living with a mental illness who are unable to function in their own homes.
- Individuals who require consistent care for extended periods in order to increase their level of functioning.
- Individuals who are unable to function in large-group settings.
- Individuals who have reached their maximum level of independence and are in need of long-term care.
- Physically disabled individuals.
- Geriatric individuals.
- Young adults in need of small-group settings.<sup>OMH</sup>

Providers are trained to manage a variety of placements including individuals requiring consistent care for extended periods in order to increase their level of functioning, geriatric individuals, physically disabled persons, and young adults in need of a family setting.

All Family Care homes are required to undergo a standard certification-review process, which determines the capabilities and suitability of the potential provider, the home, and environment. Once the home and providers meet OMH standards, the agency will issue an operating certificate. Family Care providers must then attend all required training, deliver all required services as outlined in the resident's service plan, and make their home and records available for inspections at least monthly.

Residents are visited at least monthly in order to determine their level of satisfaction and comfort within the home. Safety inspections are conducted at least bi-annually to confirm that the home meets all current life safety standards.

## OMH offers support

Family Care providers are reimbursed for expenses incurred in providing care, such as room and board, and mileage – and may receive additional funds to meet the personal needs of the residents.

Some of the other benefits of being a family care provider:

- Monthly payment for each resident living in their home.
- 14 days paid vacation each year.
- An allowance for recreational transportation for their residents.
- In-service training.
- Help from of a team of professionals who oversee the resident's individual service plan and visit the home periodically.
- The satisfaction of helping others grow and recover.

Statewide, the program has the capacity to support 2,413 residents from 15 state-based programs and three community-based programs in a total of 470 homes. The 15 programs operated by state psychiatric centers are organizationally part of an adult residential, transitional living, or community services unit.

Each program has a designated Family Care Coordinator, who assumes day-to-day management of the program. Family Care Coordinators report progress and receive guidance from both the executive director of the psychiatric center, the Bureau of Housing Development and Support, the Adult Community Care Group, and the Bureau of Capital Operations. The three community-based programs are operated by not-for-profit corporations under contract with OMH, with oversight provided by both the Field Office and the Bureau of Housing Development.

For more information, contact the OMH facility in your area, and ask for its Family Care Program:

[https://www.omh.ny.gov/omhweb/aboutomh/omh\\_facility.html](https://www.omh.ny.gov/omhweb/aboutomh/omh_facility.html).<sup>omh</sup>



# Skills:

## Becoming a savvy caregiver



Caring for a friend, relative, or client with a mental illness presents its own set of challenges. Preparation, knowledge, and support, can help make the transition to a caregiving role easier and ensure that both their client's and their own needs are addressed.

### Self-care

Recognize warning signs of stress early – such as irritability, sleep problems, and forgetfulness. Identify what is causing stress and determine what can and cannot be changed. Taking action to reduce stress can give back a sense of control, such as walking and other forms of exercise, gardening, meditation, or having coffee with a friend.

### Understanding

A caregiver understands that a mental illness, like a physical illness, is treatable. People with mental illness are not defined by their illness and still have likes, dislikes, opinions, talents, and skills. They are mothers, brothers, friends, and colleagues. Their rights and individuality need to be respected.

They'll understand that serious mental illnesses – sometimes causing debilitating symptoms such as persistent anxiety, extreme mood swings, and hallucinations or delusions – can affect every part of a person's life, including work, relationships, and leisure. Serious mental illness and substance use disorder impacts an individual's mental as well as physical health.

### Research

A caregiver becomes savvy by gathering information from a variety of sources that holistically address the needs of the person living with mental illness – family doctors, home care agencies, and pharmacists; psychiatrists, therapists, social workers, peers living with mental illness, and mental health organizations; and trusted internet sites (such as OMH's **Find a Mental Health Program** at: <https://my.omh.ny.gov/bi/pd>, and the **NY Connects Resource Directory** at: <https://www.nyconnects.ny.gov>) that provide information about longer-term resources across service systems, including mental health and caregiver-support programs.

Caregivers also learn about the full range of treatment options, such as cognitive behavioral and motivational enhancement therapies, peer-led counselling and skill building, group programs, self-help approaches, stress management, and wellness. They may use a variety of tools to assist their care recipients in finding paths to recovery such as keeping a diary of problems or symptoms to better track for warning signs of relapse. The **Substance Abuse and Mental Health Services Administration**, through its programs and campaigns provides resources and practical tools accessible on its website at: [www.samhsa.gov](http://www.samhsa.gov), including the **National Registry of Evidence-based Programs and Practices** and wellness tools, such as self-help guides for improving mental and physical health.

### Advocacy

A caregiver helps the client navigate through the healthcare system. They help to obtain any necessary referrals from the insurance companies and learn about the structure of their local mental health service program. They offer to accompany individuals living with mental illness to talk with their doctor or pharmacist about medication options, what medications are used for, and how long they need to be taken.

They build a list of important phone numbers, including the number of the crisis or assessment team, doctor and psychiatrist, local hospitals, and support groups.

### Communication

It's important for a caregiver to share their feelings and thoughts without seeming to blame or judge the person, which can shut down effective communication. They learn to interpret a client's non-verbal cues and consider the signals they are giving off with their posture, voice, gestures, facial expressions, and eye contact.

Active listening is just as important. A caregiver pays attention without interrupting, offers empathy, acknowledgment and encouragement, and works to make sure both the client and themselves are clear on what the other means to say.<sup>OMH</sup>



# Diversity: Caregivers come in many forms



According to the National Alliance for Caregiving, at least 8.4 million Americans provide care to an adult with an emotional or mental health issue. The term “caregiver” is a broad one, and encompasses several types of roles – whether paid or unpaid, family or professional, specific duties or general household help, and medical or personal care. Titles and classifications of professionals may differ depending on the type of agency.

## Informal caregivers

In addition to caregiving responsibilities, most informal caregivers work full- or part-time. Some struggle to find a balance and have to cut back on working hours, take a leave of absence, or quit their jobs.

- **Primary family caregivers** tend to be between the ages of 45 to 64. Most are caring for an adult son or daughter, with a smaller percentage caring for a parent or spouse. On average, they provide about 32 hours of care each week, and have been providing care for an average of nine years.
- **Secondary caregivers** provide back-up to primary caregivers with tasks such as weekend visits, running errands, or helping with doctor’s appointments.
- **Community caregivers** usually live nearby and handle tasks such as keeping an eye on the house, gathering the mail, and yard work.
- **Kinship caregivers** are individuals who are caring for a child that is not biologically their own. This includes grandparents and other older relatives who find themselves caring for children due to their parents’ death, substance abuse, mental illness, incarceration, or military deployment.
- **Crisis caregivers** will provide help when a primary caregiver needs support, such as after a fall or hospitalization.
- **Long-distance caregivers** will offer support from a distance such as arranging for repairs, paying bills, scheduling visits, and researching healthcare options.

## Home care professionals

Home care workers are caregiving professionals who can provide temporary or long-term assistance with daily activities and health-related needs. Individuals with serious mental illness may need home care to combat the effects of premature aging and loss of functioning caused by persistent or severe symptoms and chronic medical conditions, such as diabetes and cardiovascular disease, that are more prevalent in this population.

- **Personal care aides** provide companionship and assist clients with homemaker and housekeeping duties, such as preparing meals, doing laundry, and changing bed linen. With additional training, personal care aides can also provide physical assistance or “hands-on” care, such as help with bathing, hygiene, dressing, walking, and limited health-related tasks, such as assistance with setting up medication for individuals to self-administer.
- **Home health aides** provide hands-on assistance with personal care as well as more extensive health-related tasks, such as assisting in some aspects of medication administration, changing dressing of stable wounds, and use of medical equipment. Home health aides must complete required training that includes practical demonstration of skills performed under the supervision of registered or license practical nurses. Personal care and home health aides are employed by Certified Home Health Agencies (CHHAs), Licensed Home Care Service Agencies (LHCSAs), and hospices.
- **Personal assistants**, hired and trained by individuals participating in the **Consumer Directed Personal Assistance Program** (CDPAP), perform the full range of personal care, home health and skilled nursing tasks, referred to as **Consumer Directed Personal Assistance Services** (CDPAS), that have been agreed upon with their care recipients. Personal assistants can be family members (spouses or parents of children younger than 21 years cannot be personal assistants), peers, neighbors, or individuals with medical training, such as a licensed practical nurse or home health aide.

## Medical professionals

- **Registered Nurses** have the widest range of duties, because they provide counseling and various other therapeutic interventions, are able to fill and administer medication, provide enteral feeding, care for wounds, change catheters, and apply ordered ointments. They are most often employed by registries, employment agencies, or CHHAs.
- **Licensed Therapists (physical, occupational and speech), Dieticians and Social Workers** provide specialized services to clients in their homes, working in collaboration with nurses and aides, to coordinate the home care an individual receives.<sup>OMH</sup>

# Regulations:

## Definition of duties, scope of practice



While many caregivers provide countless hours of unpaid care at home, the provision of paid services are subject to extensive federal and state regulations because they are primarily paid through public funding — Medicare and Medicaid — and are intended to protect clients and ensure quality. Caregivers and individuals exploring home care services benefit from reviewing the home care benefits available through their insurance plans as well as discussing with prospective home care agencies:

- Specific tasks their aides are permitted to perform.
- The organization's access to nursing supervision.
- The role of the recipient's capacity to make informed choices and predictability the medical condition plays in the services that can be provided.
- Options available for designating another person or agency to assume responsibility for making informed decisions.
- The agency's ability to perform a home care assessment and review of capacity for CDPAP.

### Personal care services and health-related tasks

Personal care services include help with nutritional, environmental support, and personal care functions that may require performance of health-related tasks. Individuals must first obtain a physician's order to receive homecare that can only be written by specific types of medical professionals — a licensed physician, a registered physician's assistant or a specialist's assistant, or a certified nurse practitioner. These services must be essential to maintaining client health and safety in their own homes, as reflected in the physician's order, based on an assessment of the client's needs, stability of their medical condition, and ability to make informed choices about their home care.

Personal care aides perform tasks that are not considered "skilled" because, according to the New York State Nurse Practice Act, they don't require a nursing license to perform. There are two levels of personal care services in New York State:

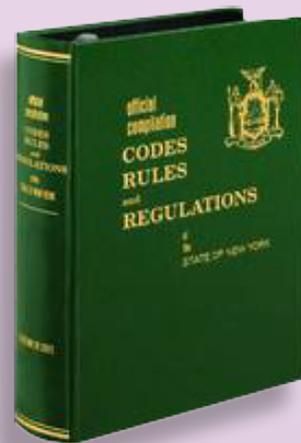
- **Housekeeping or "Level 1,"** which are for those who, because of disability, need help with housekeeping, cleaning, meal preparation, grocery shopping, and laundry, but do not need help with "personal care" tasks such as bathing or dressing. State law limits these services to eight hours per week.
- **Personal care or "Level 2,"** (referred to as "home attendant services" in New York City) includes all housekeeping tasks plus assistance with personal and hygiene needs, such as bathing, dressing, grooming, toileting, walking, feeding, and limited health-related tasks, such as administering medications set-up and disposal, preparing meals with special diets, and routine skin care. Turning and positioning was added as a task in 2015, for bedbound clients who cannot turn themselves, putting them at risk of bed sores.

**Home health aides**, who must work under the supervision of a Registered Nurse, are permitted to perform care, when certain special conditions are met, that is semi-skilled, such as giving of pre-filled insulin injections, setting or regulating of oxygen flow rate, and assembling ventilator supplies and equipment; these more extensive health-related tasks can only be provided to individuals that medical professionals have determined to be "self-directing" or capable of making choices about their daily living activities (unless responsibility is assumed by another adult stipulated in the care plan) and support a plan of care that is in keeping with the medical status reflected in the physician's order for home care.

### Standards for 24-hour personal care

There are two types of 24-hour personal care available in New York State, when determined medically necessary by a medical professional:

- **Live-in 24-hour personal care services**, which are defined as care by one personal care aide who can meet the individual's personal care needs while still being able to obtain, on a regular basis, five hours daily of uninterrupted sleep during an eight-hour sleep period.
- **Split-shift or continuous personal care services**, defined as uninterrupted care by more than one personal care aide for more than 16 hours in a day, that are necessary because the sleep requirements of a single live-in aide could likely not be met.



For more information, consult Section 505 of the New York Codes Rules and Regulations at: <https://regs.health.ny.gov/volume-c-title-18/9748687/section-50514-personal-care-services>.

Continuous personal care services or live-in 24-hour personal care services can only be provided to individuals who are assessed as being “self-directing” or capable of making informed choices, unless the care plan specifies that the responsibility for making choices about activities of daily living is assumed by a self-directing, responsible adult who lives with the person, does not reside with the person but can provide part-time assistance with making informed choices, or assumed by an outside agency or other formal organization.

Live-in 24-hour and continuous CDPAS are also available for participants in CDPAP with similar guidelines and eligibility requirements. Personal assistants of CDPAP participants can be adult relatives residing with care recipients only in cases where the amount of care required makes this living arrangement necessary.

## Home health care programs

CHHAs and LHCSAs, monitored by the New York State Department of Health (DOH), provide personal care, home health, medical social services, skilled nursing, and therapy services for both short- and long-term clients. The nature of the services provided varies based on the:

- Payer (Medicare or Medicaid and insurance plan type),
- Recipient’s needs and capabilities, and
- Approved care plan.

CHHAs can bill Medicare or Medicaid directly; LHCSAs must contract with CHHAs or a Medicaid managed care plan to provide services to individuals on Medicare and/or Medicaid. A majority of clients served by CHHAs receive short-term rehabilitation (90-day) paid for by Medicare, while LHCSAs primarily provide ongoing personal and home health care services through contracts with Medicaid managed care plans. Medicaid mainstream, Health and Recovery Plans (HARPs) and Managed Long Term Care (MLTC) plans are all required to cover personal care and home health services as documented in a physician’s order for home care.

**Long Term Home Health Care Programs** (LTHHCPs) offer a coordinated plan of care and services in the community designed to prevent unnecessary institutionalization. Referred to as “nursing homes without walls,” LTHHCP services were formerly available as a distinct Medicaid waiver until its closure in May 2016. With few exceptions, LTHHCP participants were mandatorily required to enroll in mainstream Medicaid managed care or managed long-term care plans. Most LTHHCPs contract with Medicaid managed care plans and many became or added CHHA licenses in order to receive payment for home care services.

New York State also offers the CDPAP as a Medicaid-covered service, enabling individuals or a person they designate to hire, train, and supervise their own personal assistants, who can be a person without any medical background or a licensed/certified professional with extensive medical training. Personal assistants in CDPAP can perform the full range of services provided by a personal care aide, home health aide, or nurse. Participants in CDPAP must obtain a physician’s order for home care and be assessed as being able and willing to make informed choices regarding the management of the services they receive, or have a legal guardian, designated relative, or other adult able and willing to help make informed choices on their behalf.

Fiscal Intermediaries provide wage and benefit processing, as well maintain records for consumer-directed personal assistants. Each Fiscal Intermediary has DOH-approved administrative agreements with managed care organization(s) and/or contracts with the local departments of social services. Information about CDPAP and contact for Fiscal Intermediaries can be found at The Consumer Directed Personal Assistance Association of New York State website at: <https://cdpaanys.org>.

The **Expanded In-home Services for the Elderly Program** (EISEP) provides non-medical in-home services, case management, non-institutional respite, and ancillary services. The goal of the program is to improve access to, and the availability of, appropriate and cost-effective non-medical support services for older adults who are not eligible for services through Medicaid. EISEP assists older adults who want to remain at home and need assistance with activities of daily living such as dressing, bathing and personal care, and instrumental activities of daily living such as shopping and cooking. The coordination of EISEP’s non-medical services and informal caregiver support enables older individuals to stretch their private resources to the point of delaying premature spend down to Medicaid eligibility.<sup>988</sup>

# Outlook:

## Meeting the need for more caregivers



The need for both family and professional caregivers is going to get more acute during the next several decades. Individuals living with serious mental illness or substance use disorder are at increased risk for needing more intensive services across care systems and caregiver support - particularly as they age or make transitions from higher levels of care to more independent settings.

Further, one in four older adults experiences some mental disorder such as depression, anxiety, or dementia. This number is expected to double to 15 million by 2030.

Caregivers and home care professionals will increasingly be in demand as individuals living with persistent and severe mental health conditions experience faster functional decline and need to manage often multiple chronic conditions; at the same time, numbers of older adults will increase with new behavioral health needs.

But even though more caregivers will be needed, fewer will be available, with families continuing to live further apart. Recruitment for professional caregivers, such as personal care aides and home care aides, remains difficult because of the stress of long hours on duty and frequent travel.

### Focusing on community care

OMH has been working to strengthen the resources available to support community caregivers through its Transformation Plan. During the past four state fiscal years, the plan has been re-balancing the agency's resources by developing community-based mental health services – focusing on prevention, early identification and intervention, and evidence-based clinical services and recovery supports.

There are two programs available to help clients make the transition back to the community:

- **Home and Community Based Services** are designed to allow enrollees to participate in a vast array of habilitative services. Participants have been granted access to skill-building activities while having various necessary rehabilitative needs met. Services include: care coordination, skill building, family and caregiver support services, crisis and planned respite, prevocational services, supported employment services, community advocacy and support, youth support and training, non-medical transportation, habilitation, adaptive and assistive equipment, accessibility modifications, and palliative care.
- **MLTC** is streamlining the delivery of long-term services to people who are chronically ill or disabled and who wish to stay in their homes and communities. These services, such as home care or adult day care, are provided through managed long-term care plans that are approved by DOH.

### Assessing needs in New York State

To better understand home care service needs of individuals living with mental illness, OMH conducted a series of conference calls with OMH residential providers in September and October 2017. Providers offered insight into the type of needs they were encountering with residents, barriers to accessing services, and strategies used to increase access to home care and make aging-in-place possible.

In addition, OMH, in partnership with the Home Care Association of New York State, Inc., co-facilitated a workshop panel discussion, "Aging-in-Place - Utilizing Community Long Term Services and Supports in Office of Mental Health Residential Programs," at the 2017 Association for Community Living Agencies in Mental Health conference that included representatives from home care agencies and OMH housing providers.

The panel and OMH housing providers identified the following needs of individuals trying to age-in-place:

- Additional assistance with housekeeping, personal care, home health care, skilled nursing and specialized therapies, environmental modifications (grab bars), access to elevators, medication management, and administration.
- Assistance with adapting to a more-independent environment and integrating into community when transitioning to a more-independent setting.
- Help re-instituting, applying for, and coordinating available benefits across several systems - such as aging; physical health; behavioral health; public benefits including Medicaid, Medicare, SNAP, HEAP; and the Veterans Administration.

- Managing chronic disease(s) and making lifestyle changes:
  - Individuals living with mental illness and the formerly homelessness experience accelerated aging and disability processes due to co-morbid medical conditions and self-neglect.
  - Diabetes, smoking, and sedentary lifestyle were specifically highlighted as prevalent and needing attention.
- Assistance connecting to hospice and enabling resident to die with dignity in setting of choice.

Ideas highlighted during the workshop and shared by OMH residential providers to help individuals living with mental illness to age-in-place included:

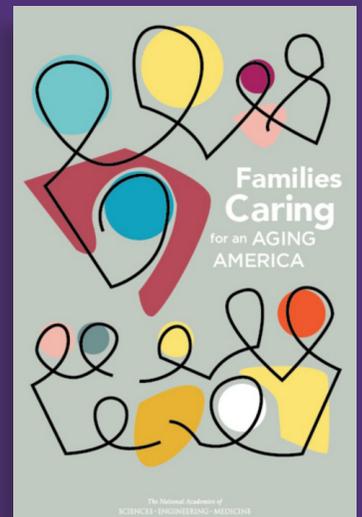
- Cultivating relationships with home health agencies – use existing residential, behavioral health staff, and case managers to partner with home health agencies and specific aides serving residents.
- Promoting “cluster care,” highlighting a home health/personal care agency’s ability to serve multiple clients within the same building.
- Advocating for residents in need of (additional) home health and personal care help – leverage professionals in regular contact with residents to consult with physicians writing orders for home/personal care.
- Providing efficient access to psychiatric, substance use treatment, and medical support (onsite/co-located, nearby, telehealth/tele-psych) enables people to age-in-place and avoid (re) hospitalizations and unnecessary ER visits.
- Reviewing care coordination and insurance plan options available to residents that may assist in more efficient access to psychiatric and medical care.
- Collaborating with managed care and community-based service providers to develop a value-based payment proposal that targets residents with complex or intense needs to help pay for needed services or building adaptations that address the social determinants of health.
- OMH housing providers also talked about connecting with informal caregivers and families, noting that when these trusted people were available, they were key members of the wrap-around support team needed for individuals living with mental illness to join, return, or remain in their communities.<sup>OMH</sup>

## Facing the challenges ahead

A 2016 report by the National Academies of Sciences, Engineering, and Medicine, *Families Caring for an Aging America*, indicated that:

- Family caregivers of older adults are more likely to exhibit symptoms of depression and suffer from anxiety, stress, emotional problems, and chronic disease.
- Those caring for “significantly impaired” older adults are most likely to be economically harmed by their caregiving, in part because of the many hours of care and supervision and the costs of hiring help.
- Caregivers who quit their jobs or cut back on work to care for a relative or friend lose income and collect less Social Security later, since Social Security is based on income during work years, and save less for retirement.
- Caregivers are often left out of treatment decisions and untrained for complicated tasks, yet are assumed to be available for a broad range of duties.
- Health care and social service systems have not been adequately prepared for the demographic shift that will affect so many older adults and their caregivers.

Yet, the report said, about one-third of caregivers report neither strain nor negative health effects, even when caregiving demands become more intense. They report that caregiving makes them feel good about themselves and as if they are needed, gives meaning to their lives, enables them to learn new skills, and strengthens their relationships with others. It suggested that supporting or helping others may be just as beneficial to health as receiving support.<sup>OMH</sup>



To order a copy of the report, visit: <https://nam.edu/families-caring-for-an-aging-america>.

# Resources:

## Find out more about caregiving services

From the New York State Office for the Aging



New York State Office of the Aging's **New York State Elder Caregiver Support Program** assists informal caregivers in their efforts to care for older persons who need help with everyday task. Visit: <https://aging.ny.gov>.



**NY Connects:** Your Link to Long-Term Services and Supports is a free long-term care information and assistance service. Visit: <https://www.nyconnects.ny.gov>.



The New York State **Office for People with Developmental Disabilities** can help families access services through its Developmental Disabilities Regional Offices. Visit: <https://opwdd.ny.gov>.



**New York State Caregiving and Respite Coalition** is a statewide coalition focused on supporting caregivers, professionals, and providers across New York State. Visit: <http://www.nyscsrc.org>.



The **New York State Kinship Navigator** is an online statewide resource for information and referral. Call (877) 454-6463, or visit: <http://www.nysnavigator.org>.



The **Alzheimer's Association** has a 24/7 helpline to help people with memory loss, caregivers, health care professionals, and others. Call (800) 272-3900, or visit: <https://www.alz.org>.



**Next Step in Care** is an online resource for caregivers and professionals to help make transitions between care settings smoother and safer. Visit: <https://www.nextstepincare.org>.



**AARP Caregiving Resource Center** offers tools, work sheets, and tips on how to plan, prepare, and succeed as a caregiver. Visit: <https://www.aarp.org>.



The **National Alliance for Caregiving** is a non-profit coalition of national organizations focused on improving the lives of family caregivers. Visit: <http://www.caregiving.org>.



OMH News is produced by the OMH Public Information Office for people served by, working, involved, or interested in New York State's mental health programs. Contact us at: [omhnews@omh.ny.gov](mailto:omhnews@omh.ny.gov).

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