

SECTION C

CAREGIVING FOR A LOVED ONE WITH MENTAL ILLNESS

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1. INTRODUCTION: CAREGIVING FOR A LOVED ONE WITH MENTAL ILLNESS

We are glad that *Pathways for Caregivers* has found its way to you and hope you find it a helpful tool.

Pathways is brought to you by **United Way Caregivers Coalition**. It was created by caregivers for caregivers. The *Coalition* is an initiative of **United Way of Northern New Jersey**, which serves Morris, North Essex, Somerset, Sussex, and Warren counties.

Whether you are planning ahead or find yourself in the middle of a crisis with decisions that need to be made quickly, information and resources can often be confusing and difficult to access.

Pathways is intended to be a source for information, advice, and ideas about caregiving. While you will find some organizations referenced, *Pathways* is not meant to be a complete list of all agencies and services available in northern New Jersey. Rather, *Pathways* is designed as a sort of “roadmap” to help put you on the right track for your particular caregiving situation and to support you along the way.

For a complete list of resources in the area, your best bets are **NJ 2-1-1**, each county’s **Department of Human Services’ Mental Health Administrator** and the **Mental Health Association** in New Jersey. You will find these organizations referenced throughout this guide.

As you read through *Pathways*, please keep in mind that it is intended to help caregivers who may be facing a wide range of situations. While planning ahead is important, we recommend that you try to focus on the caregiving stage that you are currently in and not look too far into the future. Sometimes looking too far down the road can be a bit overwhelming.

The most important thing to know is that, as you take on caregiving responsibilities, you need not caregive in isolation. Reach out. Ask for help. Contact the *Coalition* at **888.33.UWCARES (888.338.9227)**. There are resources, organizations, and fellow caregivers who can provide you with the support you need.

Important Reminder!

Information in *Pathways* was current as of printing. Careful effort has been made to provide the most current and accurate information; however information does change. Be sure to double check directly with organizations to confirm the accuracy of information.

If your loved one is over age 60, also see **Section A: Caregiving for an Aging Loved One** for additional information and resources.

2. BECOMING A CAREGIVER FOR A LOVED ONE WITH MENTAL ILLNESS

The onset of a mental illness in any family is often, and understandably, a time of turmoil. Most families report feeling unprepared to deal with the initial onset of a major mental illness in a loved one.

Families generally have little prior knowledge of mental illness and find that they not only have to deal with the upheaval that often accompanies the disease, but that the stigma associated with it further alienates them. Even those normally close – family, friends, coworkers – often do not know how to deal with the mental illness and distance themselves as a result.

The toll that mental illness takes on families is often unspoken. Many who care for a loved one with a mental illness often neglect their own health and care, focusing almost exclusively on the needs of those for whom they support.

In decades past, mental health was a phrase that referred only to mental illnesses. Mental illnesses were shrouded in such shame and stigma that many people neglected emerging mental health issues in others and even in themselves.

Today, much has changed. A “family consumer” movement that started in the early 1980s has raised awareness of many issues. New research has provided tremendous knowledge about the brain, new and effective medications have come to market, and mental health services have improved significantly.

Yet, much remains to be done. People with mental illnesses still face great stigma and discrimination.

Many people are not sure how to judge when a family member or loved one needs professional help for mental health problems. There are some behaviors – especially if they persist, become severe, or significantly impact functioning – that may be signs of trouble:

- Persistent sadness or anxiety
- Feelings of hopelessness, pessimism
- Feelings of guilt, worthlessness, helplessness
- Loss of interest or pleasure in hobbies and activities that were once enjoyed, including sex
- Decreased energy, fatigue
- Difficulty concentrating, remembering, making decisions
- Growing inability to cope with daily problems or activities
- Insomnia, early-morning awakening, or oversleeping
- Appetite and/or weight-loss, overeating, and weight gain
- Persistent physical symptoms not responsive to treatment: headache, chronic pain, digestive disorders, etc.
- Restlessness, irritability
- Mood swings
- Confused thinking
- Delusions or hallucinations
- Thoughts of death or suicide attempts

Any of these symptoms, if persistent for any length of time, may suggest a need for professional help. Fortunately, with early identification and treatment, problems causing such behavior can often be effectively treated.

If you support your loved one in any way on a regular basis – driving to appointments, helping with daily activities, personal care, housework, shopping, managing finances, speaking with doctors, or providing emotional support – you are a caregiver.

The following activities, when done on behalf of another, are traditionally considered “caregiving:”

- Occasional or daily help managing the household (chores, meals, transportation, etc.)
- Financial and/or business assistance (balancing checkbooks, paying bills, etc.)
- Daily supervision and/or personal care
- Organizing medical care (making appointments, transportation, speaking with doctors, translating, etc.)
- Medication management
- Emotional support

Whether your loved one lives with you, in their own home, in a facility, or a long distance away, if you do any of these things regularly, you are a caregiver...and we hope this guide will be of help to you.

While you may do just a few things for your loved one at the moment, it is a good idea to be aware of, and even track, changes that may occur.

Stages of Caregiving

Most caregivers will, over time, experience different stages of caregiving. Coping with these changing stages may require you to develop new skills, manage new stresses, and maintain a level of flexibility as you adapt to your loved one’s changing needs.

Realistically, most caregivers experience a steep learning curve, becoming a medical connoisseur, system navigator extraordinaire, assertive advocate, financial guru, and legal expert all in one. For many, this must be done while balancing a full- or part-time job, children, grandchildren, spouse, and other relationships and responsibilities while trying to maintain their own physical health, mental health, social life, and overall well-being.

Caregiving for a loved one with a mental illness presents a variety of challenges. These challenges can arrive suddenly, with a crisis, or can develop over time through a series of small, but sometimes disconcerting, mishaps and warning signs. You may be the only person providing care or you may be part of a larger network of family and friends willing to share caregiving duties.

Whatever the particular caregiving situation in which you find yourself, you may be unsure of which steps to take. And throughout any caregiving journey, those steps will most likely change.

Life is a journey – each of us can only take one step at a time and try to do our best along the way.

You Are Not Alone

We don't need to tell you that caregiving can be all-consuming, exhausting, frustrating, and even lonely at times. For any caregiver, the stress of providing care can generate a range of emotions on any given day – frustration, sadness, worry, even anger.

So, do not try to do the entire job alone or take on all your caregiving responsibilities in isolation. A strong network of friends, family, service providers, and community resources can support you in your caregiving role while helping you maintain your own well-being. In this guide, you can find the resources and people you need to help you take care of your loved one, and yourself.

Ask for help, whenever you need it. Seeking out information and support will help you provide the best care possible for your family member or friend – and for you. Remember, taking care of yourself means you will be better able to care for your loved one.

Your Changing Role

Throughout your caregiving journey, your loved one may require different levels of care. Having to take on additional responsibilities that your parent, spouse, partner, child, or friend was accustomed to doing independently can generate a range of emotions for you both. Being informed about and understanding your loved one's particular illness will help you cope with transitions and the changing nature of your relationship with one another.

As your caregiving role changes, flexibility will be key.

If and when you are called upon to take on a new level of care, give yourself time to adjust. Do not expect your life to return to normal right away. The social structure you knew, the friends you had, and activities you did may have to change as you take on your caregiving role. Give yourself time to develop and establish new daily routines.

If you do need to take on more and more daily tasks related to caregiving, it will become even more important to take advantage of community resources and any services for which you may be eligible.

Remember that each caregiving situation is unique – no two caregivers experience the same circumstances or transitions. There is no single way of caring. With the right information, resources, and support you will care for your loved one and yourself in the best way possible.

Call Yourself a Caregiver

It is natural for those of us who provide care for a loved one to think of ourselves as just responsible children, spouses, partners, and friends. People don't often refer to themselves as "caregiver" – but they should.

When we embrace the title of caregiver we define our caregiving journey and give scope to the work we do. When we identify as caregiver – to our families, our neighbors, our employers – we help educate the community about the vital role unpaid family caregivers play in our nation’s long-term health care system.

Embracing the new title of caregiver underscores that we are each experiencing a new “job.” It helps us understand the vital importance of training, education, and support – all things that come with any new job. We see more clearly the benefits of connecting with caregiving colleagues. Importantly, we can accept that as caregivers we deserve to take regular breaks – without guilt – from our caregiving work.

All of which help us provide quality care for our loved ones while protecting our own health and well-being.

3. WHERE TO BEGIN: FINDING THE SUPPORT YOU NEED

Where to begin often depends on WHY you are beginning to consider services and support for a loved one. Whether you are just starting to be concerned about a loved one's mental health or you have already been caring for someone with mental health issues, you may not have accessed the network of services available to you yet. The following are some helpful initial contacts for you to consider.

Non-Crisis Situations

If your loved one is developing symptoms which have you concerned, there are "information and referral" agencies that will be able to direct you to the health and human services your loved one will need. Specialists are trained to assess your loved one's needs, determine which provider(s) would be most beneficial, and direct you to them.

If Your Loved One is Under 18-Years-Old

Children and youth between the ages of five and 17 living in the State of New Jersey and who have emotional or behavioral disturbances are eligible for services through the NJ Department of Children and Families (DCF), Division of Children's System of Care (CSOC). Special consideration will be given to children under five years of age.

Young adults ages 18-21 are eligible if the youth is actively involved with Child Welfare, Child Behavioral Health, or Juvenile Justice at the time of their 18th birthday.

PerformCare serves as the statewide contracted system administrator for CSOC. They provide 24/7 customer service/call center support, coordinate access to services for children, youth, and young adults, facilitate access to specialized services, and implement a complaints, resolution, and appeals process.

- **PerformCare**
877.652.7624 (TDD: 866.896.6975)
www.performcarenj.org

If Your Loved One is 18-Years-Old or Older

NJ 2-1-1 offers confidential telephone support to people in crisis and personalized information and referrals to those needing assistance. NJ 2-1-1 operates statewide, connecting people with the resources they need to solve common life problems. It is staffed 24/7 and can be accessed by dialing 2-1-1.

- **NJ 2-1-1**
Dial 2-1-1 or 800.435.7555
www.NJ211.org

Mental Health Administrators

Each county in New Jersey has a mental health administrator who oversees the delivery of publicly funded mental health services and addresses the questions or concerns of individuals with mental illness and their loved ones regarding the mental health system. To find your county administrator, go to:

- www.state.nj.us/humanservices/dmhs/services/admin

Mental Health Association in New Jersey

This organization provides information and referrals, public education, and support services for individuals with mental illness and their caregivers. Some counties also have their own Mental Health Associations.

- **800.367.8850**
www.mhanj.org

New Jersey Mental Health Cares

This is a statewide information and referral service for all types of mental health services.

- **866.202.4357**
www.njmentalhealthcares.org

Counseling/Short-Term Treatment

Outpatient Care

Outpatient care is when an individual or family goes into a professional mental health office for treatment that has been set up on a regular appointment basis, most likely weekly or bi-weekly. Individual, family, and group counseling is provided according to the individual or family's need. Psychiatric services by psychiatrists and/or psychiatric nurses, such as evaluations and medication monitoring, are also usually available.

Inpatient Care

Hospitalization may be needed to allow for a period during which an individual can be closely monitored to provide accurate diagnosis, to help adjust or stabilize medications, or during an acute episode where a person's mental illness temporarily worsens. While seeking help voluntarily is preferable, if possible, the decision to hospitalize involuntarily might be the most helpful option if that is the only way your loved one can get the care he or she needs, especially if there is a risk of suicide or harm to others.

Crisis/Emergency Situations – What to Do

The reality of mental illness is that there may be times when a crisis occurs. You can best help your loved one by knowing the options available for him or her in any given situation.

If your loved one becomes violent, out of control, exhibits threatening behavior toward others or him or herself, or tries to commit suicide, you should immediately call 911. Often 911 responders are the best-equipped, most available resource, especially when there is a strong possibility that the person may harm him or herself or others.

If you feel the situation does NOT warrant a 911 call, the following resources offer crisis response:

If Your Loved One is Under 18-Years-Old

CSOC offers **Mobile Response and Stabilization Services (MRSS)** for emergencies and potential crisis. This service is available 24/7. Clinically trained staff assists callers in getting the services needed as quickly as possible.

MRSS helps keep your child and family safe in an emotional or behavioral crisis, and works to keep your child in their current living situation. The Mobile Response Team will work with your family in your home or community to assess and address the crisis. They will work with you and your child to stabilize the situation and can continue to work with you to develop and manage a plan to help keep your child safely at home.

PerformCare serves as the statewide contracted system administrator for CSOC.

- **PerformCare**
877.652.7624 (TDD: 866.896.6975)
www.performcarenj.org

If Your Loved One is 18-Years-Old or Older

You may choose to contact any of the local hospitals in your area that offer 24/7 Psychiatric Emergency Services (PES), either on site or by hotline. Trained professionals will provide assessment, intervention help, and referral and/or hospitalization, either voluntary or involuntary. (**See Chapter 8, Legal Matters** for additional information.)

*** These locations have mobile screening units that provide psychiatric screenings in the community when deemed necessary.**

Essex County

- **East Orange General Hospital, East Orange ***
Crisis Intervention/Psychiatric Screening Center
973.672.9685 or 973.266.4478
www.evh.org/html/inbehavioral.htm
- **Rutgers University Hospital, Newark ***
Psychiatric Emergency Service/Screening Center
973.623.2323
ubhc.rutgers.edu/crisis/crisis_services.htm
- **Barnabas Health Newark Beth Israel Medical Center, Newark ***
Psychiatric Emergency Screening Service
973.926.7416
www.barnabashealth.org/hospitals/psychiatric/facilities/newark/index.htm

Morris County

- **Morristown Medical Center, Morristown**
Crisis Intervention Services
973.540.0100
www.atlantichealth.org/Morristown/Patient+Care+Services/Behavioral+Health/24-hour+Crisis+Intervention

- **Chilton Memorial Hospital, Pompton Plains**
Crisis Intervention Services
973.831.5078
www.chiltonmemorial.org/emergencydept.shtml#BehavioralHealthServices

- **Saint Clare's Hospital, Denville ***
Psychiatric Emergency Service
973.625.0280, Screening: 973.625.6150
www.saintclares.org/services/services_ak/behavioral/acute/AcuteCare.asp

The Wellness and Recovery Center
973.625.0096 or 888.476.2660
The Center offers an array of services to assist individuals through crisis situations and difficult life circumstances by offering support, education, and linkage to community resources. The recovery-oriented services include crisis intervention, supportive counseling, case management, medication prescription and counseling, peer support, psycho-education, and family intervention to individuals 18 years of age or older who reside in Morris County.

- **Saint Clare's Hospital, Boonton**
Children's Crisis Intervention Services
973.316.1982
www.saintclares.org/services/services_ak/behavioral/acute/AcuteCare.asp

Somerset County

- **Somerset Medical Center, Somerville ***
Psychiatric Emergency Screening Services
908.526.4100
<http://www.co.somerset.nj.us/hservices/hsdept/pess.html>

Sussex County

- **Newton Medical Center, Newton ***
973.383.0973
<http://www.nmhnj.org/Programs.aspx?id=1000&ban=1078>

Warren County

- **Family Guidance Center, Washington ***
Crisis Intervention
908.454.5141
<http://www.familyguidancecenterofwc.org/programs-2/crisis-intervention/>

The Helping Professionals: Who They Are & What They Do

What follows is a brief explanation of the different professionals who help individuals with mental illness. It is important to remember that finding the right professional can be an ongoing process. Always confirm the credentials of a therapist through the appropriate professional association.

Do not hesitate to ask your provider for his or her credentials. The type and range of services provided by nurses, social workers, and counselors vary by educational degree earned and type of licensure.

Psychiatrists

A psychiatrist is a medical doctor who specializes in psychiatric disorders, is licensed to practice medicine, and has completed three years of specialty training. A certified psychiatrist has, in addition, practiced for two years and passed the examinations of the American Board of Psychiatry and Neurology. Psychiatrists can evaluate and diagnose all types of mental disorders, carry out biomedical treatments and psychotherapy, and work with psychological problems associated with medical disorders. Both psychiatrists and advanced practice nurses can prescribe drugs and medical therapies. Child psychiatrists specialize in working with children; geriatric psychiatrists concentrate on helping the aged.

Psychologists

The field of psychology includes many specialties – clinical treatment, testing, community organization, industrial relations, laboratory research, and many more. Psychologists who conduct psychotherapy and work with individuals, groups, or families to resolve problems generally are called clinical psychologists, counseling psychologists, or school psychologists. They work in many settings – for example, mental health centers, hospitals and clinics, schools, employee assistance programs, and private practice. In most states, a licensed psychologist has completed a doctoral degree from a program with specialized training and experience requirements and has successfully completed a professional licensure examination.

Psychiatric Nurses

Psychiatric nursing is a specialized area of professional nursing practice that is concerned with prevention, treatment, and rehabilitation of mental health-related problems. These nurses are registered professional nurses who have advanced academic degrees at the master's degree level or above. They conduct individual, family, and group therapy and also work in mental health consultation, education, and administration.

Advanced Practice Nurses (APN)

APNs are master's prepared registered nurses with advanced training and licensing who provide primary and preventive health care, including mental health and psychiatric services. Some APNs have their own practices, but most work in collaboration with a physician. Advanced practice nurses can prescribe medications, provide psychotherapy to individuals and groups, and order and evaluate laboratory, X-ray, and other diagnostic tests. They work in hospital settings, private practice, mental health centers, schools, and community medical centers.

Social Workers

Individual, family, and group therapy, diagnosis, referral, and consultation are some of the tasks that social workers are trained to perform. Social workers have a bachelor's degree, a master's degree, or a doctoral degree and must take an exam to be licensed to practice social work. Master's level social workers have completed field-placement programs designed to provide hands-on experiences in several areas, including assessment and treatment of mental illness, psychotherapy techniques, community organization, administration, and consultation.

Licensed Professional Counselors (LPC)

LPCs have a master's degree in counseling, psychology, or a similar discipline. They may provide services that include diagnosis and counseling (individual, family/group, or both). They must take an exam to be licensed to practice and may also be certified by the National Academy of Certified Clinical Mental Health Counselors.

Case Managers & Outreach Workers

These individuals assist persons with severe and persistent mental illnesses, including individuals with mental illness who are also homeless, to help them obtain the services they need to live in the community. Most persons who have chronic mental illnesses need medical care, social services, and assistance from a variety of agencies, including those dealing with housing, Social Security, vocational rehabilitation, and mental health.

Because such services are uncoordinated in many areas, case managers provide a critical function to monitor a person's needs and assure that appropriate agencies are involved. In many instances, they also act as advocates for the person who is ill. Case managers can be nurses, social workers, or mental health workers and can be associated with mental health centers, psychosocial rehabilitation programs, or other agencies.

Starting Points for Long-Distance Caregivers

Caring for a loved one from a distance can be logistically demanding, but connecting with the right local resources can certainly help. Consider connecting with the **National Alliance on Mental Illness (NAMI)** as a starting point. NAMI advocates for access to services, treatments, supports, and research. Hundreds of NAMI state organizations and affiliates work in local communities across the country. Contact NAMI to find your local affiliate.

- www.nami.org
www.naminj.org/affiliates.html

The Importance of Being Organized

As you begin your caregiving journey, try to start organizing information right from the beginning. Throughout **Pathways** you'll find helpful hints about how to manage your loved one's medical information, financial information, insurance information, etc. It may seem daunting at first to gather papers and organize folders, but it will save you time and frustration in the long run. For templates, lists, and other resources to help you organize information, visit **United Way of Northern New Jersey's Caregivers Toolbox: UnitedWayNNJ.org/CaregiverTools**.

Additional websites of national organizations with information on caregiving can be found in **Appendix A**.

4. CAREGIVER EDUCATION PROGRAMS

Education & Support Programs

If your loved one with mental illness attends school, see **Section B, Chapter 4** for education information.

Intensive Family Support Services (IFSS)

IFSS is a program that focuses attention on the family system. Support and education are provided to families or significant caregivers of people with serious mental illness. The services offered include: psycho-education, family consultation, support groups, advocacy, referral/service linkage, and respite. An IFSS program can be found in every county.

- **Essex County: Mental Health Association of Essex County, Montclair**
973.509.9777
www.mhaessex.org
- **Morris County: Saint Clare's Hospital, Denville**
973.625.7095
www.saintclares.org/services/services_ak/behavioral/support/IntensiveFamilySupportServes.asp
- **Somerset County: Easter Seals New Jersey, East Brunswick**
908.722.4300
- **Sussex County: Saint Clare's Hospital, Sparta**
201.317.6139
www.saintclares.org/intensive-family-support-services-2/
- **Warren County: Family Guidance Center of Warren County, Washington**
In addition to the above mentioned IFSS services, this program also provides transportation to family members in Warren County who need to go to Greystone Park Psychiatric Hospital to visit loved ones.
908.689.1000, x331 or x330
www.familyguidancecenterofwc.org/programs-2/the-intensive-family-support-services-program-ifss/

Mental Health Association in New Jersey (MHANJ)

MHANJ offers on-site presentations to workplaces, schools, health fairs, businesses, and community organizations. Presentations are conducted by MHANJ staff or other qualified speakers. They can also arrange for an MHANJ staff person or volunteer to speak about a mental health topic from a personal perspective.

- **800.367.8850**
www.mhanj.org

Mental Health Association of Essex County

This organization offers a psycho-educational series for families.

- **973.509.9777**
www.mhaessex.org

Mental Health Association of Morris County

This organization provides public education for individuals with mental illness and their caregivers.

- **973.334.3496**
www.mhamorris.org

National Alliance on Mental Illness (NAMI) New Jersey

NAMI New Jersey provides education, support, and systems advocacy to empower families and persons with mental illness. Affiliate self-help and grassroots advocacy groups located in each county offer emotional support, information, and advice about treatment and community resources. The link to locate each county's affiliate is also below.

- **732.940.0991**
www.naminj.org
www.naminj.org/affiliates.html

United Way *Caregivers Coalition* (Morris, North Essex, Somerset, Sussex, and Warren)

The *Coalition's Munch & Learn Education Series* offers programs on various aspects of caregiving by professionals in the field. Any local group, including area corporations, faith-based organizations, civic groups, etc., may schedule programs. Contact the *Coalition* Coordinator for a list of topics or to schedule a workshop.

- **888.33UWCARES (888.338.9227)**
UnitedWayNNJ.org/CaregiversCoalition

Educating yourself about the disease or disability affecting your loved one is important. There are many disease/disability-specific websites available. Make sure the information you access is from a recognized and trustworthy organization. Some recommended websites can be found in **Appendix B**.

Medicare will pay for certain types of family caregiver education when it is provided as part of a patient's medically-necessary face-to-face visit. A physician may be able to bill for family caregiver education as part of the counseling and coordination of care services provided during a patient visit, as long as the patient is on Medicare, the caregiver education directly involves the patient, and is medically necessary. This education can take place in a doctor's office or other outpatient facility, a patient's home or private residence, or an assisted living facility or other domicile.

See "Tip Sheet for Providers: Caregiving Education" at www.cms.hhs.gov/Partnerships/downloads/ProviderBillingforCaregiverEducation.pdf.

5. CAREGIVER SUPPORT



It is important for caregivers to recognize that they are not alone, to learn that caregiving is more than a one person job, and to see that taking care of themselves is vital to their loved one's well-being.

– *Caregiver Action Network*

Caregivers are characteristically unselfish, patient, and steadfast; however, they are often so busy giving care that they forget or neglect to take care of themselves. In fact, studies show that caregivers are at a greater risk for health problems. As a caregiver, your health – both physical and emotional – is as important as the health of the loved one for whom you provide care.

Self-Care – It's Absolutely Necessary

Caregivers often succumb to feelings of stress and anxiety. Stress is a natural by-product of caregiving. All caregivers experience stress. It can manifest itself in both a physical and emotional way. It is vital to find an outlet to relieve it! You may even need to **give yourself permission to take care of yourself**. That is fine, good, and necessary!

Self-care and stress management can be achieved in many ways. Paying general attention to daily activities like healthy eating, exercising, sleeping, and talking with friends is vital. Be sure to schedule (and keep!) your own doctor appointments. Reach out for support. Simplify and structure your routine. Ask for help. These are vital steps you can take as a caregiver to keep yourself healthy.

Even for the busiest of caregivers, **mini-breaks** can be lifesavers. Go to a quiet room or step outdoors and just breathe for ten minutes; clear your mind and focus only on your breath. Write in a journal. Say a positive affirmation. Light a candle. Listen to music. Call a good friend.

You might consider attending a **support group**, where people share a common experience and provide each other with various types of help, i.e., information, resources, and emotional support. Support groups can be led by a professional facilitator or be self-help groups.

As caregivers we may, at times, disagree with decisions made by our loved ones and even blame ourselves if the care we want to provide is not accepted. However, it is often helpful to be flexible in approach and to accept, even support, your loved one's decisions, as long as those decisions do not include truly dangerous choices. **Keep in mind – things will never be perfect, and they don't need to be.**

Other ideas may be helpful. These require a range of time and/or cost. Sometimes referred to as complementary or alternative therapies, there are options for everyone:

- **Aromatherapy** uses liquid plant oils and aromatic compounds to improve mood and health.
- **Art therapy** is based on the belief that the creative process is both healing and life enhancing. It uses art materials and projects as therapeutic tools.
- **Chiropractic** is a health care discipline that believes that realignment of the spine will alleviate any nerve interference that directly affects how stress manifests itself in the body. This can be especially helpful if you are physically moving your loved one from place to place, which takes a toll on your body; a chiropractor can teach proper lifting techniques that best protect your back.
- **Massage therapy** is several disciplines that utilize body techniques to promote healing.
- **Music therapy** is the systematic use of music to improve one's emotional stability.
- **Reiki** is a system of subtle energy healing using the laying on of hands and distinct healing techniques, designed to relax, destress, and heal.
- **T'ai Chi** is a slow, gentle body movement that helps the flow of body energy by breathing deeply and meditating. The gentle flowing motion reduces stress and improves health.
- **Yoga** is a physical and mental discipline, and also a lifestyle practice, the goal of which is the union of the mind, body, and spirit.

These are examples of some types of therapies that can help you manage your stress, as well as reduce pain, anger, anxiety, and even depression. Choose one or more that is right for you. Whether relaxing muscles and reducing inflammation, improving strength, balance, and mobility, or getting a more restful sleep...these are all critical ingredients of self-care that will help you protect your own emotional and physical health as you continue your caregiving journey.

Support for Caregivers

Family Support Organizations

The Family Support Organizations are family-run organizations devoted to the needs of families whose children have emotional and behavioral challenges. Families receive peer support, information and referral services, education, and advocacy within a compassionate and culturally sensitive environment. Assistance is also offered in helping caregivers navigate the complex public children's mental health system in New Jersey.

- **Essex County**
973.395.1441
www.fsoec.org
- **Hunterdon, Somerset, Warren counties**
908.213.9932
- **Morris and Sussex counties**
973.940.3194
<http://fso-hsw.org/>

Intensive Family Support Services (IFSS)

IFSS programs provide services and support groups for those who have an adult family member who has a mental illness:

- **Essex County: Mental Health Association of Essex County, Montclair**
973.509.9777
www.mhaessex.org
- **Morris County: Saint Clare's Hospital, Denville**
Parent Support Groups
Weekly support group for relatives or caregivers of an individual with depression or bipolar disorder.
973.625.7069
- **Family/Caregivers Support Groups**
Weekly support group for any family member or caregiver of an individual with mental illness.
973.625.7131
- **Family Workgroup**
Group designed to assist families and work through concerns with a problem-solving model.
973.625.7095 or 973.625.7069
www.saintclares.org/services/services_ak/behavioral/support/IntensiveFamilySupportServices.asp
- **Somerset County: Easter Seals New Jersey, East Brunswick**
908.722.4300
- **Sussex County: Saint Clare's Hospital, Sparta**
201.317.6139
www.saintclares.org/intensive-family-support-services-2/
- **Warren County: Family Guidance Center of Warren County, Washington**
Runs free support groups on a bi-weekly basis in Phillipsburg, NJ and Washington, NJ.
Also provides transportation to family members in Warren County who need to go to Greystone Park Psychiatric Hospital to visit loved ones.
908.689.1000, x331 or x330
www.familyguidancecenterofwc.org/programs-2/the-intensive-family-support-services-program-ifss/

Mental Health Association of Morris County: Concerned Families for the Mentally Ill

Information and referral, phone support, and bimonthly newsletter for families who have a loved one with mental illness.

- **973.334.3496**
www.mhamorris.org

United Way *Caregivers Coalition* (Morris, North Essex, Somerset, Sussex, and Warren)

Open to the public and free to join, the *United Way Caregivers Coalition* is a unique hub of information, education, and connection for caregivers. Made up of caregivers and professionals who support them, the *Coalition* helps caregivers find the specific services they need and connect with peers and professionals who share experienced advice. Those who tap into the *Coalition* report reduced stress, enhanced skills, improved access to resources, a renewed commitment to self-care, and meaningful connection to one another. All are welcome. *Coalitions* meet monthly in each county.

- **888.33UWCARES (888.338.9227)**
UnitedWayNNJ.org/CaregiversCoalition

Caregiver Counseling/Psychotherapy

There are many counseling and support services available in our region through local hospitals, human service agencies, and private practitioners. People with insurance should check with their insurance company to ensure that the provider is in their network.

New Jersey Mental Health Cares

This is a statewide information and referral service for all types of mental health services.

- **866.202.4357**
www.njmentalhealthcares.org

Aging & Disability Resource Connection of New Jersey (ADRC)

The ADRC is New Jersey's doorway to information and assistance for older persons, adults with disabilities, caregivers, and professionals looking for services and programs, and is a good portal for referrals to counseling services. Contact your county's ADRC for local information. Phone is staffed weekdays during normal working hours.

- **877.222.3737**
www.adrcnj.org

Other Supports for Caregivers

Self-Help Groups

Self-help groups can be of great help to anyone coping with the demands of caregiving. There are many local, state, and national groups that can be found by contacting the NJ Self-Help Group Clearinghouse. If the Clearinghouse cannot direct you to an appropriate group that is already set up, they will help you join with others to start one.

- **NJ Self-Help Group Clearinghouse**
800.367.6274
www.njgroups.org

Internet Support

If you are unable to attend support groups in your community, these websites may offer support:

- www.caringroad.org
- www.strengthforcaring.com
- www.caregiveraction.org
- www.caregiver.org
- www.caregiving.org
- www.wellspouse.org

6. CASE MANAGEMENT FOR LOVED ONES WITH MENTAL ILLNESS

Case managers work with individuals and their caregivers, developing individualized service plans tailored to help the person who is ill manage their illness and improve their quality of life.

Case managers do a comprehensive assessment. They are experts on available resources and help arrange for and coordinate necessary services. The case manager ensures that services continue to meet the needs over a period of time and reassesses for changes that may require additional services or readjustments in the care plan. He or she acts as an advocate for the person with mental illness.

Integrated Case Management Services (ICMS)

The purpose of ICMS is to assist adults with serious and persistent mental illness to live successfully in the community after discharge from a psychiatric hospital. Case management remains available to every individual discharged from a psychiatric hospital for at least 12 months after their discharge.

The program includes personalized outreach and linkage to available resources. ICMS, on a limited basis, provides case management services to individuals in the community who have not been hospitalized in state psychiatric hospitals but are in need of supportive services.

- **ICMS – Essex County: Mental Health Association of Essex County**
973.676.9111
www.mhaessex.org/case-management.html

- **ICMS – Morris County: Mental Health Association of Morris County**
973.334.3496, x106
www.mhamorris.org

- **ICMS – Somerset County: Easter Seals New Jersey**
908.722.4300, x611
http://nj.easterseals.com/site/PageServer?pagename=NJDR_IntegratedCaseManagementServicesICMS

- **ICMS – Sussex County: Bridgeway Rehabilitation Services of Sussex County**
973.383.8670
www.bridgewayrehab.com/community-support.shtml

- **ICMS – Warren County: Easter Seals New Jersey**
908.689.6600
http://nj.easterseals.com/site/PageServer?pagename=NJDR_IntegratedCaseManagementServicesICMS

Program of Assertive Community Treatment (PACT)

Provides intensive in-home treatment for individuals who have been frequently hospitalized and who have continually dropped out of traditional community mental health services. PACT is available for as long as needed. The program involves a multi-disciplinary team approach including crisis intervention, daily medication monitoring, and counseling available 24/7.

- **PACT– Essex County: Mt. Carmel Guild Behavioral Health Care**
973.466.1300
www.ccannj.com/PACT.php

- **PACT – Morris & Sussex counties: Saint Clare’s Behavioral Health**
973.625.7138 or 800.565.7228
www.saintclares.org/services/services_ak/behavioral/CommunityBased.asp

- **PACT – Somerset County: Bridgeway Rehabilitation Services**
908.704.8252
www.bridgewayrehab.com/pact.shtml

- **PACT – Warren County: Bridgeway Rehabilitation Services**
908.835.8660
www.bridgewayrehab.com/pact.shtml

Safety, Abuse & Other Important Care Issues

See **Section D, Chapter 2, Keeping Your Loved One Safe**, for important safety information, including what to do in instances of abuse or domestic violence, how to keep a wandering loved one from getting lost, information about guardianship, how to obtain official identification for your loved one, and more.

7. BENEFIT PROGRAMS FOR LOVED ONES WITH MENTAL ILLNESS

If your loved one is over age 60, please also see **Section A, Chapter 7** for additional benefits information.

Key Benefit Programs

There are a wide range of programs directed toward older adults and people living with disabilities or mental illness. There are public programs on the national, state, and local levels. Everyone over a specific age is eligible for some, while for others a person must meet specific criteria or live in a particular county. It is important to ensure that the loved one for whom you are caring apply for the programs for which he or she is eligible so that the assistance needed can be obtained.

BenefitsCheckUp

Sponsored by the National Council on Aging, this comprehensive online resource helps screen for more than 2,000 federal, state, and local programs in all 50 states and provides detailed information and how to apply. Types of programs included can help with medications, food, utilities, health care, housing, in-home services, and transportation.

- www.benefitscheckup.org

NJ Helps

The NJ Helps Services website is designed to give consumers a one-stop shopping resource for the wide range of programs, information, and services provided by the US Department of Human Services and its partners to assist individuals, families, and communities throughout New Jersey.

- www.njhelps.org

As a caregiver for a loved one, you should review and organize all key financial information (including tax and insurance information) and keep it in an easily accessible place. Let a person you trust know where this information can be found. For documents that can help you organize information, visit **United Way of Northern New Jersey's Caregivers Toolbox: UnitedWayNNJ.org/CaregiverTools**.

Social Security Programs

Social Security is the short name for the **Title II Old Age, Survivors and Disability Insurance** programs. It insures individuals and family members when the working family member retires, dies, or becomes disabled. Workers qualify for benefits by paying Social Security taxes. As you work and pay taxes, you earn "credits" that count toward eligibility for future Social Security benefits.

The major categories of benefits paid for through your Social Security taxes are:

1. Social Security Retirement Benefits

Social Security is a federal program providing retirement income for those who have paid into the Social Security system. Note that the “normal” retirement age is being gradually increased from age 65 to age 67. You can get Social Security retirement benefits as early as age 62, but if you retire before your full retirement age your benefits will be permanently reduced based on your age. For example, if you retire at age 62 your benefit would be about 25 percent lower than what it would be if you waited until you reach full retirement age. **NOTE:** Sometimes health problems force people to retire early. If you cannot work because of health problems, you should consider applying for Social Security disability benefits. The amount of the disability benefit is the same as a full, unreduced retirement benefit. If you are receiving Social Security disability benefits when you reach full retirement age, those benefits will be converted to retirement benefits.

For caregivers, the important aspects of Social Security involve the application process, taxation, and appeals. Upon application, Social Security will check their records to determine the exact benefit rate. This rate is a function of age and amount of reportable earnings. Once receiving a benefit, the checks increase automatically with the cost of living.

If your loved one is not able to manage his or her own financial affairs, you or another trusted individual can be appointed as a “representative payee” to handle Social Security matters. The benefits are then made payable to the representative payee who must use the funds for the personal care and well-being of the beneficiary. Records and receipts must be kept to show how the money was spent or saved. This must be reported to the Social Security Administration.

NOTE: Some people have to pay federal income taxes on their Social Security benefits. This only happens if the beneficiary has other substantial income such as wages, interest, dividends, and other taxable income that must be reported on the tax return in addition to Social Security benefits.

2. Social Security Disability Insurance (SSDI)

Your loved one’s mental illness may qualify as a disability. The definition of disability under Social Security is different than other programs. Social Security pays only for total disability. No benefits are payable for partial disability or for short-term disability. Disability under Social Security is based on a person’s inability to work. An individual is considered disabled under Social Security rules if he/she cannot do work that he/she did before, and the individual cannot adjust to other work because of his or her medical condition(s). Benefits can be paid to people at any age who have enough Social Security credits and who have a severe physical or mental impairment that is expected to prevent them from doing “substantial” work for a year or more.

SSDI Benefits for Adults with a Disability Since Childhood

The SSDI program pays benefits to adults who have a disability that manifested itself before age 22. This SSDI benefit is paid on a parent’s Social Security earnings record.

For an adult with a disability to become entitled to this “child” benefit, one of his or her parents:

- Must be receiving Social Security retirement or disability benefits, or
- Must have died and have worked long enough under Social Security

These benefits are also payable to an adult who received dependent's benefits on a parent's Social Security earnings record prior to age 18, if he or she is disabled at age 18. The disability decision is made using the disability rules for adults. SSDI disabled adult "child" benefits continue as long as the individual remains disabled. Your child does not need to have worked to get these benefits.

3. Social Security Family Benefits

It is important for families to know that if their family member is eligible for retirement or disability benefits, other members of the family might receive benefits, too. If the spouse is at least 62 years of age or under 62 but caring for a child under age 16 or a child with a disability, he or she may also be eligible for benefits. Unmarried children age 18, age 19 but still a full time student who has not yet graduated from high school, or 18 or older with a disability may also be eligible. Former spouses if they are age 62 or older and unmarried may qualify for benefits if the marriage lasted for at least 10 years.

4. Social Security Survivor Benefits

Certain members of your family may be eligible for benefits if the family wage earner dies. The family members who may be eligible include: a widow(er) age 60 or older, 50 or older if disabled, any age if caring for a child under age 16, unmarried children under age 18, under 19 but still in school, or 18 or older with a disability. Parents may also be eligible to receive benefits if they are at least 62-years-old and if the deceased provided at least one half of their support. A special one-time payment of \$255 may be made to the spouse or minor children. If divorced, an ex-spouse could be eligible for a widow(er)'s benefit.

Supplemental Security Income Benefits (SSI)

Supplemental Security Income (SSI), often also referred to as Social Security, is a Federal income supplement program funded by general tax revenues and not Social Security taxes. It provides a minimum income to low-income people who are 65 or older, blind, or disabled. Where Social Security is an insurance program requiring "paying into system," SSI is a needs based program. The basic SSI benefit is a monthly cash payment. Living arrangements or monetary assistance from friends or family may reduce benefits. The monthly benefit rate varies depending on the state you live in. Most people who get SSI also qualify for Medicaid, food stamps, and other assistance.

It is important that the caregiver or recipient monitor SSI payments; they should report any change in a situation, any overpayment, underpayment, etc. If an underpayment is discovered, you are entitled to retroactive benefits. While there is no time limit to reporting an underpayment, appeals of agency decisions must be filed within 60 days of the date of the decision.

For more information on any of these benefits, or to apply for Social Security or SSI payments, visit your local Social Security office, or call:

- **Social Security Administration**
800.772.1213
www.ssa.gov

SSI rules for children under the age of 18: If your loved one is under the age of 18, please see **Section B, Chapter 7** for information relating to Social Security benefits for minors.

Medicare & Medicaid Programs

Reminder! Information in *Pathways* was current as of printing. Careful effort has been made to provide the most current and accurate information; however information does change. Be sure to double check directly with organizations to confirm the accuracy of information.

Medicare

Medicare is a federal program of health insurance. It pays for acute illness situations. It is not designed to provide benefits for long-term or custodial care. To be eligible, one must be 65 years of age and have paid into the Social Security system. If the person you care for is 65 or older and is already receiving Social Security benefits, he or she will be enrolled automatically in Medicare. Individuals receiving Social Security Disability benefits will get Medicare coverage automatically after they have received disability benefits for two years. If he or she is not already receiving Social Security, you will need to call the Social Security Administration.

Note: If an individual does not sign up for Medicare when first eligible, he or she may have to pay a penalty or a higher premium to sign up later. Open enrollment occurs each year, from mid-October until mid-December. During that time, each Medicare enrollee is encouraged to review all their options for coverage for the coming year.

Medicare Part A

Part A is primarily hospital insurance. Following payment of a deductible, Medicare Part A will pay patient expenses for 60 days of hospitalization. After 60 days, the patient is required to pay a greater amount of the hospitalization cost. Part A will help pay, in certain circumstances, for stays in skilled nursing facilities, home health care, and hospice care. Most people do not have to pay a monthly premium for Part A.

Medicare Part B

Part B pays for doctors' services, outpatient care, outpatient physical and speech therapy, some home health care, ambulance services, and some medical equipment and supplies. Medicare Part B also covers preventive services. Part B is optional and requires a monthly premium. There is also an annual deductible that must be met before Medicare starts to pay its share.

Medicare Advantage Plans (also Known as MA Plans or Medicare Part C)

Medicare Part C offers Medicare Advantage Plans that combine your Medicare Part A (Hospital) and Part B (Medical). Private insurance companies approved by Medicare provide this coverage. In some cases the premiums and/or copays can be lower than in the original Medicare plans. Medicare Advantage Plans offer a number of types of plans including Preferred Provider Organization (PPO) Plans or Health Maintenance Organization (HMO) Plans. There is also the Private-Fee-for-Service (PFFS) and the Special Needs Plan (SNP). These plans coordinate your loved one's medical care with some plans having stricter network and referral requirements than others. Many of the plans include Medicare Part D (Prescription Drug coverage). It is important that you read the plan information carefully to ensure you are selecting the right plan for you or your loved one.

Medicare Prescription Drug Plan Part D

Medicare offers prescription drug coverage for everyone with Medicare. This is called Part D. This coverage may help lower prescription drug costs and help protect against higher costs in the future. It can give you greater access to drugs that you can use to prevent complications of diseases and stay well. These plans are run by insurance companies and other private companies approved by Medicare. Part D is optional.

If your loved one joins a Medicare drug plan, they usually pay a monthly premium. If they decide not to enroll in a Medicare drug plan when first eligible, there will be a penalty if they choose to join later. If your loved one has limited income and resources, they might qualify for extra help paying for Part D costs.

This is only a general overview of the system. Individual circumstances and situations will vary. For more information, or a comprehensive look at the details of this program:

- **Centers for Medicare & Medicaid Services (CMS)**
800.MEDICARE
www.medicare.gov

Medigap

Medigap is also called “supplemental insurance.” Generally, a person must have Medicare Part A and Part B to buy a Medigap policy. There is a monthly premium for Medicare Part B. In addition, a premium must be paid to the Medigap insurance company. A Medigap policy is health insurance sold by private insurance companies to fill the “gaps” in original Medicare Plan coverage. Medigap policies help pay some of the health care costs that the original Medicare Plan doesn’t cover. If your loved one is in the original Medicare Plan and has a Medigap policy, then Medicare and your Medigap policy will pay both their shares of covered health care costs.

- <http://www.medicare.gov/find-a-plan/questions/medigap-home.aspx>

The State Health Insurance Assistance Program (SHIP)

SHIP is a statewide program that provides free, objective information and assistance about Medicare, Medigap, and other Medicare insurance plans. Trained volunteer counselors are available to help you make informed choices. To contact counselors:

- **800.792.8820**
www.state.nj.us/humanservices/doas/services/ship

Medicaid

In October 2012, the US Department of Health & Human Services, Centers for Medicare & Medicaid Services approved New Jersey’s request for a **Comprehensive Medical Waiver (1115)**. This waiver will completely overhaul New Jersey’s Medicaid program in order to give the state more flexibility in delivering Medicaid, as well as the opportunity to maintain or improve patient care at lower costs. It will expand existing managed care programs to include managed long-term services and supports, and expand home- and community-based services to some populations.

The changes to the program have implications not just for poor families eligible for Medicaid, but also for seniors facing the prospect of a nursing home, those that obtain behavioral health or addiction services from the state, and New Jersey residents with developmental disabilities.

New Jersey's Department of Human Services (DHS), Division of Medical Assistance and Health Services (DMAHS) is in the process of developing a **Medicaid Managed Care Program (MMCP)** that will rebalance long-term care services, improve healthy outcomes and quality care, and protect consumer choice and independence.

Also, when the new **Comprehensive Medicaid Waiver (1115)** fully goes into effect, anticipated to be by late 2014, four current Medicaid Waiver Programs will be absorbed into **MMCP's** four contracted **Managed Care Organizations (MCOs)**.

The Waivers being absorbed are: **Global Options (GO) Waiver, AIDS Community Care Alternative Programs (ACCAP) Waiver, the Traumatic Brain Injury (TBI) Waiver, and the Community Resources for People with Disabilities (CRPD) Waiver.**

The current **Community Care Waiver (CCW)** will switch from the Division of Developmental Disability to the Division of Disability Services.

As this process moves towards completion and implementation, you may obtain further consumer and client information and updates, on this and all aspects of New Jersey Medicaid, by contacting New Jersey Medicaid directly.

Your county Medicaid offices can also help you with information on applying for Medicaid. These offices are usually found within the county's welfare agency or Board of Social Services. Contact information for your county can be found at:

- **NJ Medicaid**
800.356.1561
www.state.nj.us/humanservices/dmahs/clients/medicaid/

Community Care Medicaid Waiver (CCW) (Switching to Division of Disability Services in 2014)

This waiver is for individuals registered with the NJ Division of Developmental Disabilities (the disability had to have manifested before the age of 22) that are Medicaid eligible. The program pays for the services and supports they need to live in the community. Services offered by the program include: case management, rehabilitation, individual supports, environmental and vehicle accessibility adaptation, personal emergency response system, and respite care. (Use the Division of Developmental Disabilities contact information until the switch to Division of Disability Services goes into effect, after which, contact the Division of Disability Services.)

- **NJ Division of Developmental Disabilities, regional office**
973.927.2600
www.state.nj.us/humanservices/ddd/index.html
- **NJ Division of Disability Services**
888.285.3036
<http://www.nj.gov/humanservices/dds/home/index.html>

Medicaid's Personal Preference

This program allows Medicaid eligible individuals who are now receiving or eligible to receive Personal Care Assistant (PCA) services to direct and manage their PCA services. Program participants work with a consultant to develop a Cash Management Plan that is used to identify the services needed and the individual/agencies they want to hire to provide the services. The program requires greater consumer responsibility, but offers participants greater control, flexibility, and choice. If a participant is cognitively impaired or is unable to make decisions on their own, a representative can assist them.

- **NJ Division of Disability Services**
888.285.3036
<http://njgov/humanservices/dds/projects/ppp/>

State Children's Health Insurance Program (SCHIP)

The State Children's Health Insurance Program enables states to provide health insurance to children from working families with incomes too high to qualify for Medicaid, but too low to afford private health insurance. The program provides coverage for prescription drugs, vision, hearing, and mental health services and is available in all 50 states and the District of Columbia. Your state Medicaid agency can provide more information about this program or for more information:

- **877.543.7669**
www.njfamilycare.org/index.html

8. LEGAL MATTERS RELATING TO LOVED ONES WITH MENTAL ILLNESS

A list of key legal terms relating to caregiving as well as templates and lists for organizing documents and important information can be found online at **United Way of Northern New Jersey's Caregivers Toolbox: UnitedWayNNJ.org/CaregiverTools**.

The following is intended as a general informational overview of legal issues that caregivers should consider as they care for a family member or friend with mental illness and does not constitute legal advice. For specific legal advice, always seek professional counsel.

Voluntary Psychiatric Admission

When it is determined that inpatient treatment is warranted, the patient may sign him or herself into a mental health facility on a voluntary basis. At a later time, the patient may sign out at will. In New Jersey, mental health facilities delay release for 48 hours. During this time, the mental health facility can initiate involuntary commitment to treatment proceedings if it is believed that the patient is unable to provide basic care for him or herself or if the patient is dangerous to themselves, others, or property because of his or her mental illness. In addition, the mental health facility must also believe that the patient is not likely to seek and/or benefit from outpatient mental health treatment.

Involuntary Commitment to Treatment

The Legislature in New Jersey finds that the state is responsible for providing care, in the least restrictive environment possible, to individuals who meet the involuntary commitment to treatment criteria, namely, if dangerous to themselves, others, or property because of their mental illness.

Involuntary Outpatient Commitment to Treatment (IOC)

Involuntary Outpatient Commitment refers to a mental health law that provides for the compulsory, community-based treatment of individuals with mental illness who (a) are not willing to receive treatment voluntarily; (b) do not meet criteria for involuntary inpatient hospitalization (imminently dangerous to self or others due to a mental illness); and (c) are likely in the foreseeable future to become dangerous to self or others due to a mental illness. Treatment must be appropriate to the person's condition and in the least restrictive environment. Outpatient treatment may include, but is not limited to, day treatment services, case management, residential services, outpatient counseling and psychotherapy, and medication treatment.

Since becoming effective in New Jersey on August 11, 2010, programs are being implemented gradually throughout the state. In the United Way of Northern New Jersey region, only Essex and Warren counties have IOC programs to date.

- **Mental Health Association of Essex County**
973.509.9777
- **Family Guidance Center of Warren County**
908.454.5141

Privacy and Confidentiality

During treatment or the helping process, clients will often disclose private and sensitive information that they may not reveal to anyone else. Confidentiality refers to the protection of client communications, records, and information received and kept by the mental health professional or the agency. Agencies and mental health professionals are governed by policies and/or professional codes of ethics that oversee each client's right to privacy and confidentiality.

Confidential information is usually only disclosed after the client has signed consent, authorizing the release or sharing of confidential information.

Criminal Justice System

Mental Health Association of Essex County – Collaborative Justice Services (CJS)

CJS provides jail diversion as an alternative to incarceration. Forensic case management services assist consumers in their recovery by connecting them to needed services and resources. The case manager also provides effective discharge planning, linkage, and referral to community resources for mentally ill offenders who re-enter the community following their release from the Essex County Correctional Facility.

- **973.509.9777**
www.mhaessex.org

Mental Health Association of Morris County – Forensic Liaison Services

The Mental Health Association of Morris County's Forensic Liaison Services provides case management services to individuals with mental illness who have been involved in the criminal justice system, connecting them with appropriate resources.

- **973.334.3496**
www.mhamorris.org

Warren County Prosecutor's Office Mental Health Program

In cases where individuals have serious mental health illness that contributed to the commission of a non-violent offense, the Warren County Prosecutor's Office Mental Health Unit works with defense attorneys and mental health providers to develop a plan focused on treatment with the intent of a rehabilitative sentence. The individual needs to voluntarily apply for the program.

- **908.475.6275**

General Legal Considerations

It is important that the person for whom you provide care understands his or her legal rights and that they take the necessary steps to protect themselves and their interests. Depending on circumstances, it may be important for you, as the caregiver, to be involved as well in legal matters. Of course, the depth of your involvement may change as care needs increase.

If your loved one with mental illness is also a senior, there are a variety of elder law issues to consider as well. **(See Section A, Chapter 8)**

The following is intended as a general overview of law and other legal issues that caregivers should consider as they care for their loved one.

Legal Capacity

A starting point for legal documents is having the mental capability to understand the meaning and importance of these documents. Stated differently, legal capacity is the level of judgment and decision-making needed to create legally binding wills, trusts, and powers of attorney.

Legal Services

Some free civil legal services are available to low-income residents through:

Legal Services of New Jersey (LSNJ)

LSNJ is a nonprofit organization that provides legal information, advice, and referral to low-income residents of New Jersey with civil legal problems. LSNJ has offices in all 21 New Jersey counties and a hotline intake worker will refer you to a local office for assistance.

- **888.LSNJ.LAW (888.576.5529)**
www.lsnj.org

Key Legal Documents & Issues

Helping to organize your loved one's legal documents is a big, but critical job. It may take time to gather all the information you need and to maintain and update documents over time, but the peace of mind that comes with having these documents in order is worth all the effort.

Power of Attorney

A power of attorney is a legal document transferring decision-making authority to a person ("agent") designated by your loved one in advance. The power can be related to the management of your loved one's property or related to decisions about medical treatment.

A “durable” power of attorney goes into effect when your loved one signs it and stays in effect for their lifetime unless they cancel it. Your loved one must put specific language in the document stating that they want their agent’s power to stay in effect even if they become incapacitated. A “springing” power of attorney is another option, but this document only becomes effective when a specific event happens, such as when your loved one becomes incapacitated. Your attorney must carefully draft a “springing” power of attorney to avoid any difficulty in determining exactly when the “springing” event has happened.

Unlike many other uses of the term “disability,” which might refer to a physical disability, when the term is used within a power of attorney, “disability” means lacking mental capability to manage property or make decisions about medical treatment. A person in a coma would be an obvious example of having a disability and being unable to make decisions on his or her own.

Caregivers should be aware of what, who, and where powers of attorney have been provided. These documents should be current, accessible, and understood by the caregiver.

Power of Attorney Over Financial Decisions – See Section D, Chapter 5

Power of Attorney Over Medical Decisions

The power of attorney over medical decisions appoints a person to represent your loved one in making medical decisions for him or her. It defines the limits and extent of such power. **Other terms used to describe a power of attorney over medical decisions are “power of attorney for health decisions,” “health care proxy,” “medical directive,” and “advanced directive for health care.”**

Caregivers should also be aware of some key laws governing medical directives. The Patient Self Determination Act ensures that all adult patients know the extent of their right to control health care decisions, particularly through the use of health care directives.

A living will is a type of advanced directive related to medical decisions for the terminally ill. The living will comes into play when a person’s condition is terminal with no expectation of recovery. The living will sets forth the type of medical care, the extent of life support, the possible removal of life support, and instructions as to how and where your loved one would like to be cared in the final stage of life.

The New Jersey Advance Directives for Health Care Act requires a doctor or hospital to find out if your loved one has any advanced directives.

Finally, make sure that all those named in your loved one’s power of attorney are aware, have a copy of the document, and have access to the original should they ever need to act for your loved one under that power. Also, make sure to have one or two back-ups named on these documents.

Living Will

A living will, as mentioned above, is a type of directive providing comprehensive instruction as to the medical situations where a patient would want to be kept alive and what measures should or should not be used to prolong life or delay death.

A living will is a critical legal document for you, the caregiver, as it clearly articulates the wishes of your loved one. Without such instruction you, as the caregiver, could be left speculating as to how, when, and to what extent your loved one wants medical means to continue or not continue his or her life. Your loved one's guidance is most instructive and important. His or her directions go a long way to help ease your burden in carrying out decisions that your loved one may not be able to make independently.

Psychiatric Advanced Directive (PAD)

A PAD is a legal document that allows an individual with mental illness to direct who will make health care decisions for them and to state their wishes for mental health treatment if they become unable to make decisions for themselves in the future. The psychiatric advanced directive may be used to accept or refuse any procedure or treatment. Like advance directives for end-of-life care, PADs are either instructional (living will) and/or agent driven (durable power of attorney). PADs offer an approach to personal empowerment and crisis prevention that is not widely used as of yet.

Will

A will is an important document for anyone. Caregivers should be familiar with the uses of a will.

A will is the written statement of a person's wishes as to the disposition of his or her property following death. It takes effect upon death. Up until death (providing mental capacity as discussed above), a will can be amended or revoked.

In legal terms, the person whose will it is is known as the “**testator.**”

To make a valid will, the person must possess the mental capacity to know what he or she is doing. It is not an excessively high standard of “awareness,” but does require awareness of some essential facts. For example, does the person know if they are married and if their spouse is alive? If they have children, can they name them, know approximately how old they are, and where they live? Do they know, roughly, what they own, such as houses and bank accounts, and do they understand that the purpose of a will is to leave the things they own to the person whom they name in the will? If the person cannot be conversant about such basic facts, more than likely they do not have the mental capacity to execute, modify, or rescind a will.

Capacity is measured at the time a person makes and signs his or her will. This is important as many elders, who may be beginning to lose mental capacity, may have good days and bad days. As long as the person makes the will or changes to the will on a day in which they had mental capacity to understand what they were generally doing, and this can be later proven, then the legal system will uphold the wishes of the “testator.”

A will accomplishes a number of important issues: a) a will allows for the nomination of an executor; without a will, the state would determine who is to serve as executor of your loved one's estate; b) a will avoids “intestacy.” Intestacy is where, in the absence of a will, state law dictates who inherits a person's probate assets; c) a will allows a person to define who gets what property. Often a person wants to provide a specific person with a specific item of property. A will allows for such special bequests. A person may want to distribute property unequally to children, as children often have different needs; a will allows for such unequal distributions. A person may want to disinherit a natural heir; a will allows for disinheritance; d) a will allows for the nomination of a guardian or trustee, if the person dies with minor children.

As stated above, a will dictates who inherits your loved one's "probate assets." Not all assets are "probate assets." That depends upon how the assets are owned. Assets which are "not" probate assets pass directly to the person named as "beneficiary" or co-owner of the asset. Examples of assets which could pass directly and avoid probate would be joint accounts, assets in a revocable living trust, pay-on-death accounts, transfer-on-death accounts, annuities with a named beneficiary, life insurance with a named beneficiary, certificates of deposits with a named beneficiary, individual retirement accounts with a named beneficiary, and assets jointly owned ("tenancy by entireties").

It is important to note that many of these assets have a "named beneficiary," which should be reviewed annually as life changes.

Trusts

A trust is a contractual three party arrangement where one person transfers property to another person to hold in trust for the benefit of a third person. While that may sound confusing, a properly designed trust accomplishes as much as a will, while providing a greater flexibility for life and estate planning. A trust may be "revocable" or "irrevocable." A trust may be created while your loved one is living (living trust) or created via a will (testamentary trust).

Irrevocable Trust

An irrevocable trust cannot be amended or changed. The person transferring the property (the "trustor") cannot later change his or her mind. There are tax and planning reasons why a person would transfer property through an irrevocable trust.

Revocable Trust

A revocable trust can, by its definition, be amended or changed. Like a will, the person transferring the property can change his or her mind or change the terms of the trust. It is completely flexible. As such, a revocable trust serves a wide variety of needs related to lifetime planning, extending control over your loved one's estate following death, and minimizing succession transfer costs, such as probate avoidance and reduction of estate taxes.

A "living" trust is generally "funded" by the "grantor" or trust maker. This simply means that the "grantor" has transferred assets currently owned into the trust. Examples of property to be placed or funded into a living trust would be real estate, annuities, stocks, bonds, and bank accounts. Vehicles can be owned by the trust depending on the situation. Special tax deferred investment accounts such as IRAs and pension rights are usually not owned by a revocable living trust, but can be assigned to a trust.

A revocable living trust does all that a will does, plus more. It allows for the continued management of your loved one's assets should he or she become disabled due to mental illness or another disability. A trust avoids the need, delay, and cost of probate. A will becomes a public document; a trust does not and, thus, is a way to keep your loved one's affairs more private.

Special Needs Trust

A person with a disability, including mental illness, and receiving government benefits is sometimes limited as to the amount of assets that they can directly own. A Special Needs Trust is developed to manage resources while maintaining the individual's eligibility for public assistance benefits.

Two types of Special Needs Trusts exist to hold assets for a person with a mental illness in such a way as to not disqualify them such benefits. The first type is with a third party Special Needs Trust, where a third party wants to set aside monies for the benefit of the loved one. This trust can be established during the grantor's life or in the grantor's last will. The second type is where the person with the disability is the direct owner of an asset, such as an award following a lawsuit. These monies can be placed in a court approved Special Needs Trust more commonly referred to as a **D4A Special Needs Trust**. The Trust is developed to manage resources while maintaining the individual's eligibility for public assistance benefits. A trustee manages the trust on behalf of the person with the mental illness.

It is important to establish a Special Needs Trust as soon as possible and to inform family members of its existence. Sometimes family members, most often grandparents, leave a bequest in their wills to their special needs grandchild, which might then disqualify the child from continuing to receive SSI and Medicaid benefits.

Please be aware that each type of trust requires very specific language and management. Individuals should contact a special needs trust attorney for appropriate counsel.

Letter of Intent

To provide direction to carry out parental or family wishes, it is recommended that the family develop a comprehensive and flexible life plan for and with the person with a disability or mental illness. The Letter of Intent is a document that puts into writing such family wishes. The document outlines what the family wants for their child in all of the major life areas: residential placement, education, employment, socialization, religion, medical care, final arrangements, and so on. The letter is not intended to be a legally binding commitment, as it is impossible to project all of life's decisions. Rather, it is a guidepost to help aid those who will be helping to manage life for the person with a disability or mental illness. For more information on estate planning and a Letter of Intent:

➤ www.kidsource.com/kidsource/content4/estate.dis.all.3.html

Guardianship

Note: It is important to determine the necessity of a guardianship prior to your loved one's turning 18 years of age.

All individuals become legal adults at age 18, including individuals with mental illness. When a child with mental illness turns 18, a parent has no legal authority to assist in managing his or her life. As a parent of a child with mental illness you must apply for guardianship and request that the court provide you with such legal authority. If your loved one is over the age of 18 and unable to act as his or her own guardian, you will need to follow the same procedure.

Most parents of a loved one with mental illness do not realize the importance of setting up a guardianship for their child and often don't realize it until their child, now 18 or older, is hospitalized and they find that they cannot direct his or her medical care.

When no advance directive exists and a person becomes unable to manage his or her personal or property affairs, life's decisions, including medical decisions, come to a halt. In that situation, the caregiver or other involved individuals/organizations must go to the court and petition for a Letter of Guardianship. Guardianship is basically court supervised decision-making by a person appointed by the court.

Guardianship takes two forms: 1) **A guardian of the property** has authority to manage the financial affairs for the older adult or person with a disability. 2) **A guardian of the person** has authority to make health care decisions for the person. New Jersey sets forth a priority of persons who may serve as guardian, with the spouse or next of kin first in line for consideration.

Appointment of a guardian is a court process governed by statute. It requires a complaint often filed by a family member ("petitioner"), two doctors stating the person is mentally unable to handle his or her own affairs, a court appointed attorney to represent the individual, and the petitioner's attorney. Then a hearing will be scheduled. Following the hearing, a judge will rule on the complaint or request for guardianship and, if appropriate, issue a judgment appointing guardianship. If at some later time, your loved one gains the capacity to manage his or her affairs, the guardianship can and should be terminated.

There are two types of guardianship:

Limited Guardianship

The guardian is limited by the conditions in which they will have authority. Limited guardianship is appropriate when the individual with the disability or mental illness is still able to make some of his or her own decisions, but may need assistance with major decisions, such as financial or medical decisions.

Plenary Guardianship

The guardian is assigned total decision-making authority. The individual with the disability or mental illness is not able to make any of his or her own decisions.

There are two ways to appoint a guardian for a person with a disability or mental illness. If your child was registered with the Division of Developmental Disabilities (DDD), you can apply through DDD, which can be time consuming, or you can apply with a private special needs attorney. If you choose to use a private attorney, make sure that the attorney you choose has a concentration in special needs issues. Your child's school, agencies you deal with, or other families in your situation can most likely recommend attorneys that are knowledgeable and experienced in this area.

If the individual for whom guardianship is being requested is registered with the DDD, the caregiver can apply for a stipend from DDD to help cover the cost of an attorney for guardianship services. When you apply through DDD, the Division becomes the guardian for the individual with the disability. This is appropriate in cases where there is no one to take responsibility for the person and he or she is unable to be his or her own guardian.

Burial Fund

A burial fund is money set aside to pay for burial expenses. This money can be in a bank account, other financial instrument, or a prepaid burial arrangement. This can be helpful to eliminate emotional stress and financial burden on a caregiver or other family member at the time of a person's death. Parents of a child with a mental health disability can set up a burial fund to ensure that their child's end-of-life costs are covered if they will not be here to address these needs.

Conclusion

This overview is very general and many items of estate administration have not been covered. For example, individual situations may include other issues like administration of a trust, children under 18 years of age, property that does not go through probate, transferring joint tenancy and other survivorship property, claiming monies from retirement plans, special procedures for small estates, and handling bypass trusts. For these and other issues, professional advice is strongly recommended.

Probate and more: For information about how to probate a will, executor duties, taxes, and more, please see **Section A, Chapter 8**.

9. DAY TREATMENT PROGRAMS FOR LOVED ONES WITH MENTAL ILLNESS

When individuals with serious mental illness find it difficult to work, learn, socialize, and live independently outside a hospital, rehabilitation services, either through freestanding programs or through mental health centers, may be available in your community.

These programs offer a variety of skill-building activities to assist your loved one in learning, living, working, and developing interpersonal skills that will help him or her live as independently and productively as possible in the community. They also provide opportunities to access psychiatric services, counseling, social skills programs, wellness groups, and education about mental illness and medications.

While mental health services do not offer specific home care or day programs like those available for older adults or people with physical disabilities, there are options available to those who may not be in need of hospitalization, but do require a structured environment.

Rehabilitation Services: Partial Care or Day Treatment

These programs are commonly known as Rehabilitation Services, and also Intensive Outpatient Programs, Partial Care Programs, and Partial Hospital Programs. They are appropriate when hospitalization is not necessary or no longer required, but other outpatient services are too limited. They allow individuals to return home each day after treatment and begin transitioning to everyday living situations and challenges.

The programs provide adults with short-term treatment that is tailored to their level of functioning. They also provide individuals with structured activity on a full or half-day basis. Activities include group and individual counseling, case management, daily living skills, wellness and recovery activities, socialization and recreation, prevocational programs, and medication monitoring. To locate services:

- **Family Guidance Center of Warren County**
908.689.6212
www.fgcwc.org
- **Mental Health Association of Morris County**
973.334.3496
www.mhamorris.org
- **Mental Health Administrators**
<http://www.state.nj.us/humanservices/dmhs/services/admin/>

Substance Abuse Services

There are a number of substance abuse programs and services available to New Jersey residents. Call your county addictions services administrator for more information:

- **Addictions Services Administrators**
www.state.nj.us/humanservices/das/treatment/directors/index.html

10. EMPLOYMENT & VOLUNTEERING FOR LOVED ONES WITH MENTAL ILLNESS

Employment

As caregivers, we want our loved ones to lead as full a life as possible. For people with mental illness, employment often helps to promote independence and the chance to lead a more productive and fulfilling life. Working provides a sense of purpose and a source of dignity. Most people, including those with severe mental illnesses, report that they want to work or volunteer. For some people, a supportive environment or job coaching can increase the chances that they will have a long-lasting positive work experience.

Unemployment and underemployment are issues that affect individuals with mental illness. Many of these individuals do not have the same opportunity to contribute and achieve their potential because of barriers they face when trying to obtain competitive employment.

Accelerated entry into competitive work, integrated services that address needs across life areas, and ongoing supports are central to successful employment for many who are coping with mental illness. Supported Employment (SE) has been shown to be the most effective service in achieving competitive employment success.

New Jersey: Employment First

In April 2012, Governor Christie made New Jersey an “Employment First” state. It means that competitive employment is the first and preferred post-education activity for everyone, including people with disabilities. The state is “working cooperatively with the private sector to ensure that people with disabilities are a seamless part of New Jersey’s workforce, with the independence and sense of community that comes from relationships developed inside and outside of the workplace.”

For information:

- www.state.nj.us/humanservices/involved/employmentfirst.html

NJ Division of Vocational Rehabilitation Services (DVRS)

The mission of the New Jersey DVRS is to enable people with disabilities to achieve employment consistent with their strengths, priorities, needs, abilities, and capabilities. The Division will help individuals with disabilities who are having trouble finding or holding a job because of their disability.

If your loved one has a mental illness that is preventing him or her from working, or which is endangering his or her present employment, contact DVRS. For information and to locate a DVRS office near you:

- <http://lwd.dol.state.nj.us/labor/dvrs/DVRIndex.html>

DVRS will provide employment services for persons with mental illness. Based on individual circumstances, the following types of employment services are available:

Pre-vocational evaluation is a comprehensive, individualized, and systematic process in which an individual, in partnership with an evaluator and DVRS counselor, learns to identify vocational options consistent with his or her abilities, capabilities, preferences, and interests and to develop employment goals and objectives.

Work adjustment training is a comprehensive, individualized service that helps people develop or reestablish skills, attitudes, personal characteristics, work behaviors, and/or functional capacities, to achieve the identified employment goals.

Extended (sheltered) employment is a program designed to provide long-term employment by the community rehabilitation program of an individual who is presently unable to work in the competitive labor market. An individual is frequently paid less than minimum wage based upon time studies identifying his/her ability.

Supported employment increases the opportunity for individuals who might require augmented levels of support, training, and advocacy to be employed in real jobs for competitive wages. This program is intended for those who require intensive individual training on or off the work site and who, once they have learned the job and other routines, will require long-term follow along services on the job site and/or off the job site. A job coach works with each individual and their vocational rehabilitation counselor to perform a broad range of functions including helping complete job applications, seeking out appropriate transportation, and arranging the necessary accommodations in the worksite. These services are provided through community-based agencies.

For more information on Supported Employment Services for consumers with mental illness, including a link to a list of supported employment vendors:

➤ www.state.nj.us/humanservices/dmhs/services/community/

Post Employment Support may be provided for up to 90 days after the individual becomes stable on the job, thus ensuring a smooth transition into the workforce. Sometimes employment barriers are not identified until after a person goes to work (e.g. child care issues, unreliable transportation, requirements of the job changes, need for additional accommodations becomes apparent, etc.). This additional support enhances the likelihood of a more compatible job match.

Other Important Definitions Relating to Employment

Career Counseling: One-on-one counseling to help determine individual vocational goals.

Internship: Provides individuals with work-related experience. Positions are typically unpaid.

Job Coach: Professional trainer to assist in all transitional phases of employment. A job coach may act as a liaison between employer and employee.

Job Sampling: Allows candidates to sample different work environments to determine interest and ability.

Job Shadowing: Allows candidates to observe a real work environment by “shadowing” or following an employee for a day on targeted tasks.

Subcontract Work: An agency providing the facility and employees to do packaging, assembly, collating, and various other production work.

Work Opportunity Tax Credit: A federal program designed to encourage employers to hire persons who have special difficulties in finding work by giving these employers tax credits on federal taxes.

Vocational Evaluation: A short-term program that measures a person’s potential strengths, limitations and work behaviors.

If Your Loved One is Receiving Government Benefits & Wants to Work

One of the Social Security Administration’s (SSA) highest priorities is to help individuals with disabilities achieve independence by helping them to take advantage of employment opportunities. There are employment support provisions in place to assist an individual to move further on the way from benefit dependency to independence. Employment supports help an individual enter, re-enter, or stay in the workforce by protecting eligibility for cash payments and/or health care until their goal is achieved.

For information:

- www.socialsecurity.gov/pubs
Search on “*Working While Disabled – How We Can Help*”

Plan for Achieving Self-Support (PASS)

Under SSI rules, any income that you have may reduce your Social Security Income (SSI) payment. But, if you have an approved plan, you can use that income to pay for the items you need to reach your work goal. This is called PASS: Plan for Achieving Self-Support.

- www.socialsecurity.gov/pubs
Search on “*Working While Disabled – A Guide To Plans For Achieving Self Support*”

NJ WINS (Work Incentives Network Support)

The Family Resource Network’s New Jersey Work Incentives Network Support (NJWINS) program assists SSI and Social Security Disability Insurance (SSDI) beneficiaries to start, continue, or increase work efforts while maintaining benefits for as long as they are needed.

- www.njwins.org

NJ WorkAbility

The NJ WorkAbility program offers full New Jersey Medicaid health coverage to people with disabilities who are working and whose earnings would otherwise make them ineligible for Medicaid. For information and eligibility guidelines:

- www.state.nj.us/humanservices/dds/projects/discoverability/

Veterans (See also Section D, Chapter 3, Caregiving for a Veteran)

For information on programs that assist veterans with regard to employment rights and provides referrals for job assistance/training:

- www.state.nj.us/military/Veterans/programs.html

Volunteering

Volunteering in the community can provide individuals with mental illness greater independence and help them to lead productive, fulfilling lives. In addition, volunteering can be a stepping-stone toward acquiring and maintaining skills that may lead to gainful employment.

There are many different opportunities for volunteering in the community, such as local religious organizations, food pantries, libraries, shelters, not-for-profit organizations, etc. The following are some places to start:

- **Governor's Office of Volunteerism**
609.633.9627 or 9629
www.nj.gov/state/programs/dos_program_volunteerism.html
- **Jersey Cares**
973.424.1091
www.jerseycares.org
- **Mental Health Association of Morris County**
973.334.3496
www.mhamorris.org
- **United Way of Northern New Jersey (Morris, North Essex, Somerset, Sussex, and Warren)**
908.253.6503
UnitedWayNNJ.org/BecomeAVolunteer
- **Volunteer Management Center, Inc. (VMC)**
973.538.7200
www.vmcnj.org

11. HOUSING FOR LOVED ONES WITH MENTAL ILLNESS

There is a range of residential options available through mental health service providers, including group homes and shared apartments with different levels of supervision, as well as individual apartments with supportive services attached. There are also affordable housing options with or without support services and rental vouchers to assist low-income individuals and families with their rent.

The NJ Department of Human Services, Division of Mental Health Services funds a number of homeless services, residential services, and supportive housing programs in the community.

- www.state.nj.us/humanservices/dmhs/news/publications/mhs/directory_by_program.html

Homeless Services

Outreach and other homeless services are available to individuals suffering from serious mental illness, or suffering from serious mental illness and from substance abuse, and are homeless or at imminent risk of becoming homeless.

- www.state.nj.us/humanservices/dmhs/news/publications/mhs/directory_by_program.html#8

Homelessness Prevention Program

Provides limited financial assistance to low- and moderate-income tenants and homeowners in imminent danger of eviction or foreclosure due to temporary financial problems beyond their control. Funds are used to disburse payments in the forms of loans and grants to landlords and mortgage companies on behalf of eligible households in danger of homelessness.

- **NJ Department of Community Affairs**
609.292.2269 or 866.889.6270
www.state.nj.us/dca/divisions/dhcr/offices/ha.html

Projects for Assisting in Transition from Homelessness (PATH)

PATH provides outreach, case management, and other services that will enable adults, ages 18 and older, who are homeless or at imminent risk of homelessness and have a serious mental illness to engage in mental health treatment.

- **NJ Division of Mental Health Services**
www.state.nj.us/humanservices/dmhs/news/publications/mhs/directory_by_program.html#8

Supportive Housing Programs

Supportive housing is designed to ensure consumers of mental health services have a choice of permanent, safe, affordable housing. Supportive housing offers individuals opportunities for involvement in community life. Emphasis is placed on the development and strengthening of natural supports in the community.

- www.state.nj.us/humanservices/dmhs/news/publications/mhs/directory_by_program.html#23

Residential Services

There are programs throughout New Jersey for mentally ill adults in community residences owned or leased by the provider or through service agreements providing support and encouragement in the development of life skills required to sustain successful living within the community. Clients live in the most normalized, least restrictive environment possible to promote individual growth and safety. Programming focuses on empowering the client's use of generic community supports to meet physical, psychological, and social needs to promote an improved quality of life and emotional well-being.

- www.state.nj.us/humanservices/dmhs/news/publications/mhs/directory_by_program.html#19

Rooming & Boarding Homes

These residences serve populations with diverse backgrounds and needs: the transient construction worker who needs a bed, veterans, persons with disabilities who can function with community support, the older adult who may need some help with activities of daily living. Some homes are specialized, serving those with mental illness, developmental disabilities, Alzheimer's, HIV/AIDS, substance abuse, veterans, or victims of abuse. Boarding homes are licensed by the Department of Community Affairs. There are five classes of licenses:

- Class A: Valid for rooming houses only
- Class B: Valid only for rooming houses and for boarding houses offering no financial services and no personal services other than meals and other food services and laundry
- Class C: Valid for all rooming and boarding houses
- Class D: Valid only for facilities operated under contract with an agency of the State of New Jersey
- Class E: Valid only for alcohol and drug rehabilitation facilities owned and operated by nonprofit religious organizations

Affordable Housing

There are various housing options available for people with disabilities. A good starting place may be the New Jersey Housing Resource Center (NJHRC). The NJHRC is a partnership between the NJ Department of Community Affairs, the NJ Department of Human Services, Division of Disability Services, and the New Jersey Housing and Mortgage Finance Agency. They provide an online tool to assist people with disabilities in finding affordable housing.

- **New Jersey Housing Resource Center (NJHRC)**
877.428.8844
www.njhrc.gov

The largest group of affordable units is public housing. Housing authorities administer this federal program. New Jersey has about 100 housing authorities.

Housing authorities get federal funds to build and run public housing developments. Most have rental units, but some have houses for sale. Rents and sale prices depend on household income and can be no more than 30 percent of adjusted earnings. People who live in public housing typically earn less than 80 percent of the median family income. Federal rules require housing authorities to keep a certain percentage of these units for very low-income households, earning 50 percent or less than median family income. Some housing authorities must reserve units for extremely low-income households with earnings at or below 30 percent of median. Use federal income standards to determine eligibility. All rental units must be within Fair Market Rent.

Housing authorities often have waiting lists, depending on local conditions. Public housing authorities may give priority to people who live or work in the communities they serve. The people who operate these authorities are an excellent resource. They know the local housing market and are aware of other programs and opportunities that might be available.

Call your municipality or your local ADRC to locate the public housing authority in your community.

- **Aging & Disability Resource Connection of New Jersey (ADRC)**
877.222.3737
www.adrcnj.org

New Jersey Low- & Moderate-Income Program/Mount Laurel (MtL)

Individuals looking to rent an apartment or buy a house or condominium in New Jersey may consider a Mount Laurel unit. Mount Laurel units can be for the elderly, families, or those with special needs. All MtL developments have income restrictions and must be affordable to low- and moderate-income households as defined by the federal rule or by state regulation, depending on how the developments were funded. The list of units created by the Council on Affordable Housing (COAH) can be found at:

- <http://www.state.nj.us/dca/affiliates/coah/reports/units.pdf>

Subsidized Housing/Rental Vouchers

Rental vouchers are available to individuals and families who are low- or very low-income. To determine whether your loved one meets these income criteria, consult the HUD website. The income limits change every year. Search on “*Income Limits.*”

- www.huduser.org/datasets/il.html.

Some New Jersey programs use income limits published by the Council on Affordable Housing (COAH). These numbers are similar to HUD, but slightly different:

- http://www.nj.gov/dca/services/lps/hss/admin_files/incomelimits.pdf

Some voucher programs have “set-asides” for those who are considered low- or moderate-income (below 80 percent of the area median income), those who have special needs (such as a mental illness), and those over age 62. If your loved one falls into any of these categories, ask for information on programs specific to that group(s).

There are two types of rental vouchers: **tenant-based** and **project-based**.

Tenant-based vouchers are provided directly to the tenant and allow the tenant to pay a portion of their income toward rent. The amounts vary by program, but typically the tenant pays 30 percent to 40 percent of the monthly household income toward rent and utilities – the remaining rent is paid directly to the landlord from the subsidy provider. When the tenant moves, the voucher can be transferred to another rental unit.

Agencies often have waiting lists for vouchers. Depending on the length of the lists, the agency may “close” the list until the number falls beneath a certain threshold. Assuming that you will be placed on a waiting list, it is advised that you contact as many of the agencies that you can. There is no penalty for being on more than one list (but ultimately, you can only accept one voucher). Each agency may represent a different geography and/or type of housing.

Project-based vouchers are attached to the property, which means a tenant is entitled to the rental subsidy for as long as they live in that unit. When a tenant moves, the voucher is given to the next tenant in that unit. Tenants pay 25 percent to 40 percent of monthly household income toward rent and utilities, depending on the subsidy program attached to the project.

Be prepared that most have waiting lists, and consider having your loved one place his or her name on as many agency lists as appropriate based on geography and housing type desired.

Call your municipality or your local ADRC to put you in contact with the public housing authority in your community.

- **NJ Department of Community Affairs**
609.292.4080
www.state.nj.us/dca/divisions/dhcr/offices/srap.html
- **US Department of Housing and Urban Development**
Local Office – One Newark Center, 1085 Raymond Blvd, Newark, New Jersey 07102
973.622.7900
www.hud.gov

Legal Services of Northwest Jersey provides free civil legal services, including addressing landlord and tenants rights, to low-income residents, seniors, and more: www.lsnj.org/lsnwj/

The **Community Health Law Project** offers legal, consumer protection, and advocacy services for seniors and people with disabilities: www.chlp.org

Other Housing Programs & Information

Home Improvement Programs

Some counties offer loans to homeowners to make improvements to their homes. There are typically income guidelines and other requirements.

- **Essex County Home Improvement Program**
973.655.0200
<http://www.essex-countynj.org/index.php?section=pr/print/2705a>
- **Morris County Home Improvement Program**
973.285.6060
www.morrisplanning.org/divisions/community
- **Warren County Home Improvement/Rehab Program**
908.475.3989
http://warren.nj.us/Humanservices/local_resources.html

Housing Rehabilitation Programs

Housing Rehabilitation Program funds provide rehabilitation assistance to income-eligible owner-occupants of single family homes, townhouses, condominiums, and multi-family units. The assistance is governed by federal regulations and county guidelines. Funds are typically used to improve insulation, correct code violations, renovate substandard heating, electrical, and plumbing systems, and for structural repairs and major systems failures, e.g., failing septic, furnace, inferior roof.

- **Morris County Department of Human Services**
973.285.6030 (TDD: 800.852.7897)
<http://morrishumanservices.org/behavioral/community.asp>
- **Somerset County Community Development**
908.541.5756
www.co.somerset.nj.us/hservices/comdevelopment/housingrehab.html
- **Warren County Department of Human Services**
908.475.3989
http://warren.nj.us/Humanservices/local_resources.html

New Jersey Housing and Mortgage Finance Agency (HMFA)

The New Jersey Housing and Mortgage Finance Agency (HMFA) has many housing programs funded from the sale of bonds. Some provide mortgage assistance and closing costs to homebuyers. Others help homeowners repair the houses they already own.

Those looking to buy a house or condominium should consider calling HMFA to see about the availability of homebuyer assistance programs. For information on HMFA programs:

- **800.NJHOUSE (800.654.6873)**
www.state.nj.us/dca/hmfa/

US Department of Housing and Urban Development (HUD)

Through HUD you can find local affordable housing units, information about reverse mortgages, links to homeless resources, and rental assistance programs.

- **Local Office – One Newark Center, 1085 Raymond Blvd, Newark, NJ 07102**
973.622.7900
www.hud.gov

If your loved one with mental illness is over the age of 60, see **Section A, Chapter 11** for additional housing opportunities.

12. ADVOCACY FOR LOVED ONES WITH MENTAL ILLNESS

Self-Advocacy

Self-advocacy is when an individual knows his or her rights and responsibilities, stands up for them, and makes choices about his or her life. As a parent or caregiver of a loved one with mental illness, you may be, in many instances, your loved one's best advocate. However, it is also important to encourage your loved one to learn how to advocate on his or her behalf whenever possible. No matter what his or her level of ability may be, an individual's ability to self-advocate is the first step in getting the assistance that he or she may need. The skill of self-advocacy is an important and critical one.

As a caregiver, helping your loved one acquire that skill may be difficult, as you have become accustomed to taking care of him or her. It may be difficult, but necessary, to help your loved one grow and take on as much responsibility as he or she is capable of. A part of this growth can come from making sure your loved one is made aware of and informed about available services and is involved in any planning processes.

Keys to Successful Advocacy on Behalf of Your Loved One

Communicating effectively with professionals and learning how to navigate the system are important skills for any caregiver to learn and develop. These can be acquired through help from other caregivers, caregiver coalitions, or any other advocacy groups.

Be Patient

If your loved one needs something, understand that this does not mean that he or she will get it right away. When students need a service or a piece of equipment while they are still in school, it generally gets put in place pretty quickly. That is because the laws set up for people in schools say that students are entitled to many of the things they need to be successful. Sometimes this is referred to as an **entitlement-based** system.

After graduation and moving on to adult services, the laws are set up differently. Most government and private agencies are not able to offer enough services to help everyone needing their assistance, so people usually have to apply for services. This is sometimes referred to as an **eligibility-based** system.

Depending on the organization, services or other assistance could be distributed on a first-come, first-served basis or to those who need the service the most. It is up to you to know how the organization you are trying to work with makes these decisions and plan accordingly. Sometimes, there may even be long waiting lists for services. You may not know how long it takes to get to the top of the waiting list and get what you need, but one certainty is that if you don't apply and get on the list, you will not get the services you need.

You Just Might be the Expert in the Room

Be prepared to assist professionals who may have limited experience with your loved one's exact needs. Your family doctor may be wonderful, but he or she may have little or no experience with mental illness. Share your expertise by discussing your loved one's needs, giving as much detail as possible to help him or her understand the situation.

Stay on People's Good Side

Find the line between advocacy and aggression. A successful advocate lets the system work for them. You want to stay on top of things, but don't turn into a pest and make it harder for the professionals to do their jobs. Smile when you are talking to people...even if you are on the phone, your smile will come through in your tone of voice. Professionals are people too, and words like "please" and "thank you" will go a long way toward developing a strong working relationship.

Keep Accurate Notes

Record keeping may seem like a hassle at first, but saves a great deal of time down the road. Whenever you have a conversation with any professional, it's a good idea to write it down. Some caregivers keep a notebook just for this purpose. Include all contact names, phone numbers, dates of calls, and a quick summary of the discussion.

Know What You Need; Do Your Research

When advocating for equipment or services, make sure to collect all the details and product information ahead of time. If insurance is being used for payment, ask both the insurance company and the equipment provider if there are pre-set guidelines or other information that will be needed. This will save a lot of time later on in the process.

Understand Your Insurance Benefits

Do not be afraid to ask questions when you are unsure of something about your insurance. Review the terms of each program and policy. Know when referrals or pre-certifications are necessary. Pay careful attention to copays, service limits, and equipment ownership and replacement responsibilities. Remember, you can always appeal an insurance company's decision in the event of a denial, no matter what type of plan you are on.

Systems Advocacy

Systems advocacy is a process by which organized groups or individuals come together to advocate for positive change to programs, services, and legislation. Advocacy for changes in policy or service delivery may be most effective when there is a united voice that speaks on behalf of issues. There are numerous organizations that advocate regarding specific issues, policies, disabilities, and diseases on local, state, and national levels. Following are a few local organizations:

Family Support Organizations

Family Support Organizations are family-run organizations devoted to the needs of families and caregivers whose children have emotional and behavioral challenges. Families receive peer support, information and referral services, education, and advocacy within a compassionate and culturally sensitive environment. Assistance is also offered in helping caretakers navigate the complex public children's mental health system in New Jersey.

- **Family Partners of Morris and Sussex Counties**
973.940.3194
- **Family Support Organization of Essex County**
973.395.1441
www.fsoec.org
- **Family Support Organization of Hunterdon, Somerset and Warren**
908.213.9932
www.fso-hsw.org

Mental Health Administrators & County Advisory Boards

The County Mental Health Administrator oversees the delivery of publicly funded mental health services and addresses the questions or concerns of individuals with mental illness and their loved ones regarding the mental health system. Additionally, the administrator is the contact person for the Mental Health Advisory Board in their county.

The mission of each county's Board is to ensure that a full continuum of care is available, accessible, and affordable to address the mental health and/or substance abuse prevention, education, and treatment needs of residents. The Board advocates for a seamless system of care for individuals with a mental illness and monitors the use of state and county public dollars related to mental health and/or substance abuse services. To contact your local Board, visit:

- www.state.nj.us/humanservices/dmhs/services/admin/

Mental Health Association in New Jersey, Inc.

This agency and its affiliates empowers individuals with mental illness and family members by connecting them to various forums in which they can influence mental health policy and services for both themselves and others.

- **800.367.8850**
www.mhanj.org

National Alliance on Mental Illness (NAMI) New Jersey

This organization brings a voice to the concerns of families, friends, and persons who are affected by mental illness.

- **732.940.0991**
www.naminj.org

United Way *Caregivers Coalition*

The United Way *Caregivers Coalition's* work on behalf of caregivers includes advocacy at the local, state, and national level. Your ideas and experiences could help direct the *Coalition's* advocacy efforts. Please contact the *Coalition* if you are interested in joining advocacy efforts on behalf of caregivers.

- **888.33UWCARES (888.338.9227)**
UnitedWayNNJ.org/CaregiversCoalition

13. KEY NUMBERS AT A GLANCE

| | |
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| Aging & Disability Resource Connection of New Jersey (ADRC) | 877.222.3737 |
| NJ 2-1-1 | Dial 2-1-1 or 800.435.7555 |
| <u>Benefits</u> | |
| US Medicare | 800.MEDICARE or 800.633.4227 |
| NJ Medicaid | 800.356.1561 |
| US Social Security Administration | 800.772.1213 |
| <u>County Addictions Services Administrators</u> | |
| Essex County | 973.395.8455 |
| Morris County | 973.285.6867 |
| Somerset County | 908.704.6309 |
| Sussex County | 973.948.6000, x225 |
| Warren County | 908.475.6080 |
| <u>County Caregiver Coordinators & Support Programs</u> | |
| Essex County | 973.395.8389 |
| Morris County | 800.564.4656 |
| Sussex County | 973.579.0555, x1225 |
| Warren County | 908.475.6591 |
| <u>County Mental Health Administrators</u> | |
| Essex County | 973.571.2821 |
| Morris County | 973.285.6852 |
| Somerset County | 908.704.6300 |
| Sussex County | 973.948.6000 |
| Warren County | 908.475.6092 |
| <u>Intensive Family Support Services (IFSS)</u> | |
| Essex County – Mental Health Association | 973.509.9777 |
| Morris County – Saint Clare’s Hospital | 973.625.7095 |
| Somerset County – Easter Seals New Jersey | 908.722.4300 |
| Sussex County – Saint Clare’s Hospital | 201.317.6139 |
| Warren County – Family Guidance Center | 908.689.1000, x331 or x330 |
| Mental Health Association in New Jersey, Inc. | 800.367.8850 |
| National Alliance on Mental Illness (NAMI) New Jersey | 732.940.0991 |
| NJ Department of Community Affairs | 609.633.0973 or 866.889.6270 |
| NJ Division of Vocational Rehabilitation Services (DVRS) | 609.292.5987 |
| New Jersey Mental Health Cares | 866.202.4357 |
| State Health Insurance Program (SHIP) | 800.792.8820 |
| PerformCare | 877.652.7624/TDD: 866.896.6975 |
| United Way of Northern New Jersey Volunteer Coordinator | 908.253.6503 |
| United Way Caregivers Coalition | 888.33UWCARES (888.338.9227) |