

SECTION B

CAREGIVING FOR A LOVED ONE WITH A DISABILITY

1. Introduction	50
2. Becoming a Caregiver for a Loved One with a Disability	51
3. Where to Begin: Finding the Support You Need	54
4. Education for Individuals with a Disability & Education for Caregivers	58
5. Parent/Caregiver Support & Self-Care Respite, Support Groups & Counseling	71
6. Care Management & Support Coordination	78
7. Benefit Programs: Social Security, Medicare & Medicaid Information	80
8. Legal Matters & Important Papers Legal Services, Key Documents & Issues	89
9. Day & Home Care Programs	96
10. Employment & Volunteering	102
11. Housing for a Loved One with a Disability Types of Housing & Programs, Issues, Questions to Ask	106
12. Advocacy	111
13. Key Numbers at a Glance	115

1. INTRODUCTION: CAREGIVING FOR LOVED ONES WITH A DISABILITY

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, Somerset, Suburban Essex, 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** and each county’s **Division of Senior or Aging and Disability Services**, also known as the **Aging and Disability Resource Connection (ADRC)**. 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, as 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 do so 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, please see **Section A: Caregiving for an Aging Loved One** for more information and resources.

2. BECOMING A CAREGIVER FOR A LOVED ONE WITH A DISABILITY

If you support your loved one with a disability 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 with a disability lives with you, in their own home, in a facility, or even a long distance away, if you do any of these things on a regular basis, you are a caregiver...and we hope this guide will be of help to you.

Disability can happen to anyone at any time. A disability may be present at birth, develop during early childhood, young adulthood, the middle or later years, or may occur as the result of an injury, illness, or accident. Regardless of the onset or type of disability, becoming a caregiver for a person with a disability is a life changing event. The caregiving journey will bring a wide range of experiences and emotions for all those involved. Providing care often becomes THE major focus for the primary caregiver and has an impact on the entire family system.

There are many paths along the caregiving journey, some more promising than others. A successful journey is possible. The key is in how well you prepare for the journey and how well you utilize the resources available to you.

Providing care for someone with a disability requires patience, determination, and persistence. The caregiver will be faced with a wide variety of issues over the years and will have to deal with a range of professionals in matters of health, education, recreation, employment, housing, etc. The spectrum of issues can seem daunting and it is natural for any caregiver to feel overwhelmed.

If you provide care for someone with a disability, it helps to remember that you are the constant, you provide continuity. You are the one who knows your loved one the best.

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 disability 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 disability 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 parents, 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.

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

3. WHERE TO BEGIN: FINDING THE SUPPORT YOU NEED

Your First Call is an Important One

Whether you are just beginning to provide care for a loved one with a disability, or have been a caregiver for some time but without any real support, the following are some helpful first calls to consider based on the age of your loved one and their age when the disability occurred.

If You Think an Infant or Toddler (Birth to 3 Years of Age) is Not Growing or Developing as He or She Should, Seek Help Early

The first three years of life are important formative years in maximizing a child's future potential. Naturally, any concerns should first be addressed with the child's pediatrician. But additionally, if you suspect that an infant or toddler may be experiencing developmental delays, you should contact New Jersey's Early Intervention System. **The NJ Early Intervention System (NJEIS)**, under the Division of Family Health Services, implements New Jersey's statewide system of services for infants and toddlers, birth to age three, with developmental delays or disabilities and/or health related needs, and their families.

- **New Jersey Early Intervention System**
888.653.4463
www.nj.gov/health/fhs/eis

If a Disability Occurs in a Person Younger Than 21-Years-Old

As of January 2013, the **NJ Department of Children and Families (DCF), Division of Children's System of Care (CSOC)** assumed responsibility for determining eligibility of individuals under age 18 for developmental disability services. CSOC also assumed responsibility for providing support and services deemed clinically and functionally appropriate for individuals under age 21 with developmental disabilities.

CSOC utilizes PerformCare NJ as the single point of entry for New Jersey's eligible children to obtain any of the state's publically available behavioral health and developmental disability services. Application information and materials are provided on the PerformCare website. If you do not have computer access, contact PerformCare for a mailed application.

- **PerformCare**
877.652.7624 (TDD: 866.896.6975)
www.performcarenj.org
www.performcarenj.org/families/disability/determination-eligibility.aspx

As the Person with Disability Approaches the Age of 18

It is very important to know about the NJ Department of Human Services' Division of Developmental Disabilities (DDD). DDD provides and funds services for state residents with developmental disabilities aged 21 and older.

- **NJ Division of Developmental Disabilities (DDD)**
800.832.9173
www.state.nj.us/humanservices/ddd/home/

To locate the DDD office for your county, go to:

- **www.state.nj.us/humanservices/ddd/staff/cso/**

The application process for DDD eligibility should take place between the ages of 18 and 21. Families seeking developmental disability eligibility as part of their child's life-long planning are encouraged to apply for eligibility with DDD as soon as their child turns 18.

- **800.832.9173**
www.state.nj.us/humanservices/ddd/home/index.html

NOTE: Effective January 22, 2013, the Division of Developmental Disabilities (DDD) eligibility regulations changed to require Medicaid eligibility as a condition of receiving Division-funded services. Visit the website below for information and to begin the application process for DDD eligibility.

- **www.state.nj.us/humanservices/ddd/services/apply/index.html**

If a Disability Occurs in a Person 21 Years of Age or Older

The NJ Department of Human Services' Division of Disability Services (DDS) is the single point of entry for all people seeking disability-related information in New Jersey.

- **NJ Division of Disability Services (DDS)**
888.285.3036
www.state.nj.us/humanservices/dds

Other Disability Resources for All Ages

NJ Department of Human Services, Division of Disability Services (DDS)

The NJ Department of Human Services' Division of Disability Services (DDS) is the single point of entry for all people seeking disability-related information in New Jersey.

- **888.285.3036**
www.state.nj.us/humanservices/dds

The Division of Disability Services (DDS) also produces an excellent resource for any individual with a disability, or their caregiver, called the New Jersey Resources Guide.

- **www.state.nj.us/humanservices/dds/documents/RD13webqxd.pdf**

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 an excellent portal to a wide variety of resources. Services can differ from county to county. Use the phone number below to contact your county's ADRC. Phone is staffed weekdays during normal working hours.

- **877.222.3737**
www.adrcnj.org

NJ 2-1-1

NJ 2-1-1 offers both confidential support to people in crisis and personalized information and referrals to those needing assistance. NJ 2-1-1 now 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.

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

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 starting with **Disability.gov**, a federal government website that has comprehensive information on disability programs and services nationwide.

- **www.disability.gov**

If your loved one is age 60 or older, consider connecting with the local Office on Aging where your loved one resides to learn about other disability resources in the area. The national Administration on Aging site can give you local Office on Aging contact information.

- **www.aoa.gov**

Additionally, if your loved one is a senior, you may want to consider hiring a qualified geriatric care manager in the area where your loved one resides. This professional care manager will know about local resources and can do an assessment and develop a care plan for you.

- **www.aginglifecare.org**

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. EDUCATION SERVICES FOR INDIVIDUALS WITH A DISABILITY & EDUCATION RESOURCES FOR PARENTS/CAREGIVERS

New Jersey Early Intervention System – NJEIS (Birth to Age 3)

The New Jersey Early Intervention System (NJEIS), under the NJ Division of Family Health Services, implements New Jersey's statewide system of services for infants and toddlers, birth to age three, with developmental delays or disabilities, and their families. The NJ Department of Health is appointed by the governor as the state lead agency for the NJEIS.

The mission of the NJEIS is to enhance the capacity of families to meet the developmental and health-related needs of children, birth to age three, who have delays or disabilities by providing quality services and support to families and their children in a natural setting.

NJEIS Referral & Evaluation Process

Anyone can make a referral to the NJEIS: parents, doctors, child care workers, family, friends, etc. To make a referral to NJEIS call the statewide toll-free referral number:

- **888.653.4463 (Language line services and translators are available)**

The number connects you to the regional System Point of Entry (SPOE) office for early intervention services. The SPOE will assign a service coordinator to the family and a team of trained professionals will determine eligibility with input from the parents. Parents must give approval for the evaluation. The evaluation is provided at no cost to the families. If the evaluation determines that early intervention services are appropriate, an Individual Family Services Plan (IFSP) will be developed, which identifies the levels and types of services to be provided and how and where services will take place. Services are provided in the home or a community-based center. Parents may be responsible for contributing to the cost of ongoing services depending on their income and family size.

For children, birth to age three, with special health care needs, referral for early intervention services can be made through the Special Child Health Care Management Unit located in the county where they live. For contact information for each county:

- **www.nj.gov/health/fhs/sch/sccase.shtml**

Regional Early Intervention Collaborative (REICs)

In New Jersey, four nonprofit organizations, called Regional Early Intervention Collaboratives or REICs, have been established to plan and coordinate the state's early intervention system at the regional and community levels. REICs provide information and resources for families, early intervention programs, and professionals and ensure the protection of family rights.

In northern New Jersey, the REICs are:

- **Family Link REIC (Essex, Morris, Sussex, Union, and Warren counties)**
908.964.5303
www.familylinknj.org
- **Mid-Jersey CARES for Special Children REIC**
(Hunterdon, Mercer, Middlesex, Monmouth, Ocean, and Somerset counties)
732.937.5437
www.cjfhc.org

For more information on NJEIS eligibility criteria, the evaluation process, and services available:

- www.nj.gov/health/fhs/eis/

Project Child Find

Information and referral to early intervention and other services for children:

- **800.322.8174**
www.nj.gov/njded/specialed/childfind/

Special Education & Related Services (Ages 3-21)

If your child has a disability or other health or behavioral condition that interferes with their ability to learn in a typical classroom setting, parents, teachers, or others concerned for the welfare of the child may contact their local school district for an evaluation from the Special Services Department. Each school district has a Director of Special Services who oversees the Child Study Team (CST), an interdisciplinary group of professionals who are trained to assess a student's eligibility for special education and/or related services.

Requesting an evaluation for special services can be made at any time. Parents begin the process by submitting a written request for an evaluation to the school district where the child resides.

Determination of Eligibility for Special Education & Related Services

If your child has a disability that adversely affects educational performance, your child is eligible for special education services under the Individuals with Disabilities Education Act (IDEA). This Act guarantees children with disabilities, ages 3 to 21, the right to a free, appropriate, public education (FAPE) delivered in the least-restrictive environment (LRE).

Section 504

Section 504 of the Rehabilitation Act is a civil rights law, which prohibits recipients of federal funds from discriminating on the basis of disability. School districts are required by Section 504 guidelines to provide a free and appropriate public education to eligible students in their jurisdiction. There are procedural safeguards in place for students protected by a 504 plan, however they are not as comprehensive as those in place for students covered under IDEA.

Children who are eligible for special education services under IDEA are also protected under Section 504 (but the converse is not true).

If your child has a disability that does not adversely affect educational performance, then your child will not be eligible for special education services under IDEA, but will usually be entitled to protections under Section 504.

The Evaluation Process

With consent of a child's parents, the Child Study Team (CST) evaluates the child to determine his/her eligibility for special education services. The CST includes a school psychologist, Learning Disabilities Teacher Consultant (LDTC), social worker, a speech therapist for children under age 5, and other professionals as deemed appropriate. A case manager is appointed from the group of CST members. Upon completion of the evaluation and determination of eligibility, and prior to placement in special education, an Individualized Education Program (IEP) outlines present levels of educational and functional performance, specific and measurable goals and objectives, accommodations, modifications, and related services. The IEP is written by a team, which includes the case manager, teacher, parent, and other school staff as deemed appropriate. It is the responsibility of the school district to provide the parents with a copy of the Parental Rights in Special Education (PRISE) manual prior to the IEP meeting.

- **PRISE (Parental Rights in Special Education)**
www.nj.gov/education/specialed/form/prise/prise.pdf

Preschool Special Education & Related Services (Ages 3-5)

If your child received services through NJEIS, the service provider is required to contact your child's school district 120 days prior to the child's third birthday, unless parents opt-out of an evaluation for special services in writing. Parents who wish to proceed with an evaluation must submit a letter to the school district to provide consent for the CST evaluation. If the child has not received services prior to age 3, parents, teachers, or others concerned for the welfare of the child may contact their local school district for an evaluation from the Special Services Department.

School-Age Program (Ages 5-21)

If your child received special services in preschool, they will be reclassified by June 30th of the year he or she is expected to enter kindergarten. Regardless of whether the child is new to services or if continuance of special services is needed, the child will be classified according to the special education categories.

For a complete listing of the various classifications of eligibility refer to Chapter 14 of the New Jersey Administrative Code for Special Education, subchapter 3.5:

- **New Jersey Administrative Code for Special Education**
www.state.nj.us/njded/code/current/title6a/chap14.pdf

Parents must give written consent for an evaluation, even if it is a reclassification, by the Child Study Team (CST). After the written request is made, the CST will set up a meeting with the parent to discuss the child's situation and determine the next steps, either a CST evaluation to determine eligibility for an Individualized Education Program (IEP) or a referral to the Intervention & Referral Services Committee (I&RS Team).

The **Intervention & Referral Services Committee (I&RS Team)** is typically composed of, but not limited to: guidance counselor, classroom teacher, principal, parent, student (if appropriate), and any others deemed appropriate (school psychologist, speech therapist, social worker, etc.). In some instances, simple accommodations can be made and services can be provided without the involvement of the CST. In other words, the I&RS Team can coordinate the services necessary to prevent the need for special education classification. However, if the accommodations, modifications, and services are not effective, the CST will step in. Parents maintain the right to request a CST evaluation for special education at any time. Districts cannot require a child to try I&RS before receiving a CST evaluation. The I&RS Team meets once a year to review and assess the strategies and interventions being implemented in the classroom.

Special Education Placement or Settings

School districts are required to provide services in the least restrictive environment (LRE), beginning with the general education classroom. However, parents and the CST must take into consideration the specific needs of the child and what environment offers the best opportunity for the child to learn and thrive. Placements beyond the general education classroom may include use of a resource room for certain subjects, a self-contained special education classroom, an out-of-district placement at another public or private special education school, a residential facility, or home-based instruction. It is important for parents to remember that the educational setting is not permanent and can be reevaluated and changed as appropriate.

Annual IEP Reviews & Reclassifications

Every year, and sometimes more frequently, you will meet with the Child Study Team to review your child's progress, make necessary revisions to the IEP, and plan for the future. Every third year, your child may be reevaluated prior to the IEP meeting to determine if your child is still eligible for special education services and, if so, to ensure that the educational plan is appropriate. Families have the option of refusing reevaluations; however, these assessments can provide valuable information in the planning process at the IEP meeting.

It is important that you, as the parent and caregiver, come to these meetings well prepared, as you are a member of the planning team and are considered to be the expert on your child. Bring any medical reports, relevant schoolwork, and any other documents that you feel may be important. Prior to each meeting, write down your concerns and ideas.

Statewide Parent Advocacy Network (SPAN)

SPAN is an excellent source of information for families about the IEP process. SPAN representatives can also provide technical assistance and guidance on identifying advocacy support. (Spanish available)

- **800.654.SPAN; 973.642.8100**
www.spanadvocacy.org/

SPAN offers an excellent document, *Positive Student Profiles & Goals-at-a-Glance*, that provides team members with a snapshot of your child.

- **www.spannj.org/BasicRights/appendix_c.htm**

Resources to Mediate and/or Resolve Disputes

It is not uncommon to encounter differences of opinions among team members. There are numerous resources to assist in mediating any disagreement. The resources below will provide guidance on how to request modifications to the IEP, mediation, due process, “stay put,” or other interventions. Of course, always try informal approaches to resolving disputes first.

- **NJ Department of Education, Office of Special Education Programs**
www.nj.gov/education/specialed/complaint/
- **Center for Parent Information and Resources (formerly NICHCY)**
www.parentcenterhub.org/repository/disputes-landing/
- **Kidlaw Resource Center, “A Basic Guide to Special Education Services 2011”**
www.kidlaw.org, click on “*Education*” to find title listed above
- **Wrightslaw**
www.wrightslaw.com, click on “*Topics from A-Z*”
- **Education Law Center**
www.edlawcenter.org/

Should you need to consult an attorney regarding educational entitlements for students with disabilities, use an attorney with expertise in New Jersey Special Education laws. There are many excellent law firms in the area. Begin your search with this site:

- **<http://www.lawyers.com/special-education/new-jersey/find-law-firms-by-city>**

The following website of Hinkle, Fingles, Prior & Fischer provides a great deal of important information, including videos relating to special education concerns, guardianship, estate planning, advocacy, Special Needs Trusts, and more.

- **www.hinkle1.com**

School Transportation for a Child with Disability

Transportation is included in the IEP as a related service. There are several different options for transporting your child to and from school, and possibly to after-school activities. If your child attends school in your local district, they might be assigned to ride on a regular school bus or on a bus used only for students who are classified. If your child attends an out-of-district school, your local school district, your county, or a private company might provide transportation.

Do not minimize the importance of transportation to and from school in your child's day. It is important to make sure the transportation mode is appropriate for your child and one in which he or she is safe and comfortable. If your child needs an aide, make sure one is provided.

Remember, you know your child best. Informing a driver and/or aide about your child's individual needs will make for a smoother ride. Tell them about the disability and about any potential medical issues, such as seizures. Let them know if there are things that your child likes or dislikes such as music (watch the volume), sitting in a certain seat such as by a window or near the driver, being near a friend, etc. Also, advise them what to do if your child is having a difficult time. Consider having your child bring things on the bus that they enjoy, such as books, music with headphones, activity books, or video games.

If you are having difficulties with transportation, speak with the driver, aide, or contact person at the transportation company. If that does not help, contact your child's case manager in your school district. You may also find some assistance and suggestions from your child's school.

Camps & Recreation for Individuals with Disabilities

Camps

Camp can be a wonderful experience for anyone with a disability, providing a welcome change from the daily routine while giving the rest of the family a well-deserved break. Some typical day camps and sleep-away camps welcome those with special needs. Other camps specialize in hosting campers with a specific disease or disability. Schools, work programs, disability organizations, and other families are all good sources of information about camp options for your family member.

When considering a camp, it is a good idea to visit during a session or an open house to ensure it has the necessary supports for your family member. Prepare your loved one in advance about what to expect, how long they will be away, and what the experience will be like. Let them help with planning and packing. Consider sending along written specifics about your loved one to make it easier for staff to get to know him or her. Think about sending a disposable camera with instructions so staff can take pictures of fun times for future memories. Here are some good starting points for information:

- **Center for Parent Information and Resources (formerly NICHCY)**
www.parentcenterhub.org

- **Directory of Camps/Summer Programs for Children/Youth with Disabilities in New Jersey**
908.665.0607
www.kidsguidenj.com/special_needs/specneeds_camps.html
- **Applications for Camp Assistance for Children Under 21 Can Be Found at PerformCare**
877.652.7624
www.performcarenj.org

Recreation

There are recreational opportunities for individuals with varying types of disabilities provided by various organizations. Each program has eligibility criteria and, in some cases, income eligibility requirements. There may be a registration fee or fee per activity required to participate. In addition, each municipality is required to provide inclusive programs to the residents of their community regardless of ability to participate.

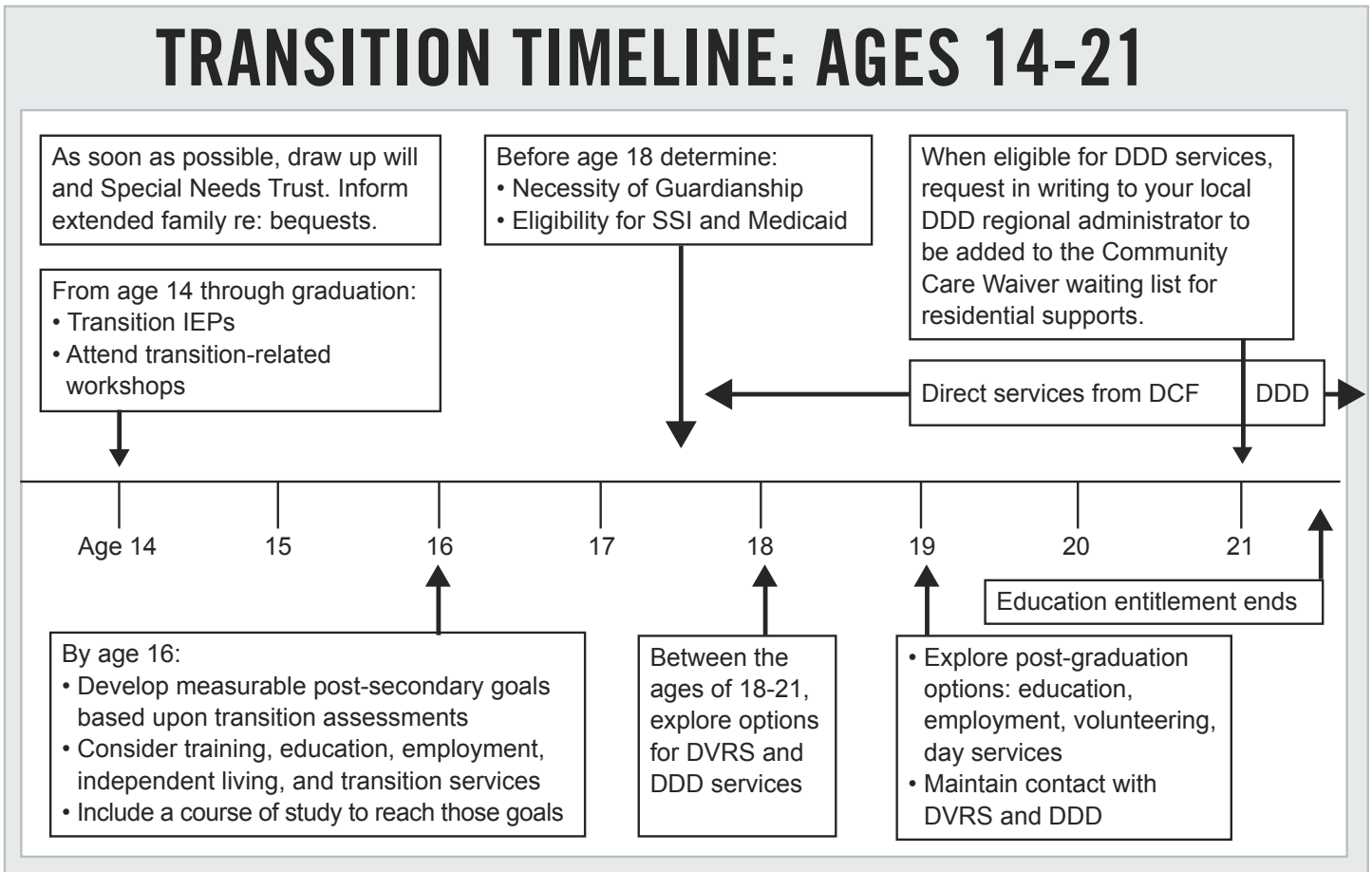
Contact your local municipality, religious organizations, and your local YMCA/YWCA for programs that might be of interest. You might also get some ideas from other caregivers, schools, and adult programs, and from organizations that provide services to individuals with disabilities.

Information on statewide programs can be found at:

- **State of NJ Department of Community Affairs: Recreation and Leisure Services for Individuals with Disabilities Resource**
www.state.nj.us/dca/divisions/dhcr/rec/resource_directory.html
- **New Jersey Special Olympics**
www.sonj.org
- **VSA Arts of New Jersey**
www.vsanj.org

Transition from School to Adult Life

Below is a “Transition Timeline” overview for children from ages 14-21. It highlights important actions for parents to take, and the timing of such actions, to help maximize services and legal protections on behalf of a child with a disability.



Transition services are a coordinated set of activities for a child with a disability focused on improving academic and functional achievement to facilitate movement from school to adult life. This is a process that requires careful planning. It typically begins at age 14 and is addressed annually in the IEP until the child graduates.

Transition planning is based on the individual child’s needs, taking into account the child’s strengths, preferences, and interests. Planning includes: instruction, related services, community experiences, development of employment, and other post-school adult living objectives, and, if appropriate, acquisition of daily living skills and provision of a functional vocational evaluation.

Post-school outcomes are designed to be within a results-oriented process and may include college, postsecondary education, vocational education, integrated employment (including supported employment), volunteering, continuing and adult education, adult services, independent living, or community participation.

- **NJ Department of Education – Office of Special Education Program**
www.nj.gov/education/specialed/transition/

Please refer to **Chapter 8, Legal Matters** for additional information about life transitions, guardianship, etc.

Planning for the Future (21 Years of Age & Older)

Note: It is important to start planning for your child’s future well before they turn 21.

There is a dramatic change when a young adult with a disability leaves school (usually the June after their 21st birthday). The “entitlement” period ends and the school district no longer has the responsibility to provide services.

At that point, he or she may be eligible to receive services from the Division of Developmental Disabilities (DDD). These can include day programming, residential services, self-directed, and family support services (the latter may already be in place). There is valuable information available on the DDD website in regard to available services.

Note: DDD was undergoing major programmatic and procedural changes at the time of this printing. For the most up-to-date information, refer to the DDD website.

- **Division of Developmental Disabilities (DDD)**
www.state.nj.us/humanservices/ddd/home/

Medicaid Supports Program

All Medicaid-eligible individuals who are also eligible for DDD functional services will be able to access the Supports Program, unless they are enrolled on the Community Care Waiver. The Supports Program is a Medicaid program, which requires individuals to maintain their Medicaid eligibility in order to continue to participate.

Types of Services Provided

Employment/Day Supports: DDD will provide employment services and other day supports to supplement employment when an individual’s educational entitlement ends.

Individual and Family Supports: DDD will provide self-directed individual and family supports such as adaptive technology, behavioral supports, environmental and vehicle modifications, respite, etc. via a self-directed model based upon assessed need. Individuals will choose from approved providers using established budgets.

- **Supports Program**
www.state.nj.us/humanservices/ddd/programs/supports_program.html

In addition to the Supports Program, DDD has a Community Care Waiver Program. DDD maintains a waiting list for individuals who want to receive waiver services. Individuals are served off the waiting list in chronological order, based on the date they were first added to it. DDD is only able to approach individuals on the waiting list for waiver services as state resources become available. At that point, DDD is able to begin an assessment to determine the individual's needs.

Only individuals who have been determined eligible by DDD to receive the services it funds can be added to the waiting list for waiver services.

➤ **Community Care Waiver**

www.state.nj.us/humanservices/ddd/services/ccw/index.html

NJ Division of Vocational Rehabilitation Services (DVRS)

The NJ Division of Vocational Rehabilitation Services (DVRS) provides services that enable individuals with disabilities to find jobs or keep their existing jobs, such as training, placement and job coaching, and more. Individuals with a physical or mental impairment, which serves as a significant barrier to employment, may qualify for services through DVRS. For information and the full list of DVRS services:

➤ **609.292.5987**

http://careerconnections.nj.gov/careerconnections/plan/foryou/disable/vocational_rehabilitation_services.shtml

Post-Secondary Education

There are many types of schools your child may want to consider attending after high school graduation, and it is important to know the differences between them. Examples include vocational programs and private residential schools that address life skills/independent living. It pays to do your research while your child is still in high school so that continuing education is in place when they are ready to move on. For information:

National Council on Disability

Post-secondary education resources for individuals with disabilities.

➤ **www.ncd.gov/publications/2003/Sept152003**

HEATH Resource Center

The HEATH Resource Center gathers and disseminates information to help people with disabilities reach their full potential through post-secondary education and training.

➤ **<https://heath.gwu.edu/>**

College

A young adult with a disability may be interested in and able to attend an institution of higher education. If your child had an Individualized Education Program (IEP) during his/her last year of high school, he/she is eligible under Section 504 of the Rehabilitation Act for assistance in setting up a plan of accommodations.

Many schools have special support systems in place to assist individuals with disabilities. Some supports include: taping lectures, providing a note-taker, untimed tests, sitting in on multiple sessions of the same class, summer transition sessions, taped textbooks, tutoring, and counseling.

Students considering higher education who were classified and received special education services in high school should contact each institution's department of disability services before enrolling to ensure the school can provide the accommodations needed for success.

Note: It is the responsibility of the student to inform the institution as well as the professors of any accommodations that he or she may need.

NJ Commission on Higher Education: Special Needs Regional Centers

This is a system of eight regional centers that provide support services for college students with special needs (learning disabilities, visual impairments, hearing impairments).

- **Special Needs Regional Centers**
www.tcnj.edu/~technj/2006/regcenters

Adaptive Aids

An adaptive technology center has been established at The College of New Jersey to assist students with disabilities in meeting the academic demands of college by providing access to appropriate technology tools.

- **Center for Assistive Technology & Inclusive Education Studies**
<http://caties.pages.tcnj.edu/>

Education Resources for Parents/Caregivers

Parent education is a vital component of being an effective advocate. In order to fully participate in decisions regarding your child's education, it is imperative to understand your rights and responsibilities. Take advantage of parent education workshops and resources within your community. Although much of this training will be "on the job," there is a lot to be said for attending formal parent education trainings. At parent education trainings you may receive assistance with your particular situation, as well as learning about the "nuts and bolts" of parenting a child with special needs and/or with a specific disability. Such workshops are a great place to network and share information with other parents. Some sources of parent education to consider are your child's school, your local school district, and the following organizations:

Statewide Parent Advocacy Network (SPAN)

SPAN is an excellent source of information for families about the IEP process. SPAN representatives can also provide technical assistance and guidance on identifying advocacy support. (Spanish available)

- **800.654.SPAN; 973.642.8100**
www.spanadvocacy.org/

Family Support Center New Jersey (FSCNJ)

The Family Support Center is a clearinghouse of up-to-date information on national, state, and local family support programs, services, and disabilities. The Center operates a statewide toll-free number for family members, professionals, and other interested individuals to call for access to a broad array of support services.

- **800.372.6510**
www.fscnj.org

Centers for Independent Living (CILs)

These are community-based, private, not-for-profit organizations that work with people with all disabilities to advance their independence. Services provided include peer counseling, skills training, advocacy, and information and referral services. Each CIL promotes the Independent Living movement which seeks to change community attitudes and beliefs which perpetuate dependence. Independent Living is a philosophy, which states that people with disabilities should have the same civil rights, choices, and control as people without disabilities.

- **DAWN Center for Independent Living (Morris, Sussex, and Warren)**
973.625.1940; 888.383.DAWN
www.dawncil.org
- **Alliance Center for Independence (Middlesex, Somerset, and Union)**
732.738.4388
www.adacil.org
- **DIAL Center for Independent Living, Inc. (Essex and Passaic)**
973.470.8090
www.dial-cil.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 an excellent portal for caregiver education programs in your county. Contact ADRC to get in touch with your own county's ADRC. Phone is staffed weekdays during normal working hours.

- **877.222.3737**
www.adrcnj.org

United Way *Caregivers Coalition* (Morris, Somerset, Suburban Essex, 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 workshops or to schedule a workshop.

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

Visiting Nurse Association of Northern NJ (VNANNJ) (Morris)

The VNANNJ In-Home Caregiver Education and Support Program provides FREE in-home education and support to unpaid caregivers residing in Morris County so they may improve their ability and effectiveness as caregivers. The care recipient must be over age 18 and functionally impaired with a chronic disease or disability. There are no income or asset eligibility requirements for this program.

The program provides a registered nurse to meet with the caregiver at their home to conduct an initial assessment and to set up a teaching plan that will help to relieve caregiver stress and increase caregiver effectiveness. Other services include in-home instruction to enable caregivers to identify the skills needed to provide proper care, including lifting and transferring, bathing, personal care, nutrition, disease education, stress management, and accessing community resources. The program allows for up to five professional home visits by a registered nurse, physical, speech or occupational therapist, social worker, or nutritionist to provide educational and support services, including stress management.

- **800.WE.VISIT (800.938.4748)**
www.vnannj.org

Educating yourself about the disability that is 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 sites 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. PARENT/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.

At times caregivers may disagree with decisions made by their loved ones and even blame themselves if the care they want to provide is not accepted. However, it is often helpful to be flexible in approach and to encourage decisions by loved ones, as long as these 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. See the next page for examples.

- **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 just 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, or 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.

Respite for Caregivers

Respite literally means a period of rest or relief. Respite care gives a caregiver temporary relief from the responsibilities of caring for a loved one with chronic illness, physical disabilities, or mental disabilities. Respite is important for all caregivers and is a key component to maintaining caregiver health. And caregiver health is, ultimately, vital for the loved one requiring care. Caregivers should take respite breaks regularly, without guilt.

Length of respite care can be anywhere from a few hours to several weeks. Services that provide respite may be used for a variety of reasons, ranging from emergencies to vacation, and with a range of frequency, from one day per week or month, to weekends, even to respite everyday. Respite can be in-home or at respite centers. All members of the family will benefit when respite becomes a regular event.

In-Home Respite

In-home respite services consist of a worker who comes to the family home so that the caregiver can leave the house for a period of time. These services are usually provided by agencies that recruit, screen, and train workers. This type of respite is usually less disruptive to the individual needing care, provided there is a good match between the worker and the individual.

Out-of-Home Respite

Out-of-home respite can take place in adult day centers, camps, assisted living communities, or skilled nursing facilities. This type of respite often offers peace of mind to the caregiver, while providing a stimulating environment for the individual. However, centers usually restrict the length of stay and may exclude individuals based on severity of disability. One good local starting point for lists of in-home respite agencies and respite centers is the ADRC.

Statewide Respite Care Program

This program provides respite care services for older adults, and for functionally impaired persons age 18 and older, to relieve their unpaid caregivers of stress arising from the responsibility of providing daily care. You must meet specific income requirements to be eligible. To reach the Statewide Respite Care Program provider in your county, contact the ADRC.

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 respite services. Contact your county's ADRC for local information. Phone is staffed weekdays during normal working hours.

- **877.222.3737**
www.adrcnj.org

Respite for Families with Children & Youth Under Age 21 with Behavioral Health or Developmental Disability Needs

Children's System of Care (CSOC)

CSOC offers a wide range of services for children up to age 21 with behavioral health or developmental disability needs. Services include community-based services, in-home services, out-of-home residential services, family support services, and respite. For questions about behavioral health or developmental disability services:

- **877.652.7624 (24-hours, toll-free) (TTY: 866.896.6975)**
www.state.nj.us/dcf/families/csc/

Family Support Services

Family Support Services are intended to help support uncompensated caregivers for individuals who are eligible for developmental disability services and living in their own homes. CSOC evaluates requests for Family Support based on an individual's need, the services and supports already available and/or being used, and the availability of CSOC resources. Family Support is not an entitlement and cannot be guaranteed. Budget allocations dictate the availability of services. Families must exhaust any other services to which they are entitled before they can receive assistance through Family Support.

Respite is usually provided by an agency that contracts with CSOC. Respite includes:

- Afterschool activities
- Weekend recreational activities
- A short-term placement in a licensed setting
- In-home respite
- Self-directed respite
- Camp

Some assistance with camps may be available through Family Support. Before requesting funding for camp, a family should ask the Department of Education for an extended school year for their child. Applications for camp assistance for children under 21 can be found at PerformCare. Applications are accepted between March 15th and April 30th each year.

➤ www.performcarenj.org

Respite for Families with Loved Ones Over 21 Who Are Registered with the Department of Developmental Disabilities

Family Support Services

Family Support Services are intended to help support uncompensated caregivers for individuals over 21 who are eligible for developmental disability services through DDD and living in their own homes. DDD evaluates requests for Family Support based on an individual's need, the services and supports already available and/or being used, and the availability of DDD resources. Family Support is not an entitlement and cannot be guaranteed. Budget allocations dictate the availability of services. Families must exhaust any other services to which they are entitled before they can receive assistance through Family Support. Contact your Support Coordinator for more information on the DDD Individual Supports Program.

➤ **800.832.9173**
www.state.nj.us/humanservices/ddd/services/fss/

Other Supports/Services Available Through CSOC

Assistive Technology Devices (ATD)

Used to increase, maintain, or improve an individual's functional capabilities. Unless an Assistive Technology Device is available from only one vendor, families seeking them must obtain three competitive bids. A physician or therapist must prescribe the device. The individual must have received a denial from his or her insurance carrier, including Medicaid. Individuals may receive no more than \$11,000 for ATDs over a three-year period.

Home & Vehicle Modifications

These are removable, structural modifications, such as ramps, grab-bars, etc. Although an exception may be granted in cases where a modification affects an individual's mobility, such as a roll-in shower or a garage conversion. Individuals may receive no more than \$11,000 for home and vehicle modifications over a three-year period.

Other Caregiver Supports

MOM2MOM Helpline Program

This 24/7 telephonic support system coordinated by Rutgers University Behavioral Health Care provides peer support, telephone assessments, referral information, and support groups.

- **877.914.6662**
www.mom2mom.us.com

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

Open to the public and free to join, the *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

Self-Help Groups

Self-help groups can be of great help to those trying to cope 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 be able to help you to 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.caregiveraction.org
- www.caregiver.org
- www.caregiving.org
- www.wellspouse.org

Caregiver Counseling/Psychotherapy

There are many counseling and support services available in our region through local hospitals, human service agencies, and private practitioners. In some instances, counselors may make home visits or will arrange to meet with and support those of you who are providing care to a family member and/or friend with issues of aging and/or disability. People with insurance should check with their insurance company to ensure that the provider is in their network.

Mental Health Association in New Jersey, Inc.

The Mental Health Association in New Jersey strives for mental health for children and adults through advocacy, education, training, and services. The vision of the MHANJ is a statewide community in which people with mental illnesses can achieve full potential, free from stigma and other barriers to care and recovery.

- **800.367.8850**
www.mhanj.org

NJ Department of Children and Families

Information on children's mental health services.

- **877.652.7624**
www.performcarenj.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 caregiver counseling services in your county. Use the phone number below to contact your county's ADRC. Phone is staffed weekdays during normal working hours.

- **877.222.3737**
www.adrcnj.org

Other Care Issues Related to Everyday Living

Travel

When you are planning a trip with an individual with a disability, it may be necessary to consider issues such as accessibility of rooms and transportation, bringing along service animals, etc. Most travel destinations can make accommodations. There are organizations that cater specifically to the needs of individuals with disabilities in travel, both with and without caregivers. Some helpful resources include:

- **AAA**
www.aaa.com

- **AbilityPath**
Support for parents of children with special needs
www.abilitypath.org
- **Disability Travel and Recreation Resources**
www.makoa.org/travel.htm
- **Hammer Travel**
Travel experiences for adults with developmental disabilities
877.345.8599
www.hammertravel.org

Worship

For information on faith-based supports:

- **New Jersey Coalition for Inclusive Ministries**
<http://rwjms.rutgers.edu/boggscenter/projects/NJCoalitionforInclusiveMinistries.html>

Service Animals

The Americans with Disabilities Act (ADA) defines a service animal as any guide dog, signal dog, or other animal individually trained to provide assistance to someone with a disability. If the animal meets this definition, it is considered a service animal under the ADA, regardless of whether it has been licensed or certified by a state or local government. Service animals perform some of the functions and tasks that the individual with a disability cannot perform. Under ADA, privately owned businesses that serve the public, such as restaurants, hotels, retail stores, taxicabs, theaters, concert halls, and sports facilities are required to allow people with disabilities to bring service animals into any area where customers are generally allowed. For information:

- **Canine Companions for Independence**
www.cci.org
- **Canine Partners for Life**
www.k94life.org
- **Pet Partners**
www.petpartners.org
- **Seeing Eye, Inc.**
www.seeingeye.org

6. CARE MANAGEMENT AND/OR SUPPORT COORDINATION

Care management and/or support coordination is a service which assists in determining eligibility and identifying appropriate programs and services which would be most beneficial to an individual. A comprehensive assessment is completed in collaboration with the individual and the caregiver, a plan is developed, services are identified, and delivery is facilitated to meet the individual's needs over a period of time.

These services are made available in certain instances, depending on your loved one's age, disability, level of need, county of residence, and/or the agency involved. The term for this service may vary from agency to agency, however, regardless of the title, this person is typically your primary contact. For example, during the school-age years (0-21) each student who is classified and covered by the Individuals with Disabilities Education Act (IDEA) has a case manager through his or her school district.

Remember, working with a care manager is a partnership – the care manager knows the community resources and you know your loved one. Don't be afraid to voice your concerns or preferences in services to be provided.

If a Disability Occurs in a Person Younger Than 21-Years-Old, Services Could Be Provided Through:

- **NJ Early Intervention System: Birth-3 Years of Age**
888.653.4463
www.nj.gov/health/fhs/eis
- **Special Child Health Services: Birth-21 Years of Age**
www.nj.gov/health/fhs/sch/sccase.shtml
- **PerformCare: Under 21**
877.652.7624
www.performcarenj.org

For Adults Over Age 21 with a Disability, Services Could Be Provided Through:

- **NJ Division of Developmental Disabilities (DDD)**
800.832.9173
www.state.nj.us/humanservices/ddd/home/
- **NJ Division of Disability Services (DDS)**
888.285.3036
www.state.nj.us/humanservices/dds
- **Aging & Disability Resource Connection of New Jersey (ADRC)**
877.222.3737
www.adrcnj.org

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 A DISABILITY

Key Benefit Programs

There is a wide range of programs directed toward people of all ages with disabilities. 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 for applies 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 US states and provides detailed information and application instructions. 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 trusted family member or friend 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

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 you, 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)

The loved one you care for may have developed issues along the way that 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/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 dependents 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 when 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 they meet certain requirements. 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.

SSI Rules for Children Under the Age of 18

The following criteria will be considered when determining if a child is eligible:

- Your child's income and resources
- The income and resources of family members living in the child's household

These rules apply if your child lives at home. They also apply if he or she is away at school but returns home from time to time and is subject to your control.

Providing Information About Your Child's Condition

When you apply for benefits for your child, you will be asked for detailed information about the child's medical condition and how it affects his or her ability to function on a daily basis. You will also be asked to provide information from the doctors, teachers, therapists, and other professionals who have assessed your child's condition. The more information you are able to provide, the quicker the process will be completed. Your child must meet all of the following requirements to be considered disabled and therefore eligible for SSI:

- The child must not be working and earning over an allowable limit every month, an earnings amount that changes every year. If he or she is working and earning that much money, your child will not be considered for disability benefits. There are different exclusions for students, so be sure to check with the Social Security Administration.
- The child must have a physical or mental condition, or a combination of conditions, that result in "marked and severe functional limitations." This means that the condition(s) must very seriously limit your child's activities.
- The child's condition(s) must have lasted, or be expected to last, at least 12 months or must be considered terminal.

When Your Child Turns Age 18

For disability purposes in the SSI program, a child becomes an adult at age 18 and different medical and non-medical rules apply in determining whether an adult is eligible for SSI disability payments. For example, the income and resources of other family members are no longer considered when deciding whether an adult with a disability meets the financial limits for SSI.

- If your child was already receiving SSI payments, the child's medical condition must be reviewed when he or she turns age 18. This review usually takes place during the one-year period that begins on your child's 18th birthday.
- If your child was not eligible for SSI before his or her 18th birthday because you and your spouse exceeded income or resources limits, he or she may become eligible for SSI at age 18.

For more information about any of the above Social Security benefits:

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

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 & Medicaid Programs

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 limited 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 preventative 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 both pay their share 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, the 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 office 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
www.nj.gov/humanservices/dds/services/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

Medicaid Only/Nursing Home

This program provides nursing home care for those who qualify medically and financially. Participants must be in need of support in areas such as washing, dressing, self-feeding, self-toileting, walking, and cognitive awareness. There is an income cap and the resource evaluation includes a five-year look-back to rule out the transfer of resources for less than their fair market value.

Medically Needy Nursing Home

This program shares the medical guidelines for Medicaid Only/Nursing Home (see above). However, the income limit is expanded to accommodate those individuals with incomes that exceed the Medicaid Only/Nursing Home income cap. The resource limit is also expanded, but contains the five-year look-back.

Medicaid Benefits in Assisted Living Facilities

This program provides residential care in an assisted living facility. Participants must need medical support, but they are more independent than those in nursing homes. Assisted living facilities provide all medical necessities plus housekeeping, laundry, congregate meals, planned social activities, and case management. The financial guidelines are the same as Medicaid Only/Nursing Home (see above). Note that many assisted livings require 18-24 months of private pay before potentially accepting Medicaid for the resident.

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

Assistance Programs for Individuals with a Developmental Disability

Supports Program (DDD)

All Medicaid-eligible individuals who also are eligible for DDD functional services will be able to access the Supports Program, unless they are enrolled on the Community Care Waiver. The Supports Program is a Medicaid program, which requires individuals to maintain their Medicaid eligibility in order to continue to participate. Types of services provided include employment and day supports, and individual and family supports, such as adaptive technology, behavioral supports, environmental and vehicle modifications, respite, etc. via a self-directed model based upon assessed need. Individuals will choose from approved providers using established budgets.

➤ **NJ Division of Developmental Disabilities**

www.state.nj.us/humanservices/ddd/programs/supports_program.html

8. LEGAL MATTERS RELATING TO LOVED ONES WITH A DISABILITY

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 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 their loved one and does not constitute legal advice. For specific legal advice, always seek professional counsel.

It is also 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.

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 handicap, 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 a clear example of someone having a disability and being unable to make a decision independently.

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 his or her medical decisions. 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 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.

Will

Elder planning often starts with a will, an important document in any elder plan. 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.**”

Understanding Capacity: 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 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. A trust avoids the need, delay, and cost of probate. A will becomes a public document; a trust does not and, thus, is a great way to keep your loved one's affairs more private.

Special Needs Trust

A person with a disability and receiving government benefits is often limited as to the amount of assets that they can own directly. 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 disability 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 of Special Needs Trust 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 disability.

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. 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. For more information on estate planning and a Letter of Intent:

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

Guardianship

It is important to determine the necessity of a Guardianship prior to your loved one's turning age 18.

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

Most parents of a loved one with a disability 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 another 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 elder, 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 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 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. 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 Division of Developmental Disabilities, 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 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.

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

9. DAY PROGRAMS/SERVICES & HOME CARE PROGRAMS

There are a variety of day and home care services available in the community, depending on your loved one's disability and the level of need.

For persons with developmental disabilities, these services can include community-based supports, day programs, in-home supports, career planning, and pre-vocational training and could be part of an Individualized Service Plan (ISP). Families have the ability to choose a Support Coordination Agency and work in partnership with a support coordinator to develop and maintain the ISP. The support coordinator is responsible for the ongoing monitoring of the provision of services included in the ISP. For more information, contact:

- **NJ Division of Developmental Disabilities (DDD)**
www.state.nj.us/humanservices/ddd/services/day/

Day Services

This is a general term used to describe the programs and activities that individuals participate in for up to 25-35 hours per week. These services can be provided any time during the day and any day during the week. To participate in DDD-funded services an individual must be:

- DDD eligible
- At least 21-years-old
- Have completed their educational entitlement

Different Day Service Options

There are many ways an individual can participate in day services, including:

- Regular employment
- Traditional day programs
- Special needs day programs
- Self-directed day programs
- Combination of part-time employment and traditional programs
- Combination of part-time employment and self-directed day programs
- Combination of traditional day programs and self-directed activities

Types of Day Services

In general, DDD provides three different types of day services: **Traditional Day Programs, Special Needs Programs, and Self-Directed Day Programs.**

Traditional Day Programs

- Operate year round (at least 230 days/year)
- Provide a structured day, five hours a day, five days a week, although hours vary
- Provide transportation within a defined geographic area
- Have a 1:6 staff-to-consumer/client ratio
- Examples of day program activities include: arts and crafts, activities of daily living, volunteer activities in the community, contract work with a crew of peers, pre-employment skill training, socialization/recreational activities

Special Needs Programs

- Closely resemble traditional day programs
- Provide enhanced staff supports, with a typical staff-to-consumer/client ratio of 1:3
- May offer related support services such as nursing, behavioral supports, or mental health supports

Self-Directed Day Services

- Allow individuals to help identify their own activities
- Allow individuals to schedule their own activities
- Require some involvement by family and/or friends
- Begin with an assessment completed by phone
- Assign a budget that individuals can use to obtain services

Adult Day Programs

Adult day programs are also known as “adult day services.” There are three types of day programs: medical, social, and Alzheimer’s/dementia care. Programs are designed for adults and eligibility is based on age, rather than disability.

Each type of service provides care with a planned program of activities designed to promote well-being through social activities and/or health related services for adults who are isolated or need assistance in activities of daily living. These services operate during the day. Meals are provided. In some cases, transportation to and from the facility is also available. Payment for services includes private payment and, in some instances, Medicaid.

Home Care Options

Home care allows people to remain in their own homes while receiving the assistance they need to help them remain independent. Services are delivered at home to recovering, disabled, chronically, or terminally ill persons in need of medical, nursing, social, or therapeutic treatment and/or assistance with the essential activities of daily living.

Generally, home care is appropriate whenever a person prefers to stay at home, but needs ongoing care that cannot easily or effectively be provided solely by the caregiver and circle of family or friends. Services may be provided as frequently as needed, ranging from daily visits to 24-hour stays. Accepted methods of payment include private pay, commercial insurance, and Medicare or Medicaid.

Home Health Care Coverage

Home health care may be covered under Medicare, Medicaid, veterans' benefits, or insurance. A person qualifies for these services if they have a "skilled need" for a nurse or rehab therapist (physical, occupational, speech therapist). These skilled services generally last a short time (6-8 weeks). A home health aide may also come for a short visit to provide personal care during this time. Often these services are ordered when you come home from the hospital, but they can also be ordered by your doctor in order to prevent a hospitalization.

When there is not a skilled nursing need or if home health care is needed beyond the period covered by insurance, home care services can be paid for directly by the patient and his or her family members. Your county's ADRC may also know of programs that assist, such as Jersey Assistance for Community Caregiving (JACC) which may assist eligible New Jersey residents 60 and older. (See Section A, Chapter 7)

➤ **877.222.3737**
www.adrcnj.org

Home Care Agencies

These agencies provide personal care (bathing, dressing, toileting), meal preparation, household chores, and supervision. These services are available by a certified home health aide on an hourly basis or as a 24-hour live-in and are generally paid privately. Make sure that the home care agency you are dealing with is licensed under New Jersey law. Some companies merely refer caregivers to clients; they are not licensed or monitored by the state and are not required to screen, do background checks, etc. In this case, you actually become the "employer" and are responsible for worker's taxes, insurance, etc.

Suggested Interview Questions for a Home Care Agency

- Is this agency a licensed Health Care Service Firm under New Jersey law?
- Are its workers "employees" or "independent contractors?" Who is responsible for their payroll, taxes, and workers compensation insurance?
- What training do the workers receive?
- Will an RN monitor care? Does the RN visit the home regularly or only at the onset of care?
- Are the caregiver employees citizens or legal residents of the US?
- Is the agency contracted with a high quality, local hospital?
- What are the hiring standards of the agency? What about background checks for caregiver employees?
- Is there a person on call 24/7?
- What if I am not comfortable with, or just do not like, the person chosen by the agency?
- Do you have Geriatric Care Managers or Social Workers on staff?

Non-Medical Companion Agencies

These agencies are designed for individuals who need minimal care. These services will typically provide personal services in the home relating to daily activities such as dressing, cooking, medication supervision, cleaning, and transportation. These services are paid privately.

For persons with disabilities, the following may or may not apply depending on the level of care needed:

Medicaid Personal Care Assistant (PCA)

This is a statewide service reimbursed by the New Jersey Medicaid Program for people eligible for Medicaid services in the community. The purpose of personal care is to accommodate long-term chronic or maintenance health care as opposed to short-term skilled care as is provided under Medicaid's home health program. PCA services are health-related tasks performed by qualified staff in an eligible beneficiary's home or workplace. Services include assistance with activities of daily living and household duties essential to the individual's health and comfort. For information, visit the Division of Disability Services, Office of Home and Community Services:

- <http://nj.gov/humanservices/dds/ohcs/pca/>

Personal Assistance Services Program (PASP)

This is a state program for individuals from 18-65 years of age who are capable of self-direction. It provides routine, non-medical assistance to individuals with disabilities who are employed, preparing for employment, involved in community volunteer work, or attending school. Personal assistants help with tasks such as light housekeeping, bathing, dressing, preparing meals, shopping, driving, or using public transportation. The number of hours of assistance a person receives depends on individual need, up to a maximum of 40 hours per week. For information and a link to PASP County Sites and Coordinators, visit:

- <http://nj.gov/humanservices/dds/projects/pasp/>

Personal Preference Program (PPP): New Jersey Cash and Counseling Program

This service allows Medicaid recipients who are eligible for Medicaid PCA services to direct their own care. Through use of a monthly cash allowance, participants work with a consultant to develop a cash management plan by which they decide the services needed and the individuals and/or agencies to provide the identified services. The program requires greater consumer responsibility, but offers participants greater control, flexibility, and choice.

- www.nj.gov/humanservices/dds/services/ppp/

Hospice

Hospice is a program of care for terminally ill patients and their families, which takes place in the home, a nursing home, or dedicated hospice unit. The goal is to provide physical, emotional, and spiritual support with a dignified, peaceful approach to comfort in the final months of life, regardless of disease. Hospice care is covered under Medicare, Medicaid, and most private insurance. No one is denied hospice care because of an inability to pay.

- **New Jersey Hospice & Palliative Care Organization**
908.233.0060
www.njhospice.org
- **National Hospice and Palliative Care Organization**
Information on end-of-life issues and state-specific advance directives
703.837.1500
www.nhpco.org
- **Ageing & Disability Resource Connection of New Jersey (ADRC)**
877.222.3737
www.adrcnj.org

Nutrition Programs

Home Delivered Meals

Nutritious meals can also be delivered to homebound individuals in the following counties:

- **Essex County - Mobile Meals of Essex**
973.744.8103
www.chrill.org/mobilemeals.htm
- **Morris County Senior Citizen Nutrition Program**
800.564.4656
<http://morriscountynj.gov/hs/adv/nutrition/>
- **Somerset County Nutrition Program**
908.704.6346
www.co.somerset.nj.us
- **Sussex County Home Delivered Meal Program**
973.209.0123
www.sussex.nj.us/documents/seniorservices/resourcedirectory.pdf
- **Warren County Division of Aging and Disability Services**
908.689.4140
www.co.warren.nj.us
- **SAGE Eldercare**
Delivers to Berkeley Heights, Chatham, Chatham Township, Millburn, Mountainside, New Providence, Short Hills, Springfield, and Summit
908.598.5302
www.sageeldercare.org
- **All Counties: Aging & Disability Resource Connection of New Jersey (ADRC)**
877.222.3737
www.adrcnj.org

Meal Sites

Located throughout New Jersey, sites provide a hot midday meal and opportunity to socialize with others.

- **Essex County - Senior Congregate Nutrition Program**
Provided by Chrill Care, with sites in Bloomfield, Caldwell, Newark, and Nutley.
973.744.8103, x 244
www.chrill.org/congregate.htm
- **Morris County Senior Citizen Nutrition Program**
Sites in Butler, Chatham, Chester, Denville, Dover, Jefferson Township, Long Hill Township, Madison, Montville, Morristown, Mt. Olive Township, Parsippany, Rockaway, and Roxbury
973.285.6856
<http://morriscountynj.gov/hs/adv/nutrition/>

- **Somerset County Nutrition Program**
Sites in Hillsborough, Manville, Somerset, Raritan, Warren, Bridgewater and N. Plainfield
908.704.6346
www.co.somerset.nj.us

- **Sussex County Congregate Nutrition Programs**
Franklin: **973.827.2973**, Hopatcong: **973.398.2608**
Vernon: **973.764.5454**
www.sussex.nj.us/documents/seniorservices/resourcedirectory.pdf

- **Warren County Division of Aging and Disability Services**
Sites in Belvidere, Hackettstown, Phillipsburg, and Washington
908.475.6591
www.co.warren.nj.us

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

10. EMPLOYMENT & VOLUNTEERING FOR LOVED ONES WITH A DISABILITY

As caregivers, we want our loved ones to lead as full a life as possible. For people with disabilities, employment often helps to promote independence and the chance to lead a more productive and fulfilling life. Vocational rehabilitation services assist those who are disabled in the development, acquisition, or updating of skills that will enable them to secure and maintain employment. This may include working in the labor force, operating his or her own business, and/or working in what is known as “supportive” employment.

Employment

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 disability 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://careerconnections.nj.gov/careerconnections/plan/foryou/disable/vocational_rehabilitation_services.shtml

NJ Commission for the Blind and the Visually Impaired (CBVI)

The NJ Commission for the Blind and Visually Impaired promotes and provides services in the areas of education, employment, independence, and eye health with persons who are blind or visually impaired and their families. For information:

- **973.648.3333**
www.state.nj.us/humanservices/cbvi/home/index.html

Employment Services through State Agencies, DVRS and CBVI

Both state agencies, **DVRS** and **CBVI**, will provide employment services for persons with disabilities. Individuals with visual impairments will receive support through CBVI, while those with other disabilities will be served through DVRS.

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. Those needing these services are most often people with multiple disabilities who have never worked before or have not been in the workforce for many years. 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 VR 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 DDD clients, including a link to a list of supported employment vendors:

➤ www.state.nj.us/humanservices/ddd/services/ses/

Post Employment Supports 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.

What if Your Loved One is Receiving Government Benefits and 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.ssa.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 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.ssa.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 (NJ WINS) program assists Supplemental Security Income (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 disabilities 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**
973.533.1993
www.jerseycares.org
- **United Way of Northern New Jersey (Morris, Somerset, Suburban Essex, Sussex, and Warren)**
973.993.1160
unitedwaynnj.org/volunteer/volunteer.php

11. HOUSING FOR LOVED ONES WITH A DISABILITY

New Jersey Housing Resource Center (NJHRC)

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.

- **877.428.8844**
www.njhrc.gov

Supportive Housing Association of New Jersey (SHA)

The Supportive Housing Association of New Jersey (SHA) is a statewide nonprofit organization focused on promoting and maintaining a strong supportive housing industry in New Jersey to serve people with special needs. SHA has a resource list that includes developers of supportive housing.

- **908.931.1131**
www.shanj.org

Specialized Housing for Individuals with a Developmental Disability (DDD Eligible)

If you are seeking state-funded residential services for a person with a developmental disability in the State of New Jersey you must be in the DDD system. When it is no longer possible for a person with a developmental disability to remain living at home, DDD may help the family make other living arrangements that best meet the individual's needs. Individuals who receive residential services may be required to contribute toward the cost from their disability benefits or other personal resources.

There currently is a "Community Care Waiver Waiting List" for residential programs. Individuals should be served in the order in which their names were added to the list. Should circumstances arise that make it impossible for the individual to remain in the home with appropriate supports, the DDD case manager should be called immediately. The case manager will work with the individual to either find them emergency placement or give them services in the home if they can remain living there alone.

The Division should work with the individual and the family to determine the most appropriate option for the individual. The Division provides a variety of community residential options, including:

Group Homes feature on-site, 24-hour staffing support to serve the individual and up to three roommates.

Supervised Apartments are apartments in which an individual lives alone or with a roommate or roommates. The apartment is leased or owned by a service provider agency, which also employs staff that is available to serve the individual 24-hours a day.

Supportive Housing is where a consumer leases his or her own apartment and help is available on an as-needed basis either in person or through phone contact 24/7.

Community Care Home is when the individual lives as part of the family of a trained caretaker and receives 24-hour care and assistance from that person and from an agency on a routine basis.

For information on housing options through DDD, individuals should contact the DDD Community Services regional office that serves the county in which they live. Those numbers can be found at:

- **NJ Division of Developmental Disabilities**
www.state.nj.us/humanservices/ddd/services/residential/index.html

Affordable Housing

There are various housing options available. A good starting place may be the New Jersey Housing Resource Center (NJHRC). The New JerseyHRC is a partnership between the New Jersey Department of Community Affairs, the New Jersey 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 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 family income. 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 put you in contact with the public housing authority in your community.

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

- <https://www.huduser.gov/portal/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.

Contact your local housing authority or:

- **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
portal.hud.gov/hudportal/HUD

Other Housing Programs & Information

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**
866.889.6270
www.state.nj.us/dca/divisions/dhcr/offices/ha.html

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, x 316
<http://essexcountynj.org/wp-content/uploads/2015/04/HIP-Brochure-01.16.2015.pdf>
- **Warren County Home Improvement/Rehab Program**
908.475.3989
www.co.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**
973.285.6032
<http://morriscountynj.gov/hs/wp-content/uploads/2015/03/HousingRehab.pdf>
- **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
www.co.warren.nj.us/Humanservices/local_resources.html

Some service provider organizations have also developed projects that are accessible and affordable for people with disabilities. Check with your case manager or local ADRC for more information.

Homeownership

This is an option for individuals and/or families with sufficient resources. For those individuals registered with DDD, they may combine personal and Division funds and/or pool funds with other individuals to rent a house or condo. Additionally, all first time homeowners, people with any type of disability, or seniors may be eligible for funding from the state Housing and Mortgage Finance Agency to purchase a home or even repair an existing home.

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)

In addition to finding information on local affordable housing units, caregivers can find 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

New Jersey Housing Resource Center provides an online tool to help people with disabilities find housing options: www.njhrc.gov.

12. ADVOCACY FOR LOVED ONES WITH A DISABILITY

Self-Advocacy

Self-advocacy is defined as knowing your rights and responsibilities, standing up for them, and making choices about your own life. As a parent or caregiver of a loved one with a disability, in most instances you are 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 the individual's level of ability, the capability for an individual to advocate for him or herself is the first step in getting the assistance that individual may need.

Whether the individual is born with a disability or acquires one later in life, the skill of self-advocacy is one of the most important and critical skills for that individual. As a caregiver, helping that individual acquire that skill is sometimes difficult because you have become accustomed to taking care of that individual. It is a difficult, but necessary task to ensure the individual has the opportunity to be responsible for him or herself.

Being aware of and informed about services available to you and your family (and when these services end) as well as the individual's rights can make the road to planning easier to navigate.

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 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 writing prescriptions for wheelchairs or special software for a learning disability. Share your expertise by discussing your loved one's needs, giving as much detail as possible about what you are looking for. You may want to speak with agencies about equipment and service evaluations before approaching a doctor for authorization.

Your local Center for Independent Living (CIL) or people you already know who have the same disability as your loved one and have successfully advocated for their own needs may have some helpful ideas. These people may also be able to connect you with professionals who have experience with exactly what you are looking for.

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. Professionals are people too, and words like "please" and "thank you" will go a long way toward developing a strong working relationship.

Start Early and Be Prepared to Wait

Most people notice a definite change when stepping out of the entitlement-based world and into the eligibility-based world. Don't worry. There are ways to make this work in your favor. Sometimes, people who are the best at standing up and advocating for themselves are the first to get the assistance they are looking for. So, if you are a good advocate, this type of system could work in your favor.

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. These issues are especially important for parents with children who will outgrow equipment or those whose functional abilities may change with time. 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 coalitions that advocate regarding specific issues, policies, disabilities, and diseases on local, state, and national levels. Below are a few local organizations. For a more comprehensive listing check the **New Jersey Resources Guide at www.state.nj.us/humanservices/dds**.

Centers for Independent Living (CILs)

These are community-based, private, not-for-profit organizations that work with people with all disabilities to advance their independence. Services provided include peer counseling, skills training, advocacy, and information and referral services. Each CIL promotes the Independent Living movement which seeks to change community attitudes and which perpetuate dependence. Independent Living is a philosophy, which states that people with disabilities should have the same civil rights, choices, and control as people without disabilities.

- **DAWN Center for Independent Living (Morris, Sussex, and Warren counties)**
973.625.1940, 888.383.DAWN
www.dawncil.org
- **Alliance Center for Independence (Middlesex, Somerset, and Union counties)**
732.738.4388
www.adacil.org
- **DIAL Center for Independent Living, Inc. (Essex and Passaic counties)**
973.470.8090
www.dial-cil.org

Developmental Disabilities Councils (DDC)

According to federal law, their mission is to engage in advocacy, capacity building, and systemic change that contribute to a coordinated, consumer and family-centered, consumer and family-directed, comprehensive system. This includes needed community services, individualized supports, and other forms of assistance that promote self-determination for individuals with developmental disabilities and their families.

- **www.njcdd.org**, for publications click on *Publications*

The Monday Morning project (under DDC) is a grassroots organization of advocates concerned with the issues affecting the disability community. Made up of county-based networks, Monday Morning is the voice of people with disabilities speaking out for justice, equal opportunities, improved public access, and a greater voice in community planning.

- **www.njddc.org**, click on *Monday Morning*

NJ Office of the Ombudsman for the Institutionalized Elderly (OOIE)

The NJ Office of the Ombudsman for the Institutionalized Elderly (OIEE) is part of a national resident-focused advocacy program that seeks to protect the health, safety, welfare, and civil and human rights of institutionalized individuals who are over the age of 60. Staff and volunteers work with individual residents to help them address the challenges they face. OIEE investigates, resolves, and/or refers complaints to the appropriate agency. In addition to individual advocacy, OIEE advocates to bring about systems change on local, state, and federal levels.

- **609.826.5090 or 877.582.6995**
www.nj.gov/ooie/

Regional Family Support Planning Councils (RFSPC)

These groups of parents assist and advise the Division of Developmental Disabilities as to how resources can best meet the needs of families and individuals living in your region.

- **609.292.3745 or 800.792.8858; TDD 609.777.3238**
www.njcdd.org

The Arc of New Jersey

The Arc of New Jersey engages in ongoing advocacy and oversight on issues related to transparency, communication, and regulations within the NJ Division of Developmental Disabilities. The Arc's legislative activities include monitoring and responding to all state legislation and budget issues that impact individuals with intellectual and development disabilities, their families, and provider agencies.

- **732.246.2525**
www.arcnj.org

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

The *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

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>	
Centers for Medicare & Medicaid Services (CMS)	800.MEDICARE
NJ Medicaid	800.356.1561
Social Security Administration	800.772.1213
<u>Centers for Independent Living (CILs)</u>	
DAWN Center for Independent Living (Morris, Sussex, Warren)	973.625.1940 or 888.383.DAWN
Alliance Center for Independence (Middlesex, Somerset, Union)	732.738.4388
DIAL Center for Independent Living, Inc. (Essex, Passaic)	973.470.8090
Children’s System of Care (CSOC)	877.652.7624
<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
Family Support Center New Jersey (FSCNJ)	800.FSC.NJ10 or 732.528.8080
Mental Health Association in New Jersey, Inc.	800.367.8850
NJ Department of Children and Families (DCF)	855.463.6323
NJ Division of Vocational Rehabilitation Services (DVRS)	609.292.5987
NJ Division of Developmental Disabilities (DDD)	800.832.9173
NJ Division of Disability Services (DDS)	888.285.3036
<u>New Jersey Early Intervention System</u>	888.653.4463
Essex, Morris, Sussex, Union, and Warren counties	908.964.5303
Hunterdon, Mercer, Middlesex, Monmouth, Ocean, and Somerset counties	732.937.5437
New Jersey Housing Resource Center (NJHRC)	877.428.8844
PerformCare	877.652.7624/TDD: 866.896.6975
Project Child Find	800.322.8174
State Children’s Health Insurance Program (SCHIP)	877.543.7669
<u>State Health Insurance Program (SHIP)</u>	800.792.8820
Essex County – Newark Day Center	973.643.5710
Morris County – NORWESCAP, Inc.	973.784.4900, x208 or SHIP x3501
Somerset County – Aging & Disability Services	908.704.6319
Sussex County – Division of Senior Services	973.579.0555, x1223
Warren County – Aging & Disabilities Resource Connection	908.475.6591
United Way of Northern New Jersey Volunteer Coordinator	908.253.6503
United Way Caregivers Coalition	888.33UWCARES (888.338.9227)