

# Section 2

## Caregiving for a Loved One with a Disability



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# 1.

## Introduction to *Pathways* for Caregivers of 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 intended to be a source of information, advice, and ideas about how to get the support you need on your caregiving journey.

Whether you are planning ahead for a loved one with a disability, 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.

While you will find some organizations and agencies referenced, *Pathways* is not meant to be a complete list of all the County agencies and services that are available. **2-1-1 First Call for Help** and the **Morris County Division on Aging, Disabilities, and Veterans/NJ EASE** are your best bets for that. You will find them referenced throughout this guide.

Rather, *Pathways* IS designed as a “roadmap” to help put you on the right track for your caregiving situation, and to support you along the way.

*Pathways for Caregivers* was created by members of the Caregivers Coalition of Morris County. This means it was created BY caregivers FOR caregivers - created by caregivers, for you.

As you read this guide, 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 trying to look too far down the road can be a bit overwhelming.

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

If your loved one is over age 60, please see *The Caregiving for an Aging Loved One* section of this guide 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, from driving to appointments or shopping, to managing his or her finances, to discussing medical issues with his or her doctor, to providing emotional support, you are considered a caregiver.

The following is a list of activities that, if done on behalf of another, are traditionally considered “caregiving”:

- Occasional or daily help at home (chores, meals, transportation, etc.)
- Financial and/or business assistance (balancing checkbooks, paying bills, etc.)
- Emotional support
- Daily supervision and/or personal care
- Arrangements for doctors’ appointments (making calls, transportation, explanations or translations, etc.)
- Medication management

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 anytime: a developmental disability in a newborn, a paralyzing spinal cord injury to a teenager, an acquired brain injury to a once independent adult.

If you become a caregiver for someone with a disability, one thing is for certain, you are embarking on a new journey that will bring a wide range of experiences and emotions. There are many paths to choose, some more promising than others. A successful journey is possible, however. The key is in how well you prepare for the journey and how well you utilize the resources available to you. Perseverance and determination will be vital.

Whether a disability appears at birth or occurs later in someone’s life, it will generally have an impact across that person’s lifespan. Certain issues will result from the disability that will be present for the person’s entire life. Other issues related to the disability will come and go with different life stages; for example, school-related issues will disappear after graduation, to be replaced by issues of employment, or housing.

Regardless of the onset of disability, it is naturally a “life-altering” event for the individual, and for those caring for him or her. Often, providing care becomes THE major focus of the family/support system.

Providing care for someone with a disability requires patience 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. Others may be in your loved one’s life for just a while, but you will be there throughout. You are the one who knows your loved one the best.

## **Stages of Caregiving**

In caring for your loved one you may, over time, experience different stages of caregiving. Coping with these changing stages will require you to manage stress, perhaps develop new skills, all while maintaining a level of flexibility as you adapt to your loved one's changing needs.

But, really, how many caregivers are given the opportunity to fully prepare?

Realistically, most caregivers climb a steep learning curve, as they become 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.

Life is a journey – each of us can only take one step at a time. Caregiving for a loved one with a disability is no different.

Caregiving for a parent, spouse, domestic partner, relative, or close friend presents a variety of difficult challenges. These challenges can arrive in an instant, as with a sudden crisis, or can develop over time, through a series of small, but sometimes disconcerting, mishaps and warning signs. You may be the only person to step in, or you may be part of a larger network of family and friends willing to share caregiving duties.

Whatever the caregiving situation, you may find yourself unsure of which steps to take. And, of course, throughout any caregiving journey, those steps will change.

## **You Are Not Alone**

We don't need to tell you that caregiving can be exhausting, even frustrating 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 all alone! A strong network of friends, family, and service providers can help you, and keep emotions and exhaustion from becoming overwhelming. Ask for help, whenever you need it.

Again, remember, it is important that you do not take on all your caregiving responsibilities in isolation. Through organizations noted in this support guide, you can find the resources and people you need to take care of yourself – taking care of yourself means that you will be better able to take care of your family member or friend.

No matter what each stage of caregiving brings, it will always help to reach out to find the information and support you need to provide the best care possible, for your loved and for YOU.

## **Your Changing Role**

Throughout your caregiving journey, you may notice that your loved one requires different levels of care. Having to assume responsibilities that your loved one was used to doing independently can generate a range of emotions for you both. Identifying the issues that are associated with the illness or disability will help you cope with the role transition that you are

experiencing, as well as the changing nature of your relationship with your family member or friend.

In most caregiving situations, flexibility is the key. You will need to develop stress and time management skills that are necessary to cope with changes and increased demands that will occur over time.

If you must take on more and more daily tasks related to caregiving, it will become increasingly important to take advantage of resources in the community and whatever services you and/or your loved one are eligible for.

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.

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

***Based on material from CHATS - Community Home Assistance to Seniors, Ontario,  
and Aetna Intilihealth***

### 3.

## Where to Begin: Finding the Support You Need

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

### 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, here are some helpful first calls to consider:

### If you think an infant or toddler (0-3 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. If you suspect that an infant or toddler may be experiencing developmental delays, **Family Link** is the single point of entry into the early intervention system in New Jersey.

A service coordinator will speak with you and your family about your concerns and offer referral information if needed. If a developmental evaluation is needed, the service coordinator will work with you to schedule a multidisciplinary evaluation of the child's developmental levels and needs. Evaluation and assessment services are provided at public expense with no cost to parents.

- **Family Link – Early Intervention**  
**1-888-653-4463**  
**[www.familylinknj.org](http://www.familylinknj.org)**

### If the disability occurs in someone younger than 21 years old:

#### **NJ Division of Developmental Disabilities (DDD)**

In order to receive services from DDD, you will need to register with them. This is a paperwork procedure. Although the process may seem cumbersome, it is important to register as soon as possible for a few reasons:

- The sooner you register, the sooner you can receive services.
  - You will be helping DDD plan for the future, because they will have a better idea of who will be eligible for services
  - The documentation required will be easier to find now, as opposed to waiting and possibly misplacing it.
- **NJ Division of Developmental Disabilities**  
**973-927-2600 (Northern Regional Office)**  
**[www.state.nj.us/humanservices/ddd/index.html](http://www.state.nj.us/humanservices/ddd/index.html)**

## **If the disability occurs in someone 21 years or older:**

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

The Division of Disability Services is the single point of entry for all people seeking disability-related information in New Jersey.

- **NJ Division of Disability Services**  
**1-888-285-3036**  
**[www.state.nj.us/humanservices/dds](http://www.state.nj.us/humanservices/dds)**

## **Other Resources**

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

The Division of Disability Services has produced an excellent resource for any individual with a disability, or their caregiver, called the **New Jersey Resources Guide**. For more information, and for access to the guide:

- **NJ Division of Disability Services**  
**1-888-285-3036**  
**[www.state.nj.us/humanservices/dds](http://www.state.nj.us/humanservices/dds)**

### **2-1-1 First Call for Help**

2-1-1 First Call for Help offers both confidential telephone support to people in crisis and personalized information and referrals to those needing assistance. 2-1-1 now operates statewide, connecting people with the resources they need to solve common life problems. It is staffed 24 hours/7 days per week and can be accessed by dialing **2-1-1**.

- **Dial 2-1-1, or 1-800-435-7555**  
**[www.NJ211.org](http://www.NJ211.org)**

### **Family Support Center of New Jersey**

The Family Support Center has an excellent resource for parents/caregivers of children with disabilities, known as **The Options Manual**. For more information:

- **973-244-0850**  
**[www.fscnj.org](http://www.fscnj.org)**

### **Morris County Division on Aging, Disabilities and Veterans**

The County provides information, referrals, and direct client assistance for older adults, adults with disabilities, veterans, and caregivers.

The Morris County NJ EASE office is a great place to start when seeking information on a variety of services. NJ EASE, which stands for *Easy Access, Single Entry*, is a statewide program that provides easy, local access to a coordinated system of responsive services.

- **NJ EASE**  
**1-800-564-4656**  
**[www.morrishumanservices.org/dvs/](http://www.morrishumanservices.org/dvs/)**

## 4.

# Education for Individuals with a Disability; Education for Caregivers

## Education Services - Ages 0 to 21 Years

### 0-3 years old (Early Intervention)

The Early Intervention System (EIS), under the NJ Division of Health and Senior 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 and Senior Services is appointed by the Governor as the state lead agency for the EIS.

The mission of the EIS 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.

### New Jersey Early Intervention System Point of Entry

Morris County families or professionals who are interested in referring a child with special needs to the early intervention system in New Jersey should refer directly to Family Link.

- **Family Link – Early Intervention**  
**1-888-653-4463 (press 1 for Morris County)**  
**[www.familylinknj.org](http://www.familylinknj.org)**

### Regional Early Intervention Collaboratives (REICs)

In New Jersey, four nonprofit organizations, called Regional Early Intervention Collaboratives, have been established to plan and coordinate the state's early intervention system at the regional/community level. The Collaborative listed below (for Morris County families) provides technical assistance to families, early intervention programs and professionals, and ensures the protection of family rights.

- **Family Link REIC: A Regional Early Intervention Collaborative**  
**908-964-5303**  
**[www.njeis.org/familylink/](http://www.njeis.org/familylink/)**

For details on eligibility, the evaluation process, services available and potential cost shares to families:

- **[www.state.nj.us/health/fhs/documents/intervention.pdf](http://www.state.nj.us/health/fhs/documents/intervention.pdf)**

### Project Child Find

A source of information and referral to Early Intervention and other services for children:

- **1-800-322-8174**  
**[www.state.nj.us/education/specialed/childfind/](http://www.state.nj.us/education/specialed/childfind/)**

# Information if Your Loved One with a Disability Attends School

Morris County has 40 school districts and 150 schools. There are also 87 private schools in the County. There are child study teams in each district headed by a Director of Special Services.

As a parent or caregiver seeking help for a struggling student, use the following steps as a guideline:

First, submit a letter to the Child Study Team (CST) office in your child's school requesting an evaluation. Be sure to attach any pertinent medical records or diagnoses. The CST will set up a meeting with you to discuss your child's situation and then 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, the following people: guidance counselor, classroom teacher, principal, parent, student (if appropriate), and any other person 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 Child Study Team. In other words, the I&RS Teams can coordinate the services necessary to prevent the need for special education classification. However, if the accommodations, modifications, and services are not effective, the Child Study Team will step in.

## **Determination of eligibility for special education and 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).

Each local school district has a Child Study Team, which, with consent of a child's parents, evaluates children to determine his/her eligibility for special education services. The team includes a case manager, special education teacher, regular education teacher, representative of the district (usually the case manager), a speech therapist if the child is between ages 3 and 5, and the student where appropriate. Upon completion of the evaluation and determination of eligibility, and prior to placement in special education, an Individualized Education Program (IEP) with present levels of educational and functional performance, specific and measurable goals and objectives, accommodations, modifications, and related services is written by the IEP team which includes the parent. 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](http://www.nj.gov/education/specialed/form/prise/prise.pdf)**

It is not uncommon to encounter differences of opinions among team members. In that instance, there are numerous resources to assist in mediating the disagreement. The resources below will provide guidance on how to request modifications to the IEP, mediation, due process, "stay put" or other interventions.

Resources for legal issues regarding special education and special needs:

- **Hinkle, Fingles & Prior, Attorneys at Law**  
**[www.hinkle1.com](http://www.hinkle1.com) (Click on "In Print")**

- **Wrightslaw**  
[www.wrightslaw.com](http://www.wrightslaw.com) (Click on “Topics from A-Z”)
- **Education Law Center**  
[www.edlawcenter.org/elcpublic/studentrights/specialeducation.htm](http://www.edlawcenter.org/elcpublic/studentrights/specialeducation.htm)  
(Click on “The Right to Special Education in New Jersey: A Guide for Advocates)

From 3 to 5 years old, a child is classified as “eligible for a pre-school handicapped program.” At age 5, the child will be reclassified, based on the child’s condition and the impact the disability has on the child’s educational performance.

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](http://www.state.nj.us/njded/code/current/title6a/chap14.pdf)

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 school work, and any other documents that you feel may be important. Prior to each meeting, write down your concerns and ideas.

An excellent document that you can use to provide team members with a snapshot of your student is called **POSITIVE STUDENT PROFILES & GOALS-AT-A-GLANCE** available from **SPAN (Statewide Parent Advocacy Network.)** SPAN is an excellent source of information to families regarding the IEP process. SPAN representatives can also provide technical assistance and guidance on identifying advocacy support.

- **SPAN**  
**1-800-654-SPAN; 973-642-8100**  
[www.spannj.org](http://www.spannj.org)

## **Section 504**

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.

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.

# Transportation for a Child with Disability

## To and From School

There are several different options for transporting your child to school. If your child attends school in your local district, he or she 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, bus transportation might be provided by your local school district, your county, or a private company. The “bus” might also be a van or a car.

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

Remember, you are the one who knows your child’s needs best, and informing a driver and/or aide about your child’s 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, avoiding someone who teases them, 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 and/or aide. If that does not help, contact your child’s case manager in your school district. You may also be able to get some assistance and helpful suggestions from your child’s school.

## Transition from School to Adult Life

Transition planning begins at age 14 and is addressed annually until the child graduates. A “Statement of Transition Service Needs” must be included as part of the child’s IEP where applicable. This is an identification of and planning for the courses and educational experiences in the school or community that the child will be taking each year from age 14 until graduation. If it is appropriate, this Statement will also include the need for technical consultation from the Division of Vocational Rehabilitation Services (a Division of Vocational Rehabilitation Services counselor will provide information and assistance, either in person or over the phone, regarding transition planning issues related to employment and vocational training). Depending upon the severity of the disability, the Division of Developmental Disabilities (DDD) may be involved.

For further information, see **Chapter 10: Employment and Volunteerism.**

### College

A young adult with a disability may be interested in and able to attend an institute 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 notetaker, 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.

**IMPORTANT** - 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.

There are other 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 are vocational programs and private residential schools that address 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.

### **NJ Commission on Higher Education: Special Needs Regional Centers**

This is a system of seven regional centers that provide support services for college students with special needs, such as learning disabilities, visual impairments and hearing impairments.

- **NJ Commission on Higher Education**  
**Office of Academic Affairs**  
**609-292-2955**  
**[www.state.nj.us/highereducation](http://www.state.nj.us/highereducation)**

### **Adaptive Aids**

An Adaptive Technology Center has been established at The College of New Jersey to provide access to appropriate adaptive aids.

- **Adaptive Technology Center**  
**<http://adaptivetech.tcnj.edu>**

## **Education Services - 21 Years of Age and older**

**Note: It is important to start planning and preparing 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 21<sup>st</sup> birthday.) THE “ENTITLEMENT” PERIOD ENDS AND THE SCHOOL DISTRICT NO LONGER HAS THE RESPONSIBILITY TO PROVIDE SERVICES. At that point, he/she may be “eligible” to receive services from DDD. These can include day programming, residential services, and family support services (the latter may already be in place.)

There is valuable information available on the DDD website in regard to services available:

- **Self Directed Day Services**  
**[www.state.nj.us/humanservices/ddd/programs/selfdirected/](http://www.state.nj.us/humanservices/ddd/programs/selfdirected/)**
- **Pathways to Adult Life**  
**[www.state.nj.us/humanservices/ddd/programs/pathways/](http://www.state.nj.us/humanservices/ddd/programs/pathways/)**
- **Life Line for the Journey**  
**[www.state.nj.us/humanservices/ddd/programs/lifeline/](http://www.state.nj.us/humanservices/ddd/programs/lifeline/)**

There is a "Community Services Waiting List" for some of these services. Speak with the DDD Case Manager to access this. Some guidelines:

- Ask for the student to be put on the day program waiting list when he/she turns 16.
- Begin exploring housing options, as there are waiting lists for residential services. See **Chapter 11: Housing**, for more information.

### **Real Life Choices/Self-Directed Day Services**

This is a person-centered DDD program for life planning. For more information, see DDD references in **Chapter 7: Benefits and Financial Matters**. Speak with your DDD Case Manager for further details.

- **NJ Division of Developmental Disabilities**  
**973-927-2600 (Northern Regional Office)**  
**[www.state.nj.us/humanservices/ddd/index.html](http://www.state.nj.us/humanservices/ddd/index.html)**

### **Division of Vocational Rehabilitation (DVR)**

If the person with a disability does not receive day program placement through DDD, **DVR** is a source for assistance with employment. They can provide training, placement and job coaching.

- **NJ Division of Vocational Rehabilitation**  
**973-631-6304**  
**<http://lwd.dol.state.nj.us/labor/dvrs/DVRindex.html>**

### **Centers for Independent Living (CIL's)**

These are private, not-for-profit organizations that work with people with all disabilities to advance their independence. 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 do people without disabilities.

DAWN is the Center for Independent Living serving Morris, Sussex and Warren counties. For more information:

- **DAWN Center for Independent Living**  
**973-625-1940; 1-888-383-DAWN**  
**[www.dawncil.org](http://www.dawncil.org)**

## Education for the Parent/Caregiver

Parent education is a valuable component in caring for any child with a disability. Although much of this training will be “on the job,” there is a lot to be said for attending formal parent education trainings. Participation in parent education is even required at some private special-needs schools.

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. In addition, parent education classes are a good place to network with parents in a similar situation.

Some sources of parent education to consider are your child’s school, your local school district, and the following organizations:

- **SPAN: Statewide Parent Advocacy Network**  
This organization provides training, assistance, and support to parents of children with disabilities (in Spanish, as well)  
  
**1-800-654-SPAN; 973-642-8100**  
**[www.spannj.org](http://www.spannj.org)**
  
- **Autism New Jersey (Formerly known as Center for Outreach and Services for the Autism Community/COSAC)**  
**1-800-4-AUTISM or 609-883-8100**  
**[www.autismnj.org](http://www.autismnj.org)**
  
- **The ARC/Morris**  
**973-326-9750**  
**[www.arcmorris.org](http://www.arcmorris.org)**
  
- **Family Support Organization of Morris and Sussex County (FSO)**  
The Family Support Organization of Morris and Sussex Counties is a family-run organization devoted to the needs of families whose children have emotional and behavioral challenges. Families receive peer support, information and referral services, education and advocacy within a compassionate and culturally sensitive environment. Assistance is also offered in helping caretakers navigate the complex children’s mental health system in New Jersey.  
  
**973-770-2700**  
**[www.fso-ms.org](http://www.fso-ms.org)**
  
- **United Cerebral Palsy of Northern, Central and Southern NJ, Inc. (UCP)**  
**908-879-2243**  
**[www.ucpnscnj.org](http://www.ucpnscnj.org)**

### **Visiting Nurse Association of Northern NJ (VNANNJ)**

This organization provides free one-on-one education in the home environment in order to improve caregiver ability and effectiveness. The care recipient must be over age 18 and functionally impaired with a chronic disease or disability that requires the assistance of a primary caregiver to adequately perform activities of daily living. There are no income or asset eligibility requirements for this program.

**1-800-WE-VISIT (1-800-938-4748)**  
**[www.hometeam.org](http://www.hometeam.org)**

➤ **Caregivers Coalition of Morris County,**  
a United Way of Morris County Initiative

The Coalition's *Lunch & Learn Education Series* offers programs on various aspects of caregiving, presented by professionals in the field. These highly rated workshops may be scheduled by any local group, including area corporations, faith-based organizations, civic groups, etc. Contact the Coalition Coordinator for an updated list of topics, or to schedule a workshop.

**973-993-1160, ext. 139**  
**[www.LiveUnitedMorris.org](http://www.LiveUnitedMorris.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](http://www.cms.hhs.gov/Partnerships/downloads/ProviderBillingforCaregiverEducation.pdf)**

## 5.

# Parent/Caregiver Support

Including recreation, camp, and travel information.

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 wellbeing.

- *The National Family Caregivers Association*

Taking care of yourself. Scheduling (and keeping!) your own doctors' appointments. Asking for help. Taking a break. These are vital steps you can take as a caregiver to keep yourself healthy. 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

Sometimes, as caregivers, we are so busy giving care that we forget or neglect to take care of ourselves. As caregivers, it is important to acknowledge that stress is a normal, sometimes difficult but definitely manageable, part of our caregiving. Stress 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, and good, and necessary!

Self-care/stress management can be achieved in many ways. General attention to daily activities like healthy eating, exercising, sleeping, and talking with friends, is vital.

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**. Support groups are organized groups of individuals who 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.

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

- **Aromatherapy** uses liquid plant oils and other aromatic compounds to improve one's 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 re-alignment 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** encompasses several disciplines that utilize body techniques to promote healing and health.
  - **Music therapy** is the systematic use of music to maintain and 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, de-stress, and heal.
  - **T'ai Chi** is a slow gentle body movement, while breathing deeply and meditating, that helps the flow of body energy. The gentle flowing motion reduces stress and improves health.
  - **Yoga** is a physical and mental discipline. While it includes physical exercise, it is also a lifestyle practice, the goal of which is the union of the mind, body and spirit. There are many different styles of yoga. You may need to explore a number of styles before finding the one that is right for you.

These are examples of some types of therapies that can help you manage your stress, as well as reduce pain, anger, anxiety, and even depression. There are others. Choose one or more that is right for you. Whether relaxing muscles and reducing inflammations, 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 Support/Recreation**

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 any and 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. If you are eligible for Family Support through the Division of Developmental Disabilities (DDD), you can have access to In-Home Respite, Hotel Respite or Respite Group Homes. Also, if you have someone who can provide respite, you are able to use funds from a DDD Cash Stipend to pay for this respite. Contact your DDD Case Manager for more information.

### **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. Caregivers looking for this type of respite support would contact **Home Health Care** agencies.

### **Respite Centers**

Respite centers are facilities specifically designed for respite care. Adult day care programs and respite camps also fall into this category. This type of respite often offers more peace of mind to the caregiver, while providing a stimulating environment for the aging individual. However, centers usually restrict the length of stay and may exclude individuals based on severity of disability. Caregivers looking for this type of respite would contact **Adult Day Care Centers, Nursing Home Facilities, and Rehab Centers.**

One good local starting point for lists of in-home respite agencies and respite centers is:

- **Morris County Division on Aging, Disabilities and Veterans  
NJ EASE  
1-800-564-4656  
[www.morrishumanservices.org/dvs/](http://www.morrishumanservices.org/dvs/)**

**The Morris County Division on Aging, Disabilities and Veterans  
(1-800-564-4656) has a Caregiver Guide with additional local  
resources that can be accessed online:  
[www.morrishumanservices.org/dvs/publications.asp](http://www.morrishumanservices.org/dvs/publications.asp)  
Click on **Caregiver Guide****

### **New Jersey Statewide Respite Care & Morris County Respite Care Programs**

These programs provide respite care services for elderly and for functionally impaired persons age 18 and older, to relieve their unpaid caregivers of stress arising from the responsibility of providing daily care. In Morris County, the County and State programs run side by side and can be accessed through:

- **Visiting Nurse Association of Northern NJ  
1-800-938-4748  
[www.hometeam.org/index.asp](http://www.hometeam.org/index.asp)**

### **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 “Y” 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 county-wide programs can be found at the Morris County Office of Disability Services.

- **Morris County Office of Disability Services  
973-285-6855  
[www.morrishumanservices.org/dvs/](http://www.morrishumanservices.org/dvs/)**

## **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 during an open house to ensure it has the necessary supports for your family member. Prepare your family member in advance about what to expect, letting them know how long they will be away, and what the experience will be like. Let them help with the planning and packing. You might consider sending along specifics about your loved one in writing, to make it easier for the staff to get to know him or her. Think about sending a disposable camera with instructions so the staff can take pictures of fun times for future memories.

There are too many camps to list here, but here are some additional sources of information:

- **The National Information Center for Children and Youth with Disabilities**  
**[www.NICHCY.org/pubs/genresc/camps.htm](http://www.NICHCY.org/pubs/genresc/camps.htm)**
- **Directory of Camps/Summer Programs for Children/Youth with Disabilities in Metro New York Area.** Available for a fee. **212-677-4650**

## **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 agencies and organizations that cater specifically to the needs of individuals with disabilities in travel, both with and without caregivers. Some helpful resources include:

- **AAA**  
**Contact your local AAA office**
- **United Cerebral Palsy**  
**Vacation and travel for families with children with special needs**  
**[www.ucp.org/document.cfm/3910/1/111](http://www.ucp.org/document.cfm/3910/1/111)**
- **Disability Travel and Recreation Resources**  
**[www.makoa.org/travel.htm](http://www.makoa.org/travel.htm)**

# General Caregiver Support

## Morris County Caregiver Support Program

The Caregiver Support Program is designed to help caregivers access the services needed for their loved ones and themselves. The Project goes beyond information and referral to help with problem solving, advocacy, and support to sustain caregivers in their role. This is a new resource offered by the Morris County Division on Aging, Disabilities and Veterans created in partnership with the Caregivers Coalition of Morris County and United Way of Morris County. Visit the Resource Center at the County's offices located at 340 West Hanover Ave, Morris Township, or call for information:

- **Morris County Division on Aging, Disabilities and Veterans**  
**NJ EASE**  
**1-800-564-4656**  
**[www.morrishumanservices.org/dvs/](http://www.morrishumanservices.org/dvs/)**

## Caregivers Coalition of Morris County,

a United Way of Morris County Initiative

Open to the public, and free to join, the Caregivers Coalition, a United Way of Morris County initiative, was founded to respond to the increasing needs of caregivers in the community. The goals of the Coalition are to strengthen services and resources to caregivers; improve access to information about caregiving and available services, and to identify and respond to gaps in services to caregivers. The Coalition also advocates for policies and legislation to improve the quality of life for caregivers, and provides educational programs to human service and health care providers, family caregivers, corporations, businesses, and the community. All are welcome.

The Coalition's **Caregiver Advisory Panel (CAP)** is a group of caregivers who are connected via phone and email; they share ideas, discuss issues, and support one another while advising the Coalition. These caregivers manage a range of caregiving situations. All caregivers are invited to join the CAP.

- **Caregivers Coalition Coordinator**  
**973-993-1160, x139**  
**[www.LiveUnitedMorris.org](http://www.LiveUnitedMorris.org)**

## Caregiver Counseling/Psychotherapy

There are many counseling and support services available in the County 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.

### Mental Health Association of Morris County

The Mental Health Association maintains a database of private practitioners and other mental health related resources.

- **973-334-3496**  
**[www.mhamorris.org](http://www.mhamorris.org)**

### Morris County Division on Aging, Disabilities and Veterans

The Morris County Division on Aging, Disabilities and Veterans offers listings of caregiver counseling programs.

- **NJ EASE**  
**1-800-564-4656**  
**[www.morrishumanservices.org/dvs/](http://www.morrishumanservices.org/dvs/)**

## Other Supports for Caregivers

### 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. In addition, disability organizations and schools often offer support groups for families and caregivers.

- **NJ Self-Help Group Clearinghouse**  
**1-800-367-6274**  
**[www.njgroups.org/](http://www.njgroups.org/)**

### Internet Support

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

- **CaringRoad.com**  
**[www.caringroad.org](http://www.caringroad.org)**
- **Johnson & Johnson, The Caregiver Initiative**  
**[www.strengthforcaring.com](http://www.strengthforcaring.com)**
- **National Family Caregiving Association**  
**[www.nfcacares.org](http://www.nfcacares.org)**
- **NJ Department of Health and Senior Services – Caregiver NJ**  
**[www.state.nj.us/caregovernj/search/index.shtml](http://www.state.nj.us/caregovernj/search/index.shtml)**

## 6.

# Case/Care Management for Loved Ones with a Disability

Case management services are made available in certain instances, depending on your loved one's disability and/or the agency involved. In most cases, a case manager would become your primary contact and would assist you in determining eligibility and identifying appropriate programs and services which would be most beneficial.

For example, if your loved one was born with a disability or acquires the disability prior to age 22, he or she will have a case manager through the Division of Developmental Disabilities. 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.

- **NJ Division of Developmental Disabilities**  
**973-927-2600 (Northern Regional Office)**  
**[www.state.nj.us/humanservices/ddd/index.html](http://www.state.nj.us/humanservices/ddd/index.html)**

If your loved one acquired a disability from the age of 22 onward, he or she may have a case manager, if they meet specific criteria. These criteria typically pertain to the level of care they require. In most cases, the Morris County Division on Aging, Disabilities and Veterans will be the initial contact point for you or your loved one to determine if they qualify for case management services.

- **Morris County Division on Aging, Disabilities and Veterans**  
**NJ EASE**  
**1-800-564-4656**  
**[www.morrishumanservices.org/dvs/](http://www.morrishumanservices.org/dvs/)**

### **Public Case/Care Managers**

Public Case/Care Managers are funded through various Federal, State, and county tax dollars and are provided free of charge to the older adult or adult with disability. In Morris County, case management is available through the Morris County Office on Aging and other local agencies. For additional information:

- **Morris County Division on Aging, Disabilities and Veterans**  
**NJ EASE**  
**1-800-564-4656**  
**[www.morrishumanservices.org/dvs/](http://www.morrishumanservices.org/dvs/)**

### **Other Care Issues**

#### **Safety Issues for Someone with a Disability**

As the caregiver, you should notify your local police if you think that they should be aware of your loved one's disability for any reason. For example, the person may be a wanderer or might have difficulty leaving the house in an emergency. Once on record with the police department, this information will be accessible to fire and emergency health workers as well.

➤ **Project Lifesaver**

Morris County participates in Project Lifesaver, a program that will provide and fit a person who wanders with a tracking device. For information:

**Morris County Sheriff's Office**

**973-285-6675**

**[www.mcsheriff.org/main/cp-lifesaver/](http://www.mcsheriff.org/main/cp-lifesaver/)**

**Abuse**

There are different kinds of abuse to be considered when talking about vulnerable adults or children: mistreatment and neglect. Mistreatment refers to any harmful conduct that is willfully inflicted on a vulnerable person. This includes physical, sexual, emotional, or financial abuse and exploitation. Signs of maltreatment and abuse include, but are not limited to, frequent visits to the emergency room, unexplained bruises or wounds, and depression, fear, or anxiety on the part of the person receiving care.

Neglect can either be inflicted by another or self-imposed. Behavior is considered neglect when the responsible individual (i.e. caregiver, guardian, etc.) confines, isolates, or fails to provide essential services to prevent or lessen physical harm or mental anguish. Behaviors are considered self-neglect when an individual makes unnecessary or unsafe decisions or is taking part in unsafe activities. Signs and symptoms of neglect include things like malnutrition or dehydration, unsafe or unsanitary living conditions, missing or broken eyeglasses, hearing aids or dentures, and withholding of education or medical care, among others.

**There are two specific points of contact if an individual is at risk of abuse.**

**NJ Division of Youth and Family Services (DYFS)**

For children, the contact is through the New Jersey Division of Youth and Family Services (DYFS.) Anyone who has reasonable cause to believe that a child is being abused or neglected has a legal responsibility to report it.

➤ **Child Abuse Hotline**

**1-800-792-8610**

**1-800-835-5510 (TTY/TDD for the deaf)**

**[www.state.nj.us/dcf/divisions/dyfs/index.html](http://www.state.nj.us/dcf/divisions/dyfs/index.html)**

**Adult Protective Services**

Adult Protective Services (APS) investigates reports of suspected abuse, neglect, and exploitation of "vulnerable" adults age 18 or older living in the community. A person is considered vulnerable if they are unable to act on their own behalf. Reports may be made by anyone. When a report is received, APS investigates. If the report is confirmed and the person is willing to accept help, APS will identify, and put in place, services that can help the vulnerable person. If you suspect a vulnerable adult is being abused or neglected, call:

➤ **Morris County Division on Aging, Disabilities & Veterans**

**973-326-7282**

**[www.morrishumanservices.org/dvs/](http://www.morrishumanservices.org/dvs/)**

**After Business Hours: Call 911, or**

**Sheriff's Community Center: 973-285-2900**

## **The Prevention of Domestic Violence Act**

This Act provides protection from abuse to older adults and people with disabilities. The Act authorizes the issuance of a restraining order using the criminal code to define abuse. A caregiver or any person who has reasonable cause to believe that an older adult or person with a disability is subject to abuse, neglect, or exploitation should report such information to the local police.

### **Identification**

Having an official photo I.D. is a good idea for everyone. A non-driver photo ID can be acquired at age 17; six points of identification are required, just as for a driver's license. For information:

- **NJ Motor Vehicle Commission**  
**609-292-6500 or 1-888-486-3339**  
**[www.state.nj.us/mvc](http://www.state.nj.us/mvc)**

At any age, a photo ID can be acquired at the Morris County Clerk's Office. This ID can include medical alert information. For information:

- **Morris County Clerk**  
**973-285-6120**  
**[www.morriscountyclerk.org](http://www.morriscountyclerk.org)**

### **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 for him or herself. "Seeing eye dogs" are used by individuals who are blind. Other service animals assist persons with other kinds of disabilities in day-to-day activities. An animal might alert someone with hearing impairments to sounds, or pick up and carry items for someone with mobility impairments.

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.

### **Worship**

For information on worship for those with disabilities:

- **New Jersey Coalition for Inclusive Ministries**  
**<http://rwjms.umdj.edu/boggscenter/projects/faithbased.htm>**

# 7.

## Benefit Programs & Financial Matters for Loved Ones with a Disability

### Key Benefit Programs

There are a wide range of programs directed toward people of all ages with disabilities. There are public programs on the National, State, and local levels. There are programs for which everyone over a specific age is eligible. There are programs for which a person must meet specific criteria, or live in a particular county. It is important to ensure that the loved one for whom you are caring apply for the programs for which he or she is eligible so that the assistance needed can be obtained.

We will begin at the Federal level with the programs most important to the majority of people with disabilities.

As a caregiver for a loved one, you should review and write down key benefits and financial information. Keep it all in an easily accessible place. Let a trusted family member or friend know where this information can be found.

### 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% 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. Benefit payments are made for the prior month on the second, third or fourth Wednesday, depending on your date of birth.

If your loved one is not able to manage his or her own financial affairs, you or another trusted individual can be appointed as a “representative payee” to handle Social Security matters. The

benefits are then made payable to the representative payee who must use the funds for the personal care and well-being of the beneficiary. Records and receipts must be kept to show how the money was spent or saved. This must be reported to the Social Security Administration.

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

## **2. Social Security Disability Insurance (SSDI)**

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 or she cannot do work that he or she did before, and the individual cannot adjust to other work because of his or her medical condition(s). Benefits can be paid to people at any age who have enough Social Security credits and who have a severe physical or mental impairment that is expected to prevent them from doing "substantial" work for a year or more.

### **SSDI benefits for adults with a disability since childhood**

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

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

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

These benefits are also payable to an adult who received 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 if their family member is eligible for retirement or disability benefits, other members of the family might receive benefits, too. If the spouse is at least 62 years of age, or under 62 but caring for a child under age 16, he or she may also be eligible for benefits. Unmarried children under age 18, or under age 19 but still in school, or 18 or older with a disability, may also be eligible.

## **4. Social Security Survivor Benefits**

Certain members of your family may be eligible for benefits if their eligible family member dies. The family members who may be eligible include: a widow(er) age 60 or over, 50 or older if disabled or 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 if the deceased was their primary means of support. A special one-time payment of \$255 may be made to the spouse or minor children. If divorced, an ex-spouse could be eligible for a widow(er)'s benefit.

## **Supplemental Security Income Benefits (SSI)**

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

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

### **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 more quickly 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 more than \$980 a month in 2009. (This earnings amount 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 on any of these benefits, or to apply for Social Security or SSI payments, visit your local Social Security office, or call:

- **Social Security Administration**  
**1-800-772-1213**  
**[www.ssa.gov](http://www.ssa.gov)**

## **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.

#### **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. 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 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 co-pays 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. These plans coordinate your 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 your loved one greater access to drugs that he or she 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.

**Cost:** If your loved one joins a Medicare drug plan, he or she usually pays a monthly premium. If he or she decides not to enroll in a Medicare drug plan when first eligible, there may be a penalty if he or she chooses to join later. If your loved one has limited income and resources, he or she might qualify for extra help paying for Part D costs.

This is only a general overview of the system. There are many circumstances that will vary, depending on each individual situation. For more information, or a comprehensive look at the details of this program:

- **Centers for Medicare & Medicaid Services (CMS)**  
**1-800-MEDICARE**  
**[www.medicare.gov](http://www.medicare.gov)**

### **Medigap**

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

- **[www.medicare.gov/medigap/default.asp](http://www.medicare.gov/medigap/default.asp)**

### **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:

- **State Health Insurance Program (SHIP)**  
**1-800-792-8820**  
**[www.state.nj.us/health/senior/ship.shtml](http://www.state.nj.us/health/senior/ship.shtml)**
- **NORWESCAP (Local Office for SHIP)**  
**973-989-5773**

## **Medicaid**

Medicaid is a needs-based health insurance available through Social Security Income (SSI), Division of Youth & Family Services (DYFS), Department of Developmental Disabilities (DDD), municipal welfare and the Office of Temporary Assistance (OTA).

### **Medicaid Home & Community - Based Waivers**

The loved one you care for may be over age 65 or have developed medical conditions that qualify as a disability. In addition to health insurance, Medicaid provides unique services to persons with a variety of disabilities through home and community-based waiver programs. The following is a list of some of the waiver programs available. You will need to contact each individual program to determine eligibility. As there are a number of waiver programs available in addition to the ones listed here, you should contact the Office of Temporary Assistance to determine if your loved one's situation qualifies for a Medicaid waiver program.

- **Morris County Office of Temporary Assistance (Medicaid Unit)**  
**973-326-7878**  
**[www.morrishumanservices.org/hs/](http://www.morrishumanservices.org/hs/)**

### **AIDS Community Care Alternatives Program (ACCAP)**

This waiver is for those of any age with AIDS (Acquired Immunodeficiency Syndrome) and children up to age 13 who are HIV positive who are in need of institutional care and meet, at a minimum, the nursing facility level of care criteria. It provides full Medicaid benefits plus case management, private-duty nursing, medical day care, personal care assistant services, and hospice care. The purpose of the waiver is to help eligible individuals to remain in the community or to return to the community, rather than be cared for in a nursing facility or a hospital setting.

- **Morris County Office of Temporary Assistance (Medicaid Unit)**  
**973-326-7878**  
**[www.morrishumanservices.org/hs/](http://www.morrishumanservices.org/hs/)**

### **Community Resources for People with Disabilities (CRPD) Medicaid Waiver**

This waiver is for children and adults who have disabilities and/or visual impairments; it provides all Medicaid State Plan services as well as case management services. Services include personal care assistant, home health, medications, durable medical equipment, and physician services. New Jersey has recently requested adding new services to this waiver, including environmental modifications and a personal emergency response system. For information:

- **NJ Division of Disability Services**  
**1-888-285-3036, or 609-588-2620**  
**[www.state.nj.us/humanservices/dds/](http://www.state.nj.us/humanservices/dds/)**

## **Traumatic Brain Injury (TBI) Medicaid Waiver**

This waiver is for people ages 18 to 65 with an acquired brain injury. It provides case management, counseling, community residential services, therapies, behavioral programs, environmental modifications, day programming, personal care assistant, transportation, respite care, night supervision, chore services, and companion services for those who qualify. For more information:

- **Morris County Office of Temporary Assistance (Medicaid Unit)**  
**973-326-7878**  
**[www.morrishumanservices.org/hs/](http://www.morrishumanservices.org/hs/)**

## **Community Care Medicaid Waiver (CCW)**

This waiver is for individuals registered with the Division of Developmental Disabilities (the disability had to have manifested before the age of 22), and provides case management, rehabilitation, individual supports, environmental and vehicle accessibility adaptation, personal emergency response system, and respite care. For more information:

- **NJ Division of Developmental Disabilities**  
**973-927-2600 (Northern Regional Office)**  
**[www.state.nj.us/humanservices/ddd/index.html](http://www.state.nj.us/humanservices/ddd/index.html)**

## **Global Options Medicaid Waiver**

On June 21, 2006 Governor Corzine signed the Independence, Dignity, and Choice in Long Term Care bill. This program was designed to enable Medicaid nursing home residents, who are medically appropriate, to return to the community by establishing a funding balance between nursing home care and community based care. New Jersey was a pilot state for this program, known as Global Options.

Effective January 1, 2009, the following three Medicaid Waiver programs: Assisted Living, Caregiver Assistance Program (CAP) and Community Care Program for the Elderly & Disabled (CCPED), were consolidated into a single program now known as Global Options (GO) for Long Term Care.

### **Who is Eligible for GO?**

An applicant must be 65 years or older or between the ages of 21 and 64 who shall be determined disabled\* by Social Security Administration (SSA) or be determined disabled\* by the Division of Medical Assistance and Health Services, Disability Review Section.

Additionally, eligibility depends on whether there is an indication that the participant will need the level of care provided in a hospital, a nursing facility or an intermediate care facility in the near future (i.e, a month or less) unless he or she receives home and community-based services.

\* Individuals between the ages of 21 and 64 who are chronically mentally ill or developmentally disabled may be eligible after a service needs review by the DHSS/DHS Service Review Team.

**Are There Limits to GO Services?** - Yes. The service package is based on an assessment of the individual's level of care needs and is developed in collaboration with a case/care

manager. The service package builds on available supports, and takes into consideration the individual's functional abilities, personal goals and preferences, risk factors, and availability of services.

**Who Provides these Services?** - Services may be provided by traditional Medicaid community agencies or new qualified non-traditional entities. All service providers must demonstrate competence in the service to be provided and must meet qualification requirements, which have been approved by the federal government.

**What Services May be Provided?** -GO participants are eligible for all New Jersey Title XIX Medicaid State Plan services authorized in a Plan of Care.

Community choice counseling is available for nursing home residents. If an individual would like information or to be considered for Global Options, he or she and family members should speak with their nursing home's social worker or discharge planner to determine if they are eligible and if this alternative is appropriate for them.

- **Morris County Office of Temporary Assistance (Medicaid Unit)**  
**973-326-7878**  
**[www.morrishumanservices.org/hs/](http://www.morrishumanservices.org/hs/)**

### **Medicaid's Personal Preference: Cash & Counseling Demonstration Project**

This is a national research and demonstration project sponsored by the Robert Wood Johnson Foundation to study the effects of allowing Medicaid recipients with a disability who are eligible for Personal Care Assistance services to direct their own care. Through a monthly cash allowance, participants work with a consultant to develop a cash management plan by which they decide the services they need and the individuals and/or agencies they wish to hire to provide the identified services. The program requires greater consumer responsibility, but also offers participants greater control, flexibility, and choice.

For more information:

- **NJ Division of Disability Services**  
**1-888-285-3036**  
**[www.state.nj.us/humanservices/dds/](http://www.state.nj.us/humanservices/dds/)**

### **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:

- **1-877-543-7669**  
**[www.njfamilycare.org/index.html](http://www.njfamilycare.org/index.html)**

# Assistance Programs for Individuals with a Developmental Disability

## Division of Developmental Disabilities (DDD)

The NJ Division of Developmental Disabilities (DDD) has a host of financial services that may assist the individual with a developmental disability. For example:

### Cash Subsidies

If you are eligible for family support through DDD, you are eligible for a cash subsidy up to \$2,400 every two years. This stipend is designed to help you pay for expenses needed for the benefit of the person with a disability, including respite, specialized equipment including a computer, guardianship expenses, and home modifications. For information, contact your DDD Case Manager.

### Real Life Choices

*Real Life Choices* is a program option based on self-direction. The vision of *Real Life Choices* shifts the power from the professionals to the individual and their family members, and it recognizes that the individual should be able to direct the delivery of their own services. The program looks at how the supports and services mapped out in a person's plan of care builds independence, and at how satisfied the person and their family are with the results from that plan of care.

The possibility for *Real Life Choices* can occur at two distinct points in time. The first is simply by graduating from high school. The second point is when an individual's name comes up on the Division of Developmental Disabilities priority waiting list. Individuals in both categories must also qualify for the Community Care Waiver. Eligible individuals and their families are invited by DDD to an information and orientation session to learn about this new way of accessing services. For more information:

- **NJ Division of Developmental Disabilities**  
**1-800-852-7899 (TDD users call through NJ Relay)**  
**[www.state.nj.us/humanservices/ddd/index.html](http://www.state.nj.us/humanservices/ddd/index.html)**

## General Financial Planning

### Financial Planners

Professional financial planners look at a person's long-term financial goals, and analyze assets, income, investments, and personal concerns. From there, the financial planner will provide advice and plans on how to maximize returns and minimize expenses through investments and reinvestments. To find a planner:

- **Financial Planning Association**  
**1-800-647-6340**  
**[www.plannersearch.org](http://www.plannersearch.org)**
- **National Association of Personal Financial Advisors**  
**1-800-366-2732**  
**[www.napfa.org](http://www.napfa.org)**
- **AARP**  
**[www.aarp.org](http://www.aarp.org)**

## **Bill-Paying Services**

If your loved one is no longer capable of handling his or her own finances, sometimes an option is to hire an individual to pay all of the bills. These professionals will ensure that anything that is billed to your loved one is taken care of. A bill paying service will submit a report to the power of attorney. This report will include all of the money necessary to pay the bills for that month as well as the service fee.

➤ **Senior Cents  
Family Service of Morris County**

This Family Service of Morris County program is a money management and advocacy program for older adults and/or people with disabilities in Morris County who are receiving case management services through NJ EASE. The program uses trained volunteers to enable older adults to control their finances and maintain their independence.

**973-538-5260**  
**[www.fsmc.org](http://www.fsmc.org)**

➤ **American Association of Daily Money Managers (AADMM)**

AADMM is a membership organization comprised of individuals who provide money management services. AADMM provides a listing of money managers by geographic area.

**1-877-326-5991**  
**[www.aadmm.com](http://www.aadmm.com)**

## **Financial & Tax Assistance/Savings Programs**

### **Temporary Assistance/General Assistance/Food Stamps**

This program provides a variety of financial, medical, and social services to persons/families who meet certain criteria, depending on your family size, monthly income, and assets and resources.

For eligibility and benefits information, call your town's Municipal Welfare Office, or:

➤ **Morris County Office of Temporary Assistance**  
**973-326-7800**  
**[www.morrishumanservices.org/hs/](http://www.morrishumanservices.org/hs/)**

### **New Jersey's Homestead Property Relief Program**

The Homestead Credit/Rebate Program provides credits or rebates for homeowners and tenants who occupied their principal residence in New Jersey on October 1 of the year for which the credit applies, paid property taxes on that dwelling either directly or through rent, and whose gross income for the entire year does not exceed certain limits.

➤ **Taxpayer Customer Service Center**  
**609-292-6400**  
**[www.state.nj.us/treasury/taxation/](http://www.state.nj.us/treasury/taxation/)**

## **New Jersey's Property Tax Reimbursement Program** **also known as the "Senior Freeze"**

This program reimburses eligible senior citizens and people with disabilities for property tax increases. The amount of the reimbursement is the difference between the amount of property taxes that were due and paid in the "base year" (the first year that all eligibility requirements are met) and the amount due and paid in the current year for which the reimbursement is being claimed, provided the amount paid in the current year was greater.

The applicant must meet all the eligibility requirements for the base year and for each succeeding year, up to and including the current year to qualify for the reimbursement.

- **Taxpayer Customer Service Center**  
**609-292-6400**  
**[www.state.nj.us/treasury/taxation/](http://www.state.nj.us/treasury/taxation/)**

## **Prescription Assistance/Savings Programs**

### **Pharmaceutical Assistance to the Aging and Disabled (PAAD)**

New Jersey's PAAD program provides pharmaceutical assistance to residents 65 years of age or older or 18 years of age and older if receiving Social Security Disability benefits. This is a means-based program. Single adults with annual income of less than \$24,432 and married couples with annual income less than \$29,956 in 2009 are eligible. Income eligibility changes annually. PAAD beneficiaries are also required to enroll in a Medicare Part D Prescription Drug Plan. They do not pay premiums, deductibles, or any out-of-pocket costs beyond the regular PAAD copayment of \$6.00 for generic drugs or \$7.00 for brand name drugs. People eligible for PAAD are usually eligible for the Lifeline Program and the Hearing Aid Assistance to the Aging and Disabled Program (HAAAD).

- **NJ Department of Health and Senior Services**  
**1-800-792-9745**  
**[www.state.nj.us/health/seniorbenefits/services.shtml](http://www.state.nj.us/health/seniorbenefits/services.shtml)**

### **Senior Gold**

Another program of the New Jersey State Department of Health and Senior Services, this State-funded prescription program has a different co-payment structure and higher income eligibility requirements than PAAD. Members pay a co-payment of \$15 plus 50% of the remaining cost of each covered prescription until they reach annual out-of-pocket expenses exceeding \$2,000 for single persons or \$3,000 for married couples. When they have exceeded their annual out-of-pocket expense, they pay only the flat \$15 co-payment per prescription for the remainder of the year. There are other restrictions and coordination with other insurance benefits or Medicare Part D.

- **NJ Department of Health and Senior Services**  
**1-800-792-9745**  
**[www.state.nj.us/health/seniorbenefits/services.shtml](http://www.state.nj.us/health/seniorbenefits/services.shtml)**

## **FamilyWize Prescription Drug Discount Card**

FamilyWize in partnership with United Way offers a free Prescription Drug Discount Card that can offer immediate savings on prescription drugs at participating pharmacies for people that have no health insurance, during deductible periods and for prescription medicine not covered by health insurance, Medicare or other benefit plans. It is not insurance, nor is it intended to replace insurance. It can save an average of up to 30% or more off the pharmacy's usual and customary retail price of prescription drugs, with the highest savings on generic drugs. The cost will be the discount price with the FamilyWize card or the pharmacy's usual and customary retail price, whichever is lower. For more information or to receive a card:

- **United Way of Morris County**  
**973-993-1160, ext 108**  
**[www.uwmorris.org/ourwork/heal\\_hlprojects.php](http://www.uwmorris.org/ourwork/heal_hlprojects.php) ...or**
- **[www.familywize.com](http://www.familywize.com)**

## **Pharmacy Owners Providers Services (POPS)**

Provides all residents of Morris County and dependents in the same house, not currently covered through any government sponsored or employer-based prescription insurance program, with savings of up to 50% on prescription medications.

An annual, non-refundable membership fee of \$20.00, or a 3-year fee of \$40.00, is required. You may use POPS at any participating Morris County pharmacy. There are no age, income, or pre-existing condition exclusions, no deductibles, no limits on quantities, and no forms to complete, except the initial application, along with proof of Morris County residency. For more information:

- **Morris County Division on Aging, Disabilities and Veterans/NJ EASE**  
**1-800-564-4656**  
**[www.morrishumanservices.org/dvs/](http://www.morrishumanservices.org/dvs/)**

## **Rx4NJ**

Rx4NJ is a website designed to help low-income, uninsured New Jersey residents get free or discounted brand-name medicines. State agencies and community organizations worked together with America's pharmaceutical companies to develop Rx4NJ.

If you have a hard time paying for your medications, you may be eligible for help in paying for your prescriptions. Rx4NJ makes it very easy to find out if you or a loved one qualify for assistance. Follow the on-screen step-by-step directions. Once you provide the website with some basic information related to prescription medicines, income, and current prescription medicine coverage, Rx4NJ will be able to tell you what patient assistance programs you may be eligible for. If you are eligible, you will receive an application that can be printed out and returned directly to the drug manufacturer for final approval, after your doctor has approved and signed it. For information:

- **[www.rx4nj.org](http://www.rx4nj.org)**  
**1-888-793-6765**

## **Other Assistance/Savings Programs**

### **Hearing Aid Assistance to the Aged and Disabled (HAAAD)**

HAAAD provides a \$100 reimbursement to eligible persons who purchase a hearing aid. Persons must meet the PAAD eligibility requirements.

- **NJ Department of Health and Senior Services**  
**1-800-792-9745**  
**[www.state.nj.us/health/seniorbenefits/services.shtml](http://www.state.nj.us/health/seniorbenefits/services.shtml)**

### **Personal Assistance Services Program (PASP)**

This is a state program for individuals from 18 to 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.

- **Morris County Office for the Disabled**  
**973-285-6865**  
**[www.morrishumanservices.org/dvs/](http://www.morrishumanservices.org/dvs/)**

### **Telephone**

Verizon offers two assistance programs for phone service for people with low incomes. Through *Link Up America*, eligible new customers receive a 50% discount on the initial phone connection charge, with the remaining 50% paid in 12 monthly installments.

Through *Communications Lifeline*, existing Verizon residential customers may be eligible to receive discounted local telephone service. *Communications Lifeline* makes local telephone service available to people who might not be able to afford phone service.

To see if you are eligible for *Link Up America* or *Communications Lifeline*:

- **1-888-337-3339**

### **Utilities**

#### **Low Income Home Energy Assistance Program (LIHEAP) and Universal Service Fund (USF)**

**The Low Income Home Energy Assistance Program (LIHEAP)** is designed to help low-income families and individuals meet home heating and medically necessary cooling costs. Applications are usually accepted between November 1 and April 30. To apply for LIHEAP, you will need to contact the authorized local community action agency or community based organization in your area. To be eligible for LIHEAP benefits, the applicant household must be responsible for home heating or cooling costs, either directly or included in the rent; and have gross income at or below 225% of the federal poverty level. Persons who live in public housing and/or receive rental assistance are not eligible unless they pay for their own heating/cooling costs directly to the fuel supplier. The amount of the LIHEAP heating benefit is determined by income, household size, fuel type, and heating region.

**See website noted below to find LIHEAP income eligibility levels.**

**Please Note: The LIHEAP application is also an application for the Universal Service Fund Program (USF).** You apply for two benefit programs at the same time using one application.

**USF** is a program created by the State of New Jersey to help make natural gas and electric bills more affordable for low-income households. If you are eligible, USF can lower the amount you pay for gas

and electricity. To be eligible, a household gross income must be at or below 175% of the Federal Poverty Level and pay more than 3% of its annual income for electric, or more than 3% for natural gas. If a household has electric heat, it must spend more than 6% of its annual income on electricity to be eligible.

**For more information about USF:**

- **1-866-240-1347**

**For further information on LIHEAP or to locate the nearest application agency:**

- **1-800-510-3102**  
**[www.energyassistance.nj.gov](http://www.energyassistance.nj.gov)**

**Lifeline Utility Assistance**

Lifeline is a utility assistance program that offers a \$225 credit on electric and gas utility bills for persons who meet the PAAD eligibility requirements or who receive SSI.

- **NJ Department of Health and Senior Services**  
**1-800-792-9745 or**  
**[www.state.nj.us/health/seniorbenefits/services.shtml](http://www.state.nj.us/health/seniorbenefits/services.shtml)**

**New Jersey SHARES**

A statewide, nonprofit 501(c)(3) organization which provides grants to pay the utility bills of households in need through a statewide network of more than 100 community-based social service agencies. For information on applying for assistance:

- **1-866-NJSHARES**  
**[www.njshares.org/](http://www.njshares.org/)**

## **Medical Costs**

**Catastrophic Illness in Children Fund**

A catastrophic illness is any illness or condition, acute or chronic, for which expenses are incurred that are not fully covered by insurance, state, federal programs, or other sources and exceed the program's eligibility threshold. Any illness can be considered "catastrophic" based on the amount of uncovered eligible medical expenses and the family's income over the prior 12-month time period.

The following incurred expenses will be considered and may be eligible for payment/reimbursement if found reasonable. The categories include, but are not limited to:

- Specialized pediatric ambulatory care
- Addictions/mental health services
- Acute or specialized hospital care, both in and outpatient
- Physician care in all settings
- Medical equipment or disposable medical supplies
- Pharmaceuticals
- Medically related home modifications and medical transportation
- Home health care
- Experimental medical treatment or pharmaceuticals following special review

- **NJ Department of Human Services –  
Catastrophic Illness in Children Relief Fund  
609-292-0600, or 1-800-335-FUND  
www.state.nj.us/humanservices**

### **NJ Hospital Care Payment Assistance Program (Charity Care Assistance)**

This program offers free or reduced charge care to patients who receive inpatient and outpatient services at acute care hospitals throughout the State of New Jersey. Hospital assistance and reduced charge care are available only for necessary hospital care. Some services such as physician fees, anesthesiology fees, radiology interpretation, and outpatient prescriptions are separate from hospital charges and may not be eligible for reduction.

Hospital care payment assistance is available to residents who:

- Have no health coverage or have coverage that pays only for part of the bill: and
- Are ineligible for any private or government sponsored coverage (such as Medicaid); and
- Meet both income and assets eligibility criteria.

For information on eligibility and on how to apply:

- **NJ Department of Health & Human Services  
1-866-588-5696  
www.state.nj.us/health/cc/**

### **Veterans**

An individual with a disability who is a veteran or whose parent or spouse is or was a veteran, may be eligible for monthly cash payments, assistance with educational costs, medical care, vocational assistance, rehabilitation, or other benefits. In addition, a person with a disability who is a veteran may be eligible for grants for specifically adapted housing. For more information:

- **Morris County Division on Aging, Disabilities and Veterans/NJ EASE  
1-800-564-4656 or 973-285-6866  
www.morrishumanservices.org/dvs/**
- **Veterans' Affairs Hotline  
1-800-624-0508, or www.va.gov**

## **Other Funding Sources**

### **Home Modifications/Repairs**

Typical home modifications, such as building a ramp, widening doors, installing grab bars in the bathroom, or lowering countertops, can be very costly. While some home modifications are within the capacity of most do-it-yourselfers (such as changing door hardware from knobs to levers) other projects may require the aid of professional contractors. There are many different programs that can help pay for home modifications for people with disabilities. **The Assistive Technology Advocacy Center (ATAC)** of New Jersey publishes a home modification guide highlighting many of these programs. This guide is available online at the **Disability Rights New Jersey (DRNJ)** website:

- **www.drnj.org**

## Long Term Care Insurance

About 44% of all people age 65 and older will need nursing home care at some point in their lives. The average age for entering a nursing home is 83. One-third of those who enter a nursing home will stay three months or less, and 20% will stay about a year. The balance of older adults, or about one half, will remain in a nursing home more than a year, at a current cost of about \$100,000 per year.

Private insurance can play a vital role in protecting against what, for some, can become an economic catastrophe. Often, at the point when caregiving is necessary, the opportunity to insure for long term coverage to help cover nursing home costs has passed, and the person needing care is deemed “uninsurable.”

As a caregiver, you should become aware of the conditions of coverage of the insurance carried by the person you care for. Key things to watch for include:

- waiting periods
- policy requirements for Medicare approval
- what, if any, limits exist on daily medical benefits
- what are benefit coverages for:
  - Alzheimer’s
  - respite care
  - skilled, intermediate or custodial care
- types of care facilities covered or not covered
- are in-home services covered
- coverages for assisted living or community senior center
- ability to use benefit for care within a nursing home or facility
- benefits for personal grooming
- ability to upgrade to higher benefits or less restrictive coverage, protection against inflation

As a caregiver, you should review and write down key information in an easily accessible place, and know all insurance coverages, including home, auto, health, disability, and life. Easily accessible records should include location where actual policies are kept, and current contact information for each applicable agent.

As a caregiver, it is important to review key financial and insurance information, and keep copies of important documents, including those submitted to assistance programs.

Take time to review insurance coverages, including home, auto, health, disability, and life, and keep records that include location where actual policies are kept, and current contact information for each applicable agent.

Keep all records in an easily accessible place, and be sure to share with another family member where this important information can be found.

## 8.

# Legal Matters

## Relating to Loved Ones with a Disability

A list of key legal terms relating to caregiving for a loved one can be found in **Appendix C**.

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.

If your loved one is over age 60, please also see the *Caregiving for an Aging Loved One* section of this guide for more information and resources.

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

### 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.

### Key Legal Documents & Issues

#### Power of Attorney

A power of attorney is a legal document transferring decision-making authority to a person designated by you in advance. The power can be related to the management of your property or related to decisions about medical treatment. The power can be a “durable power,” meaning that it continues in the event of disability, or a “springing power,” meaning it takes legal effect only after disability.

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 an obvious example of having a “disability” and being unable to make decisions on his or her own.

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

#### Power of Attorney over Medical Decisions

The Power of Attorney over Medical Decisions appoints a person to represent your loved one in making medical decisions for him or her. It defines the limits and extent of such power.

**Other terms used to describe a power of attorney over medical decisions are “power of attorney for health decisions”, “health care proxy,” “medical directive” and “advanced directive for health care”.**

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

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

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

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

### **Living Will**

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

A living will is a critical legal document for you 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. Their 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**

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

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

The person executing the will is known as the "**testator**."

To make a valid will, the person must possess the **mental capacity** to know what he or she is doing. It is not an excessively high standard of "awareness" but does require awareness of some essential facts. For example, does the person know if he is married and if his spouse is alive? If he has children, can he name them, know approximately how old they are and where they live? Does he know, roughly, what he owns, such as houses and bank accounts, and does he understand that the purpose of a will is to leave the things he owns to the person whom he names in the will? If the person cannot be conversant about such basic facts, more than likely he does 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 and people with disabilities, who may be beginning to lose mental capacity, may have good days and bad days. So long as the person makes the will or changes to the will on a day in which he had mental capacity to understand what he was 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 will allows for the nomination of an executor; without a will, the state would determine who is to serve as executor of your estate.

A will avoids “intestacy.” Intestacy is where, in the absence of a will, state law dictates who inherits a person’s probate assets.

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.

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 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 exist 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 many 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.

For a trust to be “living,” it must be what is called “funded.” This simply means that the “grantor” has transferred assets currently owned into the trust. It makes little sense to create a “living trust” and then not transfer or convey the ownership of property 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.

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 private.

## **Special Needs Trust**

The only reliable method of making sure that an inheritance actually has a chance of reaching a person with a disability when he or she needs it is through the legal device known as a Special Needs Trust (SNT). The SNT is developed to manage resources while maintaining the individual's eligibility for public assistance benefits. By leaving whatever resources it deems appropriate to the trust, the family ensures that the money is available to the person with the disability. A trustee on behalf of the person with the disability manages the trust.

## **Letter of Intent**

A will and a special needs trust are important, but these documents rarely carry out the wishes of the family as intended unless the parents build a strong planning foundation by first developing a comprehensive and flexible life plan for and with the person with a disability. A letter of intent is a non-legal document that allows the parents of a person with a disability to put into writing their wishes for their child. The parents are asked to decide what they want for their child in all of the major life areas: residential placement, education, employment, socialization, religion, medical care, final arrangements and so on.

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

➤ [www.kidsource.com/kidsource/content4/estate.dis.all.3.html](http://www.kidsource.com/kidsource/content4/estate.dis.all.3.html)

## **Future Planning**

### **Guardianship**

All individuals become legal adults at age 18. This is true for individuals with disabilities as well. As a parent of a child with a disability you must apply for guardianship when your child turns 18; you do not automatically become the guardian just because your child has a disability.

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.

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 individual/organization, must go to the Court and petition for a Letter of Guardianship. Guardianship is basically Court supervised decision-making by another person.

Guardianship takes two forms. A guardian of the property has authority to manage the financial affairs for a senior or someone with a disability. A guardian of the person has authority to make health care decisions for the senior or someone with a disability. 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 their own affairs, a court appointed attorney to represent the individual, and the petitioner's attorney. Then, a hearing will be scheduled. Following the hearing, a judge will rule on the Complaint 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, or 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. The maximum dollar amount allowed in a burial account is \$1500 per person.

A good resource for information on funeral arrangements is [www.aarp.org/families/grief-loss/](http://www.aarp.org/families/grief-loss/)

**Probate and more:** For information about how to probate a will, executor duties, taxes, and more, please see *Caregiving for an Aging Loved One, Chapter 8*.

### **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.

## 9.

# Day Programs & Home Care Programs for Loved Ones with a Disability

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

For persons with developmental disabilities, these can range from adult day programs to in-home supports and respite and could be part of a "Self-Directed" plan.

1. **Adult training services** help individuals with basic vocational skills, such as those needed to develop social skills, manage money, and take care of their homes. It includes extended employment at **sheltered workshops**, where individuals receive work-related training, such as learning how to package and assemble products, as well as job counseling and job referrals.
2. **Supported employment services** include: on-site job coaches; crew work, in which an individual works as part of a peer group; and arrangements in which a consumer can sample different jobs to find a good "fit."

For persons with all 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 healthcare 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.

- **Morris County Office of Temporary Assistance (Medicaid Unit)**  
**973-326-7878**  
**[www.morrishumanservices.org/hs/](http://www.morrishumanservices.org/hs/)**

### **Personal Assistance Services Program (PASP)**

This is a state program for individuals from 18 to 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.

- **Morris County Office for the Disabled**  
**973-285-6865**  
**[www.morrishumanservices.org/dvs/](http://www.morrishumanservices.org/dvs/)**

## **Adult Day Programs**

Adult Day Programs are also known as “adult day services.” There are three types of day programs: Medical Day Care, Social Day Care, and Gero-Psychiatric 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 older 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 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, private pay, 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.

## **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.

## **Hospice**

Hospice is a program of care for terminally ill patients and their families that takes place in the home, a nursing home, or dedicated hospice unit. The goal of hospice 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. To find a hospice provider:

- **New Jersey Hospice & Palliative Care Organization**  
**908-233-0060**  
**[www.njhospice.org](http://www.njhospice.org)**
- **2-1-1 First Call for Help**  
**Dial 2-1-1, or 1-800-435-7555**  
**[www.NJ211.org](http://www.NJ211.org)**
- **National Hospice and Palliative Care Organization**  
**Information on end-of-life issues and state-specific advance directives.**  
**703-837-1500**  
**[www.nhpco.org](http://www.nhpco.org)**

### **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.

### **Nutrition Programs**

There are 15 “Midday Friendship Centers” located throughout Morris County, providing a hot mid-day meal and the opportunity to socialize with others. For those who are homebound, meals can be delivered.

- **Morris County Nutrition Project**  
**973-285-6856**  
**[www.morrishumanservices.org/dvs/](http://www.morrishumanservices.org/dvs/)**

# 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 assists 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.

### **NJ Division of Vocational Rehabilitation Services (DVRS)**

The mission of the New Jersey Division of Vocational Rehabilitation Services 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, call for more information:

- **Morris County DVRS office**  
**973-631-6304**  
<http://lwd.dol.state.nj.us/labor/dvrs/DVRIndex.html>

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

The New Jersey 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 more information:

- **973-648-3333**  
[www.state.nj.us/humanservices/cbvi/dhsvoc](http://www.state.nj.us/humanservices/cbvi/dhsvoc)

### **Employment Services through State Agencies**

Both state agencies, **DVRS & 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 the 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.

**Post Employment Supports** DVR provides post employment support 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. childcare 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 companies with workers for a specific time frame to utilize training in a non-paid work experience.

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. Student shadows 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 their federal taxes.

Vocational Evaluation – a short term program that measures a person's potential strengths, limitations and work behaviors.

## **Morris County Veteran's Services Office**

This office assists veterans with regard to their employment rights and provides referrals for job assistance and training. For more information:

- **973-285-6866**  
**[www.morrishumanservices.org/dvs/](http://www.morrishumanservices.org/dvs/)**

## **What happens 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 detailed information:

- **“Working While Disabled—How We Can Help**  
**[www.socialsecurity.gov/pubs/](http://www.socialsecurity.gov/pubs/)**

## **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, shelters, not-for-profit organizations, etc. In addition, Volunteer Management Center, Inc. (VMC) can connect individuals to volunteer opportunities in their local communities.

- **Volunteer Management Center, Inc (VMC)**  
**973-538-7200**  
**[www.vmcnj.org](http://www.vmcnj.org)**

# 11.

## Housing for Loved Ones with a Disability

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 NJ Housing and Mortgage Finance Agency. They provide an online tool to assist people with disabilities in finding affordable housing.

- **NJ Housing Resource Center**  
**1-877-428-8844**  
[http://www.njhousing.gov/njhrc/affordable\\_housing.html](http://www.njhousing.gov/njhrc/affordable_housing.html)

### Types of Housing

#### Public Housing

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% of adjusted earnings. People who live in public housing earn less than 80% of median family income. Federal rules require housing authorities to keep a certain percentage of these units for very low-income households, earning 50% or less than median family income. Some housing authorities must reserve units for extremely low-income households with earnings at or below 30% of median. Use federal income standards to determine eligibility. All rental units must be within Fair Market Rent.

Housing authorities may 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.

The following are County and Municipal Housing Authorities in Morris County:

- **Boonton Housing Authority:** **973-335-0846**
- **Dover Housing Authority:** **973-361-9444**
- **Madison Housing Authority:** **973-377-0258**
- **Morris County Housing Authority:** **973-540-0389**
- **Morristown Housing Authority:** **973-538-6343**

## **Subsidized Housing**

**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 published “Income Limits” page on the HUD website: [www.huduser.org/datasets/il.html](http://www.huduser.org/datasets/il.html). The income limits

change every year. Some New Jersey programs use income limits published by the Council on Affordable Housing (COAH) – these numbers are similar to HUD’s, but slightly different: [www.state.nj.us/dca/affiliates/coah/reports/incomelimits.pdf](http://www.state.nj.us/dca/affiliates/coah/reports/incomelimits.pdf)

Some voucher programs have “set-asides” for those who are considered low or moderate income (below 80% of the Area Median Income), those who have special needs (such as a physical, developmental or psychiatric disability) 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 – those that are tenant based and those that are 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% - 40% 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’ll be placed on a waiting list, it is advised that you contact as many 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. The following agencies offer tenant based vouchers:

- **Boonton Housing Authority:** **973-335-0846**
- **Dover Housing Authority:** **973-361-9444**
- **Madison Housing Authority:** **973-377-0258**
- **Morris County Housing Authority:** **973-540-0389**
- **Morristown Housing Authority:** **973-538-6343**
- **NJ Dept. of Community Affairs** **609-292-4080**  
[www.state.nj.us/dca/divisions/dhcr/offices/srap.html](http://www.state.nj.us/dca/divisions/dhcr/offices/srap.html)

**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% - 40% of monthly household income toward rent and utilities, depending on the subsidy program attached to the project.

Some agencies that provide housing to people with disabilities may have at least some units that have project based vouchers. These programs typically have long waiting lists. For more information on options:

- **Boonton Housing Authority:** **973-335-0846**
- **Dover Housing Authority:** **973-361-9444**
- **Madison Housing Authority:** **973-377-0258**
- **Morris County Housing Authority:** **973-540-0389**
- **Morristown Housing Authority:** **973-538-6343**

➤ **USDA Multi Family Apartments in Morris County:**

**Robert E. Cole Apartments in Chester**  
**908-879-9050**

**Heritage Manor Apartments in Mendham**  
**973-543-2666**

**Morris Mews**  
**99 Ketch Road**  
**Contact through the Morris County Housing authority: 973-540-0389**

Some service provider organizations have also developed projects that are accessible and affordable for people with disabilities.

- **United Cerebral Palsy of Northern, Central and Southern NJ**  
**908-879-2243**  
**[www.ucp.org/ucp\\_localsub.cfm/100/8605/16457](http://www.ucp.org/ucp_localsub.cfm/100/8605/16457)**

**Legal Services of Northwest Jersey** provides a comprehensive guide addressing landlord and tenants rights. To receive a copy: **973-285-6911**

### **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**

These homes feature on-site, 24-hour staffing support to serve the individual and no more than three roommates.

### **Supervised Apartments**

These 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**

Here 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**

In this situation, 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, contact:

- **NJ Division of Developmental Disabilities**  
**973-927-2600 (Northern Regional Office)**  
**[www.state.nj.us/humanservices/ddd/services/residential/index.html](http://www.state.nj.us/humanservices/ddd/services/residential/index.html)**

### **Home Ownership**

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 home owners, 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**

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's programs:

- **HMFA**  
**609-278-7400**  
**[www.state.nj.us/dca/hmfa/](http://www.state.nj.us/dca/hmfa/)**
  
- **HMFA Mortgage Hotline**  
**1-800-NJ-HOUSE**  
**1-800-654-6873**

NJ Housing Resource Center provides an online tool to help people with disabilities find housing options:  
**[http://www.njhousing.gov/njhrc/affordable\\_housing.html](http://www.njhousing.gov/njhrc/affordable_housing.html)**

# 12.

## Transportation Information for Loved Ones with a Disability

There are several transportation resources available to Morris County residents with disabilities.

### **2-1-1 First Call for Help**

2-1-1 First Call for Help now operates statewide, connecting people with the resources they need to solve common life problems, including transportation. It is staffed 24/7 and can be accessed by dialing 2-1-1.

- **Dial 2-1-1, or 1-800-435-7555**  
**[www.NJ211.org](http://www.NJ211.org)**

### **Morris County Public Transportation**

The Morris County Department of Transportation can provide you with a free Transit Guide of the Morris County public transportation system. Their website can provide you with transportation information and alternatives, including rail, bus, paratransit, park-and-rides, bicycle and pedestrian travel, and ridesharing. Numerous links to other transportation resources are available on this website.

- **973-829-8101**  
**[www.morrisdot.org](http://www.morrisdot.org)**

### **NJ Transit**

NJ Transit provides reduced fares for senior citizens and those with a permanent disability. Senior citizens and passengers with disabilities can travel on-board NJ TRANSIT trains, buses, and light rail vehicles at a reduced fare of one-half the regular one-way fare or lower.

Seniors and passengers with disabilities must present an NJ TRANSIT Reduced Fare ID or Medicare Card to obtain the reduced fare ticket.

To receive discounted fares, a **NJ TRANSIT Reduced Fare Card/Reduced Fare ID application** must be submitted. A Social Security Card and proof of age (a birth certificate or a driver's license) must be presented when applying.

Applications can be found at most local banks, savings and loan associations, or county Offices on Aging. Applications are also available at the NJ TRANSIT Customer Service offices at Newark Penn Station, New York Penn Station, Hoboken Terminal, and the Port Authority Bus Terminal. An application can also be mailed to you. For more information:

- **NJ TRANSIT Reduced Fare Office**  
**973-378-6401**  
**[www.njtransit.com/sf/sf\\_servlet.srv?hdnPageAction=ReducedFareTo](http://www.njtransit.com/sf/sf_servlet.srv?hdnPageAction=ReducedFareTo)**

## **Access Link**

NJ Transit also provides paratransit services for those people whose disability prevents them from using the local fixed route bus service. This service is called *Access Link* and eligibility is determined using the three categories provided in the ADA. Your loved one may be eligible for Access Link if:

1. If he/she cannot get on or off a bus or ride in an accessible bus due to a disability
2. If his/her disability prevents him/her from getting to a bus stop
3. If accessible bus service is not available in their area

The cost of this service is the cost of the usual bus fare to the desired destination. To apply for *Access Link* an assessment is necessary. Transportation can be provided for the assessment appointment. To arrange for an assessment:

- **NJ Transit**  
**1-800-955-2321 (TTY 1-800-955-6765)**  
**[www.njtransit.com/tm/tm\\_servlet.srv?hdnPageAction=AccessibleServicesTo](http://www.njtransit.com/tm/tm_servlet.srv?hdnPageAction=AccessibleServicesTo)**

## **Handicapped Parking Passes**

Handicapped parking passes are available for drivers who have lost the use of one or more limbs or are permanently disabled and cannot move without an assisting device or those who transport individuals with such disabilities on a regular basis. For more information:

- **NJ Motor Vehicle Commission**  
**609-292-6500 or 888-486-3339**  
**[www.state.nj.us/mvc/Vehicle/HandicappedPlates.htm](http://www.state.nj.us/mvc/Vehicle/HandicappedPlates.htm)**

## **MAPS**

MAPS (Morris Area Paratransit Services) is administered by the Morris County Division on Seniors, Disabilities and Veterans and provides transportation to medical facilities, education or employment sites, adult day care centers, and other locations. Most MAPS vehicles are able to accommodate wheelchairs. Your loved one may use MAPS if he or she is a Morris County resident and is age 60 or above, OR if he or she has a physical or mental disability that includes functional limitations. MAPS must be notified in advance if a caregiver will be traveling with the resident. For more information:

- **888-282-MAPS (6277)**  
**[www.morrihumanservices.org/dvs/](http://www.morrihumanservices.org/dvs/)**

## **TransOptions**

As the Transportation Management Association (TMA) for northwest New Jersey, TransOptions assists commuters, businesses, and local municipalities in Morris, Sussex and Warren Counties, as well as towns in suburban Essex, Passaic, and Union Counties with multiple commute options.

TransOptions is available to assist your loved one with transportation issues or questions regarding services in his or her area. For more information:

- **973-267-7600**  
**[www.transoptions.org](http://www.transoptions.org)**

### **American Red Cross of Northwest NJ**

Provides transportation for veterans to medical appointments and VA hospitals. For more information:

- **973-538-2160**

### **Daughters of Israel, West Orange, NJ**

Provides limited fee for service transportation through their Metro Transport Program for eligible seniors and people with disabilities. In Morris County, service is only available to Parsippany, East Hanover, Florham Park, Morristown, and Whippany. For information:

- **973-325-1359**

### **Dial-A-Ride**

Dial-A-Ride is municipally-sponsored local transportation for senior citizens and persons with disabilities. Many towns in Morris County offer Dial-A-Ride service. For a list of municipalities with phone numbers, visit:

- **[www.co.morris.nj.us/transportation/spectrans/spectrans-dialaride.asp](http://www.co.morris.nj.us/transportation/spectrans/spectrans-dialaride.asp)**

### **FISH (Friends in Service to Humanity)**

Volunteers provide rides, primarily to and from medical appointments.

- **For Mendham Borough and Township residents only: 973-543-4574.**

### **Morris on the Move (M.O.M.)**

M.O.M. can provide transportation for up to 18 passengers and two wheelchairs. Priority is given to public assistance and other low income residents commuting to or from work or work related activities. M.O.M. operates a shuttle service from Dover to Mt. Olive. Service is limited. For more information:

- **973-829-8501**

### **Morris County Organization for Hispanic Affairs**

Transportation is available for individuals in need. For more information:

- **973-366-4770**

# 13.

## 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, in most instances you are your loved one's best advocate. However, it is also important to encourage the individual to learn how to advocate for themselves. No matter what the individual's level of ability, the capability for an individual to advocate for himself 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 the caregiver to learn and develop. These can be acquired through help from other caregivers or caregiver coalitions.

#### **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 child 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.

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 the help from other caregivers or caregiver coalitions or other advocacy groups.

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

## **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 co-pays, service limits, and equipment ownership/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 the issue. 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](http://www.state.nj.us/humanservices/dds).

### **Centers for Independent Living (CIL's)**

These are private, not-for-profit organizations that promote systems advocacy. They also work with people with all disabilities to advance their independence. 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 do people without disabilities.

**DAWN** is the Center for Independent Living serving Morris, Sussex and Warren counties. For more information:

- **DAWN Center for Independent Living**  
**973-625-1940; 1-888-383-DAWN**  
**[www.dawncil.org](http://www.dawncil.org)**

### **Family Support Organization of Morris and Sussex Counties**

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

- **973-770-2700**  
**[www.fso-ms.org](http://www.fso-ms.org)**

### **RFSPC (Regional Family Support Planning Councils)**

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. For more information:

- **NJ Council on Developmental Disabilities**  
**609-222-3745**  
**TDD 609-777-3238**

**[www.njddc.org/familysupport.htm](http://www.njddc.org/familysupport.htm)**

## **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 that includes needed community services, individualized supports, and other forms of assistance that promote self-determination for individuals with developmental disabilities and their families.

- **[www.njddc.org](http://www.njddc.org) (For publications, click on “Publications”)**

Monday Morning project (under DDC) is a grass-roots 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](http://www.njddc.org) (Click on “Monday Morning”)**

## **Caregivers Coalition of Morris County**

A United Way of Morris County Initiative

The Coalition’s work on behalf of caregivers includes advocacy at the local, state, and national level. It is an advocate voice on your behalf. Your ideas and experiences could help direct the Coalition’s advocacy efforts. Please contact the Coalition if you are interested in joining its advocacy efforts.

- **Caregivers Coalition of Morris County**  
**973-993-1160, x139**  
**[www.LiveUnitedMorris.org](http://www.LiveUnitedMorris.org)**

# 14.

## Life Transitions for Caregivers of Loved Ones with a Disability

### Stages of Caregiving

In caring for your loved one you may, over time, experience different stages of caregiving. Coping with these changing stages of caregiving will require you to manage stress, perhaps develop new skills, all while maintaining a level of flexibility as you adapt to your loved one's changing needs.

Again, most caregivers climb a steep learning curve, as they become 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.

### You Are Not Alone

We don't need to tell you that caregiving can be exhausting, even frustrating 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 all alone! A strong network of friends, family, and service providers can help you, and keep emotions and exhaustion from becoming overwhelming. Ask for help, whenever you need it.

Again, remember, it is important that you do not take on all your caregiving responsibilities in isolation. Through organizations noted in this support guide, you can find the resources and people you need to take care of yourself – taking care of yourself means that you will be better able to take care of your family member or friend.

No matter what each stage of caregiving brings, it will always help to reach out to find the information and support you need to provide the best care possible, for your loved and for YOU.

### Your Changing Role

Throughout your caregiving journey, you may notice that your loved one requires different levels of care. Having to assume responsibilities that your loved one was used to doing independently can generate a range of emotions for you both, from frustration to sadness, even anger and grief. Identifying the issues that are associated with the illness, disease or disability will help you cope with the role transition that you are experiencing, as well as the changing nature of your relationship with your family member or friend.

During this time, flexibility is the key. You will need to develop stress and time management skills that are necessary to cope with changes and increased demands that will occur over time.

If you must take on more and more daily tasks related to caregiving, it will become increasingly important to take advantage of resources in the community and whatever services you and/or your loved one are eligible for.

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.

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

Importantly, always remember that your caregiving is a gift – one of the greatest gifts you can ever give to the one you care for; a gift to be proud of and to cherish.

***Based on material from CHATS - Community Home Assistance to Seniors, Ontario,  
and Aetna Intelihealth***