



Navigating the World of Disability

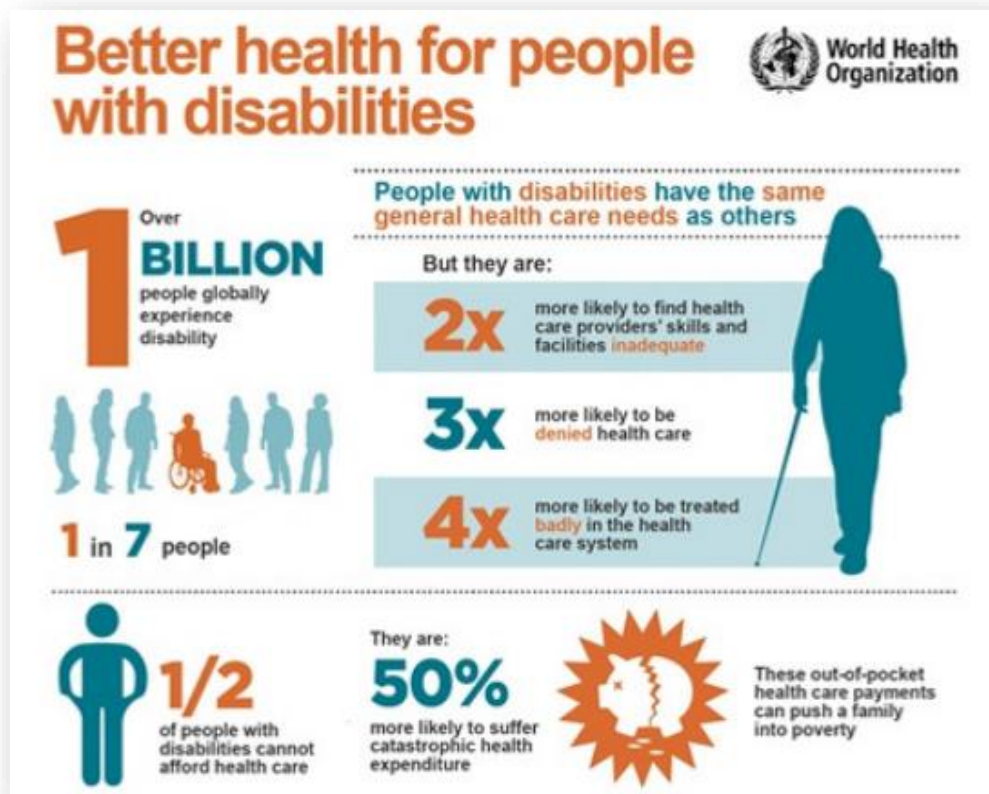
VICTORIA PENA-CARDINALI, LCSW

What is a Disability?

- ❖ Disability is an umbrella term, covering impairments, activity limitations, and participation restrictions.
- ❖ An impairment is a problem in body function or structure.
- ❖ An activity limitation is a difficulty encountered by an individual in executing a task or action.
- ❖ A participation restriction is a problem experienced by an individual in involvement in life situations.
- ❖ Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives.

Definition by the World Health Organization

Facts on Disability



Facts on Disability Continue

Rehabilitation and assistive devices can enable people with disabilities to be independent



200 MIL

people need glasses or other low-vision devices and do not have access to them



70 MIL

people need a wheelchair. Only 5-15% have access to one

360 MIL



people globally have moderate to profound hearing loss

Production of hearing aids only meets:

10%

of global need

3%

of developing countries' needs

Making all health care services accessible to people with disabilities is achievable and will reduce unacceptable health disparities



remove physical barriers to health facilities, information and equipment



make health care affordable



train all health care workers in disability issues including rights



invest in specific services such as rehabilitation

Source: World report on disability: www.who.int/disabilities/world_report

The Process of Adjustment

- ❖ Adaptation to a disability or a chronic condition is a life-long process of successful coping with the loss of health, transform social standing, environmental restrictions and reduce vocational roles.
- ❖ The process of adjustment is characterized by:
 - Learning the techniques to live with a disability.
 - Making the most of one's residual abilities.
 - Striving to have a productive and satisfying life.
- ❖ Adjustment is evolutionary, changing and highly individualized and determine by psychosocial, sociocultural and environmental interactions.
- ❖ Rehabilitation is the process of defining or re-defining oneself and reveling in the fact that one's spiritual essence is eternal and unchanging.

Areas of Adjustment and Resources: Employment and Vocational Roles

THE AMERICAN WITH DISABILITIES ACT (ADA) AND VOCATIONAL ROLES

- ❖ **American with Disabilities Act (ADA):** The ADA is a federal civil rights law that was passed in 1990 and went into effect beginning in 1992. Its purpose is to protect people with disabilities from discrimination in employment (Title I), in the programs and activities offered by state and local governments (Title II), and in accessing the goods and services offered in places like stores, hotels, restaurants, football stadiums, doctors' offices, beauty parlors, and so on (Title III).
- ❖ **Title I protects "qualified" "employees" with "disabilities."** The term "qualified" means that you satisfy the skill, experience, education, and other job-related requirements of the position sought or held, and can perform the essential job functions of the position, with or without reasonable accommodation.
- ❖ **Job Accommodation Network – JAN:** JAN provides free consulting services for individuals with physical or intellectual limitations that affect employment. Services include one-on-one consultation about job accommodation ideas, requesting and negotiating accommodations, and rights under the Americans with Disabilities Act (ADA) and related laws.
<http://askjan.org/>
- ❖ **Division of Vocational Rehabilitation Services – DVR:** The mission of the New Jersey Division of Vocational Rehabilitation Services (DVRS) is to enable eligible individuals with disabilities to achieve an employment outcome consistent with their strengths, priorities, needs, abilities and capabilities. Services include placement services, job search and skill development, supportive employment, job accommodations and mobility equipment among others.
http://careerconnections.nj.gov/careerconnections/plan/foryou/disable/vocational_rehabilitation_services.shtml

Areas of Adjustment and Resources:

Social Security / Income

- ▶ **The American Disability Act Title II** protects people with disabilities from discrimination in the programs and activities offered by state and local governments such as Social Security, Medicare and Medicaid.
- ▶ **Social Security Administration (SSA):** SSA oversees the Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) programs. The two programs that offer Social Security Disability (SSD) benefits.
- ▶ **Social Security Disability Insurance (SSDI):** Eligibility is dependent on the individual's "work credits" which refers to employment and tax-paying history.
- ▶ **Supplemental Security Income (SSI):** It is a needs-based program that provides benefits to the disable and elderly individuals who earn very little income.
- ▶ **SSDI and SSI eligibility requirements** also include prove of disability which is defined by the SSA as having a condition that is expected to last at least one year and prevents you from performing substantial gainful activity

Social Security and Compassionate Allowances

Compassionate Allowance: The compassionate allowance initiative is a program that allows the SSA to process certain diseases and diagnoses faster based on the extensive medical proof that they are extremely disabling. Multiple System Atrophy has been listed as a Compassionate Allowance condition since December 2011.

❖ **Applying for SSD with a Multiple System Atrophy Diagnosis:**

- Prior to beginning the application process, it is extremely important that you collect through medical evidence to document your illness and symptoms.
- Find a neurologist who has experience diagnosing Parkinson's Disease and its variants. Documentation must show the presence of the autonomic dysfunctions which occur only in MSA. Brain scans are useful in diagnosis as they often show characteristic activity in the affected areas of the brain.
- Other medical documentation should include records of your diagnosis, lab test results, treatment history, response to treatment, hospital visits, and even personal statements from your doctors.
- Collecting these records prior to the application process will prevent delays from occurring.
- The other qualifications for SSDI or SSI must be met such as "work credits" and financial eligibility respectively.
- For a complete description of required information and documentation, please visit the social security website and access the "starter kit" in the link below:
<https://www.ssa.gov/disability/Documents/SSA-1170-KIT.pdf>

How to Apply for Social Security Disability Benefits

- ❖ Once ready to begin, you can apply online at the SSA's website or in person at your local Social Security office. The link below will take you to the application page:
<https://www.ssa.gov/applyfordisability/>
- ❖ You can also call **1-800-772-1213** and request an appointment in your local social security office.
- ❖ Once the application is filed, under a compassionate allowance condition, in some cases you may expect to receive Social Security Disability benefits in as little as several weeks.

Health Benefit Options: COBRA, Market Place, Medicare and Medicaid

- ▶ **COBRA:** It stands for the Consolidated Omnibus Budget Reconciliation Act. It gives employees the right to pay premiums for and keep the group health insurance that they would otherwise lose after they: Reduce their work hours, quit their jobs or lose their jobs.
- ▶ Under COBRA most people can keep the insurance for up to 18 months. Some people may be able to keep it a few months longer.
- ▶ For detailed information about COBRA, call the **Employee Benefits Security Administration at 1-866-444-3272** or visit their website at www.dol.gov/ebsa. You can also find a detailed brochure called *An Employee's Guide to Health Benefits Under COBRA*, online at [chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://www.dol.gov/sites/dolgov/files/ebsa/about-ebsa/our-activities/resource-center/publications/an-employees-guide-health-benefits-under-cobra-2022.pdf](https://efaidnbmnnnibpcajpcglclefindmkaj/https://www.dol.gov/sites/dolgov/files/ebsa/about-ebsa/our-activities/resource-center/publications/an-employees-guide-health-benefits-under-cobra-2022.pdf)
- ▶ The [state insurance marketplaces](#) created by the Affordable Care Act offer more health insurance options to people who don't have access through their employers. It can also help those who leave their jobs and lose their employer's group insurance. For some people, buying insurance through their state's marketplace may cost less than paying for COBRA coverage.
- ▶ Find your state's marketplace website: visit www.healthcare.gov, select "enroll", and choose the state where you live or call the 24/7 marketplace helpline **1-800-318-2596**.

MEDICARE

- ❖ **What is Medicare:** Medicare is the federal health insurance program for people who are 65 or older and certain younger people with disabilities. If you are approved by an SSD plan even under compassionate allowance, there is a 24 months waiting period for Medicare eligibility.

Coverage:

- **Medicare Part A:** Part A covers inpatient hospital stays, care in a skilled nursing facility, hospice care, and some home health care.
- **Medicare Part B:** Part B covers certain doctors' services, outpatient care, medical supplies, and preventive services.
- **Medicare Part C: (Medicare Advantage Plans)** A type of Medicare health plan offered by a private company that contracts with Medicare to provide you with all your Part A and Part B benefits. Medicare Advantage Plans include Health Maintenance Organizations.
- **Medicare Part D:** Offers prescription drug coverage to original Medicare. These plans are offered by insurance companies and other private companies approved by Medicare. Medicare Advantage Plans may also offer prescription drug coverage that follows the same rules as Medicare Prescription Drug Plans.
- **Medigap: A Medicare Supplement Insurance** policy, sold by private companies, can help pay some of the health care costs that original Medicare doesn't cover, like copayments, coinsurance, and deductibles

MEDICAID

- ❖ **What is Medicaid:** Medicaid provides health coverage to millions of Americans, including eligible low-income adults, children, pregnant women, elderly adults and people with disabilities. Medicaid is administered by states, according to federal requirements. The program is funded jointly by states and the federal government.
- ❖ **Services Covered:** This program pays for hospital services, doctor visits, prescriptions, nursing home care and other healthcare needs, depending on what program a person is eligible for.
- ❖ **How to Apply:** 1- Fill out an application through the Health Insurance Market Place (Slide 9)
2- Contact you County Welfare Agency
<http://www.state.nj.us/humanservices/dfd/programs/njsnap/cwa/>
- ❖ **Eligibility Requirements:** NJ resident, US Citizen or Legal Alien with 5 years of legal residence in the US and meet the require standards of financial income and resources.
- ❖ **Special Programs:** The Division of Disability Services in the Department of Human Services administers the **Home and Community Based Services for people with** disabilities. These programs were implemented to provide support services to an individual in the community to: prevent placement in an institutional setting (e.g. nursing home or hospital) or provide support to individuals who are re-entering a community setting after a period of institutionalization.

MLTSS: Medicaid Managed Long Term Care Services and Supports

- ❖ **Managed Long Term Services and Supports (MLTSS)** refers to the delivery of long-term services and supports through New Jersey Medicaid's NJ Family Care managed care program.
- ❖ **MLTSS** uses NJ FamilyCare managed care organizations (also known as HMOs or health plans) to coordinate ALL services. MLTSS provides comprehensive services and supports, whether at home, in an assisted living facility, in community residential services, or in a nursing home.
- ❖ **Managed Long Term Services and Supports (MLTSS) includes:** Personal Care, Respite, Care Management, Home and Vehicle Modifications, Home Delivered Meals, Personal Emergency Response Systems, Mental Health and Addiction Services, Assisted Living, Community Residential Services, Nursing Home Care.
- ❖ **Eligibility:** Must meet Medicaid guidelines for financial requirements, clinical requirements, age and/or disability requirements. For detail information ,please visit:
http://www.state.nj.us/humanservices/dmahs/clients/medicaid/abd/ABD_Overview.pdf
- ❖ **Clinical Requirements:** A person meets the qualifications for nursing home level of care, which means that the person requires assistance with activities of daily living such as bathing, toileting and mobility.

The New Jersey Family Leave Act

- ❖ **NJFLA:** The New Jersey Family Leave Act grant eligible employees time off from work in connection with the birth or adoption of a child or the serious illness of a parent, child or spouse.
- ❖ The NJFLA provides for up to twelve weeks of leave in a 24-month period. The 24-month period begins on the first day of the employee's first NJFLA leave.
- ❖ All employers with 50 or more employees anywhere worldwide must comply with the NJFLA for their New Jersey employees.
- ❖ To be eligible for family leave under the NJFLA, an employee must be employed in New Jersey by a covered employer. The employee also must have been employed for at least twelve (12) months for the employer, and must have worked 1,000 base hours in the preceding twelve (12) months.
- ❖ For detail information on FMLA please visit the State of NJ Division of Civil Rights:
<http://www.nj.gov/oag/dcr/law.html#1>

Other Important Considerations: Advance Directives

- ❖ **Advance Directives:**

An advance directive is a legal document that you can complete on your own that can help ensure that your preferences for various medical treatments are followed if you become unable to make your own healthcare decisions.

- ❖ Your advance directive only goes into effect if your physician has evaluated you and determined that you are unable to understand your diagnosis, treatment options or the possible benefits and harms of the treatment options.

- ❖ **Types of Advance Directives:**

- ❖ **Durable Power of Attorney for Health Care or Health Care Proxy:** A proxy directive is a document you use to appoint a person to make healthcare decisions for you in the event you become unable to make them yourself.
- ❖ **Living Will or Instruction Directive:** An instruction directive is a document you use to tell your physician and family about the kinds of situations you would want or not want to have life-sustaining treatment in the event you are unable to make your own healthcare decisions.
- ❖ Access the Advance Directives Forms from the State of NJ in the following link:
<http://www.state.nj.us/health/advancedirective/ad/forums-faqs/>

POLTS: Practitioner's Order's for Life Sustaining Treatment

- ❖ **What is POLTS:**
POLTS is a healthcare planning tool that empowers individuals to work closely with their medical team to detail their personal goals and medical preferences when facing a serious illness.
- ❖ The POLTS form is designed to be completed jointly by an individual and a physician or advance practice nurse, expressing the individual's goals of care and medical preferences.
- ❖ **Unlike other documents like an Advance Directive, a completed POLST form is an actual medical order that becomes a part of the individual's medical record. It also is valid in all healthcare settings.**
- ❖ **The POLTS Form:** <http://www.njha.com/media/84188/njpolstform.pdf>
- ❖ **What is POLTS:**
POLTS is a healthcare planning tool that empowers individuals to work closely with their medical team to detail their personal goals and medical preferences when facing a serious illness.
- ❖ The POLTS form is designed to be completed jointly by an individual and a physician or advance practice nurse, expressing the individual's goals of care and medical preferences.
- ❖ **Unlike other documents like an Advance Directive, a completed POLST form is an actual medical order that becomes a part of the individual's medical record. It also is valid in all healthcare settings.**
- ❖ For help in planning and preparation of legal documents, an elder care and disability attorney can provide guidance in this processes. To locate one in your area visit the Elder Care Locator website at <http://www.eldercare.gov/Eldercare.NET/Public/Index.aspx>

Resources: Case Management and Home Care

- ❖ **Case Management:** The American Case Management Association defines case management as “a collaborative process of assessment, planning, facilitation, care coordination, evaluation and advocacy for options and services to meet an individual’s and family’s comprehensive health needs through communication and availability of resources to promote quality cost-effective outcomes.”
- ❖ A **Case Manager** working for **health insurers and HMOs** typically offer the following **services**: check benefits available; negotiate rates with providers who are not part of the plan’s network, recommend coverage exceptions where appropriate; coordinate referrals to specialist, arrange for special services; coordinate insured services with any availability community services and coordinate claims with other benefit plans.
- ❖ **Home Care:** Start your selection process early so that you are not making decisions at times of crisis. The following link from the National Association of Home Care provides guidelines to select the right home care provider:
<http://www.nahc.org/consumer-information/right-home-care-provider/>
- ❖ **Types of Home Care:** (Medicare and You 2016 publication <https://www.medicare.gov/Pubs/pdf/10050.pdf>)
- ❖ **Skill Care:** A service provided by a health care professional, primarily a nurse, therapist (PT/OT/ST) or social worker.
- Persona Care:** Help with bathing, grooming, or other tasks provided by home health aides or personal care attendants.

NOTE: Medicare does not cover just personal care if this is the only care the patient needs. Medicaid does cover some home care, but coverage varies according to Medicaid program and State.

Resources: Durable Medical Equipment (DME)

- ❖ **Durable Medical Equipment (DME)** is any **equipment** that provides therapeutic benefits to a patient in need because of certain **medical** conditions and/or illnesses. **Durable Medical Equipment (DME)** consists of items which are primarily and customarily used to serve a **medical** purpose.
- ❖ Durable Medical Equipment (DME) is covered under **Medicare part B**. Medicare covers 80% and you pay 20% of the Medicare authorized amount. Private health insurances also cover DME. Policies differ therefore inquire about your coverage with your health insurance company.
- ❖ Only your Medical Doctor can prescribe your medical equipment and the need must be documented and justified.
- ❖ Medicare will only cover your DME if your doctors and DME suppliers are enrolled in Medicare. Doctors and suppliers have to meet strict standards to enroll and stay enrolled in Medicare. If your doctors or suppliers aren't enrolled, Medicare won't pay the claims submitted by them.
- ❖ For a complete list of DME that Medicare covers, visit the following link:
<https://www.medicare.gov/coverage/durable-medical-equipment-coverage.html>
- ❖ For a complete guide on how to pay for home and durable medical equipment please visit the following link: <https://www.payingforseniorcare.com/durable-medical-equipment/how-to-pay-home.html>

Resources: Respite Care

- ❖ **What is Respite Care?** It is defined by AARP as a break to the caregiver. Whether it's for a few hours a week to run errands or a few weeks a year to take a much-needed vacation, respite care offers you the chance reduce stress, restore energy and keep your life in balance.
- ❖ **Types of Respite Care:**
 - In home respite:** can be provided by volunteer or paid help, occasionally or on a regular basis. Services may last from a few hours to overnight, and may be arranged directly or through an agency. This popular respite choice enables the patient to remain in his or her own home, and can be invaluable for caregivers.
 - Out-of-home respite Care services:** This type of respite can take place in an adult day program or residential care center where emergency and planned overnight services are provided allowing 24 hour relief.
- ❖ **Statewide Respite Care Program:** This program provides respite care services for elderly and functionally impaired persons age 18 and older to relieve their unpaid caregivers of stress arising from the responsibility of providing daily care. A secondary goal of the program is to provide the support necessary to help families avoid making nursing home placement of their relatives.
- ❖ **To discuss Respite options and financial support contact The Aging and Disability Resource Connection at 1-877-222-3737.**

Resources for Safe Travel

- ❖ **The American Disabilities Act Title III** protects people with disabilities from discrimination in accessing the goods and services offered in places like stores, hotels, restaurants, football stadiums, doctors' offices, beauty parlors, and so on.
- ▶ The Transportation Security Administration (**TSA**) under the jurisdiction of the US Department of Homeland Security created the TSA Care Helpline that provides travelers with disabilities, medical conditions and other special circumstances additional assistance during the security screening process.
- ▶ Call 72 hours prior to traveling with questions about screening policies, procedures and what to expect at the security checkpoint. **The helpline number is 855-787-2227** and speak to a passenger support specialist who can also provide support at the airport.
- ▶ For additional and detail information on traveling support visit their website at <https://www.tsa.gov/travel/security-screening>

Quote

"A hero is an ordinary individual who finds the strength to persevere and endure in spite of overwhelming obstacles." - Christopher Reeves

Contact Information

VICTORIA PENA-CARDINALI, LCSW

Capital Institute for Neurosciences
Two Capital Way Suite 456
Pennington, NJ 08540

victoriapc2@live.com

609-537-7157

Summary of Resources

- ▶ NJ Local Areas on Aging: <http://www.state.nj.us/humanservices/doas/home/saaaa.html>
- ▶ Advance Directives – Palliative Care and Hospice: <http://www.state.nj.us/health/advancedirective/ad/forums-faqs/>
- ▶ Respite Care: <http://www.nj.gov/humanservices/news/publications/respit%20care%20bro0415.pdf>
- ▶ Statewide Respite Care Program: <http://www.nj.gov/humanservices/news/publications/respit%20care%20bro0415.pdf>
- ▶ Traveling and Disability
<https://travel.state.gov/content/passports/en/go/disabilities.html>
<http://www.independenttraveler.com/travel-tips/senior-travel/disabled-travel>
<http://www.friendshipcircle.org/blog/2012/04/04/7-travel-agencies-for-special-needs-travel/>
- ▶ World Health Organization: <http://www.who.int/topics/disabilities/en/>
- ▶ State of NJ: Department of Disability Services (DDS) <http://www.state.nj.us/humanservices/dds/services/info/>
- ▶ New Jersey Protection and Advocacy Agency: <http://www.drnj.org> Tel#(609) 292-9742
- ▶ Jersey Assistance for Community Caregiving http://www.nj.gov/humanservices/news/publications/jacc_bro_0415.pdf
- ▶ Paying for Senior Care: <https://www.payingforseniorcare.com/>