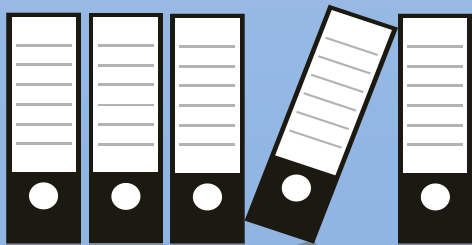


DISABILITY RESOURCES

**THE DYSTROGLYCANOPATHIES:
A PATIENT AND FAMILY CONFERENCE**

JUNE 10, 2011



Compiled by
Jennifer Britton
Director of Operations

Navigating the System



This Resource list is intended to help you find the information and guidance you might want to navigate the disability service system in the community where you live. Each resource is a portal record to a list of state specific services. The descriptions are from each website. This is a “places to start” list.

Table of Contents

Information and Referral

Navigators

Specific Topics:

Americans with Disabilities Act (ADA)

Advocacy

Assistive Technology

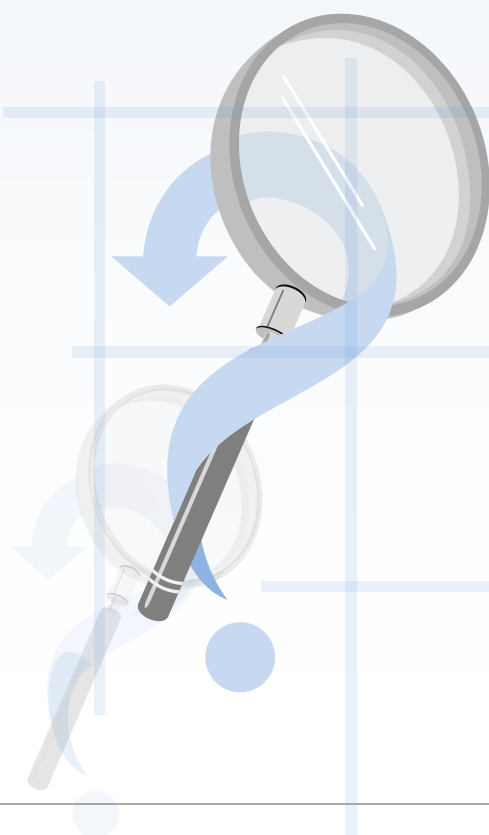
Education Resources

Employment Services

Health Insurance

Muscular Dystrophy

Social Security Benefits



INFORMATION AND REFERRAL

Centers for Independent Living

A Center for Independent Living is a consumer-controlled, community-based, cross-disability, nonresidential private nonprofit agency that is designed and operated within a local community by individuals with disabilities and provides an array of independent living services.

<http://www.ilru.org/html/publications/directory/index.html>

Parent Training Information Centers

Parent Centers provide training, information and assistance to families of children with all disabilities ages birth to 26 years and the professionals who work with them.

<http://www.parentcenternetwork.org/parentcenterlisting.html>

NAVIGATORS

Aging and Disability Resource Centers (ADRC)

ADRCs serve as single points of entry into the long-term supports and services system for older adults and people with disabilities.

<http://www.adrc-tae.org/tiki-index.php?page=ADRCLocator>

Family Navigators

Family Navigators help families to achieve their goals by providing assistance and support. This may include providing information and resources, parent-to-parent mentorship, help filling out forms, calls to agencies to find services or funding, self-advocacy skills coaching, and so on. This assistance is provided by telephone or in-person. Assistance may be comprehensive or casual.

<http://www.familyvoices.org/>



SPECIFIC TOPICS

Advocacy

National Disability Rights Network

If you are an individual with a disability in need of legal or other advocacy services, the P&A/CAP agency in your state may be able to help.

<http://www.napas.org/en/when-to-contact-your-state-paa-cap.html>

Americans with Disabilities Act (ADA)

Disability & Business Technical Assistances Centers

There are ten regional resources in the DBTAC National Network of ADA Centers funded to provide information, materials, technical assistance, and training on the Americans with Disabilities Act (ADA) and to promote technology access and inclusion by all individuals, as well as facilitate the widespread use of universal design.

<http://www.adata.org/Static/Home.aspx>

Assistive Technology

ABLEDATA

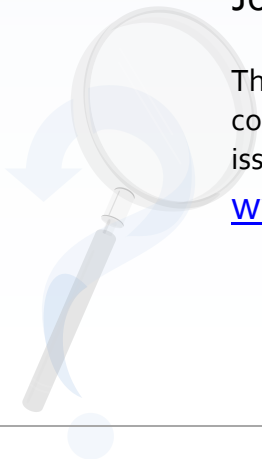
AbleData provides objective information about assistive technology products and rehabilitation equipment.

<http://www.abledata.com/>

Job Accommodation Network

The Job Accommodation Network (JAN) is the leading source of free, expert, and confidential guidance on workplace accommodations and disability employment issues.

www.jan.wvu.edu



Assistive Technology (continued)

State Technology Assistance Act Projects

These programs work to improve the provision of assistive technology to individuals with disabilities of all ages through comprehensive statewide programs of technology-related assistance. These can include:

- Information about funding sources for adapted equipment,
- Legal help to resolve funding issues and
- Information about available used equipment resources

<http://resnaprojects.org/nattap/scripts/nattapcontacts.pl>

Education Resources

State Education Offices

Each state has an office for Special Education. This can be a starting point for education services for children with disabilities, ages 0-2, served under Part C of the Individuals with Disabilities Education Act (IDEA), and children with disabilities, ages 3-21, served under Part B of IDEA.

<http://www2.ed.gov/about/contacts/state/index.html?src=ln>

Employment Services

State Departments of Vocational Rehabilitation

By contacting your local vocational rehabilitation office, you will tap into a wealth of resources related to employment options for people with disabilities. Vocational rehabilitation (VR), a state-supported division of services, assists individuals with disabilities who are pursuing meaningful careers.

<http://askjan.org/cgi-win/typequery.exe?902>



Health Insurance

Children's Health Insurance Plans

CHIP is Title XXI of the Social Security Act and is a state and federal partnership that targets uninsured children and pregnant women in families with incomes too high to qualify for most state Medicaid programs, but often too low to afford private coverage.

<http://www.cms.gov/LowCostHealthInsFamChild/CHIPASPI/list.asp>

Medicare

Medicare is health insurance that includes people under 65 with certain disabilities.

<http://www.medicare.gov/>

State Medicaid Plans and waivers

Medicaid is health insurance that is available only to certain low-income individuals and families who fit into an eligibility group that is recognized by federal and state law. Medicaid is a state administered program and each state sets its own guidelines regarding eligibility and services. Read more about your state Medicaid program.

Waivers allow states flexibility in operating Medicaid programs. Each authority has a distinct purpose, and distinct requirements.

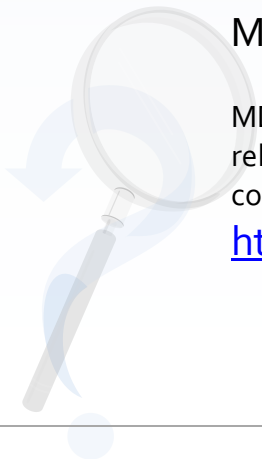
<http://www.cms.gov/MedicaidStWaivProgDemoPGI/MWDL/list.asp>

Muscular Dystrophy

Muscular Dystrophy Association

MDA is the nonprofit health agency dedicated to curing muscular dystrophy, ALS and related diseases by funding worldwide research. The Association also provides comprehensive health care and support services, advocacy and education.

<http://www.mda.org/>



Social Security benefits

Social Security Disability Insurance (SSDI)

Social Security Disability Insurance (SSDI) is financed with Social Security taxes paid by workers, employers, and self-employed persons. To be eligible for a Social Security benefit, the worker must earn sufficient credits based on taxable work to be "insured" for Social Security purposes. Disability benefits are payable to blind or disabled workers, widow(er)s, or adults disabled since childhood, who are otherwise eligible.

<http://www.socialsecurity.gov/pgm/disability.htm>

Supplemental Security Income (SSI)

SSI disability benefits are payable to adults or children who are disabled or blind, have limited income and resources, meet the living arrangement requirements, and are otherwise eligible.

<http://www.socialsecurity.gov/pgm/ssi.htm>

Tax Information

Federal Tax Information

The federal Internal Revenue Service maintains a list of disability-related federal tax publications.

<http://www.irs.gov/formspubs/article/0,,id=237193,00.html>

State Tax Information

State revenue offices can provide information about state tax policies which are disability-related.

<http://www.irs.gov/taxpros/article/0,,id=100236,00.html>

