

# Advocacy & Disability Rights



Advocacy takes many forms. Sometimes, it means sharing your opinions with your members of Congress about proposed legislation. More often, it means standing up for yourself and your community in your school, town hall, and even your own doctor's office. It always means working to make the world better for people living with paralysis. This fact sheet provides resources and information

on advocacy organizations and avenues to help you advocate for yourself and everyone living with paralysis.

#### **Able South Carolina**

https://www.able-sc.org/

Columbia Office:

720 Gracern Rd. Suite 106

Columbia, SC 29210 Phone: 803-779-5121 Greenville Office:

135 Edinburgh Ct. Suite 101

Greenville, SC 29607 Phone: 864-235-1421

Able SC advocates to create greater access and opportunities for independence for individuals with disabilities. They offer a variety of statewide programs to empower individuals living with disabilities in South Carolina. Some of their services include independent living, information and referrals, peer support and mentoring, transition services, and accessibility consultations.

#### **Access2CRT: Protect My Mobility**

www.protectmymobility.org

https://www.access2crt.org/advocacy-priorities

Access2CRT shares information regarding Complex Rehab Technology (CRT) and provides resources and tools to promote and protect access for people with disabilities. Their advocacy page lets you know what you can do to protect your CRT interests.

#### **ADAPT**

http://www.adapt.org/

1208 South Logan Street

Denver, CO 80210

E-mail: adapt@adapt.org

ADAPT is a national grass-roots community that organizes disability rights activists to engage in nonviolent direct action, including civil disobedience, to assure the civil and human rights of people with disabilities to live in freedom. There are ADAPT groups in many states: https://adapt.org/adapt-groups/

## Advancing Independence: Modernizing Medicare and Medicaid (AIMMM) <a href="http://www.aimeee.com/aimmm/">http://www.aimeee.com/aimmm/</a>

AIMMM works to modernize Medicare and Medicaid in a way that both programs work in a far more coordinated and explicit fashion to further the goals set out in the Americans with Disabilities Act: assuring equality of opportunity, full participation, independent living, and economic self-sufficiency for people with disabilities of all ages.

#### American Association of People with Disabilities (AAPD)

www.aapd.com

2020 Pennsylvania Ave., Mailbox 263

Washington, DC 20006 Phone: 202-521-4316 Toll-free: 800-840-8844

AAPD is the largest national cross-disability member organization in the United States, dedicated to ensuring economic self-sufficiency and political empowerment for 56 million Americans with disabilities. AAPD works with other disability organizations for the full implementation of disability nondiscrimination .

laws.

#### **Center for Medicare Advocacy**

www.MedicareAdvocacy.org

P.O. Box 350

Willimantic, CT 06226 Phone: 860-456-7790

The Center for Medicare Advocacy, Inc., established in 1986, is a national nonprofit, nonpartisan law organization that provides education, advocacy and legal assistance to help older people and people with disabilities obtain fair access to Medicare and necessary health care. The Center is headquartered in Connecticut and Washington, DC with offices throughout the country.

#### **Changing Spaces Campaign**

http://www.changingspacescampaign.com/

This parent-led group advocates for accessible public rest rooms with adult sized changing tables so that adults with disabilities don't have to be changed on the floor.

## Christopher & Dana Reeve Foundation: Empowering Change: Grassroots Advocacy Toolkit

https://www.christopherreeve.org/wp-content/uploads/2025/02/Reeve-Grassroots-Toolkit-2-2025-online-A.pdf

The Reeve Foundation offers a free booklet on grassroots advocacy. The booklet offers general tips and information on becoming an advocate, sharing your story, and how to contact your elected officials. It also has chapters on advocating for air travel, housing, caregivers, and disability rights. Please call an Information Specialist at 800-539-7309 if you would like a print copy.

#### **Disability History Museum**

www.disabilitymuseum.org

Straight Ahead Pictures, Inc.

Box 395

Conway, MA 01341 Phone: 413-369-4372

Email: info@straightaheadpictures.org

The Disability History Museum is a virtual collection to chronicle the disability experience and dispel lingering myths, assumptions, and stereotypes. It is a project of Straight Ahead Pictures.

#### **Disability Rights Advocates**

http://dralegal.org/

2001 Center Street, Fourth Floor

Berkeley, CA 94704-1204 Phone: 510-665-8644

655 Third Avenue, 14th Floor

New York, NY 10017 Phone: 212-644-8644

Email: frontdesk@dralegal.org

A non-profit organization dedicated to protecting and advancing the civil rights of

people with disabilities.

#### **Disability Rights Legal Center**

https://thedrlc.org

350 South Grand Avenue Los Angeles, CA 90071

Phone: 213-736-1334; 866-999-3752 (toll-free)

Video Relay: 213-908-1079 Email: <u>DLRC@drlcenter.org</u>

DRLC is a national organization whose mission is to advance the rights of people

with disabilities through education, advocacy, and litigation.

#### **Disability Rights Education and Defense Fund (DREDF)**

http://www.dredf.org/

3075 Adeline Street, Suite 210

Berkeley, CA 94703

Phone: 510-644-2555, 510-841-8645 (FAX/TTY)

E-mail: info@dredf.org

Founded in 1979 by people with disabilities and parents of children with disabilities, DREDF is a national law and policy center dedicated to protecting and advancing the civil rights of people with disabilities through legislation, litigation, advocacy, technical assistance, and education and training of attorneys, advocates, persons with disabilities, and parents of children with disabilities.

#### **Disability Social History Project**

www.disabilityhistory.org

Email: info@disabilityhistory.org

The Disability Social History Project is a community history project for people with disabilities to set forth and share a rich history and culture. The Disability Social History Project is located in Humboldt County in Northern California.

#### **End Abuse of People with Disabilities**

http://www.endabusepwd.org/

Email: <a href="mailto:cvs@vera.org">cvs@vera.org</a>
Phone: (212) 376-3096
Toll Free: 1-855-274-8222

The End Abuse of People with Disabilities provides a space to access the latest resources and research from the field and to advance the thinking around intervention and prevention. They provide free publications, training materials, events, and a search tool to find local organizations working to end abuse of people living with disabilities.

#### **HCBS Advocacy**

www.HCBSadvocacy.org

Email: <a href="mailto:hcbsadvocacy@gmail.com">hcbsadvocacy@gmail.com</a>

Info for advocates about the new Home and Community-Based Services rules including state and national information.

#### **Human Rights Commissions**

Many states have a human rights commission which helps protect people from discrimination, including discrimination against people with disabilities. Please see the state fact sheet for the state you live in for contact info.

#### **National Council on Disability (NCD)**

www.ncd.gov

1331 F Street, NW, Suite 850

Washington, DC 20004 Phone: 202-272-2004 Email: ncd@ncd.gov

NCD is an independent federal agency making recommendations to the President and Congress regarding policies and programs that guarantee equal opportunity and empowers people with disabilities to achieve economic self-sufficiency, independent living, and inclusion into all aspects of society.

#### **National Disability Rights Network (NDRN)**

http://www.ndrn.org

820 1<sup>st</sup> St. NE, Suite 740 Washington, DC 20002 Phone: 202-408-9514 TTY: 202-408-9521

NDRN (formerly the National Association of Protection and Advocacy Systems, NAPAS) is the nonprofit membership organization for the federally mandated Protection and Advocacy (P&A) Systems and Client Assistance Programs (CAP). Collectively, the P&A/CAP network is the largest provider of legally based advocacy services to people with disabilities in the U.S. Each state has a Disability Rights Network Center.

#### **National Organization on Disability**

www.nod.ora

77 Water Street, Suite 204 New York, NY 10005

Phone: 646-505-1191 Email: info@nod.org Since 1982, NOD has been working to expand the participation of people with disabilities in all aspects of American life. NOD promotes voting, housing, employment, religious access, accessible urban design, statistical surveys, and marketing to the disability community.

#### NMD United

#### www.nmdunited.org

NMD United is a non-profit organization composed of adults living with neuromuscular disabilities such as ALS, Muscular Dystrophy, Spinal Muscular Atrophy, etc. This peer-led organization fosters meaningful interactions and provides informational resources to increase self-direction while promoting independence.

#### Not Dead Yet

www.notdeadyet.org

497 State St.

Rochester, NY 14608 Phone: 708-420-0539

Not Dead Yet is a national, grassroots disability rights group that opposes legalization of assisted suicide and euthanasia as deadly forms of discrimination.

#### Patient Advocate Foundation (PAF)

http://www.patientadvocate.org/

421 Butler Farm Road Hampton, VA 23666

Phone: 800-532-5274 (Toll-free) Email: <a href="mailto:help@patientadvocate.org">help@patientadvocate.org</a>

A national non-profit organization that seeks to safeguard patients through effective mediation assuring access to care, maintenance of employment and preservation of financial stability. PAF serves as a liaison between patients and their insurer, employer, and/or creditors to resolve insurance, job retention and/or debt crisis matters relative to their diagnosis through professional case managers, doctors and health care attorneys.

#### **People for Quality Care**

https://www.facebook.com/peopleforqualitycare/

1111 W. San Marnan Dr.

Waterloo, IA 50701

They advocate for seniors and people with disabilities who benefit from home care and medical equipment. They provide tools to encourage grass-roots level political and community participation. They created a Medicare Complaint Hotline so that people can share their concerns and complaints about Medicare with Congress and important Medicare officials.

### Self Advocacy Resource and Technical Assistance Center (SARTAC)

http://www.selfadvocacyinfo.org/

SARTAC's mission is to strengthen the self-advocacy movement by supporting self advocacy organizations to grow in diversity and leadership. They offer help and technical assistance to advocacy groups and organizations, not to individuals.

## U.S. Department of Justice: Americans with Disabilities Act Home Page <a href="http://www.ada.gov/">http://www.ada.gov/</a>

Phone: 800-514-0301 (Toll-free, voice), 800-514-0383 (Toll-free, TTY) This site provides information and technical assistance with the ADA.

#### **Magazines**

#### Ragged Edge Online

http://www.raggededgemagazine.com/

Ragged Edge offers many articles on a variety of topics related to disability and disability rights. Available in online format only.

The information contained in this message is presented for the purpose of educating and informing you about paralysis and its effects. Nothing contained in this message should be construed nor is intended to be used for medical diagnosis or treatment. It should not be used in place of the advice of your physician or other qualified health care provider. Should you have any health care related questions, please call or see your physician or other qualified health care provider promptly. Always consult with your physician or other qualified health care provider before embarking on a new treatment, diet or fitness program. You should never disregard medical advice or delay in seeking it because of something you have read in this message.

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