

Disabilities: Federal and State Public Policy

TIPS AND RESOURCES

What is disability?

Disability is a physical or mental condition that affects a person's ability to function. Disability is a natural part of the human experience that in no way diminishes a person's right to fully participate in all aspects of American life. Our nation has over 54 million persons with disabilities, according to the Health and Human Services Office on Disability. Approximately 4.5 million individuals in the U.S. have developmental disabilities—severe, life-long disabilities attributable to mental and/or physical impairments, manifested before age 22.

What is disability policy?

Disability policy is specifically targeted at addressing the needs of persons with disabilities and their families. It includes laws that address the general needs of persons without disabilities as well as those with disabilities; for example, state One-Stop Career Centers assist all individuals in finding employment. The goals of disability policy are equality of opportunity, full participation, economic self-sufficiency, and independent living.

Where can public policy makers get current, authoritative disability information?

The federal Developmental Disabilities Act creates State Councils, Protection and Advocacy Systems, and University Centers for Excellence in every state and U.S. territory. (For state directories of UCEDDs, DDRCs, LENDs, see www.aucd.org.)

- **University Centers for Excellence in Developmental Disabilities (UCEDDs)**, funded by the Administration on Developmental Disabilities (ADD), work with people with disabilities, family members, state and local government agencies, and community providers in projects that provide training, service and technical assistance, research, and information sharing. The Vanderbilt Kennedy Center and the Boling Center for Developmental Disabilities are Tennessee's UCEDDs.
- **Developmental Disabilities Research Centers (DDRCs)**, funded by the Eunice Kennedy Shriver National Institute of Child Health and Human Development, represent the nation's first and foremost sustained effort to prevent and treat disabilities through biomedical and behavioral research. The Vanderbilt Kennedy Center is one of the original DDRCs.

- **Leadership Education in Neurodevelopmental and Related Disabilities (LENDs)**, federally funded by HRSA's Maternal and Child Health Bureau, provide interdisciplinary training. The MIND project is Vanderbilt University Medical Center's LEND.
- **State Developmental Disabilities Councils**, including the Tennessee DD Council, are funded by ADD and found in every state, are appointed by governors to plan, advocate, and work for change on behalf of people with developmental disabilities and their families.
- **State Protection & Advocacy** agencies, including the Tennessee Disability Law and Advocacy Center, funded by the Health & Human Services, Education, and the Social Security Administration, and operate in every state to empower, protect, and advocate on behalf of persons with disabilities.
- **National disability advocacy organizations**, with state and local chapters, most often focus on specific disabilities to support family members, individuals with disabilities, and advocates.

How can disability organizations help public policy makers?

- **Finding help for legislators' constituents**
Service systems vary greatly by state. Some states have information and referral services. Disability organizations are familiar with community and state service providers.
- **Providing evidence-based research that supports recommended practices**
The Association of University Centers for Disabilities network members are an excellent resource for the most current research and evidence-based practices.
- **Expert testimony**
When new legislation or amendments to legislation are under consideration, disability organizations are a source of expert testimony.
- **Information sessions for legislators and staff**
Disability organizations welcome visits by public policy makers to observe innovative programs and to hear personal stories about the impact of public policies on individuals with disabilities and their family members.

Please see reverse.



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RESOURCES

Who We Are and Who We Serve

The **Vanderbilt Kennedy Center (VKC)** works with and for people with disabilities and their family members, service providers and advocates, researchers and policy makers. It is among only a few centers nationwide to be a University Center for Excellence in Developmental Disabilities, a *Eunice Kennedy Shriver* Intellectual and Developmental Disabilities Research Center, and a Leadership Education in Neurodevelopmental and Related Disabilities Training Program. The following are some of the ways the Center's programs and staff can assist families, educators, and other service providers.

Tennessee Disability Pathfinder

Tennessee Disability Pathfinder is a free statewide phone, web, and print referral service in English and Spanish. It connects the Tennessee disability community with service providers and resources. Its website database has over 3,000 agencies searchable by Tennessee county and service. Pathfinder is a project of the VKC, TN Council on Developmental Disabilities, TN Department of Health, and the TN Department of Intellectual and Developmental Disabilities. Contact www.familypathfinder.org, (615) 322-8529, toll-free (800) 640-4636.

Two Easy Ways to Take Part in Research

The Vanderbilt Kennedy Center serves families through research studies. StudyFinder is a searchable database that lists current VKC studies, including ASD research. Studies seek people of all ages with and without developmental disabilities. See kc.vanderbilt.edu/studyfinder, (615) 936-0448. Research Match is a secure place for volunteers and researchers to connect. Once you sign up and get added to the registry, a researcher will contact you if you're a possible match for the research study. See www.researchmatch.org.

Communications and Dissemination

This VKC office can identify information resources and faculty and staff expertise on a broad range of topics, including genetics, brain science, typical and atypical child development, health and mental health issues, family issues, behavior, education, and disability issues across the age span. The Center also offers lectures and conferences—most of which are free and open to the public—and arranges tours and visits. Contact (615) 322-8240, kc@vanderbilt.edu

Public Policy

The VKC Public Policy Committee tracks national and state disability policy issues and is available as an information resource. Contact (615) 343-2540.

Vanderbilt University Resources

- **Office of Community, Neighborhood, and Government Relations, Nashville**
www.vanderbilt.edu/cngr/, (615) 343-6461
- **Office of Federal relations, Washington, DC**
www.vanderbilt.edu/publicaffairs/federalrelations/
(202) 216-4361
- **Health Library, Jr. League Family Resource Center, Monroe Carell Jr. Children's Hospital at Vanderbilt**
www.vanderbiltchildrens.com/healthlibrary
(615) 936-2558, toll-free (800) 288-0391

Tennessee Resources

- **The Arc Tennessee**
www.thearc.org, (800) 835-7077, (615) 248-5878
- **Fulfill the Promise for Tennesseans with Developmental Disabilities** www.fulfillthepromise.org, (615) 532-6615
- **Tennessee Developmental Disabilities Network**
www.tennddnetwork.org
- **Tennessee Disability Coalition** www.tndisability.org, (615) 383-9442, toll-free (888) 643-7811 The Coalition publishes a brochure on disability sensitive language. See: kc.vanderbilt.edu/tnpathfinder/pdfs/TalkingDisab.pdf

National Resources

- **Administration on Developmental Disabilities, HHS**
www.acl.gov/programs/aidd/index.aspx, (202) 690-6590
- **Association of University Centers for Disabilities**
www.aucd.org, (301) 588-8252
- **Center for the Study and Advancement of Disability Policy** www.disabilitypolicycenter.org, (202) 466-6550
- **DisabilityInfo.Gov** www.disability.gov
- **KidsHealth information for kids, teens, and parents**
www.kidshealth.org
- **Office on Disability, HHS**
www.hhs.gov/od, (202) 401-5844
- **State of the States in Developmental Disabilities**
www.cu.edu/ColemanInstitute/stateofthestates
- **The Arc US**
thearc.org, (301) 565-3842, toll-free (800) 433-5255

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