

# 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](http://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.



**VANDERBILT KENNEDY CENTER**  
FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES

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## How We Can Help

### Who We Are and Who We Serve

The **Vanderbilt Kennedy Center (VKC)** works with and for people with disabilities and family members, service providers and advocates, researchers and policy makers. It is among only a few centers nationwide to be both a University Center for Excellence in Developmental Disabilities and a national Developmental Disabilities Research Center.

### Tennessee Disability Pathfinder

This free statewide phone, web, and print referral service in English and Spanish connects the Tennessee disability community with service providers and resources. Its website database has 1,600 agencies searchable by Tennessee county and service. See Advocacy, Law and Voting as well as other topic pages. Pathfinder is a project of the VKC and the Tennessee Council on Developmental Disabilities. Contact [www.familypathfinder.org](http://www.familypathfinder.org) (615) 322-8529, toll-free (800) 640-4636.

### Vanderbilt Kennedy Family Outreach Center

This center provides families with a single point of entry into the many services and supports of the VKC, Vanderbilt University, and the community. Services include research projects, clinics, social work services, and recreational and arts programs. Contact [familyoutreach@vanderbilt.edu](mailto:familyoutreach@vanderbilt.edu), (615) 936-5118.

### Two Ways to Take Part in Research

The VKC serves families through research studies.

**StudyFinder**, a searchable database lists studies seeking people of all ages with and without disabilities. See [kc.vanderbilt.edu/studyfinder](http://kc.vanderbilt.edu/studyfinder). **Research Family Partners** allows families with and without disabilities to register and to be contacted when a study begins for which a family might be eligible. Contact [kc.vanderbilt.edu/RFP](http://kc.vanderbilt.edu/RFP), (615) 936-0448, toll-free (866) 936-8852.

### 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](mailto:kc@vanderbilt.edu)

### Training

Preservice training is available across a wide range of disciplines for undergraduate, graduate, and professional students. Training also is available for professionals, individuals with disabilities, family members, service providers, and advocates. Contact (615) 322-4999.

### 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/government](http://www.vanderbilt.edu/cngr/government), (615) 343-6461  
**Office of Federal relations**, Washington, DC [www.vanderbilt.edu/publicaffairs/federalrelations](http://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](http://www.vanderbiltchildrens.com/healthlibrary) (615) 936-2558, toll-free (800) 288-0391

### Tennessee Resources

**The Arc of Tennessee**, [www.thearc.org](http://www.thearc.org), (800) 835-7077 (615) 248-5878  
**Fulfill the Promise for Tennesseans with Developmental Disabilities**, [www.fulfillthepromise.org](http://www.fulfillthepromise.org), (615) 532-6615  
**Tennessee Developmental Disabilities Network**, [www.tennddnetwork.org](http://www.tennddnetwork.org)  
**Tennessee Disability Coalition**, [www.tndisability.org](http://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](http://kc.vanderbilt.edu/tnpathfinder/pdfs/TalkingDisab.pdf)

### National Resources

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

Contact the Vanderbilt Kennedy Center  
Nashville (615) 322-8240  
Toll-Free (866) 936-VUKC [8852]  
[www.kc.vanderbilt.edu](http://www.kc.vanderbilt.edu)  
[kc@vanderbilt.edu](mailto:kc@vanderbilt.edu)



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