

The Developmental Disabilities Assistance and Bill of Rights Act of 2000

Billy cannot walk very far due to his cerebral palsy. He can manage daily activities but wants to get a rolling walker to walk farther, so he can do things with his friends like going to soccer games. He misses out on some activities that are important to him because walking is so tiring. The walker would give him some support and allow him to sit and rest when he tires.

However, when Billy asked his doctor about the walker, she said that he needed more exercise rather than a rolling walker. Billy left the doctor's office feeling upset because he thought the doctor did not listen to him and try to understand his needs. Without a prescription from the doctor, Billy didn't think he could get the walker.

Please see page 4 to learn how Billy used knowledge of the DD Act to resolve his issue.

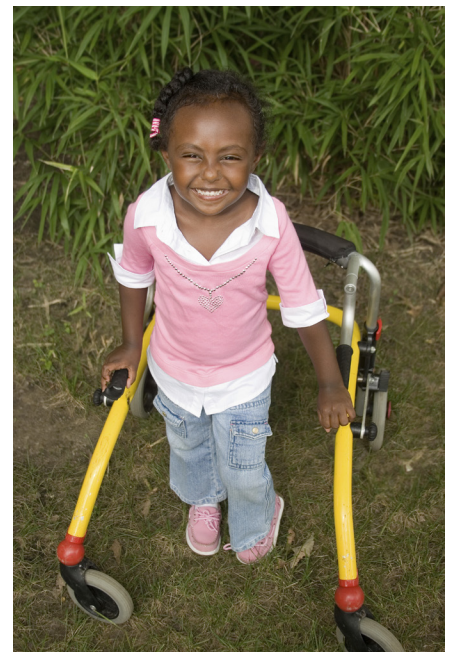
What is the Developmental Disabilities Assistance and Bill of Rights Act of 2000?

The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act of 2000) is a comprehensive federal law created to support people with developmental disabilities (DD) and their families. This law gives people with DD equal rights to access and be included in their communities. The original law was signed in 1963 by President John F. Kennedy.

The DD Act of 2000, the latest update, emphasizes the right of people with DD to achieve their maximum potential through:

- **Independence:** Being able to make choices and have control over their own lives, such as where to live or work
- **Productivity:** Having a job that pays a competitive wage
- **Integration:** Living, playing, and working in the community of their choice along with people who do not have disabilities
- **Self-determination:** Making choices for their own lives rather than having someone do it for them

The Act promotes services and supports that are tailored to the person's needs, and the participation of people with DD in the design of public programs and services in their communities.



Sections of the DD Act of 2000

Three sections or “titles” create a network of organizations that promote the rights identified in the Act.

Title I – “Programs for Individuals with DD”

Councils on Developmental Disabilities – 56 state and territorial Councils on Developmental Disabilities cover the United States. Council members are volunteer appointees, and more than half must be persons with DD or their family members. Councils promote individual, local, and statewide self-advocacy efforts. Next, they help ensure capacity-building so communities are prepared to support people with DD to live in the community. Finally, they lead systems change efforts so that new and emerging practices are available to meet changing support needs of people with DD in the community.



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Protection and Advocacy Systems (P&A) – Located in each U.S. state and territory, P&A agencies provide legal advocacy to persons or groups of persons with DD regarding disability-related concerns. Examples of P&A activities are:

- Advocacy to end sub-minimum wage standards and to close sheltered workshops or other segregated employment sites for people with DD
- Federal legal actions filed on behalf of people with DD who are denied services in their states to transition from institutions to supported housing in the community. P&A activities hold states accountable for compliance with legal precedents like the Olmstead Supreme Court decision. This decision gives citizens with disabilities the right to live in a community setting rather than an institution.

University Centers for Excellence in Developmental Disabilities (UCEDD) – Sixty-seven UCEDDs across the U.S. and its territories are hubs for information and research about the DD field. For example, UCEDDs test new model programs to provide services to people with DD, and train organizations, communities, and states on how to use evidence-based practices (methods and programs that have been successful in testing and research). Current projects include:

- Autism CARES Initiative, a collaboration between researchers on autism and DD that coordinates efforts to screen and diagnose children at risk of developing autism
- Creation of publicly available resources to share information about the most critical needs of people with DD with service providers

Projects of National Significance (PNS) – This subsection of the DD Act of 2000 funds to states for specific projects, including data collection, research, and provision of technical assistance. These funds are awarded to address emerging disability concerns, special conferences, or policy changes that promote systems change. For example, grantees produced publicly available reports that compare each state based on a set of measures for people with DD. Other PNS focused on the most critical issues, such as supported employment outcomes and increasing community living opportunities. Additionally, they support self-advocates to coordinate with the National Association of Councils on Developmental Disabilities and advocate for policy change. This support includes organizing collaborations between local self-advocate organizations, DD Councils, and UCEDDs.



Title II – “Families of Children with Disabilities Support Act of 2000”

This section of the Act was intended to recognize the key role of families of children with disabilities in community inclusion and empowerment through programs, policies, and research. This title has largely remained unfunded, however.

Most recently, the Recognize, Assist, Include, Support, and Engage Family Caregivers Act of 2017 (RAISE Family Caregiver Act of 2017), was funded for 2019, and requires the U.S. Department of Health and Human Services to develop and design an ongoing national strategy to support family caregivers.

Title III – “Program for Direct Support Workers Who Assist Individuals with Developmental Disabilities”

This title is another largely unfunded part of the DD Act of 2000. However, it established The President’s Committee for People with Intellectual Disabilities (PCPID), which serves as an expert advisory group to the U.S. President and the Secretary of Health and Human Services on DD-related topics. The group meets twice yearly and recently produced a report to the President on the national direct support workforce crisis that affects people with DD and their families. This report can be found at:

www.acl.gov/news-and-events/announcements/pcpid-releases-report-direct-support-workforce

Why is the DD Act of 2000 important to me?

This act is important to people with developmental disabilities because it promotes the right of people with DD to:

- Make decisions and choices for themselves
- Be full citizens with rights and responsibilities
- Live meaningful and productive lives as contributing members of society
- Have friends and relationships that are interdependent (mutually beneficial)
- Be protected from any type of abuse -- financial, sexual, or any other legal or human rights violations
- Receive services based on personal choices and needs

The DD Act creates a network of organizations that help people with DD and their families obtain and keep gains made at the national level. The design of this system is person-centered, which means that the person with DD is the most important and central driver of the system. How can I use the DD Act of 2000 to make my life better?

Educate – Learn who serves on your state Council on DD. Connect with them to discuss issues that are important to you. Keep informed about what is going on in your community, in your state, and in the nation for people with DD, perhaps through a mailing list or listserv (e-mail list). Volunteer if the state council has an open seat. Keep updated on issues in your state and work with your local center for independent living to learn about the larger disability community.

Advocate – Find your state’s self-advocacy group and become an active member in its work. Attend conferences and rallies or advocacy days in your state. Communicate with your state, local, and national elected representatives. And, most importantly, register to vote and then vote in elections! Voting is the best way for your voice to be heard.

Resolution to Billy's Story

Billy talked to an advocate at his local center for independent living (CIL). The advocate advised Billy that there might be another way to get the rolling walker through a program like the state assistive technology program. But the advocate felt that Billy needed to learn to be assertive with his medical providers. She advised him to make another appointment with his doctor and to do several things to prepare:

- Write a list of things he needed and why so that he would remember what to tell the doctor
- Bring along a support person to the appointment
- Tell how he had recently fallen twice while out in the community
- Ask for a consultation with a physical therapist
- Call for a referral to the Protection and Advocacy Center if the doctor still will not prescribe the walker

Billy set up another appointment with his doctor and asked an advocate from the local self-advocacy group to go with him. At this appointment, Billy referred to the list he had written and told his doctor about falling several times, and how the rolling walker would help him to participate in activities. He asked about a physical therapy consultation.

The doctor seemed to listen to Billy more than before. She agreed to order the physical therapy consult and said that she would write a prescription if the therapist recommended it. Although it took some time, Billy saw the physical therapist, got his prescription, and then worked with the self-advocate to convince his health insurer to pay for the walker.

Finally, he got the rolling walker! He also joined the local self-advocacy group to learn more about advocating for himself and about interacting with doctors and other health care providers. Billy used services available through the DD Act and learned the skills he needed to improve his life.

Resources to learn more about the DD Act of 2000 and how to use it

National Association of Councils on Developmental Disabilities — Organization of all the statewide Councils on Developmental Disabilities that maintains a list of each state and territory's designated council, with contact information.
<https://www.nacdd.org>

National Disability Rights Network — National organization for Protection & Advocacy (P&A) agencies that provides a link to every P&A in the U.S.
<http://www.ndrn.org/en/>

Association of University Centers on Disabilities — The national organization that connects all University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD).
<http://www.aucd.org>

Projects of National Significance (PNS) examples

- **National Resource Center for Supported Decision-Making** — Resource for information and training on supported decision-making for people with DD
<http://www.supporteddecisionmaking.org>
- **The State of the States in Developmental Disabilities** — Annually updated reports on key data about people with DD by state.
<http://www.stateofthestates.org>

ILRU Directory of Centers for Independent Living and Associations – 2017 (Vol. 39): Provides a national directory of Centers for Independent Living in the United States and its territories.
<http://www.ilru.org/projects/cil-net/cil-center-andassociation-directory>

Self-Advocacy Resource and Technical Assistance Center — Information about self-advocacy and self-advocacy organizations nationally.
<http://www.selfadvocacyinfo.org/>

President's Committee for People with Intellectual Disabilities – Federal advisory board to the President and the Secretary of Health and Human Services.
<https://www.acl.gov/programs/empowering-advocacy/presidents-committee-people>

The Arc – National DD agency for rights and inclusion of people with DD. Local chapters provide services for people with DD who have over 160 different disability diagnoses.
<https://www.thearc.org>

NOTE: While the DD Act applies to developmental disabilities, the RTC/PICL focuses mainly on the community participation and barriers of people who have mobility-related disabilities. This fact sheet offers general information, not legal advice. The application of the law to individual circumstances can vary. For legal advice, you should consult an attorney. The RTC/PICL is a partnership of The University of Kansas Research and Training Center on Independent Living and The University of Montana Research and Training Center on Disability in Rural Communities.

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