



Guidance to Determine Membership in Alignment with DD Act Requirements

The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (PL 106-402) requires specific representation and composition for DD Council membership. The following information and guidance will help ensure the people who apply for Council membership meet the required criteria.

This document will assist people responsible for appointing (or recommending) citizens to a State/Territory Council on Developmental Disabilities.

CITIZEN MEMBER CATEGORIES

Individuals with Developmental Disabilities

The person must meet the federal definition of developmental disability. When considering individuals for members to a DD Council in the category of individual with developmental disability, the following questions should be answered to qualify an appropriate individual.

- *Is the disability severe and chronic?*
- *Is the disability attributed to a mental impairment? or*
- *Is the disability attributed to a physical impairment? or*
- *Is the disability attributed to a mental and physical impairment?*
- *Was the disability recognized before age 22?*
- *Is the disability likely to continue indefinitely?*
- *Does the person experience substantial functional limitations in 3 or more of the following major life activity areas?*
 - *Self-care (feeding, drinking, bathing, dressing, etc.)*
 - *Receptive and expressive language (speaking and understanding others)*
 - *Learning*
 - *Mobility (individual capacity or ability to move the body)*
 - *Self-direction (making decisions for oneself)*
 - *Capacity for independent living*
 - *Economic self-sufficiency*
- *Will the person need lifelong or extended services, supports, or other assistance?*

Parents or Guardians of Children

When considering parents or guardians of children with developmental disabilities for membership, the following questions should be answered to qualify an appropriate parent or guardian.

- *Is the person a parent of a child? (Under the age of 18)*
- *Is the person a guardian of a child (legal guardian, child under the age of 18)?*
- *Is the child under the age of 9?*
- *If yes, does the child have a substantial developmental delay or specific congenital or acquired condition?*
- *Is the child aged 9 or above?*
- *If yes, does the child experience substantial functional limitations in 3 or more of the following major life activity areas?*
 - *Self-care (feeding, drinking, bathing, dressing, etc.)*
 - *Receptive and expressive language (speaking and understanding others)*
 - *Learning*
 - *Mobility (individual capacity or ability to move the body)*
 - *Self-direction (making decisions for oneself)*
 - *Capacity for independent living*
 - *Economic self-sufficiency*
- *Will the person need lifelong or extended services, supports, or other assistance?*

Immediate relatives or guardians of adults with intellectual and developmental disability conditions who cannot advocate for themselves.

When considering immediate relatives guardians of adults with intellectual and developmental disability conditions and who cannot advocate for themselves, the following questions should be answered to qualify an appropriate immediate relative or guardian.

- *Is the person an immediate relative (spouse, parent, grandparent, brother, sister)?*
- *Is the person a legal guardian?*
- *Is the person the immediate relative or guardian seeking to represent someone with an intellectual and developmental disability condition AND who **cannot** advocate for themselves?*
- *Does the person they are representing live in the same state/territory of the Council?*

People from the “citizen member categories” cannot be employees of a state agency that receives DD Council funding and cannot be a managing employee of any other entity that receives DD Council funding or provides services under Subtitle B of the DD Act.

The term "managing employee" means, with respect to an entity, an individual, including a general manager, business manager, administrator, and director, who exercises operational or managerial control over the entity, or who directly or indirectly conducts the day-to-day operations of the entity (USC Title 42, Section 1320 a-5).

Additional requirement for one person from the citizen category

At least one member from the individual, parent/guardian of a child, immediate relative/guardian of an adult who cannot advocate for themselves categories must be someone who currently resides or previously resided in an institution. For information on the definition of an institution, please review page 3 of the “Membership Information for Councils on Developmental Disabilities” TA Brief.

Additional requirements related to race, ethnicity, gender, and geographic location.

Citizen/Public members of the Council should reflect the diversity of the state/territory with respect to race and ethnicity and be geographically representative of the state.

Required Agency/Organization Members

Nine members are required by the DD Act.

7 agencies have membership on the Council and are named in the DD Act; term limits do not apply; ***each agency representative must be someone who has the authority to engage in planning and make decisions on behalf of the agency they are representing.***

1. Special Education: Individuals with Disabilities Education Act (IDEA)
2. Vocational Rehabilitation Act of 1973
3. Aging: Older Americans Act of 1965 (OAA)
4. Maternal and Child Health Program: Title V of Social Security Act (SSA)
5. Medicaid: Title XIX of Social Security Act (SSA)
6. Protection and Advocacy Agency (P&A)
7. University Center for Excellence on Developmental Disabilities (UCEDD)

2 additional members are required and must be from the following categories: these members should be appointed by the Governor and subject to term limits.

1. Local or non-governmental agency concerned with services for people with developmental disabilities.
2. Private, non-profit group concerned with services for people with developmental disabilities.

Frequently Asked Questions

Can I ask an applicant about their disability?

Yes, the DD Act is the federal law that authorizes the DD Council and membership requirements. An applicant will need to talk about their disability or family member's disability for the Governor's appointments office staff to determine eligibility to serve on a DD Council.

Am I violating HIPAA by asking these questions?

The Health Insurance Portability and Accountability Act of 1996 (HIPAA), is a federal law that sets rules for health care providers and health plans about who can look at and receive someone's health information, including those closest to them – family members and friends. (U.S. Department of Health & Human Services, Office for Civil Rights, www.hhs.gov/ocr).

Information from a health care provider about an applicant is not required or standard practice.

How do I get the information from people who want to serve on the DD Council so I can make appropriate appointments?

Develop questions and ask them. Some DD Councils or Governor appointments offices develop an additional questionnaire for potential members to provide information needed to meet the membership category requirements. Following up with an applicant to address unclear information is recommended.

Do people with a mental illness diagnosis qualify for DD Council membership?

Not unless the individual or family member with an intellectual disability or developmental disability **also** has a mental health condition. The DD Act definition refers to mental impairment, physical impairment, or a combination of mental and physical impairments. The term mental impairment refers to intellectual or cognitive ability, and physical disability. If considering someone with a mental health condition, you will want to find someone with ID or DD (or a family member) who has a co-occurring mental health condition.

Can multiple people from the same family serve on the Council at the same time?

This is not ideal. The intent of the DD Act is for the Council membership to reflect a broad range of people from all areas of the state (geographic representation), the diversity of the state with respect to race and ethnicity, and different developmental disabilities.

Can a state agency representative, DD Network partner, local non-governmental and non-profit organizational representative also serve as an individual with DD, parent, or guardian of a child with DD, or immediate family member or guardian of a person with DD who cannot advocate for themselves?

No. Citizen members must be appointed to one specific category (individual with ID/DD, parents, or guardians of children with DD, immediate relatives, or guardians of adults with ID/DD who cannot advocate for themselves, non-profit, or local non-governmental) and cannot also represent an agency or organization.

Can someone be appointed to the Council if they work for an organization or agency that receives money from the Council?

Individuals who are a managing employee in an entity that receives Council funds **cannot** be appointed as a Council member. A managing employee is defined in 42 U.S. Code § 1320a–5(b) and states “For the purposes of this section, the term "managing employee" means, with respect to an entity, an individual, including a general manager, business manager, administrator, and director, who exercises operational or managerial control over the entity, or who directly or indirectly conducts the day-to-day operations of the entity.

What is a local, non-governmental organization and an example?

A non-governmental organization (NGO) is a non-profit, citizen-based group that functions without government control, is non-religious and non-military. Local means community-based operating in the State or Territory where the Council is located. Examples of local non-governmental organizations serving on DD Councils are Family Support Center, Brain Injury Association, Community Service Provider organization, Justice Center, etc. The non-governmental organization must be concerned with services for people with developmental disabilities.

What is a private non-profit organization and an example?

A private nonprofit organization is an organization that takes no part of any net earnings for the benefit of any founder, contributor, individual, or member. It has a voluntary board and its own accounting system. Examples of private non-profit organizations that serve on DD Councils are: The Arc, state, or local self-advocacy organization, UCP, Epilepsy Foundation, Easterseals, Goodwill, etc. The private non-profit organization must be concerned with services for people with developmental disabilities.

Where do I find race, ethnicity, and geographic data for my State/Territory?

The US Census Bureau quick facts website has demographic information for US States and can be found at the following link: <https://www.census.gov/quickfacts/fact/table/US/PST045218>

Territory demographic information can be found at the following link:
<https://www.indexmundi.com/factbook/countries>

How can I make sure the appointed members meet the DD Act requirements?

Use the membership compliance resource worksheet. The worksheet shows the DD Act requirements for percentage of citizen members, state agency and other required members, diversity, geographic, and cross disability representation requirements. A column is provided for the Council or the appointing office to insert the data for the State/Territory. Gaps in required areas should be noted and prioritized for resolve.

What is the minimum number of members for a DD Council?

The total number of members for a DD Council will vary from State to State, Territory to Territory.

The lowest number of DD Council members is 23, **however** that is based on 9 total agency representatives; 1 representative from the 5 required:

- Special Education: Individuals with Disabilities Education Act (IDEA)
- Vocational Rehabilitation Act of 1973
- Aging: Older Americans Act of 1965 (OAA)
- Maternal and Child Health Program: Title V of Social Security Act (SSA)
- Medicaid: Title XIX of Social Security Act (SSA)

1 P&A, 1 UCEDD, 1 local or non-governmental agency, and 1 private non-profit group.

The DD Act requires a minimum of 60% of the total number of Council members to be from the citizen category. To determine the number of citizen members, start with the required agency member number plus the local, non-governmental and private non-profit entities; add the total number of agency/entity representatives then calculate the total number of citizen members needed.

Formula - the formula for a whole is: $\text{whole} = 100 * \text{part} / \text{percentage}$

The formula as applied to the DD Act required number of agency/organization representatives (9)

Example "what is 100% if 9 is 40%?"; Answer 22.5 – which would be 23.

Note: The Governor may appoint additional agency or organization representatives to a DD Council, however, they must also ensure additional citizen members are appointed to meet the minimum percentage of 60%.

Examples:

A minimum of 60% of the DD Council membership must be from the citizen category.

23 members

- 9 required agency/organizational representatives.
- 14 citizen members
 - 5 individuals with developmental disabilities
 - 5 parents or guardians of children with developmental disabilities or immediate relatives or guardians of adults with DD conditions and who cannot advocate for themselves.
 - 4 from a combination of both categories above (recommend 2 from the individuals with developmental disabilities category and 2 from the parent/guardian of children and immediate relative/guardian of adult who cannot advocate for themselves category).

Membership breakdown - example for 23-member Council

7 Individuals with developmental disabilities

4 parents/guardians of children with developmental disabilities

3 immediate relatives/guardians of adults with mentally impairing conditions who cannot advocate for themselves.

5 Agency representatives:

- Special Education: Individuals with Disabilities Education Act (IDEA)

- Vocational Rehabilitation Act of 1973
- Aging: Older Americans Act of 1965 (OAA)
- Maternal and Child Health Program: Title V of Social Security Act (SSA)
- Medicaid: Title XIX of Social Security Act (SSA)

1 Protection and Advocacy representative

1 University Center representative

1 local/non-governmental entity concerned with services for people with developmental disabilities.

1 private non-profit group concerned with services for people with developmental disabilities.

Example for a Council in a State/Territory with 2 UCEDD's

Formula - the formula for a whole is: whole = 100 * part / percentage

The formula as applied to the DD Act required number of agency/organization representatives (10)

Example "what is 100% if 10 is 40%?"; Answer 25

25 members

- 10 required agency/organizational representatives (2 UCEDD's)
- 15 citizen members
 - 5 individuals with developmental disabilities
 - 5 parents or guardians of children with developmental disabilities or immediate relatives or guardians of adults with mentally impairing conditions and who cannot advocate for themselves.
 - 5 from a combination of both categories above (recommend 3 from the individuals with developmental disabilities category and 2 from the parent/guardian of children and immediate relative/guardian of adult who cannot advocate for themselves category).

Membership breakdown - example for 25-member Council

8 Individuals with developmental disabilities

4 parents/guardians of children with developmental disabilities

3 immediate relatives/guardians of adults with mentally impairing conditions who cannot advocate for themselves.

5 Agency representatives:

- Special Education: Individuals with Disabilities Education Act (IDEA)
- Vocational Rehabilitation Act of 1973
- Aging: Older Americans Act of 1965 (OAA)
- Maternal and Child Health Program: Title V of Social Security Act (SSA)
- Medicaid: Title XIX of Social Security Act (SSA)

1 Protection and Advocacy representative

2 University Center representatives

1 local/non-governmental entity concerned with services for people with developmental disabilities.

1 private non-profit group concerned with services for people with developmental disabilities.