

Membership Information for Councils on Developmental Disabilities

General information:

The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (PL 106-402) requires members be appointed by the Governor of the State from among the residents of the State (Section 125 (b)(1)(A)).

The DD Act indicates any State that receives assistance (funding) shall establish and maintain a Council to fulfill the responsibilities in Section 125(c) of the Act (Section 125(a)). In order to fulfill the responsibilities of the DD Act, Subtitle B, Council Responsibilities, Council members must be able to engage in activities such as decision making, planning, monitoring, and implementing the DD Council 5 Year plan. The DD Act does not exclude the mandated representatives of relevant State entity members from voting and participating in carrying out the Council responsibilities. Each member of the DD Council should have equal status and vote.

ITACC note: A DD Council should not exclude members from voting based on membership representation. For example, a DD Council should not exclude representatives from State agencies from a DD council vote – they are members of the Council and should have all rights and privileges as other members. The DD Act indicates the Council shall fulfill certain responsibilities and includes citizen and relevant State entities are members of the Council. In addition, the majority of a DD Council rests with citizen members (60%).

Membership composition:

Council members should be geographically representative of the State and represent the diversity of the State with respect to race and ethnicity (Section 125 (b)(C)).

No less than sixty percent (60%) of members shall be individuals with developmental disabilities, parents or guardians of children with developmental disabilities or immediate relatives or guardians of adults with mentally impairing developmental disabilities who cannot advocate for themselves (citizen members) and who are not employees of State agencies that receive funds or provides services under Subtitle B of PL 106-402, and who are not managing employees of programs funded under the Social Security Act, or any other entity that receives funds or provides services under Subtitle B of the DD Act (Section 125(b)(3)).

ITACC notes: The citizen members cannot be employees of State agencies that receive DD Council funding, a managing employee of programs funded under the Social Security Act or employees of any other entity that receives or provides services with DD Council funding.

The parent, guardian category has two distinct categories. The first is a parent or guardian of a child (or children) with developmental disabilities (in other words, a minor child). The second is immediate relatives or guardians of adults with mentally impairing developmental disabilities who cannot advocate for themselves. Adults with developmental disabilities who can advocate for themselves should be considered for membership as an individual with developmental disabilities.

Of the 60% (citizen members) 1/3 shall be individuals with developmental disabilities, 1/3 shall be parents or guardians of children with developmental disabilities or immediate relatives or guardians of adults with mentally impairing developmental disabilities who cannot advocate for themselves, and 1/3 can be combination of individuals with developmental disabilities and parents or guardians of children with developmental disabilities or immediate relatives or guardians of adults with developmental disabilities who cannot advocate for themselves.

Of the 60% (citizen members), at least one member shall be an immediate relative or guardian of an individual with a developmental disability who resides or previously resided in an institution or shall be an individual with a developmental disability who resides or previously resided in an institution (must be a resident of the State).

Federally mandated members:

The DD Act (Section 125(b)(4)) requires that each council include representatives of relevant State entities including:

- 1) Rehabilitation Act
- 2) Individuals with Disabilities Education Act
- 3) Older Americans Act
- 4) Medicaid
- 5) Maternal and Child Health
- 6) University Center(s) of Excellence in Developmental Disabilities (all if more than one in State)
- 7) State Protection and Advocacy system
- 8) Local and non-governmental agency concerned with services for people with DD*
- 9) Private non-profit group concerned with services for people with DD*

ITACC notes:

- 1) *A Governor (appointing authority) can appoint relevant State entities **in addition** to the required agencies and organizations listed above but should take care to ensure the minimum of 60% citizen members is met; State Agency mandated members must have sufficient authority to engage in policy planning and implementation on behalf of the department, agency, or program such representatives represent. The required agency representatives are: Rehabilitation Act, IDEA (Education), Older Americans Act, Title V and XIX of the Social Security Act (Medicaid and Maternal and Child Health), UCEDD(s), P&A(s), local and non-governmental agencies, and private nonprofit organizations concerned with services for people with developmental disabilities are frequently appointed positions to ensure rotation of membership in these categories. In general, state agency representatives to the Council are selected by the state agency (meeting the “sufficient authority” requirement). Membership is viewed as positional rather than individual. State agencies are in the best position to identify employees who have the most knowledge to inform the Council of activities related to people with developmental disabilities and their families. If a staff vacancy occurs, the State agency can identify a different person to represent the agency without a lapse in representation.*
- 2) *The DD Act mandates that a local nonprofit organization concerned with services for people with developmental disabilities and their families be represented. A variety of nonprofit entities across the US and select territories are represented on DD Councils. For example, local ARC and Cerebral Palsy chapters, advocacy centers, catholic charities, technology non-profits, sexual*

assault centers, parent training nonprofits, self-advocacy organizations, and a variety of foundations are represented on Council membership rosters. All entities in this category must have a concern with services for people with developmental disabilities.

- 3) *TA Staff checked in with the Administration on Community Living for guidance on the definition of “institution”. There are Social Security Statutes and Center for Medicaid Services information about the definition of an institution. Because Medicaid is a state-run program, every state will have different rules for ICF/IDs; ICF/DDs and Council staff and Governor Appointment Office personnel need to be aware of state requirements in addition to the federal requirements. Using the Social Security Administration definition of ICF/IDs ICF/DDs, which are a minimum of four beds, that are not related to the owner, it meets the requirement for the DD Council position that at least one member of the DD Council (or their family member representative) be a current or former institutionalized individual. ICFs do technically count as institutions under the Social Security Act and 100 % of the beds of the ICF do not have to be occupied to retain ICF status. For further questions, please contact your assigned AIDD Program Specialist.*

Membership rotation:

The DD Act requires that appropriate provisions be made to rotate the membership of the Council. In addition, the provisions must allow members to continue to serve on the Council until a successor is appointed (Section 125(b)(2)).

The DD Act Final Rule, released in August 2015 indicates the non-state agency members of the Council shall be subject to term limits and to ensure rotating membership (45 CFR § 1386.30 State plan requirements (3)).

DD Council members representing relevant State entities are not subject to term limits.

Other membership notes:

- 1) *The Governor is the appointing authority.*
- 2) *The Chairperson is considered a member and subject to term limits and rotation.*
- 3) *At a minimum, all citizen members appointed to the DD Council should have beginning and ending terms. Terms should be consistent with the Executive Order, Council Bylaws, and other relevant documents.*
- 4) *All Council members (including mandated members) shall have one vote.*
- 5) *A copy of the Council member appointment letter should be kept on file at the Council office (or electronically).*