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# ORIENTATION OVERVIEW

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DD Act | DD Councils (Advocacy,  
Systems Change & Capacity  
Building) | DD Network & Definitions

# What is the Developmental Disabilities Act (DD Act)?

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The DD Act of 2000 Public Law 106-402 is federally implemented by the Administration on Intellectual and Developmental Disabilities.

Title I, Subtitle B in the DD Act explains that DD Councils must include and support people with developmental disabilities and their families to take part in the design of and have access to needed community services and individualized supports.

Including other forms of assistance that promote self-determination, independence, productivity, integration and inclusion in all parts of community life.

# What are the main values of the DD Act (PL 106-402)?

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- Independence – to have control
- Productivity – to work or make other contributions to a household or community
- Integration – to have the right to the same opportunities, services, and community resources as other people
- Inclusion – to fully take part in learning, living, working, and other community activities

# Administration on Intellectual & Developmental Disabilities (AIDD)

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One of the agencies in the Department of Health and Human Services is the Administration on Community Living (ACL).

The Administration on Intellectual and Developmental Disabilities (AIDD) is the U.S. Government organization responsible for seeing that the DD Act, is put into action.

AIDD, its staff and programs, are part of the Administration for Community Living, of the U.S. Department of Health and Human Services

# What is the purpose of a Developmental Disabilities (DD) Council?

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Before the first passage of the Developmental Disabilities Act in 1970, families received almost no help, children could not attend schools, and many people were sent to State institutions for life.

DD Councils are mandated to engage in ***advocacy, capacity building and systems change*** to help people with developmental disabilities to use self-determination, be independent, be productive and be integrated and included in all parts community life.

DD Council members serve as volunteers and are appointed by the state governor to represent and advocate for people with developmental disabilities and their families.

# Advocacy defined

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**The DD Act defines “advocacy”** as an active support of policies and practices that promote self-determination and inclusion in the community and workforce for individuals with developmental disabilities and their families.

# Advocacy requirements

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Advocacy is mandated for all Councils by the DD Act to address 3 major requirements:

- 1) establish or strengthen a program for the direct funding of a State self-advocacy organization led by individuals with developmental disabilities
- 2) support opportunities for individuals with developmental disabilities who are considered leaders to provide leadership training to individuals with developmental disabilities who may become leaders;

- 3) support and expand participation of individuals with developmental disabilities in cross-disability and culturally diverse leadership coalitions.

***NOTE:** the DD Act does not mandate Councils to **fund** a statewide self-advocacy organization although many Councils do.*

# Other examples of advocacy...

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Councils may choose to support advocacy in other ways in addition to complying with the DD Act mandate.

- 1) Advocating for inclusive services & supports by participating on boards and coalitions that address issues important to people with developmental disabilities and their families.
- 2) Advocating public policy and laws that support the rights of people with developmental disabilities and their families
- 3) Training parents of children with developmental disabilities about education rights (IDEA) and how to advocate for their child's inclusive education.

# **Systems change activities defined**

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**According to the DD Act, “systems change activities” means a sustainable, transferable and replicable change in some aspect of service or support availability, design or delivery that promotes positive or meaningful outcomes for individuals with developmental disabilities and their families.**

# Systems change example

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**Systems change** can take collaboration among many different agencies or within one agency. *It must involve the community and stakeholders.*

Systems change activities taken on by DD Councils should result in laws, regulations, policies, practices or organizational changes that are person centered and directed or family-centered and directed and increase access to needed services and supports.

Example: Money Follows the Person (MFP)

- changed how money was being spent to support people with DD
- changed the way in which services are delivered by giving people with DD control over their finances, resulting in person centered and directed services and supports

# Capacity Building defined

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**According to the DD Act, “capacity building activities” means activities (e.g. training and technical assistance) that expand and/or improve the ability of individuals with developmental disabilities, families, supports, services and/or systems to promote, support and enhance self-determination, independence, productivity and inclusion in community life.**

# Capacity Building example

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**Capacity building** can be individual/family, organizational or both.

Example: Sheltered Workshop to Community Employment

- service providers trained on how to support people with DD to obtain employment in the community
- employment services are now person-directed and community based

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# DD Network & Definitions



# What are the three programs that make up the DD Network?

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The three programs are:

- State and Territory DD Councils
- The Protection and Advocacy Program (P & A's).
- University Centers for Excellence in Developmental Disabilities Education (UCEDD)

# UCEDDs

University Centers  
for Excellence  
in Developmental  
Disabilities



Provide interdisciplinary  
pre-service preparation



Perform community  
services and training



Conduct research,  
evaluations, and  
information dissemination



# DD Council

Developmental  
Disabilities Council



Understanding system  
barriers and changing  
them through initiatives



Working with stakeholders  
to achieve enduring change



Empowering advocates



# P & As

Protection & Advocacy



Provide legal representation to people  
with disabilities

Ensure equal access to life in the community



Monitor and investigate conditions in  
facilities that care for people with disabilities

# Definition of Developmental Disability (DD)

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A severe, chronic disability of an individual that—is attributable to a mental or physical impairment or **combination** of mental and physical impairments;

is manifested before the individual attains age 22;

is likely to continue indefinitely;

results in substantial functional limitations in 3 or more of the following areas of major life activity:

- Self-care.
- Receptive and expressive language.
- Learning.

➤ Mobility.

➤ Self-direction.

➤ Capacity for independent living.

➤ Economic self-sufficiency; and

reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

# Definition of Intellectual Disability (ID)

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Intellectual disability is a disability characterized by significant limitations both in **intellectual functioning** (reasoning, learning, problem solving) and in **adaptive behavior**, which covers a range of everyday social and practical skills.

This disability originates before the age of 18.

# What is the difference between Developmental Disability (DD) & Intellectual Disability (ID)?

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"Developmental Disabilities" (DD) is an umbrella term that includes intellectual disability but also includes other disabilities that are apparent during childhood.

DD are severe chronic disabilities that can be cognitive or physical or both. The disabilities appear before the age of 22 and are likely to be lifelong. Some developmental disabilities are largely physical issues, such as cerebral palsy or epilepsy. Some individuals may have a condition that includes a physical **and** intellectual disability, for example Down syndrome or fetal alcohol syndrome.

Intellectual disability encompasses the **“cognitive”** part of this definition, that is, a disability that is broadly related to the thought process. Intellectual and other developmental disabilities often occur together. ([Source, AIDD](#))

# Definition of Disability (D)

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The Americans with Disabilities Act (ADA) defines a person with a **DISABILITY** as a person who has a physical *or* mental impairment that substantially limits one or more major life activity.

- Including people who have a record of such an impairment, even if they do not currently have a disability.
- It also includes people who do not have a disability but are regarded as having a disability.

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# Roles & Responsibilities



# What are the Responsibilities of a DD Council?

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- Promote and support advocacy, systems change and capacity building for people with developmental disabilities and their families.
- Support programs, projects and activities that improve the quality of life for people with disabilities.
- Develop and put into action a 5-year State plan.
- Prepare, approve and put into action an annual budget.
- Watch the progress of the 5-year State plan and make changes as necessary.

# What are the Responsibilities of a DD Council?

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- Periodically review the designated state agency.
- Report DD Council activities to AIDD. (APPR & State Plan Amendments)
- Hire an Executive Director and annually evaluate the Executive Director following state law processes.
- Establish, strengthen or collaborate with a self advocacy organization to help provide leadership opportunities for people with developmental disabilities.
- Develop and monitor grants and contracts.

# What are the basic responsibilities of a *DD Council Member*?

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- Determine mission (the purpose of a DD Council is mandated by the DD Act).
- Create and review a statement of mission and purpose that speaks to the DD Council's goals and primary people served.
- Conduct a careful search to select the most qualified Executive Director.

# Basic responsibilities of a DD Council Member continued...

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- Ensure effective planning
- Actively participate in the overall planning process for the DD Council 5 – year State plan.
- Actively participate in the implementation of the 5-year State plan (by providing leadership for strategies, activities, and approving funding) and monitor the plan's goals.

# Basic responsibilities of a DD Council Member continued...

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- Assist in developing, approving and implementing the annual budget
- Build a competent DD Council –
  - Identify potential members for appointment
  - Orient and mentor new members
  - Periodically evaluate individual and overall membership effectiveness

# Basic responsibilities of a DD Council Member continued...

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- Ensure legal and ethical integrity by being knowledgeable about legal and ethical requirements for public officials; following all conflict of interest policies and other policies, as applicable to ensure the public trust.
- Enhance the DD Council's public standing by being able to talk about the DD Council mission, accomplishments and goals to the public and gain support from the community.

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# Conflict of Interest & Additional Resources

# Conflict of Interest - Overview

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- Councils value the active participation and membership of stakeholders, state agencies, DD Act agencies, allied professionals, and leaders in disability rights.
- This active participation may at times create actual or perceived conflict of interests.
- Therefore, clear and open discussion is the path to ensure the Council maintains its public perception of integrity, while actively engaging key stakeholders.

# Conflict of Interest – Definition

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A conflict of interest is real or perceived and exists when the Council member or a member of their family appears to gain or benefit personally from their position on the Council.

# Conflict of Interest – DD Act

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What does the DD Act say? Section 124 (c) (5) (D)

The plan **shall** provide an assurance that no member of such Council will cast a vote on any matter that would provide direct financial benefit to the member **or otherwise give the appearance of conflict of interest.**

# Examples of Conflict of Interest (1)

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- Situation: A member serves on the Council as well as on the Board of Directors or Advisory Committee of a disability organization that *applies for a grant from the Council*
- Result: Even though the Council member may not receive direct financial benefit from the grant, there may be an *appearance of a conflict of interest*.
- Recommendation: The Council member can publically disclose the conflict [so that it is in the record], and recuse or remove themselves from discussions and vote on the grant

# Examples of Conflict of Interest (2)

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- Situation: A Council member has a spouse, significant other, immediate family member (or other relationship outlined within State or Territory guidelines) receiving funds from a Council funded grant or project.
- Result: This would constitute a conflict of interest for the Council member.
- Recommendation: Council member would consider resigning appointment to the Council

# Conflict of Interest – Prevention

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DD Councils use a variety of methods to prevent problems with conflict of interest. The most common are:

- Conflict of Interest policies
- Information forms that provide disclosure from Council members about other boards and organizations they represent
- Code of Conduct policies
- Recusing or removing oneself from the room when discussions or voting occurs

# Additional Resources

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ITACC WEBSITE – RESOURCES – COUNCIL MEMBERS

<http://itacchelp.org/resources/council-members/>

DD Council Member Handout

Contact: Angela Castillo-Epps – [acastillo-epps@nadd.org](mailto:acastillo-epps@nadd.org)