



Office of Program Support

UCEDD New Directors Orientation





The Administration on Intellectual and Developmental Disabilities (AIDD),
within the Administration for Community Living (ACL)

- **Lead agency** within HHS responsible for administering the Developmental Disabilities Assistance and Bill of Rights Act of 2000 -for implementing programs that promote consumer self-determination and protect the rights of people with intellectual and developmental disabilities across the lifespan.
- Oversee a network of programs that support people with disabilities and their families in every state and territory of US.

AIDD's mission

Improve and increase services & assure that individuals with developmental disabilities have opportunities to make their own choices, contribute to society, have supports to live independently, and are free of abuse, neglect, financial and sexual exploitation, and violations of their legal and human rights.

Office of Program Support

- State Councils on Developmental Disabilities
- Protection and Advocacy Systems
- University Centers for Excellence in Developmental Disabilities

OPS Themes

- Work is based on needs in the state
- Work is highly participatory (e.g., engagement with people with developmental disabilities and their families)
- Programs should promote cultural & linguistic competence and cultural diversity

State Councils on Developmental Disabilities (SCDD)

- Identify & address most pressing needs of people with Developmental Disabilities
- Engage in systems change & capacity building that promote self-determination, integration and inclusion for people with DD
- 56 Councils
- **Formula grant**

State Councils

- Contribute to system that is:
 - Consumer and family centered & directed
 - Coordinated and comprehensive
 - Includes needed community services, individualized supports that promote self-determination

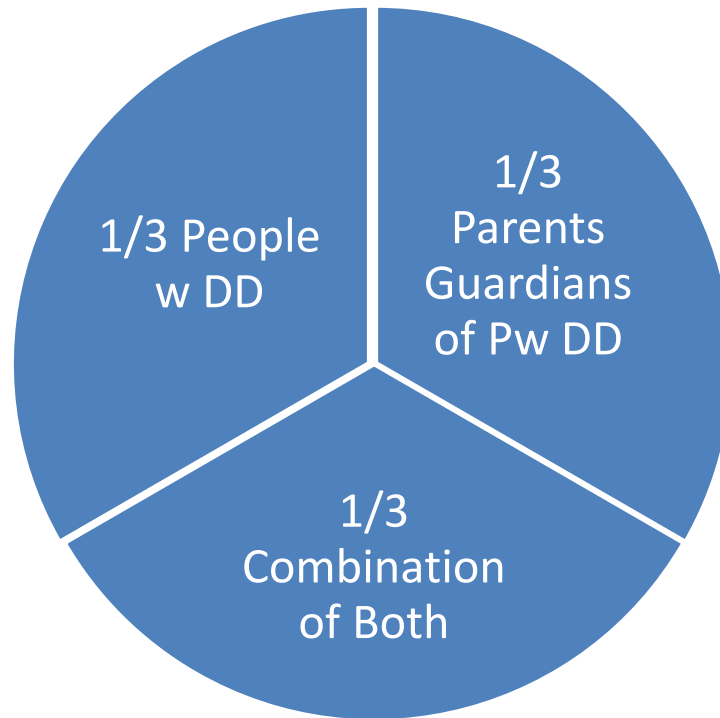
Council Membership

- Appointed by the Governor after soliciting recommendations
- Council may coordinate Council & public input to Governor
- Representative of the State (e.g., geographically, racially, ethnically)
- Membership must be rotated
- Serve on a volunteer basis

Representation of Individuals with Developmental Disabilities

- **Not less than** 60% are:
 - Individuals with DD
 - Parents or guardians of children with DD
 - Immediate relatives or guardians of adults with mentally impairing developmental disabilities

Representation of People w DD 1 Resident or former resident of an Institution



Representation of Agencies and Organizations

- ***Representatives of state entities that administer*** the Rehabilitation Act, IDEA, Older Americans Act of 1965, Titles V and XIX of the Social Security Act
- Centers in the state
- P&A system
- Local & nongovernmental agencies, and private nonprofit groups

State Plan

- Establishment and maintenance of Council
- Public input
- Comprehensive review and analysis
 - Services and supports through state programs
 - Interagency initiatives
 - Service availability to individuals with developmental disabilities
 - Collaboration
 - Rationale for goals

State Plan Goals

- 5-year goals—derived from unmet needs of individuals with developmental disabilities
 - Self-advocacy goal
 - Establish a program for the direct funding of a state self-advocacy organization led by individuals w DD
 - Individuals with DD considered leaders provide leadership training to others
 - Participation on leadership coalitions

State Plan Activities Responsibilities

- Outreach
- Training
- Technical assistance
- Supporting and educating communities
- Interagency collaboration and coordination
- Barrier elimination
- Systems design and redesign
- Coalition development and citizen participation
- Informing policymakers
- Demonstration of new approaches to services and supports

Website Links

- AIDD State Councils page:
 - <http://www.acl.gov/Programs/AIDD/Programs/DC/index.aspx>
- National Association of Councils on Developmental Disabilities (membership organization):
 - <http://nacdd.org/site/home.aspx>

Protection and Advocacy System (P&A)

- Protect legal and human rights of people with developmental disabilities
- P&As focus on people with DD who have been:
 - Neglected or abused
 - Denied access to a service
 - Denied control or choice of a service to which they have a right
 - Denied the opportunity to participate in an activity

P&As

- There are 57 P&As
- There is a Native American P&A
- **Formula grant**

Authorized P&A Activities

- Information and referral
- Investigate incidents of abuse and neglect
- Pursue legal, administrative, and other remedies (mediation, alternative dispute resolution, monitoring, training) to ensure protection and advocacy of rights

Independence

- The P&A system must have independence to pursue legal & other appropriate measures on behalf of clients with developmental disabilities **without state interference.**

P&A Access

- Access to:
 - People, including people living in institutions
 - All records

Designated by the Governor

- The Protection and Advocacy for Individuals with Developmental Disabilities (PADD) program funded under Part C of the DD Act is designated by the Governor to be the P&A system for the state.
- The Governor can only re-designate the P&A if there is “good cause.”

Other Federal P&A Programs

- **PAIMI:** Protection and Advocacy for Individuals with Mental Illness (Substance Abuse and Mental Health Services Administration, HHS)
- **PAIR:** Protection and Advocacy of Individual Rights (Rehabilitation Services Administration, ED)
- **PAAT:** Protection and Advocacy for Assistive Technology (Rehabilitation Services Administration, ED)
- **PABSS:** Protection and Advocacy for Beneficiaries of Social Security (Social Security Administration)
- **PATBI:** Protection and Advocacy for Traumatic Brain Injury (Health Resources and Services Administration, HHS)
- **PAVA:** Protection and Advocacy for Voters Access (AIDD, HHS)
- Some P&As also administer the Client Assistance Program (CAP)

PADD is the cornerstone of the P&A

Planning Responsibilities

- Provide services to individuals with developmental disabilities based on annually identifying goals and priorities
- The goals and priorities are based on:
 - Data-driven strategic planning
 - Public input

Priority Setting

- P&As choose priorities in the following areas of emphasis (in law):
 - Employment, housing, early intervention and education, safety, health, child care, recreation, transportation, quality assurance, and formal and informal community supports
- Emphasis on outcomes/impact
- Requires collaboration with DD Network and community organizations

P&A Governing Board

- Membership
 - Majority must be individuals with disabilities, including individuals with DD
 - Family members and guardians
 - Advocates or authorized representatives
 - May include a representative from the State Council, UCEDD and self-advocacy organizations

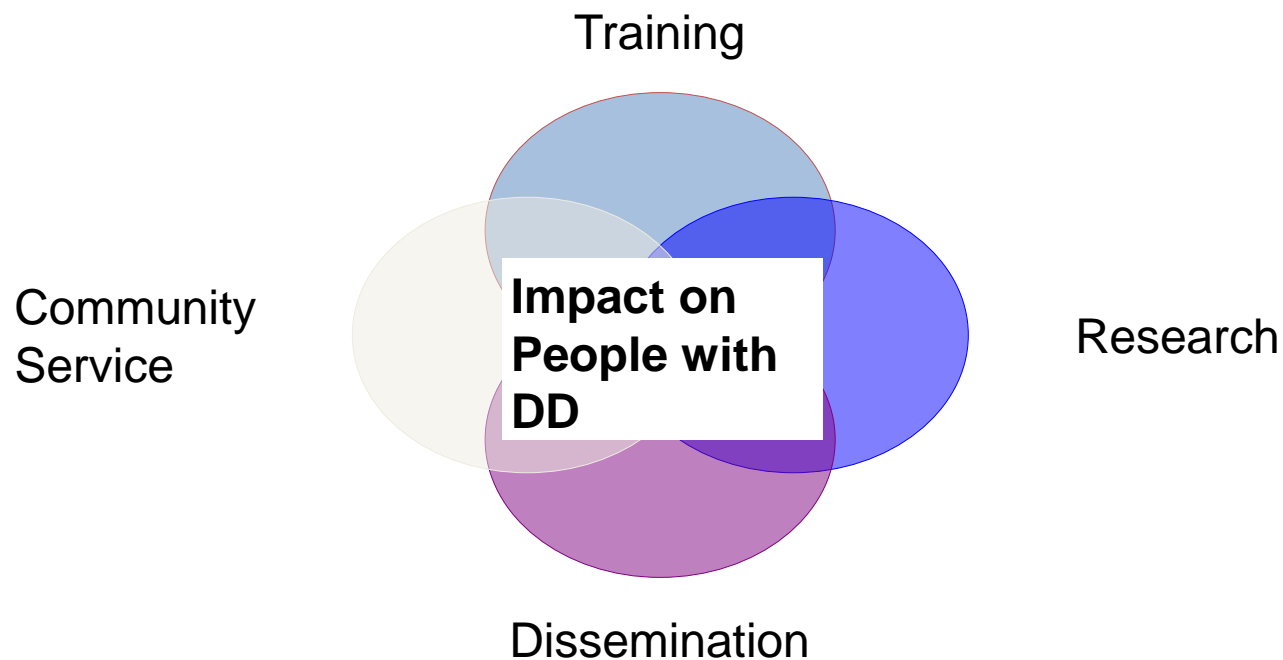
Website Links

- AIDD P&As page:
 - <http://www.acl.gov/Programs/AIDD/Programs/PA/index.aspx>
- National Disability Rights Network (membership organization):
 - <http://ndrn.org/>

National Network of University Centers for Excellence in Developmental Disabilities Education, Research & Service (UCEDDs)

- Funded to carry out 4 core functions:
 - Interdisciplinary training
 - Community services (training, technical assistance, direct and/or model demonstration services)
 - Research
 - Dissemination
- 67 UCEDDs
- Discretionary grant

The Core Functions are the Building Blocks of the UCEDD



UCEDDs:

Connecting Research to Practice

- Serve as the knowledge broker between the University and community
 - Brings expertise to real world problems
 - Practical application of strategies for achieving long-term goals for people with DD
 - Offer real world experiences for trainees
 - Provides opportunity for community to have an impact on the preparation of professionals
 - Work is innovative (interdisciplinary training, model demonstrations)

UCEDD Contributions in National Disability Initiatives

- Early intervention
- Preschool and child care
- Inclusive education
- Self-advocacy and self determination
- Assistive technology
- Family-centered care
- Community-based services
- Child abuse and neglect
- School to work transition
- Supported living and employment
- Interdisciplinary training
- Justice system
- Aging

UCEDD Planning Responsibilities

- Develop a 5-year plan
- Based on data-driven strategic planning and public input
- Based on the areas of emphasis
- Complements the DD Council State Plan and the P&A Statement of Goals and Priorities

UCEDDs Consumer Advisory Committee

- Each UCEDD has a Consumer Advisory Committee (CAC)
- Majority of members must be people with DD and family members
- Must also include a representative from the State Self-Advocacy organization, the DD Council, and P&A
- May include other organizations such as the Parent and Training Information Center

UCEDD National Training Initiatives

- **DD Act authorizes funding for National Training Initiative Grants** to address unmet needs of People w IDD
 - FY 2015, AIDD will award 1 grant to address violence against diverse Pw IDD and their families through Training programs for Law Enforcement/Legal Professionals in collaboration with P&A partners, community based providers, counselors and others.
 - Fund \$200,000 annually for 3 years.

Supplemental Grants

- Remaining funds may be used to award supplemental grants to UCEDDS for States or populations that are unserved or underserved by UCEDDS due to such factors as
- Population
 - a high concentration of rural or urban areas
 - a high concentration of unserved or underserved

Website Links

- AIDD UCEDDs page:
 - <http://www.acl.gov/Programs/AIDD/Programs/UCEDD/index.aspx>
- Association of University Centers on Disabilities (membership organization):
 - <http://www.aucd.org/template/index.cfm>

DD Network Collaboration

- The DD Councils, P&As, and UCEDDs have unique—although complementary—roles to play in achieving this purpose.
- As a general practice, these DD network partners coordinate and collaborate as appropriate to the nature of the projects, initiatives, and activities they undertake to fulfill their unique mandates.

DD Network Collaboration

- Examples include:
 - Ending the Waiting List campaigns
 - Joint planning efforts
 - Joint funding of projects
 - Efforts aimed community integration
 - Participation on coalitions