History of the UCEDD

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The Basics:

UCEDDs and the Community Advisory Board

MODULE I
Introductions

Name

Part of state you are from

Experience with disability

Parent?
Self-Advocate?
Provider?
The five most common acronyms in this slideshow are:

• **DD Act:** Developmental Disabilities Assistance and Bill of Rights Act of 2000

• **AIDD:** Administration on Intellectual and Developmental Disabilities

• **UCEDD:** University Centers for Excellence in Developmental Disabilities

• **CAB:** Community Advisory Board

• **DD Network:** Developmental Disabilities Network
Topics of Presentation

1. The DD Act
2. DD Act Programs
3. The State DD Network
4. The CAB
1. The DD Act
The DD Act

AIDD

UCEDD

P&A

DD Councils
The DD Act: A Brief History

- 1955: Mental Retardation services priority in the Children’s Bureau
- 1962: President Kennedy appoints Panel on Mental Retardation
- 1963: Congress first passed the DD Act and University Affiliated Facilities (UAFs) are established (Now called UCEDDs)
The 1970 reauthorization established funding for Developmental Disabilities Councils (DD Councils)
In 1975 Congress authorized funding for Protection & Advocacy systems (P&As)
• Congress reauthorized the DD Act in 2000
The DD Act: A Brief History

Changes in 2000 emphasized:

- Life in the community
- Lifelong services & individualized supports
- Right to live free of abuse, neglect, financial and sexual exploitation, and violations of legal and human rights
- Promoted increased collaboration with DD Councils and P&As
- Requirement to develop performance indicators – outcomes data
Mission of the DD Act of 2000

“To assure that individuals with developmental disabilities and their families participate in the design of, and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life…”

(Subtitle B – Section 121 – PL 106-402)
2. The DD Act Programs
The DD Act Established:

- UCEDDs
- P&As
- DD Councils

- These 3 programs are found in every state
- Also called the “DD Network”
The DD Act Programs all share 3 major themes:

- Advocacy
- Capacity Building
- Systemic Change
Themes

• Advocacy: active support for a program, initiative, or change

• Capacity Building: strengthening local, state, regional, and national organizations and communities

• Systemic Change: modifying entire programs, policies, services, and/or funding streams
UCEDDs

- A discretionary grant program
- All UCEDDs are part of a national network
- There are 67 grants that establish UCEDDs in every US state and territory
UCEDD core function areas...

- Training
- Service
- Research
- Information Sharing

...all related to people with intellectual/developmental disabilities and their families
In general, what is a UCEDD?

UCEDDs advise federal, state, and local policymakers on strategies to promote:

- Self-determination
- Independence
- Productivity
- Community integration

...of people with developmental and intellectual disabilities
UCEDDs

UCEDDs must be associated with a University
Understanding the UCEDD

All UCEDDs start with the basic ingredients but become their own particular flavor.
Core Funding & Leveraging Funds

• UCEDDs apply to AIDD for core funding
• UCEDDs submit a 5-Year Plan to AIDD
• The DD Act requires UCEDDs to use the core funding to leverage funding

  — Leverage funding means to use money we have to get more money from other sources
  — UCEDDs do this by getting other grants and contracts
State Councils on Developmental Disabilities (DD Councils)

• Formula grant program

• There are 55 DD Councils

• DD Councils must submit a 5-year *State Plan* to AIDD that includes, and is based on, a comprehensive review and analysis of services, supports, and other assistance

• DD Councils must include a majority of individuals with developmental disabilities and family members
State Councils on Developmental Disabilities

Guam
American Samoa
C. N. Mariana Islands

Puerto Rico

Washington, DC

Hawaii Islands

= Minimum allotment

= Above Minimum allotment
DD Councils

DD Councils use a variety of strategies, such as:

- training
- educating policy makers and communities
- coalition development
- barrier elimination
- demonstration of new approaches to service

...to make systems change and build capacity
State Protection and Advocacy System (P&As)

- Formula grant program

- There are 57 P&As: one in every US state and territory plus a Native American consortium

- Each P&A must submit a *Statement of Goals and Priorities* to AIDD each year
  - The public has to be provided with the chance to comment on the P&A’s goals, priorities, and activities
Protection and Advocacy System

Guam
American Samoa
C. N. Mariana Islands
Native American

= Minimum allotment

= Above Minimum allotment
Nebraska’s P&A is called *Disability Rights Nebraska*

P&As provide:

- information and referral services
- legal, administrative, and other remedies to resolve problems for individuals and groups of clients with developmental disabilities

The DD Act authorizes P&As to:

- investigate incidents of abuse and neglect
- have access to all client records when given permission by the client or the client’s representative
3. The State DD Network
What is the State DD Network?

UCEDD + DD Council + P&A = State DD Network
Our State’s DD Network

The P&A:
Disability Rights Nebraska
Lincoln, Nebraska 68508
Phone: 1-800-422-6691
CAB Member: Eric Evans, CEO

The DD Council:
Nebraska Planning Council on Developmental Disabilities
Nebraska Department of Health and Human Services
Lincoln, Nebraska 68509-5026
Phone: 402-471-2330
Kristen Larsen: Executive Director
Our State’s DD Network

What are the past and current partnerships with the DD Network?

– Directors meet monthly
– Annual Joint Meeting/Training
– Grants & Contracts between partners
– Nebraska Consortium for Citizens with Disabilities (monitoring legislation)
– Legislative Actions (transportation, autism waiver)
4. The Community Advisory Board (CAB)
What does the DD Act say About the Purpose of the CAB?

- Advise the UCEDD director

- Provide guidance and feedback in the development of the 5-year plan

- Each year, provide guidance and feedback on how the UCEDD is doing with their 5-year plan
What does the DD Act say About the Members of the CAB?

The majority (over half) must be individuals with developmental and related disabilities and family members, such as:

- Parents
- Siblings
- Grandparents
- Step-parents
- Aunts
- Uncles
- Nieces
- Nephews
What does the DD Act say About the Members of the CAB?

The CAB must also include representatives from:

- State P&A
- State DD Council
- Other UCEDDs in state
- Self-Advocacy organization
- Organizations such as:
  - Parent and Training Information Center
  - Those carrying out the Assistive Technology Act
  - Relevant State Agencies
  - Community groups concerned with people with developmental disabilities and their family members
What does the DD Act say About the Members of the CAB?

The members of the CAB must reflect the racial and ethnic diversity of the state.
What does the DD Act say About how often the CAB should Meet?

- The CAB should meet as often as necessary
- The CAB should meet at least 2 times a year at minimum
What is the Basic Role of a CAB?

• Advise and guide the work of the UCEDD

• Help the UCEDD achieve the goals of the 5-year plan

• Help the UCEDD comply with the DD Act

• Serve as an liaison between MMI and the community
Advisory Committees vs. Councils

• A *Board of Directors* guides an organization and its members are legally liable for the actions of the organization.

• *Advisory Councils* offer advice to an organization but its members have no legal responsibility for the actions of the organization.

UCEDDs have Advisory Councils
What are benefits of the CAB-UCEDD relationship?

The CAB is a bridge from the university and the UCEDD to the community.

Participation in the CAB can be a leadership opportunity for members as disability advocates and mentors.

- CABs bring together decision-makers and people with different ways of looking at issues that may not have met before.
- CABs provide an opportunity for a culturally diverse forum on disability.
Questions