

National Network of University Centers for Excellence in Developmental Disabilities (UCEDD)



ADMINISTRATION
ON DEVELOPMENTAL
DISABILITIES





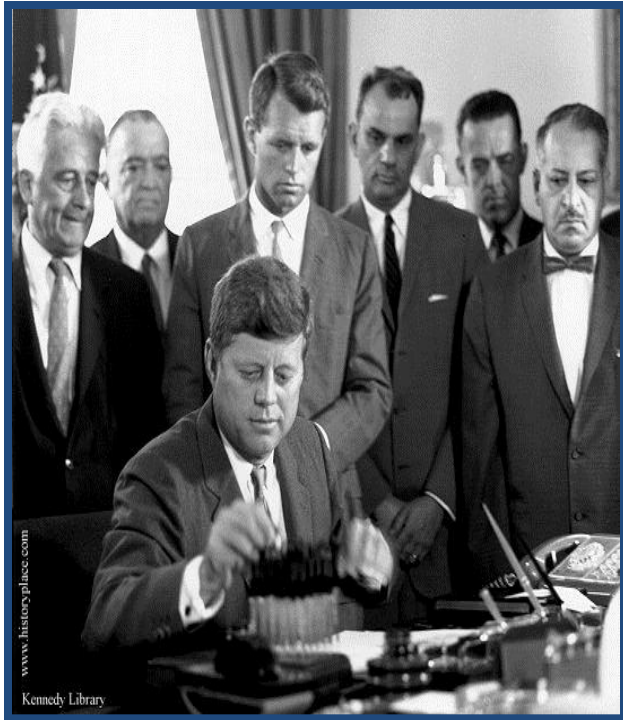
UCEDDs: Connecting Research to Practice

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

Overview of the UCEDDs

- Authorized by Federal Law: Developmental Disabilities Assistance and Bill of Rights Act of 2000
- Funded to carry out four core Functions:
 - Interdisciplinary training
 - Community services (training, technical assistance,
 - Research
 - Dissemination
- Collaborate with persons with developmental disabilities, families, and other to conduct research and training and to achieve positive outcomes


History of UCEDDs



- Idea for UCEDDs originated from John F. Kennedy's Panel on 'Mental Retardation', which called for entities to address:
 - Critical shortage of personnel
 - Need for research & statistical data
 - Role of numerous governmental agencies
 - Shortage of facilities
 - Lack of coordination
- Programs known as UAFs (University Affiliated Facilities)


Early Characteristics of UCEDDs

- University-based units that reached out to community
- Linked university resources with disability community
- Provided:
 - Interdisciplinary training
 - Service
 - Clinical research




First Generation: 1963-1974

- Known as University Affiliated Facilities
- Received construction funds from MCH
- Primary emphasis on health & allied health for people with cognitive disabilities
- Emphasized clinical diagnosis & treatment
- Interdisciplinary leadership training
- Medically focused training
- Concentration of expertise in single location




Second Generation: 1975-1986

- Known as University Affiliated Facilities
- Few received MCH training support
- Developed working relationships with State DD Councils & service agencies
- Addressed full life span
- Emphasized community-based services and developmental concepts
- Moved towards systems change
- Required to leverage ADD support




Third Generation: 1987-2000

- Known as University Affiliated Programs
- Emphasized technical assistance, outreach training & dissemination
- Community-based programs as standard
- Consumer empowerment, participation and satisfaction
- Emphasis on inclusion, ADA and community supports and services
- Completion of Network expansion (1995)
- Establishment of program standards



Fourth Generation: 2000 - present

- Known as University Centers for Excellence in Developmental Disabilities Education, Research and Services
- Emphasize national network and international resource
- Attention to research
- Continued promotion of community-based programs as standard, consumer empowerment, participation and satisfaction



Fourth Generation: 2000 - present

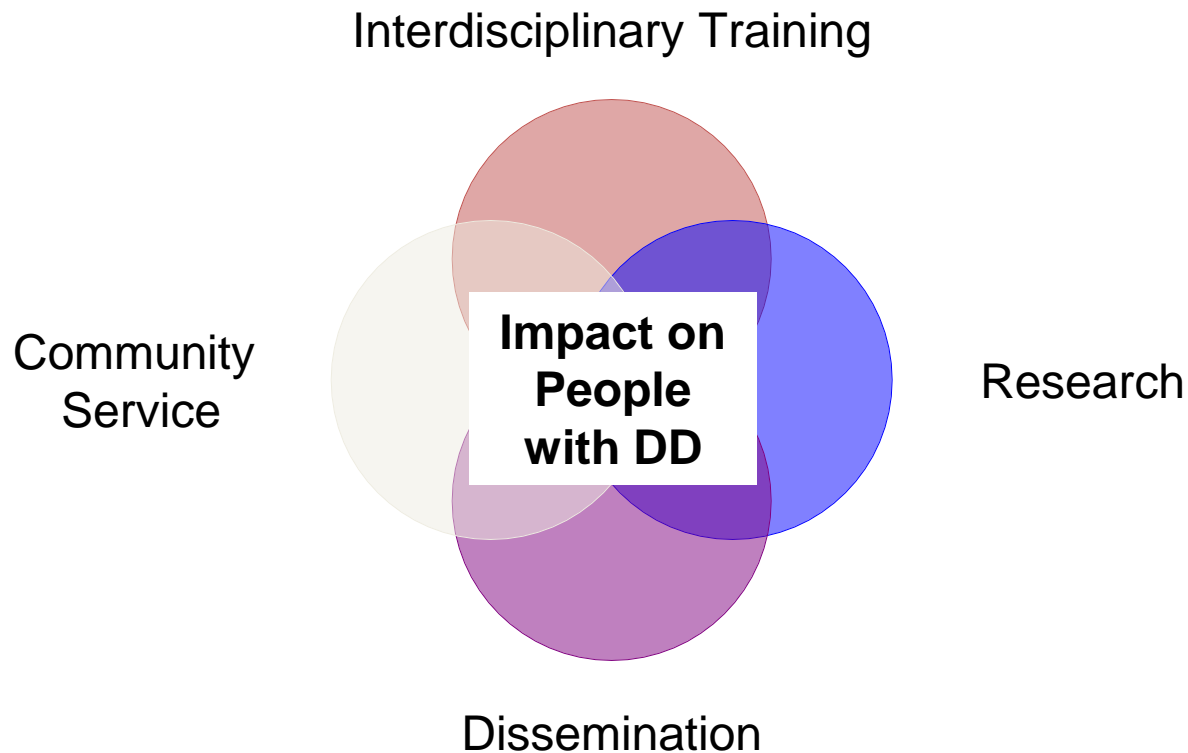
- Increased core funding allowed for further expansion of Network in 2006 and 2007
- Heightened focus on evaluation and accountability (Annual Report, indicators of progress)
- Increased attention to DD Network collaboration
- Need for diversification of funding sources
- Leadership transition



UCEDDs

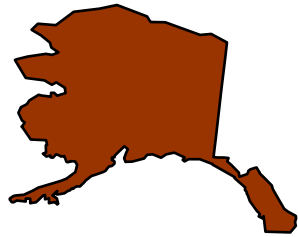
- FY 2013 funding \$37 million
- Core funding \$535,215 for each UCEDD
- NTI's funding ended (PSE, self-determination), no new initiatives announced at this time

The Core Functions are the building blocks of the UCEDD

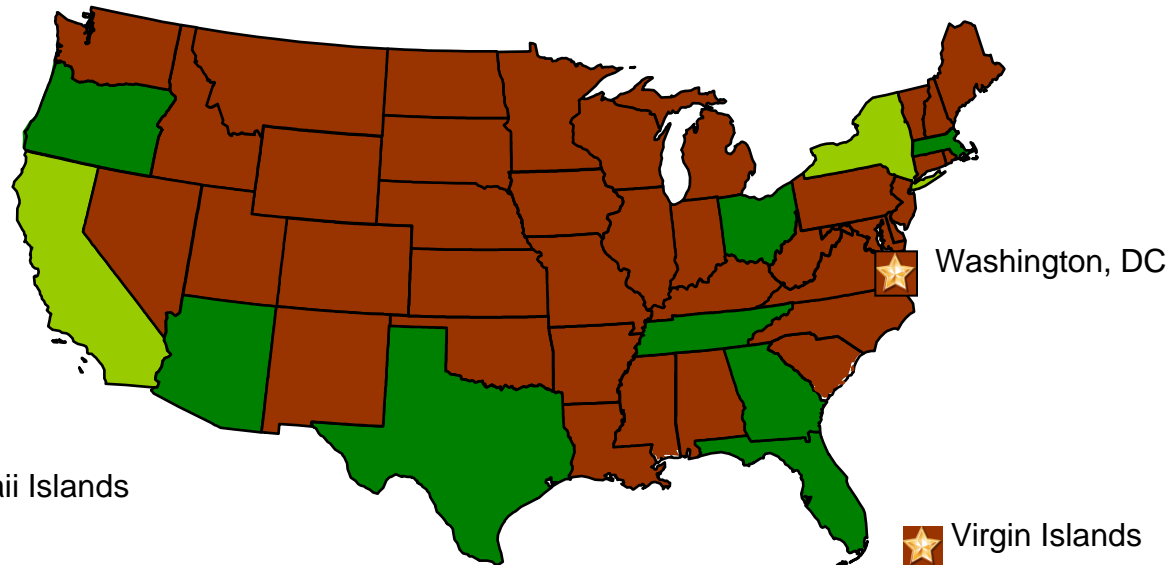


National Network of UCEDDs

68 Centers in each State and Territory



Hawaii Islands



Washington, DC

Virgin Islands

Puerto Rico

- ★ Guam
- ★ American Samoa
- ★ C. N. Mariana Islands

- = 1 UCEDD
- = 2 UCEDDs
- = 3 UCEDDs

Sources of Funding

- AIDD
 - PNS
- MCHB
 - SPRANS
 - LEND
- OSERS
 - OSEP, NIDDR, RSA
- Tech Act
- State Agencies
- Local Agencies
- CDC
- DOJ
- DOL
- SSA
- CMS
- IES - NCSE
- Foundations & Corporations



UCEDD Contributions in National Disability Initiatives

- Early Intervention
- Preschool & Child Care
- Inclusive Education
- Self-Advocacy & Self Determination
- Assistive Technology
- Family-Centered Care
- Community-based Services
- Child Abuse & Neglect
- School to Work Transition
- Supported Living and Employment
- Interdisciplinary Training
- Justice System
- Aging
- Autism



Organizational Structure

- Tremendous diversity in the network of UCEDDs
- Centers have evolved overtime and are variously organized both within the University and within the Center
- Organizational structure is contextualized in the history of the program and based on University environment, State needs, and grant portfolio

UCEDD Organizational Structure

- Different management models:
 - Area of Emphasis/Disability Specific (e.g., feeding clinic, autism services)
 - Core functions (e.g., training coordinators, community services coordinator, research coordinator, information dissemination coordinator)
 - Mixed model
- Leadership models
 - Director with full leadership responsibility
 - Director and Associate Director with responsibility variously distributed
 - Co-directors sharing responsibility

Medical/Hospital Placement

Advantages

- Access to allied health professions
- Health related expertise
- Access to multiple clinics & infrastructure
- Title V relationship



Challenges

- Dependent on changes in Health Insurance
- Hospital Admin. may not be interested in range of issues/life span and/or community based work
- Pressure to bill

School or College of Education

Advantages

- Range of expertise in education related fields
- Potential relationship with OSERS, OERI, etc
- Access to academic departments

Challenges

- Lack of access to allied health professions
- Lack of medical expertise
- Variable interest in adult populations



Stand Alone Center

Advantages

- Autonomy & flexibility in types of grants & funding sources
- Direct contact with University Administration
- Fewer academic responsibilities
- Access to various academic departments

Challenges

- Difficulty in personnel preparation activities
- May be isolated from university community



Multi-Campus or Multi-Center arrangement

Advantages

- Ability to capitalize on respective strengths
- Broader range of funding sources
- Greater infrastructure resources
- Greater statewide coverage

Challenges

- Coordination among & between entities
- Potential competition for resources
- Designating leadership
- Multiple sets of administrations