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# UCEDDs and the Consumer Advisory Committee

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Georgetown University  
Center for Child and Human Development

Adapted from the Association of University Centers on Disability  
(AUCD)

[http://www.aucd.org/template/news.cfm?news\\_id=1161&id=17&parent=522](http://www.aucd.org/template/news.cfm?news_id=1161&id=17&parent=522)

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# Acronyms

The five most common acronyms that you will hear:

- **DD Act:** Developmental Disabilities Assistance and Bill of Rights Act of 2000
- **AIDD:** Administration on Intellectual Developmental Disabilities
- **UCEDD:** University Center for Excellence in Developmental Disabilities
- **CAC:** Consumer Advisory Committee
- **DD Network:** Developmental Disabilities Network

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# Topics of Presentation

1. The DD Act- this was given to you at our first meeting
2. DD Act Programs
3. The State DD Network
4. The CAC

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# 1. The DD Act

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# What is an Act?

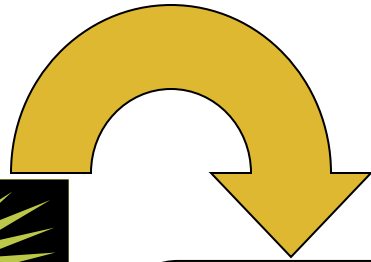
- An Act is a law
- An Act starts as a bill passed by Congress
- President signs the bill and it becomes law



# What is an Act?

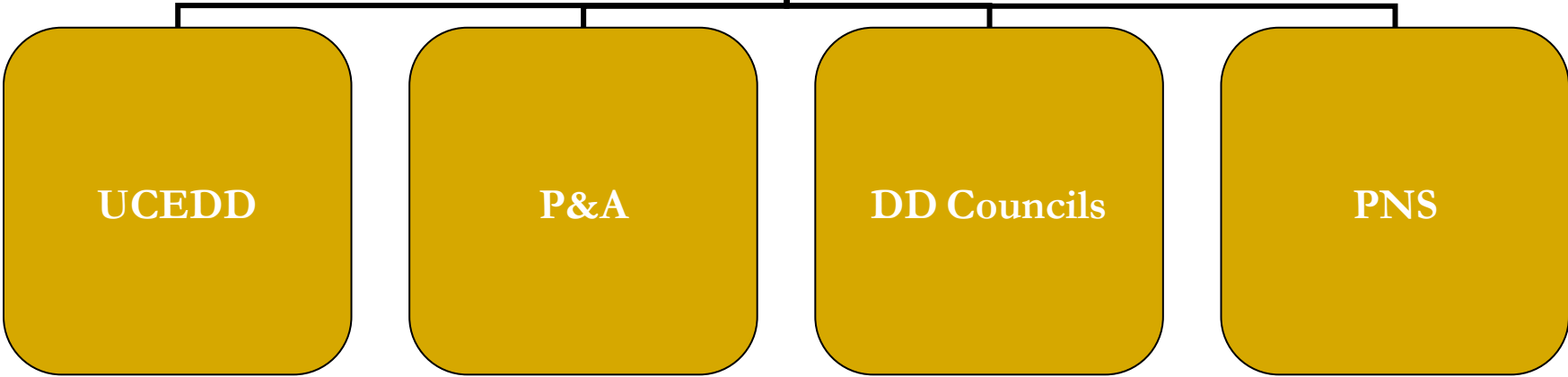
- Federal agencies are given responsibility for administering the law
- They create regulations (rules or guidelines) that interpret how the law will be followed





The  
DD Act

AIDD



UCEDD

P&A

DD Councils

PNS

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# 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)



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## 2. The DD Act Programs

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- *DD Act Programs*

- *Advocacy*: active support for a program, initiative, or change
- *Capacity Building*: strengthening local, state, regional, and national communities
- *Systemic Change*: modifying entire programs, policies, services, and/or funding streams

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# A Closer Look at the Programs Established by the DD Act

- UCEDDs
- P&As
- DD Councils
- PNS

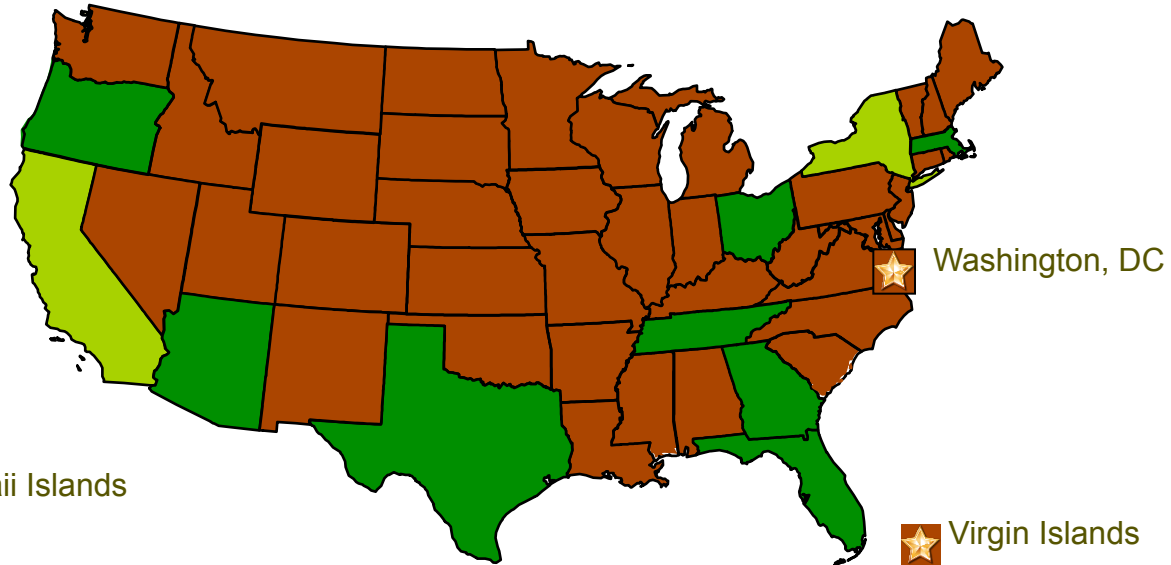


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# UCEDDs

- 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

# National Network of UCEDDs



Hawaii Islands

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

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

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# In general, what is a UCEDD?

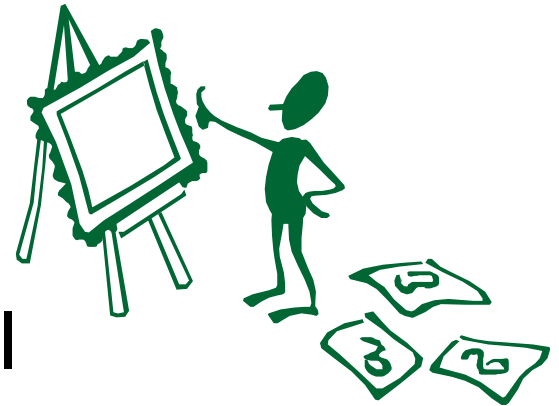
UCEDDs are leaders in four core function areas...

- Training
- Service
- Research
- Information Sharing

...all related to people with developmental disabilities

# In general, what is a UCEDD?

- UCEDDs advise federal, state, and local policymakers on strategies to promote:
  - Self-determination
  - Independence
  - Productivity
  - Community integrationof people with developmental disabilities



# UCEDDs

UCEDDs must be associated with a University





# Core Funding and Leveraging Funds

- UCEDDs apply to ADD for core funding
- UCEDDs submit a *5-Year Plan* to ADD
- The DD Act requires UCEDD to use the core funding to leverage funding
  - Leverage funding means to get money from other sources
  - UCEDDs do this by getting other grants and contracts

# Projects of National Significance (PNS)

- A discretionary grant program
- The grants respond to emerging needs of individuals with disabilities and their families
- The projects currently funded:
  - Family Support 360s
  - Youth Leadership
  - Data collection/information dissemination projects

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# 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 ADD 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

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# 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

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# 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 ADD each year
  - The public has to be provided with the chance to comment on the P&A's goals, priorities, and activities

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# P&As

- 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

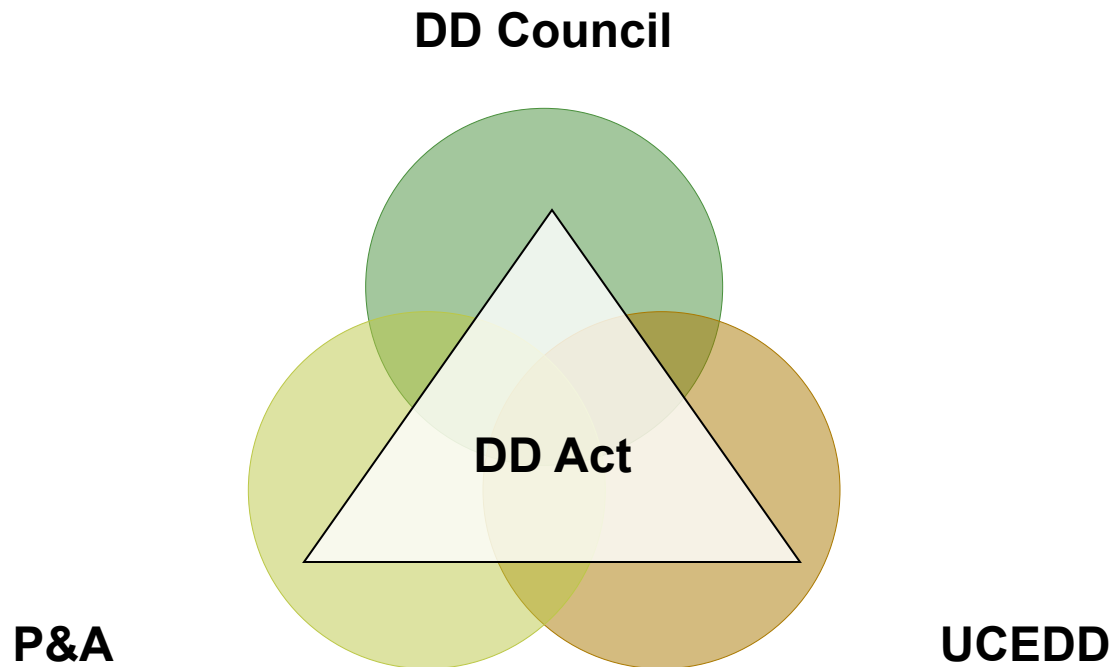
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# 3. The State DD Network

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# What is the State DD Network?

UCEDD + DD Council + P&A = State DD Network





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# Our State's DD Network

- The P&A for the District:

University Legal Services <http://www.uls-dc.org/>

- provides information and referral services
- reaches out to members of minority groups
- secure services (Rehabilitation Services Administration, assistive technology benefits programs, and voting process).

- The District of Columbia's DD Council:

- <http://odr.dc.gov/DC/ODR/DDC>

- individuals, parents and family members and representatives of State agencies
- statewide plan (address employment, education, community living, etc)

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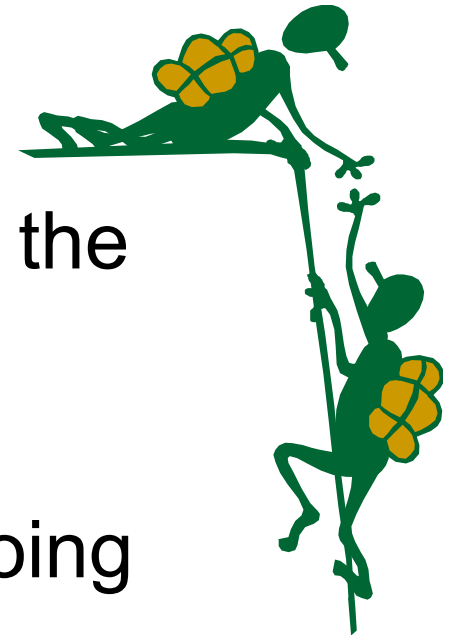
## 4. The Consumer Advisory Committee (CAC)

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So where do you fit in the picture?

# What does the DD Act say About the Purpose of the CAC?

- Advise the 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



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# What does the DD Act say About the Members of the CAC?

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

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# What is the Basic Role of a CAC?

- Advise and guide the work of the UCEDD
- Help create and move toward the vision of the UCEDD
- Contribute to compliance of the UCEDD with the DD Act: the function (and make up) of CACs is required by law
- Serve as an informal bridge between the community and the university in our state

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# How do I fit in?

