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# **The Basics: UCEDDs and the Consumer Advisory Committee**

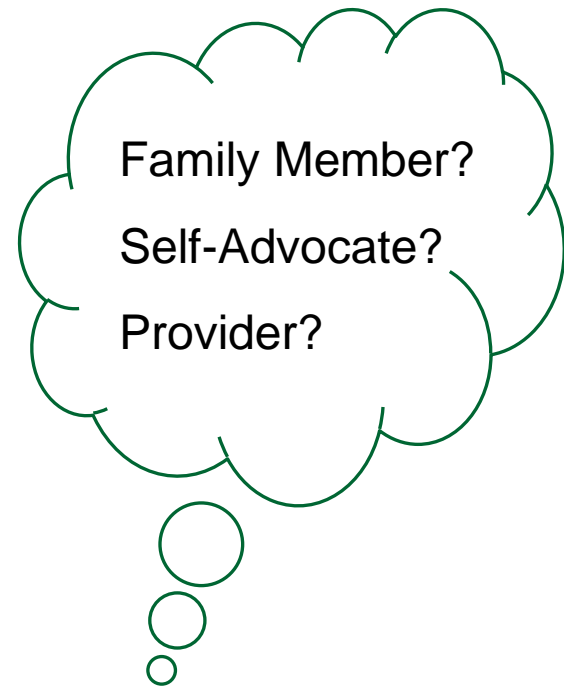
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## **MODULE I**



# Introductions

- Name
- Part of state you are from
- Experience with disability



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# Acronyms

The five most common acronyms in this slideshow are:

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

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# The use of the word “consumer”

- The word “consumer” causes a lot of discussion
- It is used in this presentation because the term is used in the DD Act
- Many Consumer Advisory Committees decide on a title other than “CAC” for their committee

People First Language

Citizens

Self- Advocates

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# Topics of Presentation

1. The DD Act
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

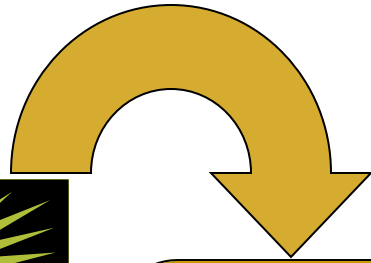


# What is an Act?

- 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

ADD

UCEDD

P&A

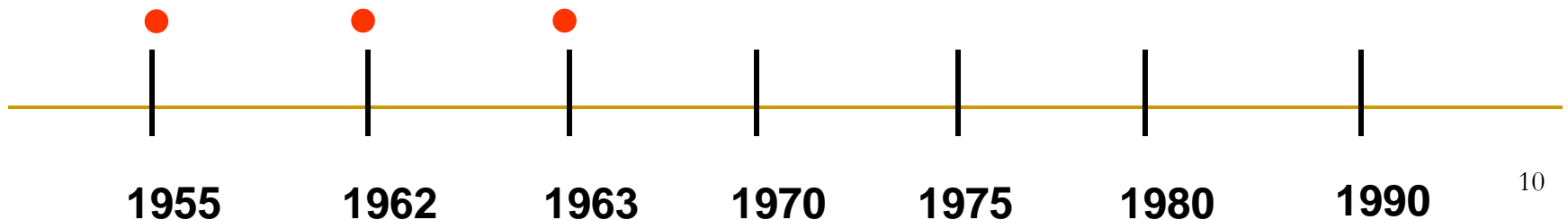
DD Councils

PNS

# The DD Act: A Brief History

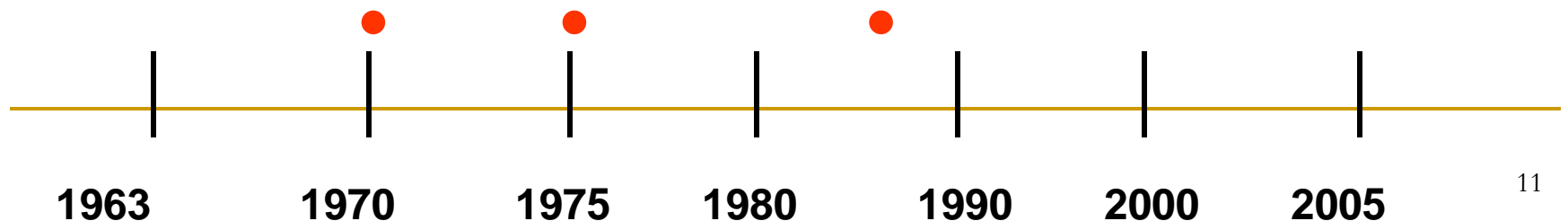


- 1955: Mental Retardation services priority in the Children's Bureau
- 1962: President Kennedy appoints Panel on Mental Retardation
- 1963: Congress first passed the DD Act and University Affiliated Facilities (UAFs) are established (present-day UCEDDs)



# The DD Act: A Brief History

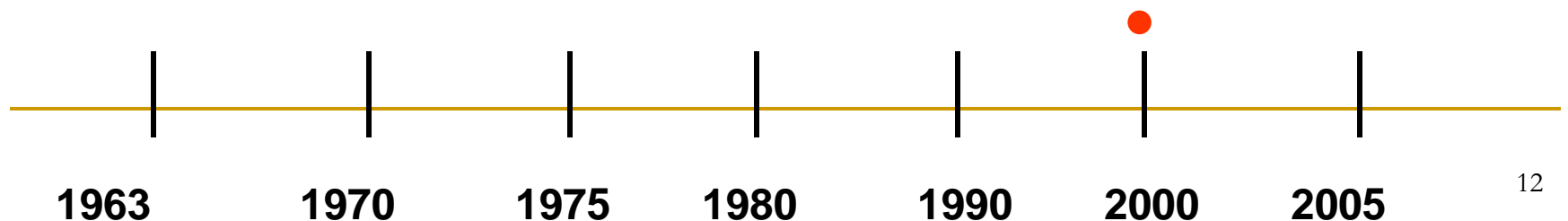
- The 1970 reauthorization established funding for Developmental Disabilities Councils (DD Councils)
- In 1975 Congress authorized funding for Protection & Advocacy systems (P&As)
- The 1975 reauthorization also provided funding for Projects of National Significance (PNS)
- 1987, the University Affiliated Facilities (UAF) name changed to University Affiliated Programs (UAP)





# The DD Act: A Brief History

- Congress reauthorized the DD Act in 2000
- 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



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# The DD Act: A Brief History

- Other changes in 2000
  - UAP name changed to UCEDD
  - Promoted increased collaboration with DD Councils and P&As
  - Requirement to develop performance indicators – outcomes data
  - UCEDDs recognized as an international resource
  - Identified Areas of Emphasis

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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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# Themes

The DD Act Programs all share 3 major themes:

- Advocacy
- Capacity Building
- Systemic Change



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- *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

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

- UCEDDs
- PNS
- P&As
- DD Councils



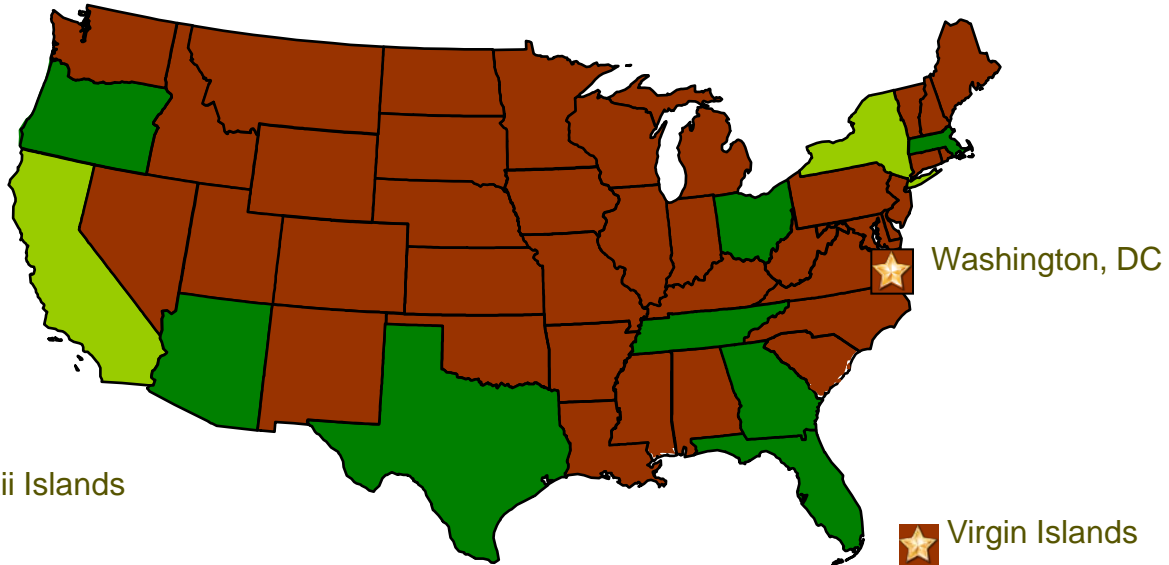


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# UCEDDs


- 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

-  Virgin Islands
-  Puerto Rico

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



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# In general, what is a UCEDD?

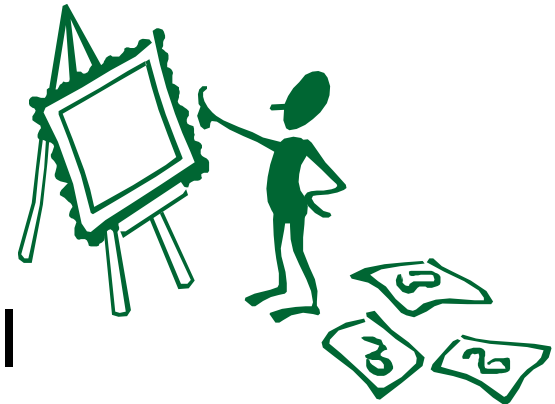
UCEDDs are leaders in four core function areas...

- 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



# Understanding the UCEDD

## Ice Cream Metaphor:

All UCEDDs start with the basic ingredients but become their own particular flavor







# 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

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# Projects of National Significance (PNS)

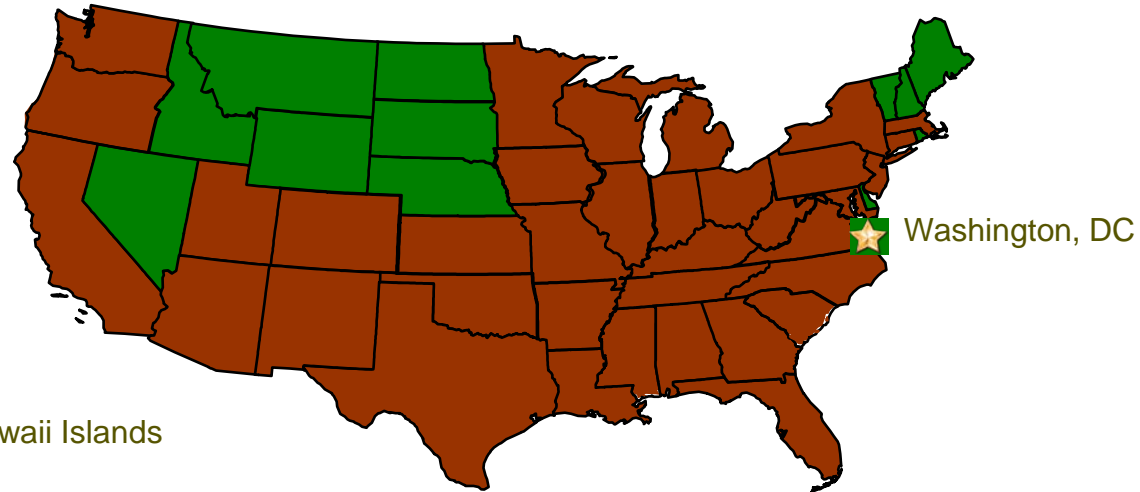
- A discretionary grant program
- The grants respond to emerging needs of individuals with disabilities and their families
- The projects currently funded:
  - Family Support 360s
  - Youth Leadership
  - Data collection/information dissemination projects

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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

# State Councils on Developmental Disabilities



★ Puerto Rico

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

= Minimum allotment  
 = Above Minimum allotment

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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

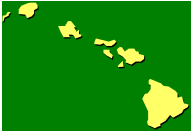
to make systems change and build capacity

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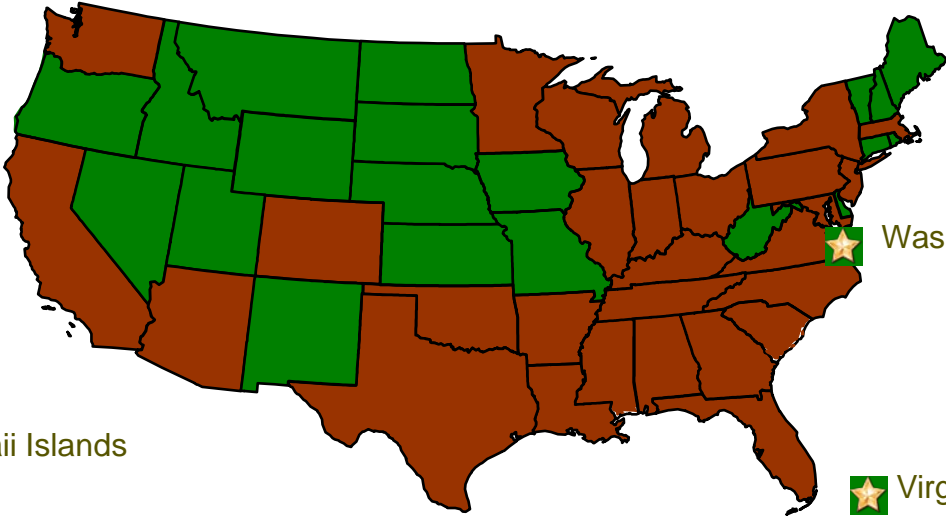
# State Protection and Advocacy System (P&As)

- 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

# Protection and Advocacy System



Hawaii Islands



Washington, DC

★ Virgin Islands

★ Puerto Rico

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

 = Minimum allotment

 = Above Minimum allotment

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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



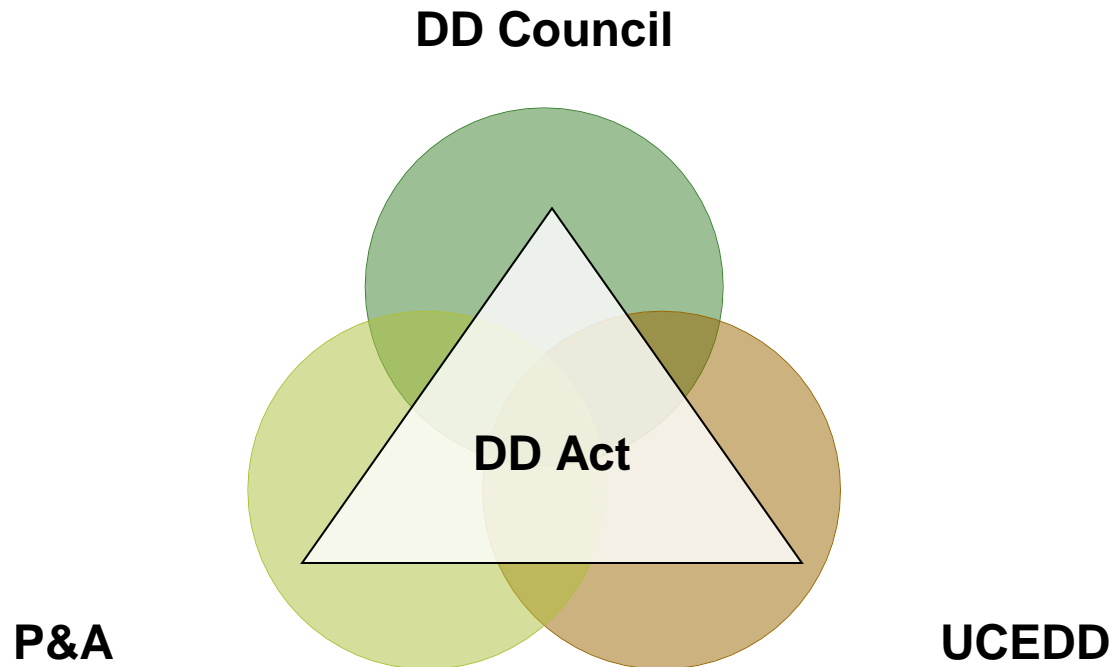
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## 3. The State DD Network

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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:
  - Where are they located?
  - What do they do?
  
- The DD Council:
  - Where are they located?
  - What do they do?

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# Our State's DD Network

- What are the past and current partnerships with the DD Network?
- What kinds of activities have the DD Network done together?

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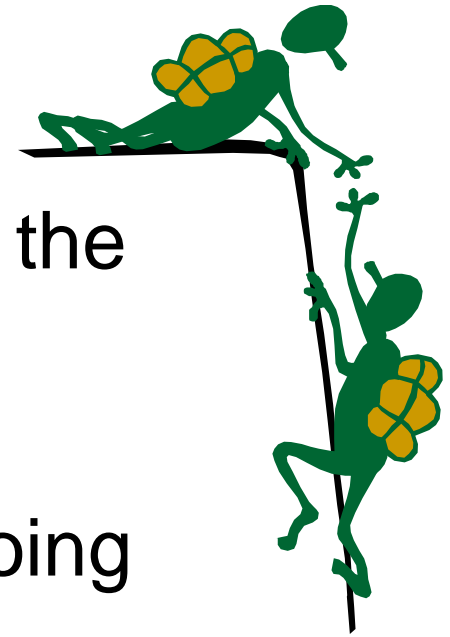
## 4. The Consumer Advisory Committee (CAC)

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

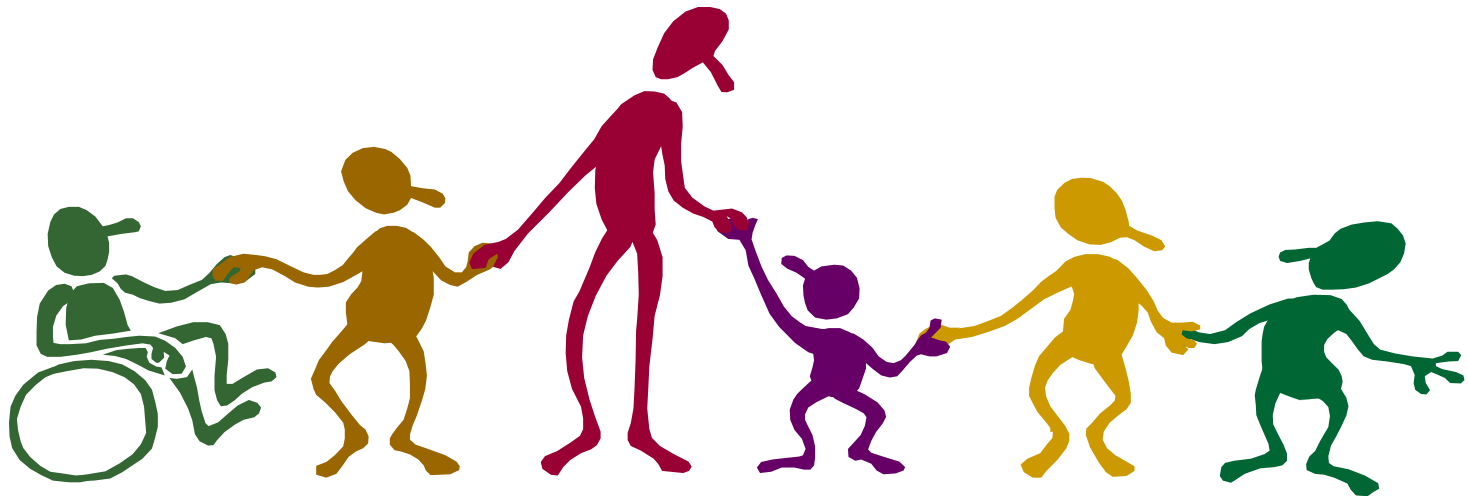
The CAC must also include representatives from:

- ❑ 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 CAC?

The members of the CAC must reflect the racial and ethnic diversity of the state



# What does the DD Act say About how often the CAC should Meet?

- The CAC should meet as often as necessary
- The CAC should meet at least 2 times a year



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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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# Advisory Committees vs. Boards

- A *Board of Directors* guides an organization and its members are legally liable for the actions of the organization
- *Advisory Committees* offer advice to an organization but its members have no legal responsibility for the actions of the organization

**UCEDDs have Advisory Committees**

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# Boards and Councils

- A P&A's board decides on the policies and priorities for the P&A to carry out in protecting and advocating for the rights of individuals with developmental disabilities
- DD Council members, appointed by the governor, are responsible for developing, funding, implementing and monitoring a state plan that will conduct or support programs, projects and activities that improve the quality of life of individuals with disabilities

# What are benefits of the CAC-UCEDD relationship?

- The CAC is a bridge from the university and the UCEDD to the community
- Participation in the CAC can be a leadership opportunity for members as disability advocates and mentors
- CACs bring together decision-makers and people with different ways of looking at issues that may not have met before
- CACs provide an opportunity for a culturally diverse forum on disability





# Questions

