

# Administration for Community Living

*Introduction to the Protection and Advocacy Systems*

## **NAPSA Conference**

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**Advancing independence, integration, and inclusion throughout life**

# Acronyms

- **AOD:** Administration on Disabilities
- **DD Act:** Developmental Disabilities Assistance and Bill of Rights Act of 2000
- **UCEDD:** University Centers for Excellence in Developmental Disabilities
- **P&A:** Protection and Advocacy System
- **DD Council:** State Council on Developmental Disabilities
- **PNS:** Projects of National Significance

# Historical Milestones

- **1961** President John F. Kennedy's Panel called for a "Proposed Program for National Action to Combat Mental Retardation"
- **1963** JFK called for and signed Mental Retardation Facilities and Construction Act (P.L. 88-164) provided for the creation of community services infrastructure
- **1966** The President's Committee on Mental Retardation (PCMR) created.
- **1970** Disabilities Services and Facilities Construction Amendments of 1970 (P.L. 91-517) established State Planning and Advisory Councils, known today as DD Council
- **1972** The Center for Independent Living (CIL) is founded in Berkeley, California
- **1973** Rehabilitation Act passes

# Historical Milestones (Cont)

- **1975** DD Act established State Protection and Advocacy Systems and Education for All Handicapped Act enacted
- **1978** Title VII of the Rehabilitation Act established federal funding for independent living
- **1987** UAFs become University Affiliated Programs
- **1990** Americans with Disabilities Act (ADA) enacted
- **1994** Projects of National Significance added to DD Act
- **1996** Traumatic Brain Injury Act authorizes funding for grants to states
- **2000** DD Act renames UAPs University Centers for Excellence in Developmental Disabilities
- **2003** President's committee renamed President's Committee for People with Intellectual Disabilities (PCPID)

# Historical Milestones (Cont)

- **2012** ACL created
- **2014** The Workforce Innovation and Opportunity Act (WIOA) enacted moving AT Act and IL programs from ED and ACL; creates IL Director

# Developmental Disability (DD Act)

- A severe, chronic disability of an individual that:
  - Is attributable to a mental or physical impairment or combination of mental and physical impairments
  - Is manifested before the individual attains age 22
  - Is likely to continue indefinitely
  - Results in substantial functional limitations in 3 or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency
  - Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated

# Purpose of the DD Act

## Purpose:

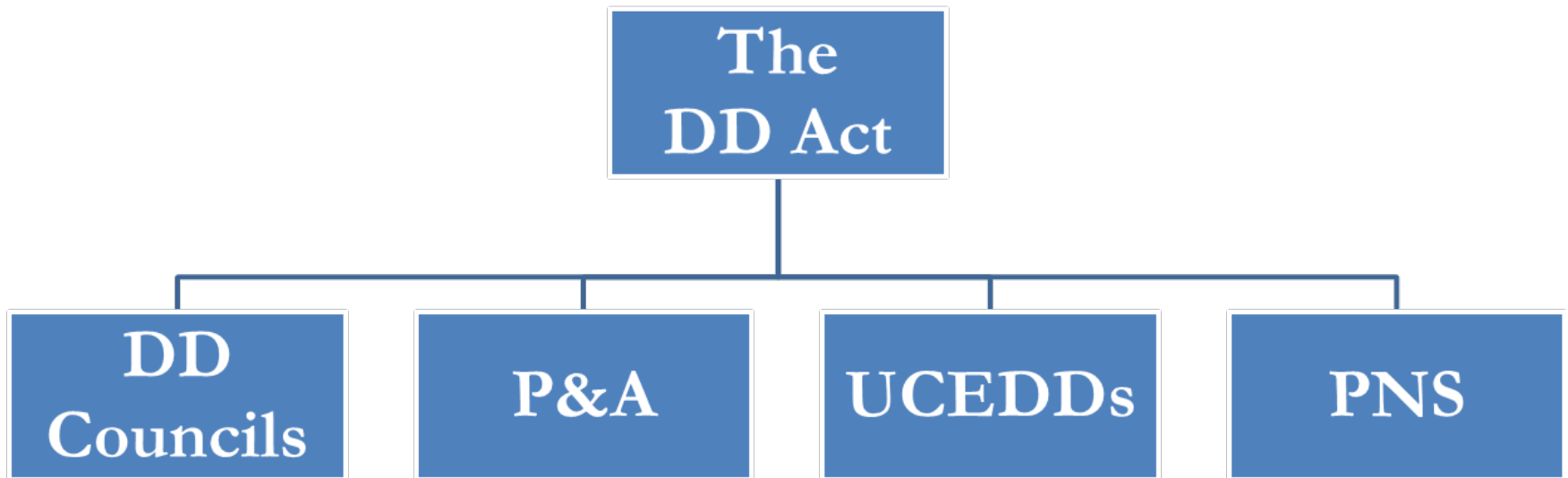
- To assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion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

# Principles of the DD Act

- **Independence:** To have control
- **Productivity:** To work or make other contributions to a household and community
- **Integration:** Right to the same opportunities, services, community resources as all other Americans
- **Inclusion:** Acceptance and encouragement of presence and participation in social, educational, work and community environments.

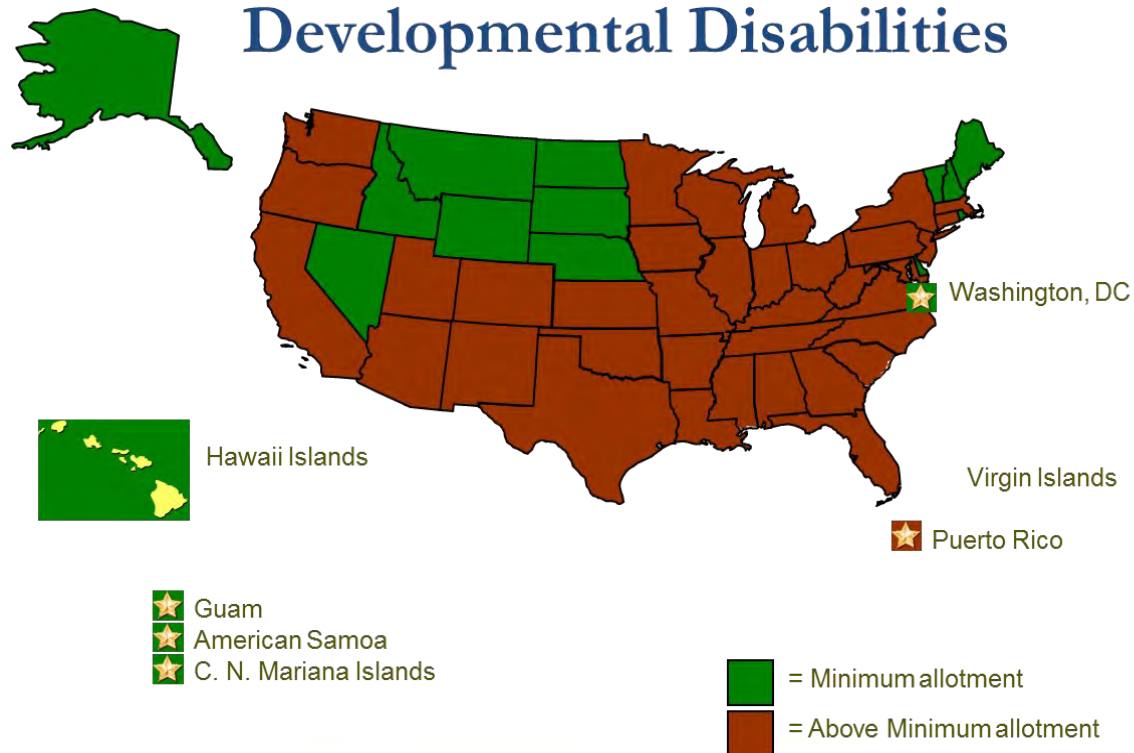


# The DD Act Programs



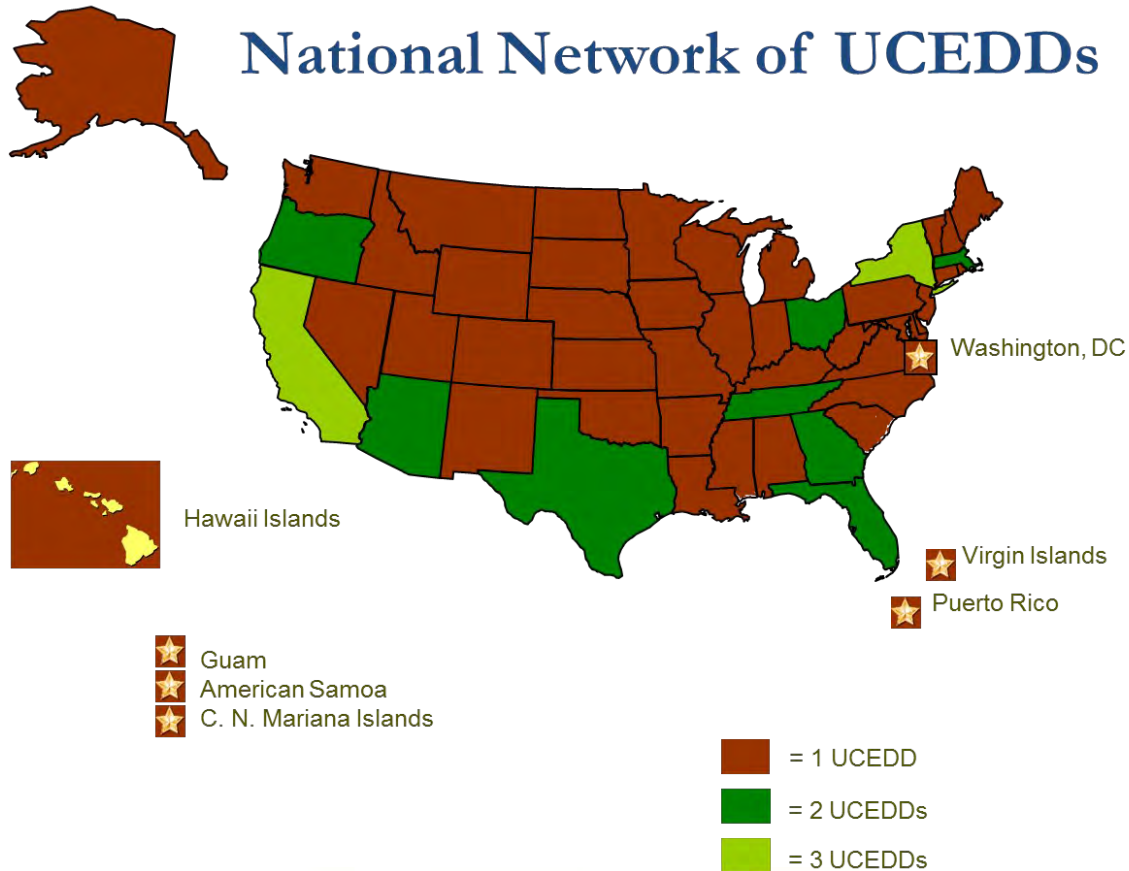
# DD Councils

## State Councils on Developmental Disabilities



# UCEDDs

## National Network of UCEDDs



# Raising Awareness about Abuse and Neglect

- Willowbrook:

<https://www.youtube.com/watch?v=zgGSTNLVeko>

- Pennhurst:

<https://www.bing.com/videos/search?q=pennhurst&view=detail&mid=22A9300F3071134E786A22A9300F3071134E786A&FORM=VIRE>

# Olmstead vs L.C.

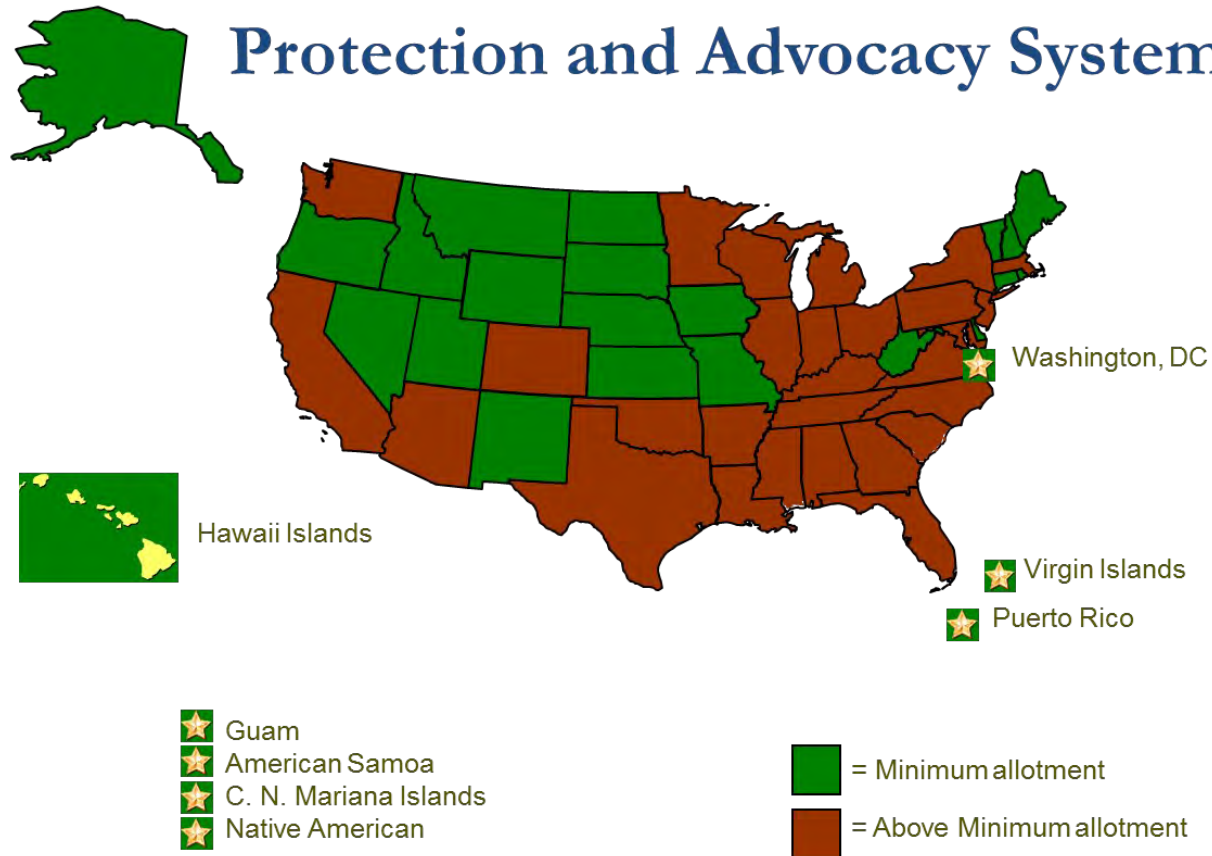
- 1999, the United States Supreme Court held in Olmstead v. L.C. that unjustified segregation of persons with disabilities constitutes discrimination in violation of title II of the Americans with Disabilities Act.
- The Court held that public entities must provide community-based services to persons with disabilities when (1) such services are appropriate; (2) the affected persons do not oppose community-based treatment; and (3) community-based services can be reasonably accommodated, taking into account the resources available to the public entity and the needs of others who are receiving disability services from the entity.

# The Impetus for Creating a System of Protection and Advocacy

[https://www.youtube.com/watch?v=RA7sX\\_FYSCY](https://www.youtube.com/watch?v=RA7sX_FYSCY)

# P&As

## Protection and Advocacy System



# P&As

- Provide services to individuals with developmental disabilities based on the identification of goals and priorities based on public input.
- Activities of the P&As include:
  - The protection and advocacy of legal and human rights
  - Information and referral
  - Investigation of complaints of violations of rights of individuals with developmental disabilities
  - Working to resolve complaints through mediation, alternative dispute resolution and litigation



# Purpose of the P&As

- P&As help individuals with developmental disabilities secure their human and civil rights.
- P&As help people with developmental disabilities who:
  - Have been neglected or abused
  - Have been denied access to a service
  - Have been denied control or choice of a service to which they have a right
  - Have been denied the opportunity to participate in an activity

# Authority and Independence

- The P&A system must have independence to pursue legal and other appropriate measures on behalf of clients with developmental disabilities without state or other interference.
  - Access to people, access to records, access to institutions for monitoring
  - Authority to pursue legal remedies
- The system must have the ability to investigate incidents of abuse and neglect of individuals with developmental disabilities.

# Designated by the Governor

- The Protection and Advocacy for Individuals with Developmental Disabilities (PADDD) 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.”

# ACL-Funded P&A Programs

- **PADD:** Protection and Advocacy for Developmental Disabilities (the cornerstone of the P&A)
- **PAAT:** Protection and Advocacy for Assistive Technology
- **PATBI:** Protection and Advocacy for Traumatic Brain Injury
- **PAVA:** Protection and Advocacy for Voting Access

# PAAT

- Funded by the Assistive Technology Act of 1998 as amended
- Assist individuals of all ages with disabilities in the:
  - acquisition,
  - utilization or
  - maintenance of assistive technology services or devices.
- P&As provide information, advocacy, representation, training, technical assistance, and general guidance to increase access to and provision of AT devices and services.

# PATBI

- Created in 2002 to provide protection and advocacy services to individuals with traumatic brain injury
- Part of ACL TBI grant network

# PAVA

- Part 5, Section 291
  - payments for protection and advocacy systems (P&As)
  - awards to 55 P&As (**excluding CNMI & Native American Consortium**)
  - traditionally known as the “VOTEP” or “PAVA” grant program
  - 7% of funds allocated for Protection & Advocacy (P&A) Systems used to provide Training & Technical Assistance to the P&As.

# 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)
- **PABSS:** Protection and Advocacy for Beneficiaries of Social Security (Social Security Administration)
- Some P&As also administer the Client Assistance Program (CAP)



# Duties of the P&As

- Train people about their legal and human rights
- Educate others about the rights of individuals with developmental disabilities
- Investigate complaints of violations of rights
- Information and referral
- Work to resolve complaints through discussion, mediation, alternative dispute resolution, and litigation
- Referrals to other agencies (state, Federal, local)

# Planning Responsibilities

- Goals and priorities setting
  - The goals and priorities of each P&A are based on data-driven strategic planning... multi-year cycle with annual updates.
  - The P&A provides an annual opportunity for the public to comment on goals and priorities and activities of the system, including comments by the Council and UCEDDs.
  - Goals and priorities are submitted to AIDD annually.

# 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 developmental disabilities
  - Family members and guardians
  - Advocates or authorized representatives
  - May include a representative from the State Council, UCEDD and self-advocacy organizations

# Website Links

- ACL P&As page:  
<https://acl.gov/programs/aging-and-disability-networks/state-protection-advocacy-systems>
- National Disability Rights Network  
(membership organization and T/TA provider):  
<http://ndrn.org/>

# Funding

- In FY2019, the P&As received over \$56 million including Training and Technical Assistance
- Full appropriated amounts can be found at <https://acl.gov/sites/default/files/about-acl/2019-01/PADD-2019.pdf>

# Reporting Function

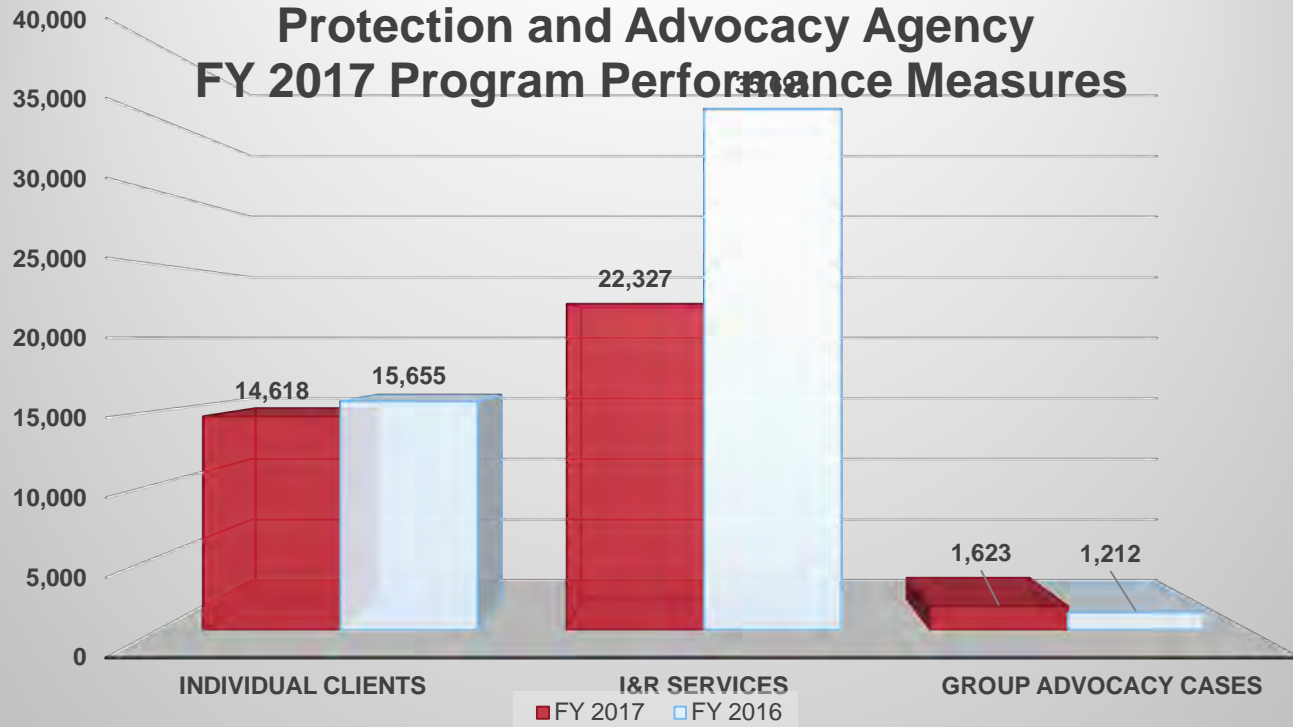
- P&As provide program performance reports which reflect qualitative and quantitative data on an annual basis
- P&As report on fiscal activities on an annual basis (SF425) and on a quarterly basis in the Payment Management System

Telling the P&A Story

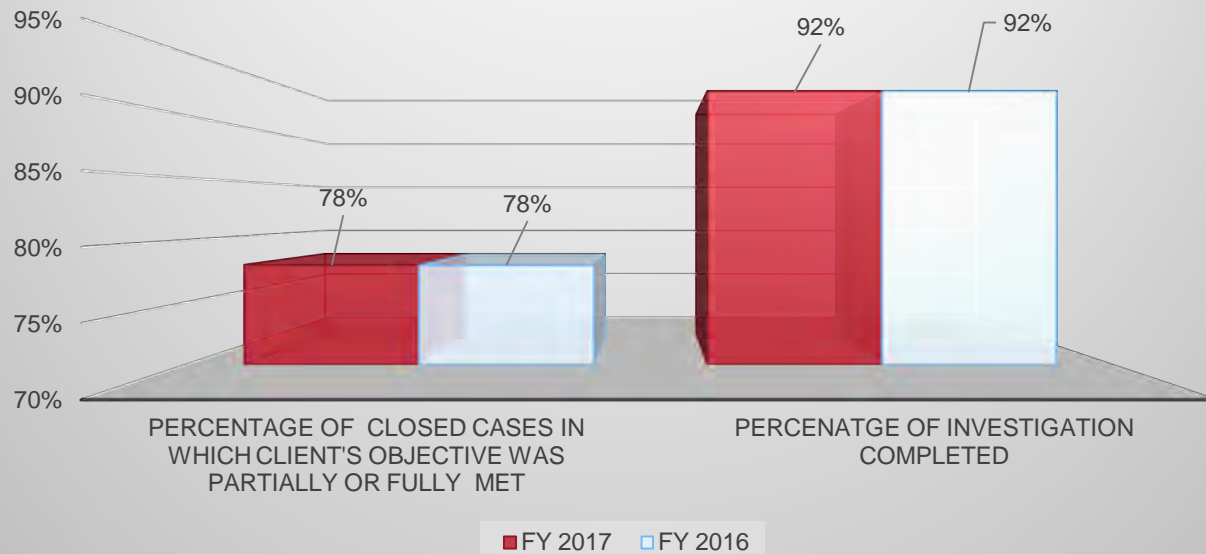
# DATA AND ANALYSIS



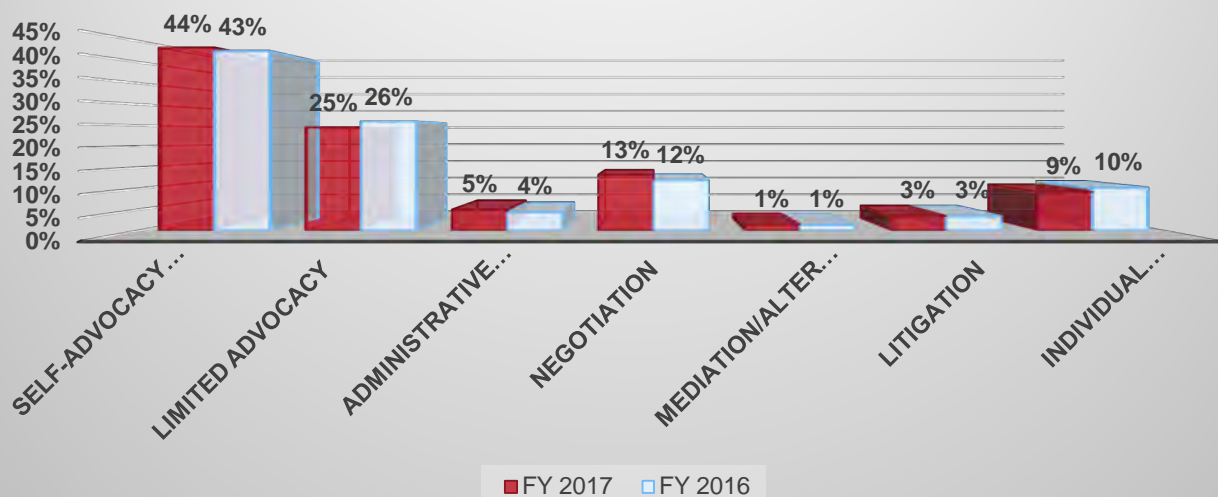
# Administration on Intellectual and Developmental Disabilities Protection and Advocacy Agency FY 2017 Program Performance Measures



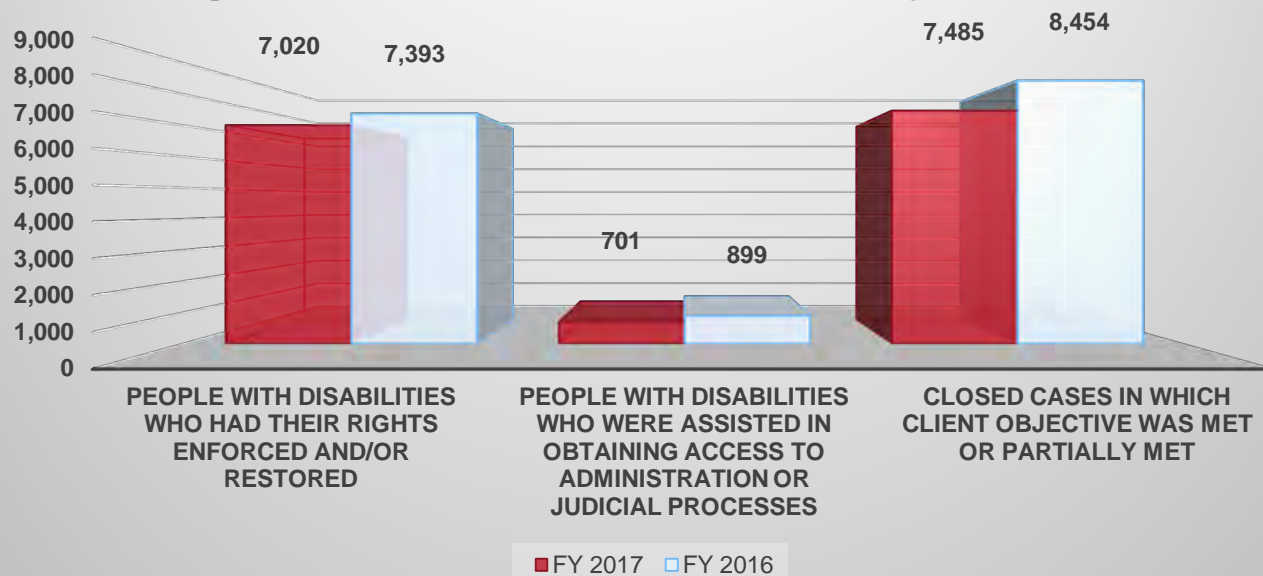
# Administration on Intellectual and Developmental Disabilities Protection and Advocacy Agency FY 2017 - Reasons For Closing Individual's Case Files



**Administration on Intellectual and  
Developmental Disabilities  
Protection and Advocacy Agency  
FY 2017-FY 2016  
Intervention Strategies Used In Serving  
Individuals**



**Administration on Intellectual and  
Developmental Disabilities  
Protection and Advocacy Agency  
FY 2017-FY 2016  
Rights Based Individual Advocacy Services**



# Success Stories

## Bobby's Hard-Fought Journey

Bobby is a wonderful example of how advocates work to provide choice and independence.

In 1978, Bobby was one of the “Gang of 19” protesting that Denver buses were not accessible.

Bobby longed to live an independent life outside of a nursing home.

Advocates worked for two years with Colorado Choice Transitions to get Bobby out of the nursing home and into more independent living.



Questions? Comments?