



Meeting the Needs of Aging Persons with Developmental Disabilities

Cross Network Collaboration for Florida

INTRODUCTION

Module 1

Based on ADRC training
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Goals of Training

- To bring together the resources of the Aging and Developmental Disabilities Networks
- To assist adults with developmental disabilities (and their families) to navigate long-term health, supports, and service systems



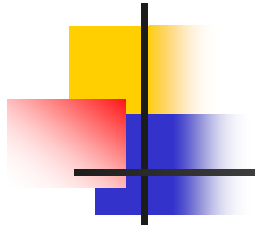
Objectives of Training

- Identify the needs of individuals with developmental disabilities
- Identify the needs of caregivers
- Understand eligibility and available resources to assist with decision-making



Objectives of Training

- Provide comprehensive information and community long-term care options
- Offer streamlined access to resources
- Assist individuals with disabilities and their caregivers to engage in community activities and to experience an improved quality of life



Exercise

Worksheet



Purpose of Module 1

- Provide overview of aging and developmental disability networks in Florida
- Identify how to break down “silos” hindering collaboration
- Explain the ADRC concept
- Recognize commonalities and differences between networks



Purpose of Module 1

- Explain why collaboration enhances referral and intake
- Recognize effects of aging on the adult developmental disabilities population and their caregivers



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Breaking Down Silos



What Are Silos?

- Networks and agencies within networks function independently
- Little interaction or communication between networks
- Little understanding of services, language, or funding streams between networks
- Limited cross-network sharing of information



Why Break Down Silos Through Collaboration?

- To understand each network's resources and criteria for eligibility
- To improve cross-network cooperation and communication
- To encourage sharing of resources
- To reduce duplication of effort



Networks in This Project

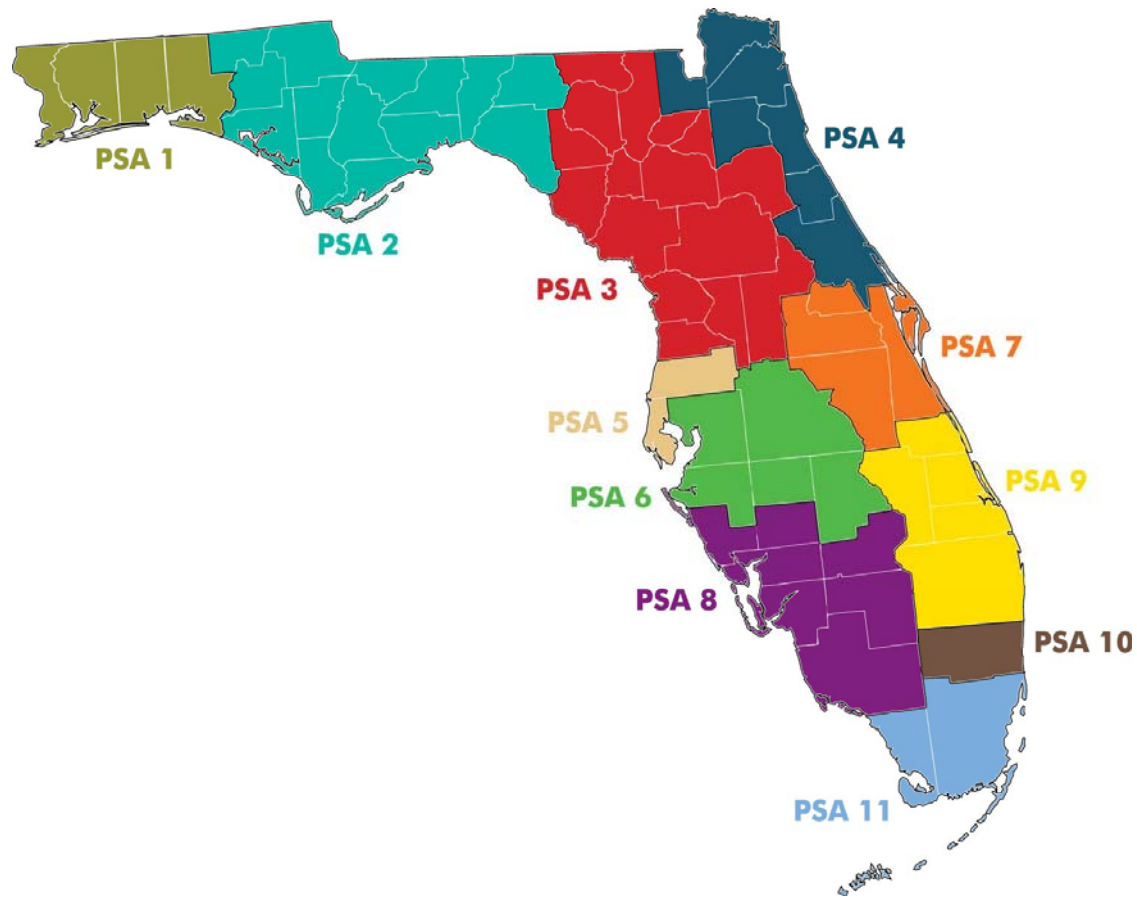
- Aging Network
 - Department of Elder Affairs (DOEA)
 - Aging and Disability Resource Centers (ADRC)
 - Community providers of aging services
- Developmental Disability Network
 - Agency for Persons with Disabilities (APD)
 - Private developmental disabilities service providers



DOEA

- Provides services that include
 - Elder Helpline (800-963-5337)
 - Case management
 - In-home supports
 - Nutrition assistance
 - Caregiver training and respite
 - Alzheimer's disease screening and day care
- Operates through Area Agencies on Aging in 11 Planning and Service Areas (PSA)

DOEA PSA Map





What Is an ADRC?

- A function of the Area Agency on Aging
 - Creates linkages between aging and disability communities
 - Offers information on community resources
 - Provides access to public and private long-term care services
 - Streamlines screening and eligibility determination for public services



Florida's ADRC Expansion Grant

- Awarded by the U.S. Administration on Aging
- Pilot sites located in PSAs based in St. Petersburg and Ft. Myers
- Serve persons with developmental disabilities
- Establish a five-year plan to expand ADRCs statewide



Florida's ADRC Expansion Grant

- Provide information about the Elder Helpline to APD providers
- Expand community resource database
- Reach out to older adults on the APD waitlist for supplemental services
- Assess caregivers age 55 and older for DOEA service eligibility



APD

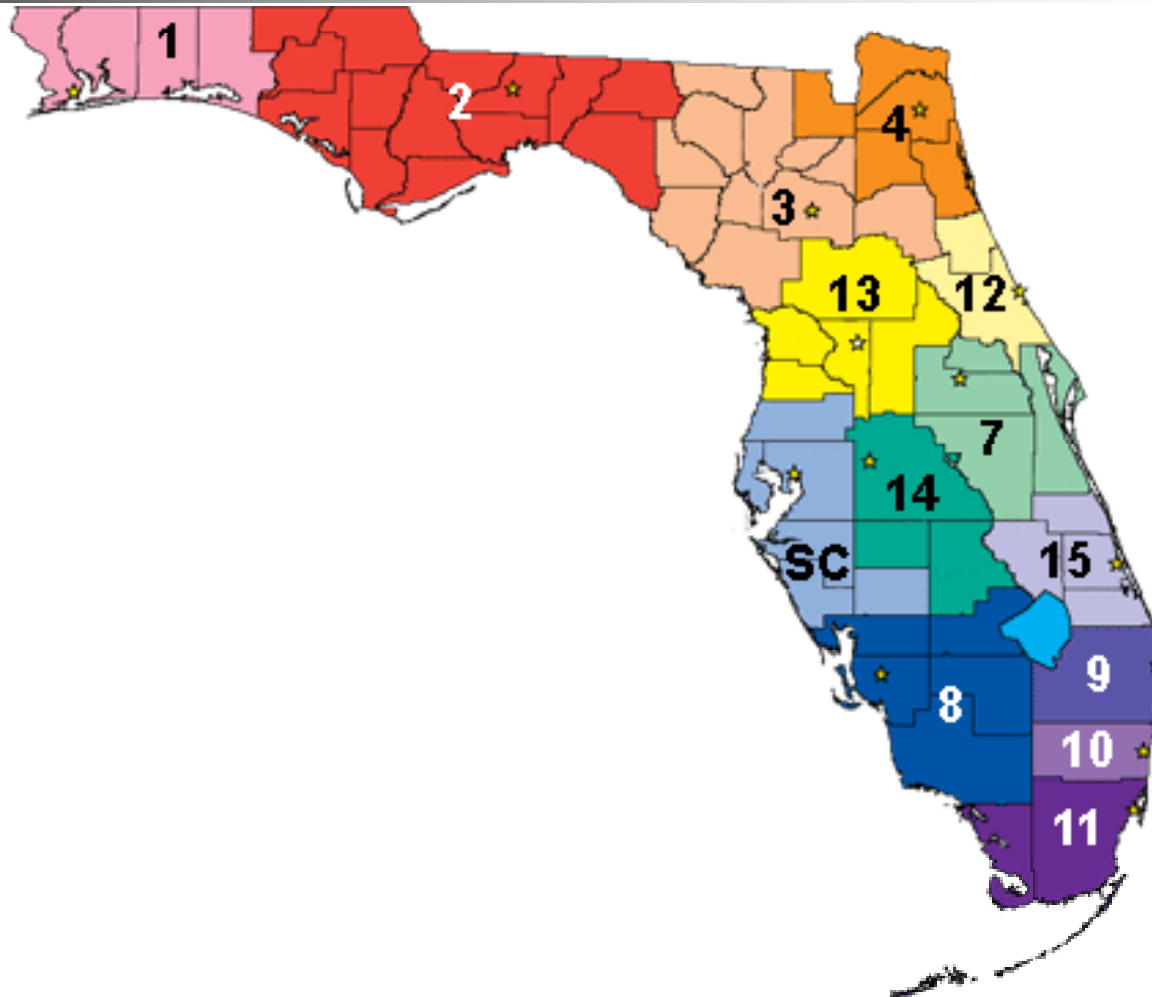
- Serves Floridians with developmental disabilities and their families
- Targets five developmental disabilities mandated by state law
 - Retardation
 - Cerebral palsy
 - Autism
 - Spina bifida
 - Prader-Willi syndrome



APD

- Provides services that include
 - Support coordination
 - Transportation
 - In-home supports and medical supports
 - Supported living & supported employment
 - Residential habilitation
 - Adult day training
- Operates through 13 Area Offices and one Regional Office

APD Area and Regional Offices





Benefits of Collaboration

- Supports reduction of duplicated services
- Ensures fewer gaps in services
- Limits number of crisis situations
- Develops joint process and supports
- Increases consumer satisfaction
- Encourages agencies outside of APD or ADRC networks to work together



How Does Collaboration 'Bridge the Networks'?

- By joint awareness and understanding of needs and services
- By cooperative application process
- By cross-network understanding of aging and the impact on caregivers
- By sharing ideas among ADRC and APD staff
- By identifying commonalities
- By establishing formal relationships



Building Collaborations

- One person and one service at a time
- Continuous and evolving process
- Ongoing cooperation and knowledge of systems
- Increased expertise and familiarity over time
- Knowing the people



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Commonalities and Differences Between Networks



Commonalities

- Changing needs of the older caregivers
 - The caregiver is the most likely area for bridging
- Providing services in the least restrictive environment
- Providing a single coordinated system of services
- Supporting consumer self-determination



Commonalities

- Similar aging needs of clients and caregivers
- Waiting lists for services
- Most services have eligibility criteria
- Service prioritized by client's needs and caregiver's status
- Both empowered by the federal government to provide services



Differences

- Service eligibility criteria
- Funding streams
- Services provided
- Language and acronyms
- Regulations and mandates
- Case managers vs. support coordinators



Differences

- Different catchment areas
- Different agency structures
 - ADRCs are private not-for-profit organizations
 - APD Area Offices are government agencies



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Changing Dynamics for Adults with Developmental Disabilities



Changing Dynamics

- Living longer with fewer financial resources
- Less likely to have health insurance
- More likely to be living with parents or family member
- Less likely to have social support network outside the family



Typical Lifespan

- Mid-70s: Mild to moderate developmental disabilities
- Mid-50s: Severe developmental disabilities and Down syndrome



Demographics

- 75% live with families
- 25%+ caregivers over 60
- 38% caregivers between 41 – 59
- Approximately two persons unknown to network for every one person known
- Population to double by 2030

Fujiura, G.T. (1998). Demography of family households. American Journal on Mental Retardation, 103, 225-235



Possible Changes

- Declining stamina and increased chronic health problems
- Change in lifelong interests
- Desire for different day activities
- Pursuit of retirement with meaningful activity and choices



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Stress in Caregivers of Adults with Developmental Disabilities



Why Are Caregivers at Risk?

- Lack of planning to avoid crisis
- Family members not included in planning
- Reluctant to accept government services
- Few resources available for informed legal and financial planning
- Difficulty in finding health care and social services
- Waiting lists for services and assistance



What Is the Likely Impact of Stress on Caregivers?

- Few supports for caregivers
- Increased health problems
- Declining stamina from lifelong caregiving
- Family structure collapse
- Crisis



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Referral and Intake



Collaborative Referral

- Increased points of entry from community
- May enter through APD or other agencies and networks
- Central referral for services



Collaborative Intake

- Coordinated intake to identify service needs
- Eligibility determination
- Identification of appropriate services
- Access to database of aging and developmental disability resources
- Reduced duplication of services



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Common Truths About Aging



Common Truths About Aging

- Aging Is Aging Is Aging
- There is no significant cognitive or physical decline in the typical aging process
- Increased risk for pre-mature aging in adults with Down syndrome and cerebral palsy



Common Truths About Aging

- Increased stress on caregivers and family members
- Practitioners not prepared for aging adults with developmental disabilities
- Older adults with developmental disabilities 'age' into medication



Common Truths About Aging

- Physical environment becomes challenging
- Dementias not a 'normal' part of aging
- Society and services not oriented to aging
- Myths about adults with developmental disabilities



Summary of Module 1

- ADRC expansion to include persons with developmental disabilities
- Collaboration across the networks can help Floridians age well



Group Discussion

- Questions