Meeting the Needs of Aging Persons with Developmental Disabilities

Cross Network Collaboration for Florida

INTRODUCTION

Module 1

Based on ADRC training developed by:
Kathleen M. Bishop, Ph.D., and Ron Lucchino, Ph.D.
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
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
Meeting the Needs of Aging Persons with Developmental Disabilities

Cross Network Collaboration for Florida

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)
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
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
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
Meeting the Needs of Aging Persons with Developmental Disabilities

Cross Network Collaboration for Florida

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
Meeting the Needs of Aging Persons with Developmental Disabilities

Cross Network Collaboration for Florida

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

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
Meeting the Needs of Aging Persons with Developmental Disabilities

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
Meeting the Needs of Aging Persons with Developmental Disabilities

Cross Network Collaboration for Florida

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
Meeting the Needs of Aging Persons with Developmental Disabilities

Cross Network Collaboration for Florida

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