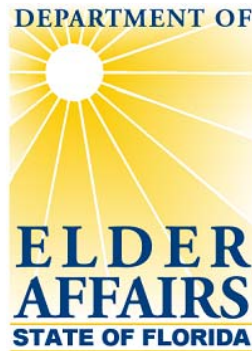# Meeting the Needs of Aging Persons with Developmental Disabilities and Their Families

PRESENTER'S MANUAL

Acknowledgements

The authors[*] would like to acknowledge the following for their invaluable inputs to this innovative expansion initiative that will become a template for further development of the five-year ADRC expansion curriculum covering all aging persons with disabilities. We all are in hopes that this could serve as a national standard in curricular development and training delivery on this subject.

Florida Department of Elder Affairs (DOEA):

Sandi Smith   Mary Hodges   Sylvia Peacock   Linda Riddle

Florida Agency for Persons with Disabilities (APD):

Steve Dunaway   Melinda Coulter

The Area Agencies on Aging (AAA) currently operating as expansion grant pilot sites:

Area Agency on Aging of Pasco-Pinellas, Inc.
Area Agency on Aging for Southwest Florida, Inc.

As well as the future AAAs that this curriculum will aid in their coming on board as designated ADRCs.

Table of Contents

Instructions on Use of Presenter's Manual for:

Meeting the Needs of Aging Persons with Developmental Disabilities and Their Families

This manual has been developed for use by trainers of the Meeting the Needs of Aging Persons with Developmental Disabilities and Their Families: *Cross Network Collaboration for Florida* presentation slides. Included in this manual are:

- o Five modules of the curriculum,
    - o **Module 1 Introduction** – (45 minutes – 1 hour) Module 1 can be presented alone or in conjunction with Module 2. It can also be presented as a seven-hour training day with the additional four modules. The trainer can refer to the notes on the slides as she/he is training and to the manual with the summaries for each slide. This module is intended as an introduction to the *Cross Network Collaboration for Florida* project for the expansion of Aging and Disability Resource Centers (ADRCs) for the 11 Planning and Service Areas of Florida. Handout #1 is used with this module, located in Appendix C.
    - o **Module 2 Aging and Developmental Disabilities Systems –** (45 minutes – 1 hour) Module 2 provides additional information on aging and developmental disabilities including eligibility criteria and systems overviews. This module can be presented with Module 1, by itself, or with all 5 modules. Handout #2 with Scenarios #1 and #2 is used with this module. It is located in Appendix C with instructions for the use of the scenarios.

- o **Module 3 Aging in Individuals with a Developmental Disability –** (45 minutes – 1 hour) Module 3 is an overview of aging in persons with developmental disabilities including risk factors, possible adverse effects of medications, and specific issues related to aging in persons with Down syndrome and cerebral palsy. There is no handout for Module 3. It can be presented with Modules 1 and 2, by itself, or with all 5 modules.

- o **Module 4 Bridging the Networks –Needs for Caregivers of Individuals with Developmental Disabilities –** (45 minutes – 1 hour) Module 4 is an overview of issues related to caregivers of persons with developmental disabilities. The caregivers are often the commonality between the networks. It is important as the Aging and Disability Resource Center is expanding to understand some of the issues, possible risks for health based on history and increased stress for the caregivers of persons with developmental disabilities as well as some specific health-related concerns. Handout #3 with Scenarios #3 & #4 is used with Module 4. This handout is located in Appendix C with instructions for the use of the scenarios. This module can be presented with #1, 2, and 3, all five modules or by itself.

- o **Module 5 Sensory Processing, Environmental Modifications and Adaptive Technology –** (45 minutes – 1 hour) Module 5 is an overview of sensory processing issues with aging, possible environmental barriers to healthy aging in persons with developmental disabilities, and environmental modifications or adaptive technology suggestions. If the training room has internet access, videos on adaptive technology can be shown to participants. The trainer can view those videos on his or her laptop by clicking on the titles of the videos in the appropriate slide when there is internet access. While environmental barriers may impact
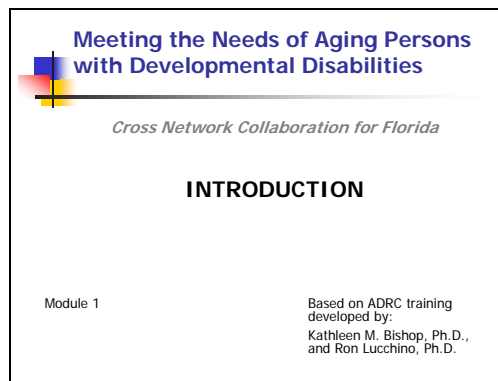
all older persons, people with developmental disabilities are at increased risk of reduced quality of life from environmental barriers as they age. There are no handouts for Module 5. Module 5 can be presented by itself, with all 5 modules, or in combination with any other modules.

o Summaries providing additional information for each slide for the trainer

o Handouts with instructions for use

o References for further information on aging with developmental disabilities

o Glossary of acronyms and terms

Cross Network Collaboration for Florida

MODULE 1

Introduction

Slide 1

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.

Module 1 is the introductory module. It should be used in combination with Module 2. The other 3 modules can each be used individually or as a package with Modules 1 and 2. Module 1 should always be the first presented as it provides the background for the Cross Network Collaboration project.

The purpose of Module 1 is to introduce the concept of collaboration between the aging and developmental disability networks through the development of additional Aging and Disability Resource Centers (ADRC) in Florida. Modules 1 and 2 provide the background information on the networks, purpose for the expansion, and Florida eligibility criteria for developmental disabilities.

Slide 2

> ### 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
>
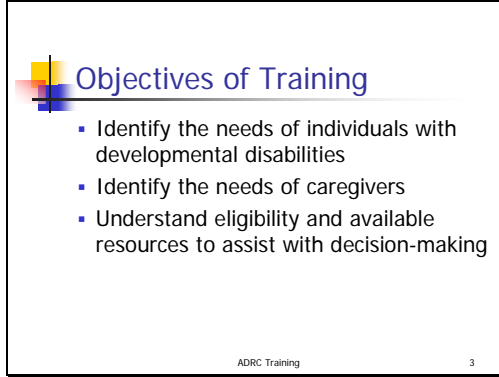> ADRC Training   2

The purpose of the Aging and Disability Resource Center development is to encourage collaboration across networks. Ultimately, the intent is to reduce duplication and enhance the available services for older persons with developmental disabilities.

Nearly every state in the country has been awarded a grant to establish Aging and Disability Resource Centers (ADRCs). In Florida, the plan is to develop an ADRC in each of the state's 11 Planning and Service Areas (PSAs). Since 2005 three of the 11 Area Agencies on Aging have been designated as ADRCs, with the goal of transitioning the other eight to ADRCs in the future. PSAs 5, 7 and 10 were locations for the initial three ADRCs (see map on slide #13). The ADRC model is designed to provide easier access to community resources for seniors and caregivers, regardless of pre-existing diagnosis of mental illness, disability, or developmental disabilities.

The current ADRCs also provide information and referral services to adults with mental illness or disability. The experience of those ADRCs has demonstrated that sharing the resources between service delivery networks can accomplish the goal of helping families navigate through the often complex service system.
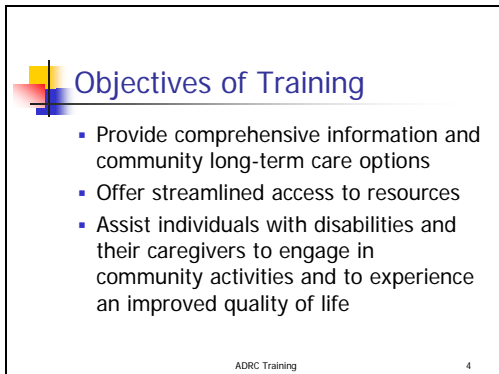
Slide 3

> ## 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
>
> ADRC Training   3

These are the objectives for all five of the modules. It is always a good practice to share objectives with trainees. Training becomes a shared responsibility for both trainee and trainer.
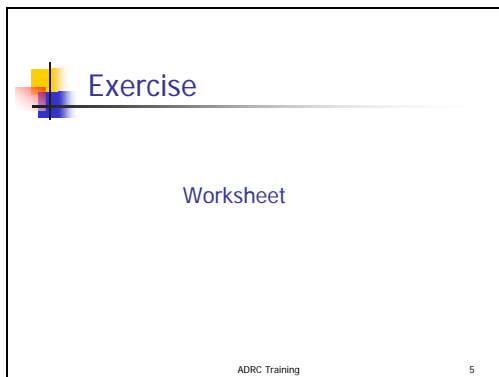
Slide 4

> ## 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
>
> ADRC Training   4

These are additional objectives for the five modules to give participants an overview of the training and project intent.

Slide 5

> ## Exercise
>
> Worksheet
>
> ADRC Training   5
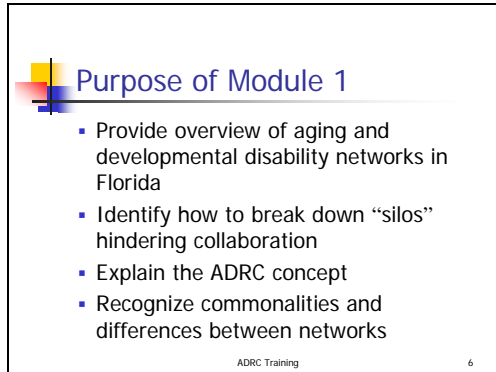
After the goals and objectives of the training have been introduced, it is a good time for an exercise designed to facilitate conversation among the participants. It will be especially helpful if participants from both the aging and developmental disabilities network are seated together and able to get to know one another and begin the collaboration process from the beginning of the training.

Handout #1 is available with instructions on use in Appendix C. This handout is intended for participants to share contact information on the Planning and Service Areas (PSAs) under the Florida Department of Elder Affairs (DOEA) and the appropriate offices

of the Florida Agency for Persons with Disabilities (APD) specific to the service areas of those attending the training.

Approximately 10 minutes should be allotted to this exercise. At the end of Module 1, trainers can review the group information to make sure that the information is correct.

Slide 6

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

ADRC Training   6

The purpose of Module 1 is to provide attendees with background information on the key components of the aging and developmental disabilities networks in Florida and their available services. It is also intended to introduce the subject of aging with developmental disabilities as a means to identify persons with developmental disabilities and their caregivers as potential service recipients of the Aging and Disability Resource Centers (ADRC).

Slide 7

Purpose of Module 1

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

ADRC Training   7

Collaboration across the networks is important to minimize duplication and maximize service availability. Both networks can benefit from the collaboration. There are barriers that may impede networking but there are also commonalities such as the needs of the caregivers.

Because the caregivers often have needs for supports from both networks, ADRCs can help caregivers navigate the appropriate network for needed services as well as assist with eligibility determination. The term 'breaking down silos' refers to

the removal of barriers that may prevent collaboration across the networks.

Slide 8

Meeting the Needs of Aging Persons with Developmental Disabilities

Cross Network Collaboration for Florida

Breaking Down Silos

ADRC Training   10

The transitional slide for the next section 'Breaking Down Silos.'

Slide 9

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

ADRC Training   11
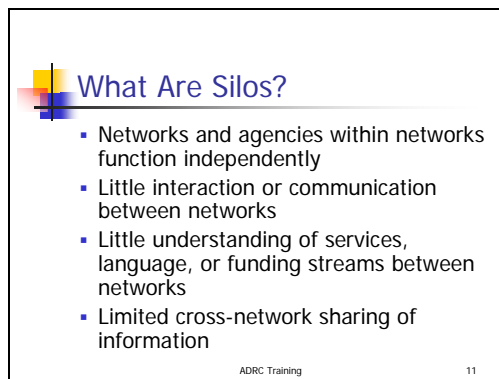
To provide services or supports across the networks, it is important to break down the barriers (silos). Language can be a strong barrier to collaboration as the meaning of the language used by each network can be misunderstood, limiting understanding among agencies. Each network has its own unique language, organizational structure, and funding mechanisms.

Slide 10

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

ADRC Training   12

Each network has specific eligibility criteria for services as well as different organizational structures and available resources. Agencies within the networks are likely to receive requests for information or services from the other networks. Additionally, there is often duplication of services and gaps of services that may be minimized by the development of cross-collaboration.

Slide 11

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

ADRC Training   13

This is a brief outline of the key components within each network.

Slide 12

DOEA

- Provides services that include
  - Elder Helpline (1-800-963-5337)
  - 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)

ADRC Training   12

This information on the Department of Elder Affairs (DOEA) includes a partial listing of aging services. The Elder Helpline phone number provides direct access to the 11 Area Agencies on Aging.

Slide 13

Map of the 11 Planning and Service Areas (PSAs), which are the geographical designation of the Area Agency's service area: Point out the PSAs represented by attendees in this session.

Slide 14

This slide identifies the key functions of an Aging and Disability Resource Center (ADRC). To become an ADRC, an Area Agency on Aging must demonstrate how it is offering services to an expanded population covered under the ADRCs.

Slide 15

Details of the Florida Aging and Disability Resource Center Expansion Grant.

Slide 16

Details on the purpose of the grant and ADRC expansion.

Florida's ADRC Expansion Grant

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

ADRC Training   18

Slide 17

This is an overview of the Agency for Persons with Disabilities (APD) and the population it serves.

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

ADRC Training   19

Slide 18

Additional information on APD.

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

ADRC Training   20

Slide 19

APD Area and Regional Offices
ADRC Training   21
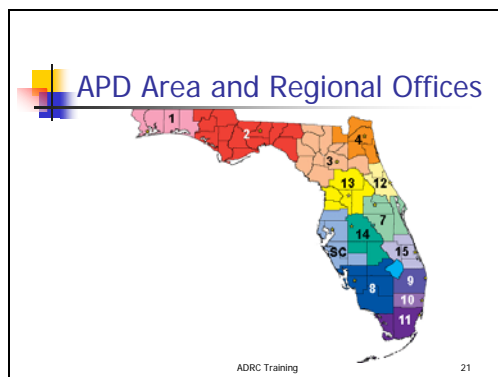
A map of the 13 area offices and one regional office: Point out the office(s) represented by attendees in this session.

Slide 20

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

ADRC Training   22

This slide highlights the benefits of collaboration. If there is time at the end of Module 1, groups can discuss specific benefits for their region (see worksheet #1).

Slide 21

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

ADRC Training   21

Reasons why collaboration helps to 'bridge the networks' and 'break down silos.' Either term can be used to reference the collaboration of the aging and developmental disabilities networks.

Slide 22

> ## 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
>
> ADRC Training   24

Building collaborations can help maximize services and supports for all older Floridians. It is easier to develop the collaboration one person and one service at a time. The experience gained by each network representative will provide information and expertise for the next person eligible for services from ADRCs.

Slide 23

> **Meeting the Needs of Aging Persons with Developmental Disabilities**
>
> *Cross Network Collaboration for Florida*
>
> Commonalities and Differences Between Networks
>
> ADRC Training   25

Transitional slide for commonalities and differences between the networks.

Slide 24

> ## 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
>
> ADRC Training   26

The caregivers of persons with developmental disabilities are usually the most common bridging point between the networks as they often need services from both networks. Each network strives to provide supports to keep individuals at home in their communities and to help maintain the independence of their consumers. Both networks have a goal of as much consumer input and oversight for their own care as possible.

Slide 25

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

ADRC Training   25

A list of additional commonalities between the networks.

Slide 26

Differences

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

ADRC Training   28

Differences between the networks are listed here. Each network uses its own terminology including different titles for staff providing similar services. The example listed here is case managers versus support coordinators.

Slide 27

Differences

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

ADRC Training   27

Additional differences listed.

Slide 28

> ### Meeting the Needs of Aging Persons with Developmental Disabilities
> *Cross Network Collaboration for Florida*
>
> Changing Dynamics for Adults with Developmental Disabilities
>
> ADRC Training   30

Transitional slide for Changing Dynamics for Adults with Developmental Disabilities.

Slide 29

> ### 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
>
> ADRC Training   31

Some of the changes common for persons with developmental disabilities and their families.

Slide 30

> ### Typical Lifespan
>
> - Mid-70s: Mild to moderate developmental disabilities
>
> - Mid-50s: Severe developmental disabilities and Down syndrome
>
> ADRC Training   30

The typical lifespan for persons with developmental disabilities across the nation.

Slide 31

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

ADRC Training   31

An overview of the known life situations throughout the nation with Florida's statistics similar to the rest of the nation.

Slide 32

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

ADRC Training   34

Possible changes that can be expected based on research, health care status surveys, and statistical information gathered internationally.

Slide 33

Meeting the Needs of Aging Persons with Developmental Disabilities

Cross Network Collaboration for Florida

Stress in Caregivers of Adults with Developmental Disabilities

ADRC Training   35

Transitional slide for Stress in Caregivers of Adults with Developmental Disabilities.

Slide 34

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

ADRC Training   34

Information gathered from research, caregiver forums, surveys, and agencies across the US providing services to persons with developmental disabilities and their caregivers.

Slide 35

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

ADRC Training   35

Increased stress is very common in older caregivers of persons with developmental disabilities, especially as a result of the accumulation of stresses across the family lifespan. Crisis is common, especially for families that have not planned for the future aging of the family member with developmental disabilities or for the needs of the caregiver. Crisis can result in loss of independence and quality of life.

Slide 36

Meeting the Needs of Aging Persons with Developmental Disabilities

Cross Network Collaboration for Florida

Referral and Intake

ADRC Training   38

Transitional slide for Referral and Intake.

Slide 37

Collaborative Referral

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

ADRC Training 37

Requests for services and information may come to agencies and offices within either network. It helps to respond to requests if the offices in each network know how to contact the other network. The opening exercise is intended to provide training attendees with specific contact information.

Slide 38

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

ADRC Training 38

Each network has different eligibility criteria for services and supports. A collaborative intake process is established when each network teaches the other about its requirements. This coordinated approach can help minimize frustration and time spent determining if potential consumers are eligible for services in either or both networks. The ADRCs should be able to provide individuals with information about the intake process for each network.

Slide 39

Meeting the Needs of Aging Persons with Developmental Disabilities

Cross Network Collaboration for Florida

Common Truths About Aging

ADRC Training 41

Transitional slide for Common Truths About Aging.

Slide 40

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

ADRC Training   40

The patterns of aging are similar for all persons as they age, regardless of any pre-existing disabilities. The factors of aging interact with the developmental disability to affect aging, possibly increasing specific risk factors for each individual. In general, the more severe the disability the more likely the individual will experience earlier aging with an increased risk for diseases associated with aging.

Individuals with Down syndrome and cerebral palsy have potentially increased risk for disease and earlier aging as a result of the disability. The specific risks for disease will be discussed in more detail in later modules.

Slide 41

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
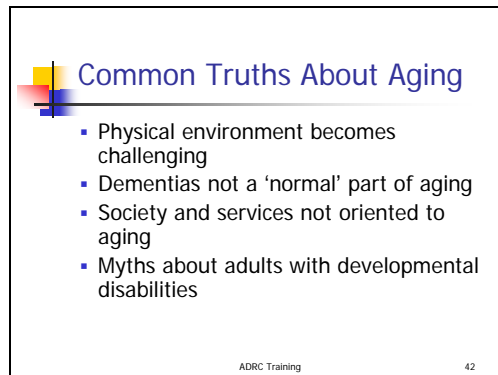
ADRC Training   43

Research and statistical information demonstrate that having a family member with a developmental disability will increase the stress for caregivers over the lifespan. This stress can include increased risk for poverty, lack of time to care for one's own health, and difficulties obtaining services.

As the individual with developmental disability ages, practitioners who are the resources for the caregiver are not usually prepared for aging of individuals with developmental disabilities. This includes lack of knowledge about aging in persons with developmental disabilities, lack of available services in a system that has generally concentrated on services for younger people, and lack of available information on healthy aging practices.

Older people with developmental disabilities are more likely to be on more medications than people in the general population. They are also more likely to be on medications that are not commonly used by the general population such as psychotropic medications. As in the general population, people age into increased risk for adverse affects of medications.

Slide 42

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

ADRC Training   42

The physical environment becomes more challenging for the older person due to age-associated conditions such as arthritis, visual and hearing impairments. For people with developmental disabilities resulting in earlier onset of sensory impairments and mobility challenges, the physical environment can be even more difficult.

Dementias are not a 'normal' part of aging. It is important to consider that a disease process due to an underlying condition could be causing the cognitive and functioning loss.

In general, society and available services are not oriented for older people. An example is a typical office building with significant glare and mobility barriers.

There are myths about aging and older people in society. A pre-existing disability can complicate the perceptions, thus increasing myths about older people with developmental disabilities.

Slide 43

> ### Summary of Module 1
>
> - ADRC expansion to include persons with developmental disabilities
> - Collaboration across the networks can help Floridians age well
>
> ADRC Training   45

The intent of Module 1 is to support the expansion of the ARCs to ADRCs by including persons with developmental disabilities and their caregivers.

Collaboration across networks can result in increased resources to help Floridians age well.

Slide 44

> ### Group Discussion
>
> - Questions
>
> ADRC Training   46

If there is time, ask the participants to recheck their contact information on the "Meeting the Needs of Aging Persons with Developmental Disabilities" worksheet for Module 1, which was completed earlier in the individual workgroups.

MODULE 2

Aging and Developmental Disabilities Systems

Slide 1

Meeting the Needs of Aging Persons with Developmental Disabilities

Cross Network Collaboration for Florida

Aging and Developmental Disabilities Systems

Module 2

Based on ADRC training developed by:
Kathleen M. Bishop, Ph.D., and Ron Lucchino, Ph.D.

Slide 2

Purpose of Module 2

- Develop an inclusive referral and intake system
- Provide overview of aging and developmental disability networks
- Identify commonalities and differences

ADRC Training   2

Over 50 percent of caregivers of an adult with developmental disabilities are not receiving *supportive* developmental disability services for a variety of reasons. Caregivers seeking services for the first time are usually seeking aging services for themselves or a family member. This often occurs when a crisis is approaching.

The overlapping commonalities between the networks are strong bases for successful bridging in the development of the ADRC's referral network and seamless intake process. Although there are differences between the networks, these should not be barriers to providing aging services to the caregivers and the adult with developmental disabilities.

Slide 3

Purpose of Module 2

- Understand Florida eligibility criteria for developmental disabilities services
- Foster cooperation between networks

ADRC Training   3

A major purpose of this module is to encourage networks to work together developing a database that includes a referral system and intake process that is inclusive of the traditional and non-traditional aging and developmental disabilities networks.

Slide 4

Meeting the Needs of Aging Persons with Developmental Disabilities

Cross Network Collaboration for Florida

Referral and Intake

ADRC Training   6

Transition slide for Referral and Intake.

Slide 5

Cross Referral Outcomes

- Referral provided by developmental disability and aging networks
- A seamless integrated system
- Inclusion of all agencies
- Expanded referral network for early crisis intervention

ADRC Training   7

The caregiver, at high risk of stress, is vulnerable to experiencing a crisis. The caregiver needs supportive services from both networks – thus cross referral is essential in meeting caregiver needs and reducing the likelihood of a crisis. Accessing resources in the ADRC database can reduce the risk of crisis through early identification of possible service interventions.

Slide 6

Referral Sources – Aging Network

- Senior centers/nutrition programs
- Adult transportation programs
- Home health agencies
- Day care/respite programs
- Companion agencies
- Assisted living facilities/nursing homes

ADRC Training   8

There are many aging referral sources included in the ADRC database that are recognized as traditional aging agencies. It is helpful to include those agencies that provide supportive services to individuals with disabilities and their caregivers.

Slide 7

Referral Sources – Developmental Disability Network

- Agency for Persons with Disabilities (APD)
- For-profit and not-for-profit private disability service providers
- Centers for Independent Living
- Neighbors, family, friends

ADRC Training   9

The APD network of referral and intake agencies should be included in the ADRC database. There are agencies and networks outside of the APD system that provide supportive developmental disability services, which should also be included in the ADRC database. The more inclusive the ADRC database, the better a resource it is for individuals with developmental disabilities and their caregivers.

Slide 8

Referral Sources - Community

- Health care practitioners
- Funeral homes
- Hospital and long-term care facility discharge planners
- First responders including police, fire department, and ambulance
- Places of worship
- Hospice
- School teachers and counselors

ADRC Training   8

The agencies, organizations and networks listed on this slide are examples of "non-traditional" supportive aging networks. These and others like them are valuable sources of referral to the ADRC because many caregivers are introduced to the aging network through initial contact with these agencies.

ADRC Training   27

Slide 9

Intake - Access Care Options

- Determine for caregivers and older adults with developmental disabilities:
  - Service needs related to aging
  - Service needs related to disability
  - Past and current history for services
  - Availability of services
- Coordinate to assure no duplication of services

ADRC Training   11

Older caregivers needing aging services, either for themselves or family members, will seek ADRC intake services. During the intake process it may be revealed that the adult with developmental disabilities may not be receiving APD services. Based on knowledge of eligibility criteria, both networks can cooperate in determining the type of aging and disabilities services the family may need.

Slide 10

Meeting the Needs of Aging Persons with Developmental Disabilities

Cross Network Collaboration for Florida

Aging Network

ADRC Training   12

Transition slide for the Aging Network

Slide 11

Structure of the Aging Network

- Administration of Aging (AoA)
  - Older Americans Act (1965)
- Florida Department of Elder Affairs (DOEA)
  - State Unit on Aging (SUA)
- Area Agencies on Aging (AAA)
- Community providers of aging services

ADRC Training   13

The Older Americans Act created the Administration on Aging to provide funding and empower the states to develop units on aging. In Florida the state unit on aging is known as the Department of Elder Affairs.

Slide 12

Structure of the Aging Network- DOEA

- Serves 624,000+ elders and their families annually
- Designated by AoA as the State Unit on Aging
- Contracts services to Area Agencies on Aging (AAAs) – private, non-profit organizations

ADRC Training   14

The DOEA contracts with the Area Agencies on Aging which subcontract with community providers for services supporting the aging population.

Slide 13

Structure of the Aging Network - AAA

- Coordinate aging services through a network of providers
- Designated by DOEA within a Planning and Service Area (PSA)
- Eleven PSAs divided by counties

ADRC Training   15

The 11 Area Agencies on Aging operate within designated geographical areas known as Planning and Service Areas. Their responsibilities include strategic planning and funding to support the future service needs of the aging population.

Slide 14

DOEA PSA Map

ADRC Training   16

The 11 PSAs are grouped according to counties.

Slide 15

AAA as ARC/ADRC

- 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

ADRC Training   17

The AAAs are designated as Aging Resource Centers providing central referral and intake services – "one stop shopping" – for an aging population. The ARCs are currently evolving into Aging and Disability Resource Centers by including aging adults with developmental disabilities and their caregivers. The role of the ADRC is to create a cooperative link with the APD to enhance the provision of information and identification of appropriate services to the aging caregivers. This is best accomplished through a seamless referral and intake system.

Slide 16

Aging Services

- Information and Referral
  - Elder Helpline (800-963-5337)
- Case management
- In-home supports
- Nutrition assistance
- Caregiver training and respite
- Alzheimer's disease screening and day care

ADRC Training   18

This is a partial list of the services available through the aging network. The Elder Helpline number on this slide is the toll-free state referral number for accessing ADRC services. The calls to this number are routed to the ADRC/ARC in the Planning and Service Area where the caller is located.

Slide 17

Eligibility for Aging Services

- Age
- Frailty
- Resources
- Funding

ADRC Training   19

There are four eligibility criteria for aging services:

Age - Depending on the funding source and services, the age of eligibility can range from 18 for Alzheimer's Disease Initiative to 55 for some Older Americans Act programs. For most services, individuals must be 60 years of age.

Frailty - Some services are based on the functioning ability of the older adult.

Resources – Eligibility for services takes into account the resources within an individual's support system. Also for some programs, eligibility is based on the economic need of an older adult.

ADRC Training   30

Funding - The availability of funded services is matched to the client's need. When there are funding limitations, individuals are placed on a waiting list.

Slide 18

Contact ADRC
(http://www.agingresourcecentersofflorida.org)

ADRC Training   18
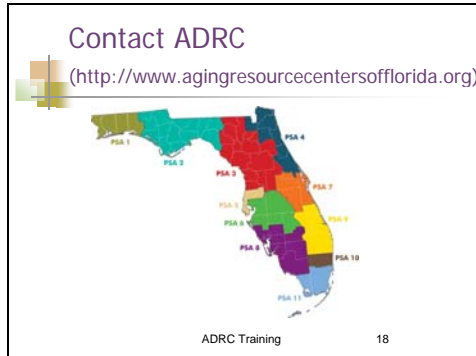
The map is interactive with an Internet connection. Clicking on the map for the ADRC you wish to contact or through the contact information below can access information.

- PSA 1 - Escambia, Santa Rosa, Okaloosa, Walton – (850) 494-7101
- PSA 2 - Bay, Calhoun, Franklin, Gadsden, Gulf, Holmes, Jackson, Jefferson, Leon, Liberty, Madison, Taylor, Wakulla, Washington – (866) 467-4624
- PSA 3 - Alachua, Bradford, Citrus, Columbia, Dixie, Gilchrist, Hamilton, Hernando, Lafayette, Lake, Levy, Marion, Putnam, Sumter, Suwannee, Union – (800) 963-5337,
- PSA 4 - Baker, Clay, Duval, Flagler, Nassau, St. Johns, Volusia – (904) 391-6600
- PSA 5 - Pasco and Pinellas – (727) 217-8111
- PSA 6 - Hillsborough, Polk, Manatee, Highlands and Hardee – (813) 740-3888
- PSA 7 - Brevard, Orange, Osceola, Seminole – (407) 514-1800
- PSA 8 - Charlotte, Collier, DeSoto, Glades, Hendry, Lee, Sarasota – (239) 652-6900
- PSA 9 - Indian River, Martin, Okeechobee, Palm Beach, St Lucie – (866) 684-5885
- PSA 10 - Broward – (954) 745-9779
- PSA 11 - Miami-Dade, Monroe – (305) 670-4357

Slide 19

Meeting the Needs of Aging Persons with Developmental Disabilities

Cross Network Collaboration for Florida

Developmental Disabilities Network

ADRC Training   21

Transition slide for the Developmental Disabilities Network.

Slide 20

Structure of the Developmental Disability Network

- Federal Administration on Developmental Disabilities (ADD) mandated services
- Florida's Agency for Persons with Disabilities (APD) – separated from Dept. of Children and Family Services in 2004
- Private providers

ADRC Training   20
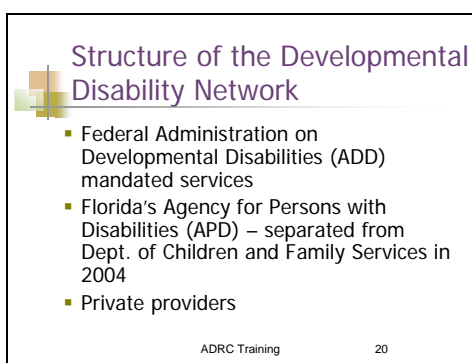
The Federal Administration on Developmental Disabilities is comparable to the Administration on Aging in mandating services in the 50 states. In Florida, the APD was established to provide referral and intake services for persons with developmental disabilities.

Slide 21

Structure of the Developmental Disability Network - APD

- Central office in Tallahassee
- Thirteen Area Offices in Florida
- One Regional Office
- Area and Regional Offices divided by counties

ADRC Training   21
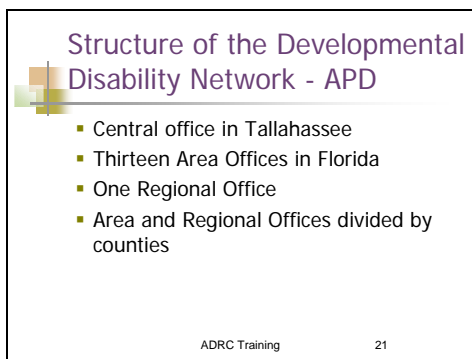
APD operates through local offices, serving geographical areas designated by counties.

Slide 22
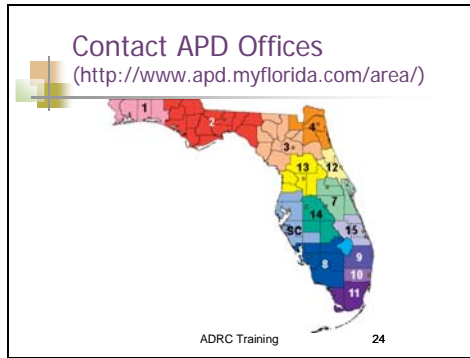
The map is interactive with an Internet connection. Information on the 13 APD areas and one regional office can be accessed by clicking on the map for the APD office you wish to contact or though the contact information below:

- Area 1 - Escambia, Okaloosa, Santa Rosa, Walton - (850) 595-8351
- Area 2 - Bay, Calhoun, Franklin, Gadsden, Gulf, Holmes, Jackson, Jefferson, Liberty, Leon, Madison, Taylor, Wakulla, Washington - (850) 487-1992
- Area 3 - Alachua, Bradford, Columbia, Dixie, Gilchrist, Hamilton, Lafayette, Levy, Putnam, Suwannee, Union - (352) 955-6061
- Area 4 - Baker, Clay, Duval, St Johns, Nassau - (904) 992-2440
- Area 7 - Brevard, Orange, Osceola, Seminole - (407) 245-0440
- Area 8 - Charlotte, Collier, Glades, Hendry, Lee - (239) 338-1370
- Area 9 - Palm Beach - (561) 837-5564
- Area 10 - Broward - (954) 467-4218
- Area 11 - Dade, Monroe - (305) 349-1478
- Area 12 - Flagler, Volusia - (386) 947-4026
- Area 13 - Citrus, Hernando, Lake, Marion, Sumter - (352) 330-2749
- Area 14 - Hardee, Highlands, Polk - (863) 413-3360
- Area 15 - Indian River, Martin, Okeechobee, St Lucie - (772) 469 4080
- Suncoast - DeSoto, Hillsborough, Manatee, Pasco, Pinellas, Sarasota - (813) 233-4300

Slide 23

History of Florida's Developmental Disability Network

- 1900s to 1960s: Development of large institutional care facilities
- 1980s: De-institutionalization
  - Inclusion in families and communities
  - Focus on supports and services
- 1990s: Expansion of Medicaid waiver and family supports
- 2000s: Focus on person-centered approach
  - Self-directed services   23

The evolution of the developmental disabilities network has gone from the most restricted environment (institutionalization) to the least restricted (person-centered planning and Medicaid waiver community-based services). The aging network is undergoing a similar evolution, from most restricted (nursing home) to least restricted (home and community-based services).

Slide 24

Functions of APD

- Serves Floridians with developmental disabilities
- Partners with local communities
- Coordinates with private providers

ADRC Training   24

The APD, in addition to determining eligibility for services and contracting with community service agencies, will now partner with ADRC to determine aging services for the older caregiver and the aging adult with developmental disabilities.

Slide 25

Functions of APD

- Assists to identify the needs and individual expectations of persons with developmental disabilities
- Maintains a waiting list for services of approximately 20,000
- Contracts with support coordinators and other community providers

ADRC Training   25

Slide 26

Services of APD

- Serves approximately 50,000 Floridians with developmental disabilities and their families
- Services include –
  - Support coordination for services
  - Transportation
  - Supported living and employment
  - Adult day programs

ADRC Training   26

This is a partial listing of the services available through APD. The APD contracts all services from for-profit and non-profit agencies supporting eligible individuals with developmental disabilities. Aging services for older caregivers, although not provided by APD, may be available from DOEA.

Slide 27

Developmental Disabilities Resources in Florida

- Florida Developmental Disabilities Council (www.fddc.org) – publications:
  - Planning Ahead
  - People First Language/Disability Etiquette
- Able Trust (www.abletrust.org)
- Family Care Council (www.fccflorida.org)
- Family Network on Disability (www.fndfl.org)

ADRC Training   27

Slides 27 and 28 are important resources to help individuals with developmental disabilities.

Slide 28

Developmental Disabilities Resources in Florida

- Florida Alliance for Assistive Services and Technology, Inc. (www.faast.org)
- FDLRS - Florida Diagnostic and Learning Resource System (www.paec.org/fdlrsweb)
- CARD – Centers for Autism and Related Disorders (www.centerforautism.com)

ADRC Training   28

Slide 29

**Meeting the Needs of Aging Persons
with Developmental Disabilities**

Cross Network Collaboration for Florida

Developmental Disabilities Eligibility Criteria

ADRC Training   29

Transitional slide for Developmental Disabilities Eligibility Criteria.

Slide 30

Florida's Service Eligibility Criteria for Developmental Disabilities

- Retardation
- Cerebral palsy
- Autism
- Spina bifida
- Prader-Willi syndrome

Chapter 393.063(9), Florida Statutes

ADRC Training   30

Florida's five APD eligibility categories do not include all categories for developmental disabilities identified by the Federal government. The new term for developmental disabilities is intellectual or developmental disabilities (IDD or ID/D).

Slide 31

Eligibility Criteria for APD Services

- One of the five disabilities identified by Florida Statutes
- U.S citizen or resident alien
- Persons must be domiciled in the State of Florida
- Determination of residency through a Florida driver license, school records, utility bill, employment information, rental or mortgage statement

ADRC Training   31

Slides 31 and 32 provide additional eligibility criteria for APD services. It is necessary that families from other states provide documentation to be considered for services in Florida. Moving from another state where developmental disability services were received does not guarantee eligibility in Florida. Having documentation is critical in eligibility determination.

Slide 32

Eligibility Criteria for APD Services

- Disability diagnosed before age 18
- ADP determines eligibility by:
  - Testing and diagnostic workup
  - Review of school or medical records, if available
- Documentation of life-long (not psychiatric) impairment or dysfunction

ADRC Training   32

In Florida, the responsibility for providing services to individuals with developmental disabilities is shared by three agencies:

- Children's Medical Services in the Dept. of Health serves those from birth to three years of age;
- The Dept. of Education is responsible for providing services to those up to age 22 in the school system; and
- APD serves those age four and older.

Slide 33

Eligibility Criteria for APD Services

- Adults with developmental disabilities may move up the waiting list for services by meeting the crisis criteria as defined by Florida Statutes:
  - Homelessness
  - Aging caregiver can no longer provide care
  - A danger to self or others

ADRC Training   33

This slide describes the three crisis eligibility criteria used by APD to prioritize individuals for services. The second criteria "aging caregiver can no longer provide care" occurs when there are no adequate aging services to support an older caregiver. This could result in a physical and social network collapse for the individual and caregiver. This is the one key benefit of the ADRC working with the APD for early intervention: to stop or delay collapse and crisis.

Slide 34

Eligibility Criteria for APD Services

- Medicaid eligibility through Department of Children and Families
- Services provided through a waiver or within an Intermediate Care Facility (ICF)

ADRC Training   **34**

The Department of Family and Children determines eligibility for Medicaid funds, which is necessary to receive waiver services from APD. The Social Security Act created ICFs to support "institutions" (four or more beds) for people with retardation and it specifies that institutions must provide "active treatment." (ICF is a link to the map of Florida Intermediate Care Facilities.)

Slide 35

Florida's Service Eligibility Criteria for Developmental Disabilities

- The following five definitions have been paraphrased from Florida's statutes. The specific statute is listed under each definition ...

ADRC Training   35

The definitions for each of the five categories were paraphrased for brevity because the specific definitions are more detailed and contain medical terms.

Slide 36

Definition of Retardation

- Significantly sub-average general intellectual functioning
- Difficulties with adaptive behavior across the lifespan –
  - Personal independence
  - Social responsibility expected of age, cultural group, and community

Chapter 393.063(31), Florida Statutes

ADRC Training   36

The definition of retardation is "significantly sub-average general intellectual functioning existing concurrently with deficits in adaptive behavior that manifests before the age of 18 and can reasonably be expected to continue indefinitely."
Chapter 393.063(31), F.S.

"**Significantly sub-average general intellectual functioning**" means performance that is two or more standard deviations from the mean score on a standardized intelligence test as specified in the rules of the agency.

"**Adaptive behavior**" means the effectiveness or degree with which an individual meets the standards of personal independence and social responsibility expected of his or her age, cultural group, and community.

Slide 37

Definition of Cerebral Palsy

- A group of disabling symptoms of extended duration
- Results from damage to the developing brain that may occur before, during, or after birth
- Results in the loss or impairment of control over voluntary muscles

Chapter 393.063(4), Florida Statutes

ADRC Training   37

The definition of cerebral palsy is "a group of disabling symptoms of extended duration which results from damage to the developing brain that may occur before, during, or after birth and which results in the loss or impairment of control over voluntary muscles." Chapter 393.063(4), F.S.

Slide 38

Definition of Autism

- With age of onset during infancy or childhood
- Individuals with autism exhibit:
  - Impairment in reciprocal social interaction
  - Impairment in verbal and nonverbal communication and imaginative ability
  - A markedly restricted repertoire of activities and interests

Chapter 393.063(3), Florida Statutes

ADRC Training   38

The definition for autism is "a pervasive, neurologically based developmental disability of extended duration which causes severe learning, communication, and behavior disorders with age of onset during infancy or childhood." Chapter 393.063(3), F.S.

Individuals with autism exhibit impairment in reciprocal social interaction, impairment in verbal and nonverbal communication and imaginative ability, and a markedly restricted repertoire of activities and interests.

Slide 39

Definition of Spina Bifida

- A birth defect where the spinal cord is not covered by tissue

Chapter 393.063(35), Florida Statutes

ADRC Training   39

The definition for spina bifida is a medical diagnosis of spina bifida cystica or myelomeningocele: A condition where the tissue covering the spinal cord sticks out of the spine as a defect but the spinal cord remains in place. Chapter 393.063(35), F.S.

Slide 40

Definition of Prader-Willi Syndrome

- Inherited condition characterized by:
  - Poor muscle tone
  - Failure to thrive
  - Obesity usually at 18 to 36 months of age
  - Mild to moderate mental retardation
  - Characteristic neurobehavioral

Chapter 393.063(23), Florida Statutes

ADRC Training   40

The definition for Prader-Willi is "an inherited condition typified by neonatal hypotonia with failure to thrive, hyperphagia or an excessive drive to eat which leads to obesity usually at 18 to 36 months of age, mild to moderate mental retardation, hypogonadism, short stature, mild facial dysmorphism, and a characteristic neurobehavior."
Chapter 393.063(23), F.S.

Slide 41

Disabilities Not Covered in APD Statute

- Learning disabilities
- Asperger's syndrome – One of the autism spectrum disorder classifications with an average to above average intellectual functioning
- Down syndrome – unless meets criteria for retardation as defined by Florida Statutes
- Epilepsy

ADRC Training   41

Florida is a destination state for many retirees, some with adult children with developmental disabilities. Florida Statutes do not recognize these categories but the Federal government does. An adult with developmental disabilities who has moved to Florida with family may not be eligible for APD services without a Florida identified developmental disability. The ADRC should look beyond the APD service network for agencies that may provide developmental disabilities services. This is a reason for an inclusive referral system as mentioned earlier.

Slide 42

Meeting the Needs of Aging Persons with Developmental Disabilities

Cross Network Collaboration for Florida

Commonalities and Differences Between the Networks

ADRC Training   36

Transition slide for network comparisons.

Slide 43

Commonalities Between the Networks

- Provide services in least restrictive environment
- Operate a coordinated service system
- Support consumer self-determination
- Address needs of older caregivers
  - Caregivers are the most likely area for bridging

ADRC Training   37

The key take-home message from this slide is that both the APD and the ADRC have the common goal of self-determination in choosing services in the least restrictive environment.

Slide 44

Commonalities Between the Networks

- Similar aging needs
- Waiting lists for services
- Many services are not entitlements
- Services prioritized by client needs
- Empowered by the federal government to provide services

ADRC Training   38

It is important to emphasize that both networks are empowered by the Federal government to provide services, which are not entitlement programs but eligibility based. Each network maintains a waiting list for eligible services; being eligible does not guarantee services.

Slide 45

Differences Between the Networks

- Eligibility criteria
- Regulations and mandates
- Service provision
- Service areas
- Organizational structure
- Agency structure and process

ADRC Training   40

The differences between the networks are not impediments to bridging referral and intake for older adults with developmental disabilities and their caregivers. The differences are mainly eligibility criteria for services and the configuration of the service areas. The other differences can be overcome through understanding each other's structure and language.

Slide 46

Differences Between the Networks

- Aging
  - ADRC Structure – private non-profit organizations
  - Language/acronyms
    - Case managers
    - Aging Resource Centers (ARCs)
- Developmental Disability
  - APD Structure – government agency
  - Language/acronyms
    - Support coordinators
    - Arcs – also known as Association for Retarded Citizens

ADRC Training 39

Slide 47

Area Comparison Maps

ADRC Training   47

This slide illustrates the differing boundaries of the APD and the ADRC service areas. In some instances, they are identical, and in others, they are not. This inconsistency results in difficulty when the ADRC/APD collaboration may have to include more than one area in the network.

Slide 48

Summary of Module 2

- Aging and disability networks share commonalities that can build collaboration
- Understanding eligibility criteria for services can help match consumer needs to available services
- Caregiver is often the bridge for collaboration between the networks

ADRC Training   51

Emphasize the three major summary points of Module 2:
- Bridging networks can be a success based on commonalities.
- Eligibility for developmental disability services does not preclude receiving aging services that meet the ADRC criteria.
- Based on their aging needs, caregivers are often the bridge between the two networks.

Slide 49

Exercise

- Scenarios
  - See handout for scenarios and questions
- Group discussion
  - Questions

ADRC Training   52

See Appendix C for instructions on how to use the scenario group exercises.

MODULE 3

Aging in Individuals with a Developmental Disability

Slide 1
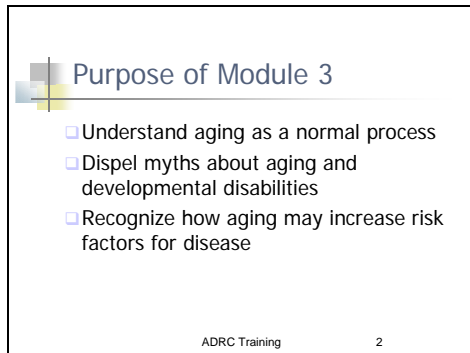
> **Meeting the Needs of Aging Persons with Developmental Disabilities**
>
> *Cross Network Collaboration for Florida*
>
> **Aging in Individuals with a Developmental Disability**
>
> **Module 3**   Based on ADRC training developed by: Kathleen M. Bishop, Ph.D., and Ron Lucchino, Ph.D.
>
> ADRC Training   1

Slide 2

> ### Purpose of Module 3
>
> ❑ Understand aging as a normal process
> ❑ Dispel myths about aging and developmental disabilities
> ❑ Recognize how aging may increase risk factors for disease
>
> ADRC Training   2

The purpose of Module 3 is to increase the ADRC's awareness that although aging is a normal process, there are special circumstances that must be understood about the aging process in individuals with development disabilities. Some of these circumstances include the prevalence of myths, an increased vulnerability to disease, the interaction of their disabilities with aging, and the adverse drug reactions associated with their medications. Any or all of these may mimic or mask the aging process in individuals with developmental disabilities.

Slide 3

Purpose of Module 3

- Understand aging with developmental disabilities is the overlap of aging and disabilities
- Recognize how medications may affect adults with developmental disabilities

ADRC Training   3

Slide 4

Meeting the Needs of Aging Persons with Developmental Disabilities

Cross Network Collaboration for Florida

What Is Aging?

ADRC Training   5

Transition slide for What Is Aging.

Slide 5

Aging Factors

- Determined by interaction of three factors
  - Life-long choices (diet, physical and mental exercise, self-esteem)
  - Environment (physical, cultural and social)
  - Genetics
  - Successful aging from positive genes
  - Negative aging from life-long or late-onset gene

ADRC Training   5

The interaction of the three factors of aging is the same for everyone. Genetics cannot be controlled. Lifestyle and environment can be controlled through individual choices and can influence whether an individual experiences successful or negative aspects to aging. In the developmental disability population, lifestyle is sometimes overlooked as a factor, resulting in an increased prevalence for diseases or disorders.

Slide 6

Aging Changes

- Age related: Common to everyone
  - Interventions may slow decline
- Age associated: Not common to everyone
  - Associated with disease, disorders, poor lifestyle choices, negative environment
  - Controlled by individual choices

ADRC Training   6

Although aging changes are common to everyone, the changes may occur at different ages because aging is an individual experience. What's not a common aging change are the diseases caused by negative influences from the three factors of aging; these are individual and determined by the interaction of the aging factors. It is important for ADRCs to encourage services that reduce negative aging through better lifestyle.

Slide 7

Aging in Adults with Developmental Disabilities

- Interaction of pre-existing disability with factors of aging may result in:
  - Increased risk factors with earlier onset of symptoms
  - Increased risk for inappropriate medical treatment
  - Increased vulnerability to a more restrictive environment

ADRC Training   8

Overlaying disabilities with aging may mask or mimic diseases or disorders in the older adult with developmental disabilities. Many health care professionals may not be trained in aging and developmental disabilities resulting in inaccurate diagnoses putting individuals at risk of early signs of aging and early loss of independence leading to a more restricted environment.

Slide 8

Aging in Adults with Developmental Disabilities

- Interaction of pre-existing disability with factors of aging may result in:
  - Increased challenging behaviors due to communication difficulties
  - Increased cost for treatment and interventions
  - Increased staff/family frustration due to lack of communication and knowledge

ADRC Training   9

Adults with developmental disabilities may have difficulty expressing reactions to inappropriate services resulting from misdiagnosis. This may cause challenging behaviors resulting in staff frustration. Change in behavior is an indication that something is not right. If adjustments are not made, the individual may experience deteriorating health and increased health care costs.

Vision decline is an example of a pre-existing condition that may affect a person's behavior and the reason for the change in behavior may not be apparent or communicated. In this example, the appropriate service is to schedule a visit to the optometrist for an eye examination.

The decline in visual and auditory senses may result in behavior changes due to an individual's confusion about the surroundings. These changes may include disorientation and memory loss, which mimic dementia.   Services that address these signs of dementia (medications) will not stem the confusion but exacerbate the behavior because there is still reduced sensory input. In this situation, individuals need to have their vision and hearing checked.

Slide 9

Meeting the Needs of Aging Persons with Developmental Disabilities

Cross Network Collaboration for Florida

Myths About Aging and Developmental Disability

ADRC Training   10

Transition slide for Myths About Aging and Developmental Disability. This section debunks three myths that increase vulnerability to an inappropriate intake process.

Slide 10

Myths - Aging and Developmental Disability

- All individuals with developmental disabilities experience earlier onset of aging - **False**
- All adults with Down syndrome will exhibit the symptoms of Alzheimer's disease - **False**
- Majority of adults with developmental disabilities live in supervised residential care facilities - **False**

ADRC Training   11

Myths concerning adults with developmental disabilities can do harm, especially if the health care professionals accept them. The ADRCs must be alert that these myths are not barriers to receiving appropriate services.

Slide 11

Consequences of Myths

- Affect quality of assessment and intervention
- Influence attitudes of staff, family, and providers
- Limit available choices and resources
- Affect quality of life

ADRC Training   11

This slide identifies the consequences when these myths are prevalent.

Slide 12

Myth 1 – Early Onset of Aging

- Persons with mild to moderate developmental disabilities and the general adult population experience:
  - Same rate and age-related changes
  - Similar longevity
  - Individual aging influenced by genetics and lifestyle choices

ADRC Training   13

In the literature there are references to early aging in the developmental disabilities population. This perception may be due to the overlay of disabilities interacting with normal aging changes. The aging developmental disabilities population has the same aging changes and rates of change as the general population.

Slide 13

Adults with Down syndrome and cerebral palsy experience the same changes and rates, but at an earlier age than the general and developmental disabilities populations.

Slide 14
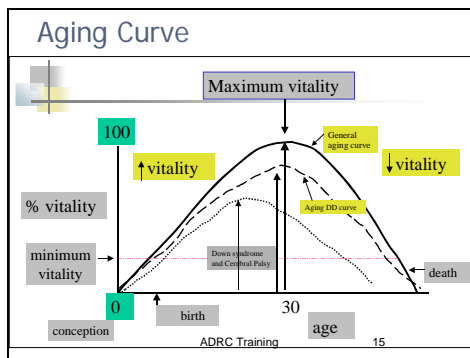
Vitality is the measure of the functioning level of the body. At 100 percent it means the body is at its maximum prime. Maximum vitality in the general population means a full reserve or full capacity in function. Maximum vitality in individuals with developmental disabilities is lower because the capacity level is lower – less reserve to lose while aging.

The three curves on the aging graph emphasize that the aging developmental disability population and general population experience the same aging and rates of change. The difference in individuals with developmental disabilities is the lower level of vitality. This reduction in vitality is due to disabilities.

In the Down syndrome and cerebral palsy curve, the changes are the same and the rates are similar but both occur earlier and the vitality is lower due to the disability, which makes them susceptible to diseases and vulnerable to early death.

For example, in these populations, early reduction in thyroid function due to their disability and compounded by aging may cause hypothyroidism and go un-noticed due to their young age. This may place them at risk for a misdiagnosis of a decline in cognitive function due to a tumor or dementia.

Slide 15
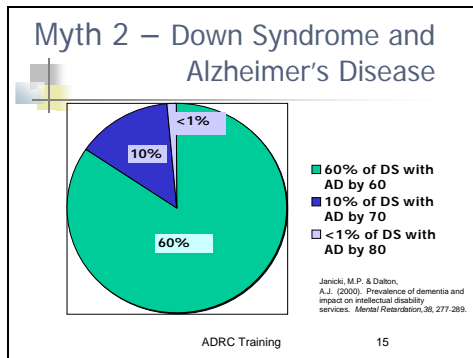
This is an important myth to debunk. Although 100 percent of Down syndrome adults will have neuropathology associated with Alzheimer's, only 70 percent will be diagnosed with Alzheimer's disease by 70 and less than 1 percent after 70. Many health care professionals still believe that 100 percent of Down syndrome adults will be diagnosed with Alzheimer's disease.

Down syndrome adults are very vulnerable to acute dementia, which mimics Alzheimer's disease. Acute dementia is a sudden loss of cognitive ability, including memory that can be reversed if the underlying cause for the loss is determined and treated.

Slide 16
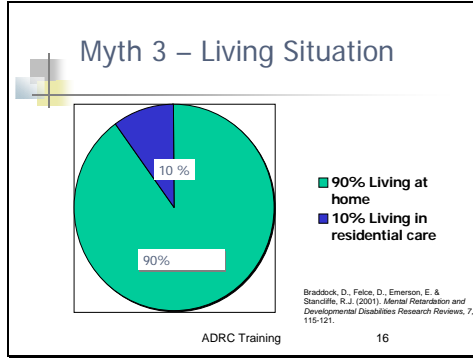
This myth is based on the past. Many adults with disabilities were institutionalized and isolated from society. Over the years the focus has changed to adults with developmental disabilities receiving services in the community but the myth still persists.

Ninety percent of adults with developmental disabilities live at home, either with a caregiver, by themselves or with a spouse or partner. The notion that most live in institutions deflects the concern that the majority of caregivers are 50 and over. It is important for the ADRC to understand the major focus of services will be on aging caregivers.

Slide 17

Transition to Aging in Individuals with a Developmental Disability.

Slide 18

Differentiate "Normal" Aging Changes from Disease

❑ Determine types of interventions to best meet needs
❑ Determine appropriate services
❑ Develop activities appropriate for age-related cognitive/physical changes
❑ Maintain quality of health through increased awareness of changes

ADRC Training   19

There has been very little research on aging in adults with developmental disabilities due to lack of federal funding for research. The general scientific community is reluctant to conduct research on a small population without a funding incentive. Thus there are relatively few scientists trained in developmental disabilities. Longevity studies are just starting to take place because the child with a developmental disability was previously not expected to live beyond 20.

As a result there is difficulty separating "normal" aging from diseases associated with aging. The ADRC must work closely with the APD to ensure services are appropriate for the aging changes and not a response to disease or disorder. This will require more time for assessing the appropriate services than for older adults from the general population.

Slide 19

Pre-existing Developmental Disability Aging Effects

❑ Likelihood of "diagnostic over-shadowing"

▪ Changes related to the disability result in inappropriate or no interventions
▪ Pre-existing cognitive challenges assumed to be symptoms of dementia
▪ Pre-existing disability may be misdiagnosed as disease

ADRC Training   20

Diagnostic over-shadowing is the same as overlay of aging and disabilities associated with a specific diagnostic disorder. As mentioned in slide 18, the ADRC must be careful that the appropriate services are identified to meet aging needs, not the disability needs. Some individuals with developmental disabilities who have a diagnosis of retardation may be misdiagnosed as dementia.

Slide 20

Risk from Inappropriate Intervention

- Reduced vitality and quality of life
- Modified aging process
- Increased misdiagnosis for other diseases (especially Alzheimer's disease)
- Increased behavioral changes

ADRC Training   21

Slide 14 illustrates the reduction in vitality for both the general developmental disabilities population and the greater reduction in adults with Down syndrome or cerebral palsy. This reduced vitality is an example of the over-shadowing that increases vulnerability to misdiagnosis, especially of Alzheimer's disease and Down syndrome.

Slide 21

Meeting the Needs of Aging Persons with Developmental Disabilities

Cross Network Collaboration for Florida

Age-Related Changes Everyone Experiences

ADRC Training   22

Transition slide ...

Slide 22

Sensory Changes Affect the Older Adult

- Reduced sensory acuity
- Increased masking of sensory impairments
- Reduced potential for quality of life and independence
- Increased social isolation

ADRC Training   23

Sensory decline starts at 30. The decline is very slow and not noticed until about 55. The major declines are in vision and hearing, reducing acuity, which may increase the vulnerability of older adults to sensory isolation.

Although the sensory decline is similar in adults with developmental disabilities, the reduced reserve or vitality in some individuals with developmental disabilities may result in a more marked decline.

The decline may result in reduced social interaction that may mimic acute dementia.

The information from the senses tells the brain what is happening in the environment. If the information is not clear, the brain will have difficulty in processing the information. This may result in confusion or slowing of response.

Reduced sensory input due to early disability-related changes and compounded by age-related changes may result in an older adult with developmental disabilities disengaging from social activity. They may not be able to communicate the visual and auditory decline and feel isolated. This can result in anger or depression.

Slide 23

How Is Hearing Affected by Aging?

- ❑ Increased loss of high frequency sounds (children and females voices in particular)
- ❑ Increased interference with hearing
  - ▪ Background sounds interfere with communication
  - ▪ Increased tinnitus – ringing in the ears

ADRC Training   24

The most noticeable change in hearing in all individuals is decline in ability to hear high frequency sounds. You may not hear the full sentence or it may be unclear. As mentioned in Slide 22, this could lead to social isolation. Communication should be slow and background noises reduced. Older adults with developmental disabilities should have their hearing checked periodically for hearing decline and earwax accumulation.

Slide 24

How is Vision Affected by Aging?

❑ Increased glare (light reflection) sensitivity
❑ Increased difficulty adjusting to reduced lighting
❑ Increased difficulty with busy visual patterns

ADRC Training   25

The concerns of decline in vision are similar to hearing. The changes are over a long period and are not noticed but can begin to interfere with independence. If the visual input to the brain is not understood, it can lead to confusion, isolation and behavior problems. The changes in visual acuity include:

1. Decline in ability to measure distances,
2. Need for greater light intensity,
3. Increased sensitivity to glare, and
4. Longer time to adapt to a darkened room.

Slide 25

Effects of Hearing and Visual Impairments on Older People

❑ Increased risk of falls
❑ Decreased social interaction
❑ Increased inappropriate behavior
❑ Decreased verbal communication
❑ Increased misdiagnosis of dementia

ADRC Training   26

The combination of hearing and vision changes usually does not interfere with independence but if the decline is severe it could result in sensory "depravation." This may occur more frequently in adults with developmental disabilities. The changes in Slide 25 are flags that something is amiss and could be mimicking diseases or disorders.

Slide 26

Other Age-related
Changes in Older People

❑ Reduced muscle mass by 15%
  ▪ Increased risk of falls
  ▪ Decreased ability for physical activities
❑ Decreased thyroid function
  ▪ Decreased body temperature
  ▪ Increased symptoms of acute dementia

ADRC Training   27

Age-related[1] muscle mass reduction is about 15 percent, but age-associated is 33 percent (see slide 6). Exercise is critical to keep muscle strength up. The ADRC should help educate caregivers about the benefit of good lifestyle for the aging adult with developmental disabilities.

The thyroid gland activity declines with age, accompanied by some sign of decline in energy. A condition called hypothyroidism can result in a serious decline in energy and stamina, confusion and symptoms of acute dementia. Adults with Down syndrome are very vulnerable to hypothyroidism and misdiagnosis of Alzheimer's disease.

Slide 27

Other Age-related
Changes in Older People

❑ Reproductive system (male)
  ▪ Enlarged prostate - reduced flow of urine and reduced ability to urinate
❑ Reproductive system (female)
  ▪ Decreased estrogen - menopause
  ▪ Increased bone loss
  ▪ Increased risk of depression
  ▪ Increased risk of heart disease
  ▪ Increased short-term memory impairment

ADRC Training   28

There is a condition in aging males of enlarged prostates called Benign Prostate Hypertrophy (HPT). Although the signs mimic prostate cancer, it is not a serious condition unless the enlarged prostate interferes with the ability to urinate. Older men with developmental disabilities may experience reduced ability to urinate but not be able or willing to tell any one. This could lead to a behavior change.

Menopause symptoms occur in all females. The intensity of the symptoms is individual. The

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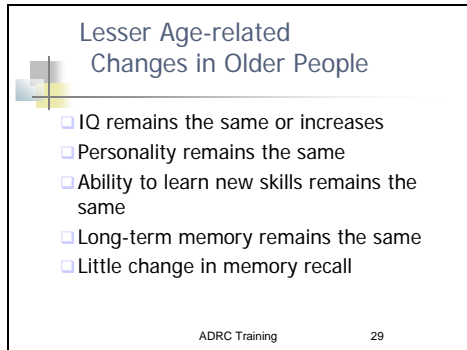
[1] Age-related changes – every one will experience the same aging changes sometime in their aging process – "normal" aging. Age-associated changes – changes are associated with aging, 'not normal" because of the accumulative changes that appear later in life – not everyone will experience these changes – depends on genetics and life style.

ADRC Training   56

concern is that caregivers may not be aware that behavior changes may be due to menopause. Menopause is often not considered in older women with developmental disabilities.

Slide 28

> ### Lesser Age-related Changes in Older People
>
> ❑ IQ remains the same or increases
> ❑ Personality remains the same
> ❑ Ability to learn new skills remains the same
> ❑ Long-term memory remains the same
> ❑ Little change in memory recall
>
> ADRC Training   29

The slowest decline in body function occurs in the nervous system. Marked declines in cognitive function, behavior, memory and ability to learn new skills are not normal aging, but a red flag that there is a problem. Although there is a slow decline in short-term and long-term memory, it has been shown that providing mental stimulation may slow the decline. As in exercise to maintain muscle tone, the adult with developmental disabilities should also be engaged in mental exercises (reading, puzzles, games, etc).

Slide 29

> **Meeting the Needs of Aging Persons with Developmental Disabilities**
>
> *Cross Network Collaboration for Florida*
>
> Early Aging Changes Experienced by Adults with Down Syndrome and Cerebral Palsy
>
> ADRC Training   30

Transition slide...NOTE: The reason for focusing on these two populations is that they are more representative of the overall developmental disability population. The numbers are larger than the other categories of developmental disabilities, the changes are more obvious, there are stronger support groups, and there are very few older adults in the other categories.

Ninety percent of the research for aging and developmental disabilities is on Down syndrome and cerebral palsy. Due to lack

of funding and the limited size of the population, there is very little research on aging and the other developmental disabilities.

Slide 30

Early Aging Down Syndrome and Cerebral Palsy Risk Factors

❑ Increased early symptoms
❑ Increased severity of symptoms
❑ Increased symptoms may be:
  ▪ Overlooked
  ▪ Assumed to be "normal" aging
  ▪ Misdiagnosed as dementia

Note: An individual with Down syndrome must also have a diagnosis of retardation to be eligible for APD services.

ADRC Training   31

Refer to Slide 14. Adults with Down syndrome and cerebral palsy experience early aging. These changes may overlay with the disability resulting in "over-shadowing" and mimicking or masking diseases or disorders. Remember that diseases and disorders may be misdiagnosed when health professionals are not trained in geriatrics or aging and developmental disabilities.

Slide 31

Early Aging in Down Syndrome Adults

❑ Shorter longevity
❑ Reduced cognitive and physical function
❑ Increased behavioral problems
❑ Changes may mimic or mask diseases or disorders

ADRC Training   31

Adults with Down syndrome can receive APD services if they have been diagnosed with retardation; this will include many individuals with Down syndrome.

Slide 32

Early Aging in Down Syndrome Adults

❏ Slowing of the thyroid (hypothyroidism) increases risk for:
  - Increased feelings of cold, tiredness, lethargy
  - Decreased appetite
  - Increased need for sleep
  - Increased short-term memory impairment
  - Increased confusion

ADRC Training   33

Hypothyroidism is a major concern in adults with Down syndrome. The ADRC should be aware that many of the symptoms of hypothyroidism are similar to Alzheimer's disease and often health care professionals are not aware of this connection. This can lead to adults with Down syndrome being inappropriately diagnosed with Alzheimer's disease.

Slide 33

Early Age-related Changes in Cerebral Palsy Adults

❏ Decreased muscle strength after many years of no change
❏ Increased risk for urinary tract infections and incontinence
❏ Increased difficulty in swallowing
❏ Reduced stamina
❏ Increased fatigue

ADRC Training   34

Individuals with cerebral palsy do not experience changes in muscle strength, fatigue, or stamina until later in life. The overlay of disabilities on aging results in reduced reserve. As the adult with cerebral palsy declines in ability, increased caregiver stress can be offset by supportive services from the aging network.

Slide 34

Meeting the Needs of Aging Persons with Developmental Disabilities

Cross Network Collaboration for Florida

Adverse Drug Reaction Risk Factors in Adults with Developmental Disabilities

ADRC Training   35

Transition slide ...

Slide 35

Medication Risk Factors in Older Adults

- ❑ Increased levels of medications in the blood for longer times
- ❑ Increased use of multiple medications
- ❑ Little understanding of medication interaction
- ❑ Increased adverse drug reactions (ADRs) masking or mimicking dementia

ADRC Training   36

Medication is important in treating diseases and disorders in all populations. The aging process changes how the older adult metabolizes medications. Therefore, medications can become a two edged sword: providing help against diseases and disorders while causing and mimicking or masking diseases or disorders.

Many physicians are not trained to recognize or intervene in adverse drug reactions. Older adults have higher risk factors for adverse drug reactions because of having higher medication concentrations in the blood for a longer time.

Slide 36

Medication Risk Factors in Older Adults

- ❑ Increased dosages of medications
- ❑ Few studies of medication use in older adults with developmental disabilities
- ❑ Few health care providers trained to identify adverse effects of medications

ADRC Training   37

The lack of research on adverse drug reactions in the developmental disabilities population is a major concern. It appears that the developmental disabilities population is equally at risk for adverse drug reactions.

A best practice would be to gradually introduce new drugs to older adults and increase them as determined necessary.

Slide 37

Additional Risk Factors Affecting Drug Reactions in Older Adults

- Population variations due to gender, race, ethnicity
  - Increased side effects from anti-depressants Prozac & Paxil are twice that in Caucasions than in Hispanics
  - Increased Tardive Dyskinesia from anti-psychotic drugs in African-Americans
  - Increased response to anti-psychotic drugs by Asians
  - Little knowledge of how medications affect females

ADRC Training   37

Recent research has shown that gender, culture, race and ethnicity must be considered in potential adverse drug reactions. This is true both in the general and the developmental disabilities populations.

Slide 38

Additional Risk Factors Affecting Drug Reactions in Older Adults

- Individual variations in response
  - Age-related differences
- Disability specific variations in response
- Older adults with developmental disabilities will "age into" medications with long-term use

ADRC Training   39

Little research has been conducted on adults with developmental disabilities resulting in limited knowledge of how they respond to medications. In the general population, behavior changes have been attributed to disease but may be, in fact, caused by adverse reactions. It is not known if this is also true in the developmental disabilities population.

The concept of "aging in" is a new concept in the developmental disabilities population. "Aging in" is the result of the aging process increasing the concentration of medications in the blood. Medications used for a long time may now be at a higher concentration resulting in adverse drug reactions where previously none would have existed.

Slide 39

Adverse Drug Reactions Affect Body Function

- Examples of biological changes
  - Increased/decreased blood pressure
  - Increased urine retention or incontinence
- Examples of behavioral changes
  - Increased risk for depression
  - Increased risk for paranoia

ADRC Training   40

Adverse drug reactions (ADRs) fall within four categories. The first two are most common: biological and behavioral changes. The important lesson is that any changes are a flag for possible adverse drug reactions to the medication.

Slide 40

Adverse Drug Reactions Affect Body Function

- Examples of neurological changes
  - Increased change in sleep patterns
  - Increased risk for seizures
- Examples of decline in muscle coordination
  - Increased risk for muscle tremors
  - Decreased coordinated muscle movement

ADRC Training   41

The third and fourth categories can mimic many disorders and may result in misdiagnosis. The important lesson, as in Slide 39, is that any changes are a flag for possible adverse drug reactions to medications.

Slide 41

Adverse Drug Reactions That Mimic Dementia

- Increased agitation
- Increased anxiety
- Increased behavioral changes
- Increased decline in cognitive functioning

ADRC Training   42

Many adverse drug reactions mimic dementia. This has been a major problem in the general population, and probably in the developmental disabilities population, but there is limited research to say for certain. If the caregiver or the adult with developmental disabilities exhibits dementia-like symptoms, evaluation of medications must be considered first.

Slide 42

Adverse Drug Reactions That Mimic Dementia

- Decreased communication skills
- Increased disorientation to person, place or time
- Increased loss of interest in normal activities

ADRC Training   43

The same ADRs that mimic the signs of dementia also mimic signs of other diseases, except in dementia a cluster of at least three signs is required to define the type of dementia.

Slide 43

Adverse Drug Reactions That Mimic Dementia

- Increased risk for confusion
- Increased risk for delusions
- Increased risk for depression, sadness
- Increased risk for unexplained excitability
- Increased risk for restlessness, wandering

ADRC Training   44

Many adverse drug reactions to medication mimic dementia and the ADRCs should be aware of this.

Slide 44

Summary of Module 3

- Myths may affect how services are applied
- Aging is experienced by everyone
  - Aging is an individual process
  - Influenced by genetics and lifestyle
  - Disabilities over-lay influences on aging

ADRC Training   45

Everyone experiences the same aging changes and rates of change, including individuals with developmental disabilities. The overlay of disability with aging may mimic or mask diseases or disorders. The ADRC role is not to assess for this but to be aware so that the proper services are identified.

Slide 45

Summary of Module 3

- Increased risk of mimicking or masking diseases or disorders from early aging in adults with Down syndrome and cerebral palsy
- Increased risk for adverse drug reactions that mimic or mask diseases

ADRC Training   45

Adults with Down syndrome and cerebral palsy are at increased risk for early aging that may mimic or mask disease or disorders. This includes the "aging in" of medications. Health care professionals may not recognize this problem. Knowledgeable ADRC staff can advocate for a proper evaluation.

Slide 46

Group Discussion

- Questions

ADRC Training   47

MODULE 4

Bridging the Networks - Needs of Older Caregivers of Adults with Developmental Disabilities

Slide 1

Meeting the Needs of Aging Persons with Developmental Disabilities

Cross Network Collaboration for Florida

Bridging the Networks - Needs of Older Caregivers of Adults with Developmental Disabilities

Module 4

Based on ADRC training developed by:
Kathleen M. Bishop, Ph.D., and Ron Lucchino, Ph.D.

Slide 2

Purpose of Module 4

- Understand role of caregivers in bridging networks
- Identify caregiver needs, changing focus and challenges
- Understand changing family dynamics of older caregivers

ADRC Training   2

The purpose of Module 4 is to demonstrate how meeting the need of caregivers creates the bridge between the aging and developmental disabilities networks.

Slide 3

Purpose of Module 4

- Recognize impact of overlapping aging and disability needs on caregivers and the child with developmental disabilities
- Identify vulnerability of older caregivers and what triggers a crisis

ADRC Training   3

Increasing awareness of the factors creating vulnerability in caregivers of adults with developmental disabilities is another purpose of Module 4. As is recognizing that changing family dynamics increase the risk of stress resulting in crisis.

Slide 4

Meeting the Needs of Aging Persons with Developmental Disabilities

Cross Network Collaboration for Florida

Caregiver Characteristics

ADRC Training   6

Transition slide for Caregiver Characteristics.

Slide 5

Characteristics of Older Caregivers

- Large percentage of caregivers 65+
  - Face similar age-related needs and concerns
- Aging of spouse/partner
- Increased multi-caregiving responsibilities
- Limited resources

ADRC Training   7

The major characteristic that defines an aging caregiver is spending a great portion of life caring for a child with developmental disabilities. As the caregiver grows older, there are increasing responsibilities, such as the caregiver's own aging and the aging of a spouse and the adult child with developmental disabilities. As life changes, the caregiver may experience diminishing resources due to multiple health care issues.

Slide 6

> ### Characteristics of Older Caregivers
>
> - Increasing health care costs for caregiver and spouse or other family members
> - Changing focus of caregivers
> - Role reversal of adult child caring for parent
>
> ADRC Training   8

As the caregiver ages, there is a role reversal. After receiving care for many years, the adult child with developmental disabilities is beginning to provide some supportive care. As the caregiver needs help, the adult child with developmental disabilities may demonstrate unrecognized abilities to meet the parent's needs.

Slide 7

> ### Caregivers as Primary Providers of Care
>
> - 10% Living in residential care
> - 40% Living with parents 40-60 years old
> - 20% Living with parents over 60
> - 20% Living at home without caregiver
> - 10% Other living situations
>
> *Fujiura, G.T. (1998). Demography of family households. American Journal on Mental Retardation,103, 225-235*
> ADRC Training   7
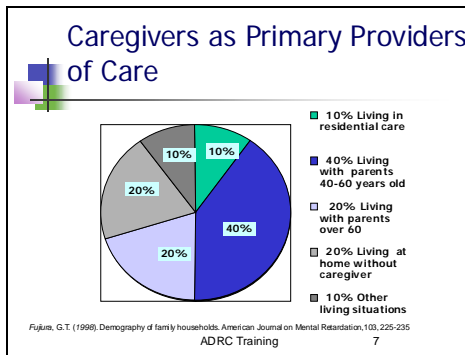
Remember the myth in Module 3 that most individuals with developmental disabilities live in institutions. The reality is only 10 percent live in residential care; 90 percent live in non-residential care settings.

The key to this slide is the number of caregivers that will need aging services within the next 10 years. Forty percent are ages 40-60, and 20 percent are over 60 possibly needing aging services now. The remaining 30 percent either have a spouse or live on their own. They will need aging services soon[1].

---

[1]

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

Slide 8

Meeting the Needs of Aging Persons with Developmental Disabilities

Cross Network Collaboration for Florida

Changing Focus of Caregivers

ADRC Training   10
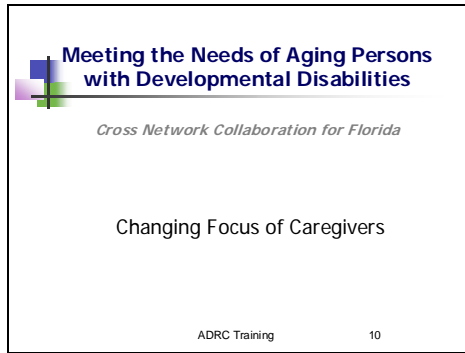
Transition slide for Changing Focus of Caregivers.

Slide 9

Focus of Younger Caregivers (Under 60)

- Caring for child or adult with developmental disabilities
  - Education
  - Vocation
  - Independent living
- Caring for parents or grandparents
- Preparing for own retirement

ADRC Training   11
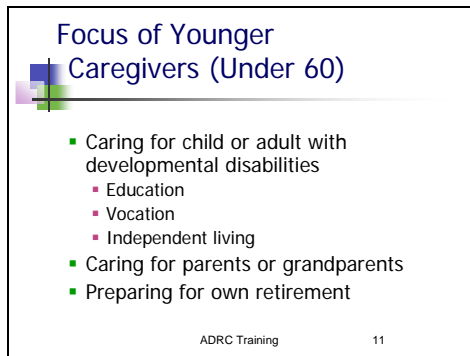
The primary focus of the caregiver has been on the child with developmental disabilities -- on the health, vocation, education and independence of the child. Added to these responsibilities for the caregiver is the possibility of caring for aging parents or grandparents, with the associated need to develop a supportive structure within the family. Although not as important during this time, the caregiver is also thinking about the future.

Slide 10

Focus of Aging Caregivers (60)

- Changing focus from son/daughter to other family members in need of assistance
- Begin future planning for transition of care, if not already done
  - Financial
  - Social, vocational, leisure
  - Independence or other family members assuming care

ADRC Training   12
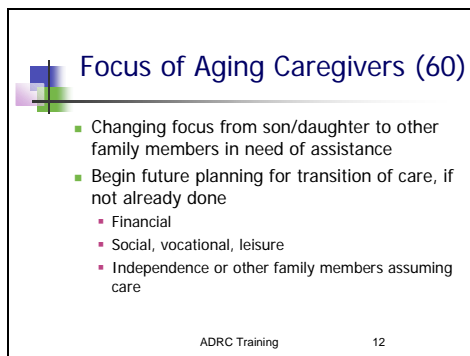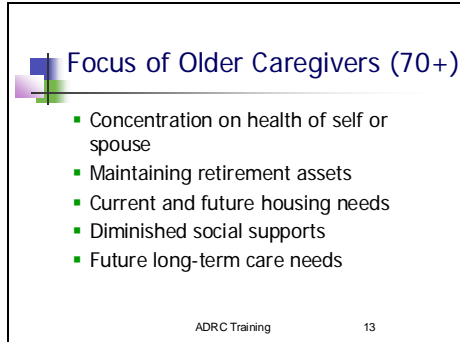
Around age 60, the caregiver's focus transitions from the adult child with developmental disabilities to the caregiver's own needs. The caregiver and spouse are aging. If they have other children, these children may have moved on with their lives, reducing the supportive family structure.

The caregiver is experiencing concern about the future and the future of the child with developmental disabilities when the caregiver can no longer provide care. This increases the

risk of stress and is the time in life when the caregiver may begin to search for answers. Knowledge within the APD network of what the ADRC can do to provide assistance may limit the risk of caregiver crisis.

Slide 11

Focus of Older Caregivers (70+)

- Concentration on health of self or spouse
- Maintaining retirement assets
- Current and future housing needs
- Diminished social supports
- Future long-term care needs

ADRC Training   13

As the caregiver continues to age, the focus shifts to growing concerns for the caregiver's own aging issues, and that of a spouse and the adult child with developmental disabilities. The caregiver may see the family support network diminishing further. The social network may be shrinking because of the loss of friends due to death or their own health problems. The caregiver is also concerned about reduced resources for services.

There is a growing anxiety about the caregiver's future and that of the adult child with developmental disabilities. This is usually the time when the family starts to seek services as they move closer to crisis. In some situations, it may be the older grandparent as the caregiver and not the parent, further increasing the risk of crisis.

Slide 12

Challenges for the Older Caregiver

- Avoiding crisis
- Maintaining independence
  - Caregiver and spouse
  - Child with developmental disabilities
- Maintaining normal routine
- Preparing family unit for change

ADRC Training   14

The aging caregiver faces many challenges that may not be obvious. Life is in a state of flux resulting in stress. The caregiver wants to remain independent and in control, but faces multiple issues making this difficult and stressful. To appropriately assist the family, the ADRC should consider the total family needs and not just aging needs.

Slide 13

Meeting the Needs of Aging Persons with Developmental Disabilities

Cross Network Collaboration for Florida

Impact of Aging on Caregivers

ADRC Training   15

This section discusses how aging impacts the health of caregivers and the family.

Slide 14

Impact of Aging on the Caregiver and Family

- Similar aging changes
  - Family members, primary caregiver
  - Adult with developmental disabilities
- Multiple roles of caregiving
  - Older spouse requiring increasing assistance
  - Other family members with multiple diagnoses and needs
  - Adult child with developmental disabilities

ADRC Training   16

Note that the aging curve in Module 3 illustrates that everyone experiences the same aging changes and rates of change. The aging of the total family increases the demands on the caregiver. Each family member brings his or her own unique changes and problems with which the caregiver must cope.

Slide 15

Issues Impacting the Older Caregiver and Family

- The adult with developmental disability experiences
  - Frailty
  - Age-associated diseases
  - Need for aging services
  - Reduced independence

ADRC Training   17

Because of the over-lay of aging on the disability, the adult with developmental disabilities may be at risk for age-associated diseases and fragility at an earlier age and may need services when they are younger than 60 years of age. Within the family there may be value in providing different aging services depending on the individual family member's needs.

Slide 16

Meeting the Needs of Aging Persons with Developmental Disabilities

Cross Network Collaboration for Florida

Caregivers of Adults with Down Syndrome

ADRC Training   18

Because of the early aging changes overlaying disabilities, the adult with Down syndrome is at greater risk for age-associated diseases or disorders prior to the age of 60. This section focuses on how these age-associated changes increase the risk of crisis for the caregiver.

Slide 17

Four Unique Challenges with Down Syndrome

- Early aging changes
- Many aging changes and rate of change similar to the general population
- Early age-associated disorders or diseases
- Increased risk of early onset of Alzheimer's disease

Note: An individual with Down syndrome must also have a diagnosis of retardation to be eligible for APD services.
ADRC Training   19

The aging caregiver must contend not only with the normal early aging changes in the Down syndrome adult child (Module 3), but also with the normal aging changes and the increase in age-associated diseases. Added to this is an increased risk for Alzheimer's disease. This quadruple impact increases stress levels earlier, prior to 60, compared to caregivers in the general developmental disabilities population. The increased stress on the aging caregiver elevates the risk for crisis to a very high level.

Slide 18

Challenges for Caregivers of Adults with Down Syndrome

- Age-related changes occur 20 years earlier
- Older than other caregivers
  - Own medical concerns
  - Lifetime of not caring for own needs
  - Increased risk for disease
- Changed expectation of outliving adult child with Down syndrome

ADRC Training   20

The caregivers, who have been providing care for most of their lives, are now beginning to experience changes of early aging and a higher risk of diseases in the Down syndrome adults. This results in the caregiver's need for services at an earlier age than other caregivers.

Slide 19

Challenges for Caregivers of Adults with Down Syndrome

- Complicated diagnosis and treatment of adult child
- Increased risk of Alzheimer's disease
  - Assumption of Alzheimer's disease by health care providers
  - Other underlying diseases not treated

ADRC Training   21

Most Down syndrome adults have complicated diagnoses due to multi-system decline in vitality. The disabilities may be over-laid by aging, mimicking or masking diseases including Alzheimer's disease. A major risk factor for the caregiver is a misdiagnosis of Alzheimer's or other disease.

Slide 20

Challenges for Caregivers of Adults with Down Syndrome

- Reluctance to seek services from disability network
- Lack of knowledge by practitioners concerning aging adults with Down syndrome
- Increased need for support
  - Activities of daily living (ADLs)
  - Lifting and moving

ADRC Training   22

Families with children born with developmental disabilities prior to 1970s were pressured to place their children in institutions. Many families resisted. The memory of this pressure has made families reluctant to seek any government services.
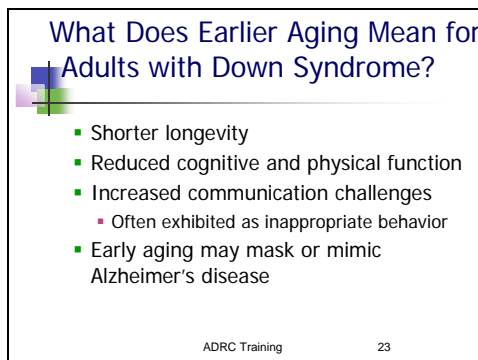
As indicated in Module 1, for every one family seeking services, there are two who do not. Although there is still reluctance in these families to seeking developmental disabilities services, they will seek aging services because of their changing needs. In many of these situations, the adult

child with developmental disabilities may be eligible for APD services if the family has the proper documentation and eligibility criteria.

Because many health care practitioners have little training in geriatrics and less in developmental disabilities, they may misdiagnose the situation and order inappropriate services. This can be frustrating for the caregiver. It is important to question a diagnosis of Alzheimer's disease in the Down syndrome adult.

Slide 21

What Does Earlier Aging Mean for Adults with Down Syndrome?

- Shorter longevity
- Reduced cognitive and physical function
- Increased communication challenges
  - Often exhibited as inappropriate behavior
- Early aging may mask or mimic Alzheimer's disease

ADRC Training   23

Early aging changes in adults with Down syndrome may result in reduction in cognitive and physical function. The degree of decline may be the extent of the overlap of the aging changes (Module 3) and the disabilities. Any sudden change in cognitive and physical function must be reported to health care providers for assessment.

The aging curve in Module 2 shows a decline in longevity that depends on the level of compromise created by the disability. Those with mild to moderate disabilities will have longevity closer to the general developmental disabilities population; for those with severe disabilities, their longevity will be shorter.

Slide 22

What Does Earlier Aging Mean for Adults with Down Syndrome?

- Increased risk at an earlier age for
  - Sensory impairments (vision and hearing)
  - Onset of symptoms of Alzheimer's disease
  - Acute dementia
  - Cardiovascular disease
  - Seizures

Note: An individual with Down syndrome must also have a diagnosis of retardation to be eligible for APD services.

ADRC Training   24

Adults with Down syndrome have hearing and vision impairment as part of their disability. The overlaying of early aging sensory changes may further reduce sensory acuity. The adult with Down syndrome is at a very high risk for acute dementia or reversible dementia. When the reduction in sensory acuity mimics cognitive changes, they may be misdiagnosed as Alzheimer's disease.

Slide 23

What Does Earlier Aging Mean for Adults with Down Syndrome?

- Thyroid changes
  - Increased fatigue
  - Feeling cold, lethargic
  - Increased short-term memory loss
  - Change in sleep patterns
  - Confusion

ADRC Training   25

The adult with Down syndrome experiences hypothyroidism to a greater degree than does the general population. Aging overlay further reduces the function of the thyroid gland (Module 3) making adults with Down syndrome vulnerable to symptoms of acute dementia. If an adult with Down syndrome is diagnosed with dementia, specifically Alzheimer's, the possibility of hypothyroidism needs to be ruled out.

Slide 24

Age-associated Obesity in Adults with Down Syndrome

	Males	Females
Down syndrome	60%	95%
DD but not DS	50%	63%
General Population	40%	32%

Bell AJ, Bhate MS. J Intellect Disabil Res. 1992 Aug;36 (Pt 4):359-64.

ADRC Training   26
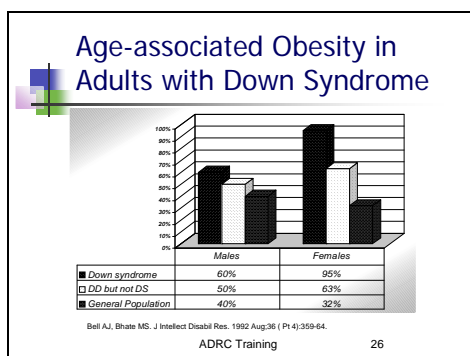
While obesity in the general population is becoming epidemic, in the Down syndrome population it has reached serious crisis level (especially in females). This is due to the disability as well as lifestyle issues (types of food). In the general population there is a movement to healthy lifestyle choices in food. This approach must also extend to the Down syndrome population, and the general developmental

disabilities population. The ADRC's focus on health and wellness can emphasize better lifestyle choices[2].

Slide 25

Health Problems in Adults with Down Syndrome

- Increased risk due to obesity
  - High blood pressure
  - Diabetes
  - Heart problems
  - Alzheimer's disease

  Note: An individual with Down syndrome must also have a diagnosis of retardation to be eligible for APD services.

ADRC Training   27

The health problems associated with obesity are the same in all populations. The overlaying of aging changes coupled with poor lifestyle choices may increase the severity of these conditions in the Down syndrome population. This will increase stress levels of caregivers who are concerned with their own aging issues as well.

Slide 26

Age-associated Diseases in Adults with Down Syndrome

- Decreased immune system with resulting infections, illness, and diseases
- Gastrointestinal problems
- Sleep apnea
- Leukemia

ADRC Training   28

The individual with Down syndrome is at high risk for age-associated diseases that are caused, in part, by the disability and an overlay of aging changes. Many of the early age-associated diseases will add stress to the caregiver. Health care professionals must be made aware of these changes.

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[2] Bell AJ, Bhate MS. J Intellectual Disabililities Research. 1992 Aug;36 (Pt 4):359-64

Slide 27

Alzheimer's Disease in Adults

- No cure or prevention
- Medications (Aricept, Namenda)
  - Treatment for short-term memory loss
  - Does not work for every one; significant behavioral changes in some people
- Value of social interaction may slow decline
- Increasing dependence on caregiver

ADRC Training   27

The medications prescribed for Alzheimer's diseases are used to slow the loss of short-term memory, not to prevent or cure the disease. The effectiveness of these medications diminishes over time. The research shows that the same medication can be used in the Down syndrome adult diagnosed with Alzheimer's disease with similar results.

An Alzheimer's disease diagnosis of the adult with developmental disabilities will increase the stress of the caregiver. These medications may help reduce some of the stress by alleviating some of the symptoms of Alzheimer's disease, no matter how short the time.

Slide 28

Increased Risk for Dementia in Adults with Down Syndrome

- Acute dementia – reversible
  - Remove underlying causes to reduce or eliminate symptoms
  - Symptoms of sudden changes in memory, behavior, or cognitive functioning
- Vascular dementia (stroke/heart disease)
- Higher risk for Alzheimer's disease

ADRC Training   29

Down syndrome adults are at high risk for acute dementia, which may mimic Alzheimer's disease. The risk factors include: medications, dehydration, impaired senses, hypothyroidism, infection, and nutrition.   The adult with Down syndrome needs a full medical assessment to rule out other causes when a diagnosis of dementia is made.

Slide 29

Alzheimer's Disease in Adults with Down Syndrome

- Typical timeline
  - Early onset of symptoms by 40s
  - 60% exhibit symptoms of Alzheimer's disease by age 60
  - Fewer than 10% exhibit symptoms after age 60
  - Short duration (4 – 7 years)
  - Note: An individual with Down syndrome must also have a diagnosis of retardation to be eligible for APD services.

ADRC Training   31

The onset of symptoms for Alzheimer's disease is earlier in the Down syndrome population than in the general and developmental disabilities populations: at age 40 versus 60. The duration is much shorter: seven versus 14 plus years, and the symptoms progress at a faster rate.

The first symptoms are usually a decline in activities of daily living (ADL), learned skills and increased apathy. In the general population the early symptom is memory loss. Services will be needed for a relatively shorter time for this population than in the general population.

Slide 30

Alzheimer's Disease in Adults with Down Syndrome

- Not every adult with Down syndrome will exhibit symptoms
- Must rule out all possible underlying causes to diagnose Alzheimer's disease
- Most common type of dementia
- Symptoms are slow, progressive loss
- Depression common as a secondary condition

ADRC Training   30

As mentioned in Module 3, only 70 percent of adults with Down syndrome will be diagnosed with Alzheimer's disease. Many health care professionals confuse the fact that 100 percent of Down syndrome adults may exhibit the neuropathological changes associated with Alzheimer's disease, but only 70 percent will express the diagnostic symptoms.

The over diagnosis of Alzheimer's in the Down syndrome population results from this misunderstanding. All possible causes, including acute dementia, must be ruled out ensuring an accurate diagnosis. The symptoms of Alzheimer's are slow in expression. Any quick onset is due to other causes such as stroke.

Slide 31

**Meeting the Needs of Aging Persons
with Developmental Disabilities**

Cross Network Collaboration for Florida

Caregivers of Adults with Cerebral Palsy

ADRC Training   33

Transition slide.

Slide 32

Three Unique Challenges with Cerebral Palsy

- Early aging changes
- Many aging changes and rate of change similar to the general population
- Early age-associated disorders or diseases

ADRC Training   34
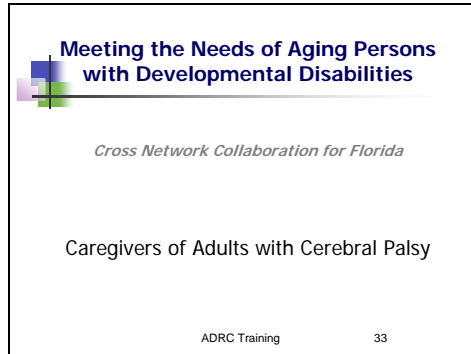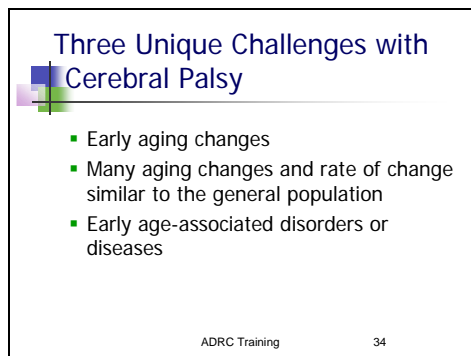
The aging caregiver must contend with not only the normal early aging changes in the adult child with cerebral palsy (Module 3), but also with the normal aging changes that occur later. Added to this is the increase in the age-associated diseases. The triple impact increases the stress level at an earlier age (prior to 60) in the caregiver compared to caregivers in the general developmental disabilities population. This increased stress on the aging caregiver elevates the risk for crisis to a very high level.

Slide 33

Challenges for Caregivers of Adults with Cerebral Palsy

- Earlier onset of age-related conditions
  - Decreased muscle strength after many years of no changes
  - Sensory impairments
  - Urinary tract disorders
  - Swallowing disorders
  - Significant reduction in stamina
  - Increased fatigue

ADRC Training   35

The age-associated diseases or disorders are caused by the overlay of aging on the disability. The adult with cerebral palsy will not have noticeable muscle decline until later in life (about age 35) when they will complain of a loss of strength.

Many symptoms may not be known because of reduced communication ability of the adult with cerebral palsy. Changes may be expressed through behavior. Any behavior change is a red flag that must be investigated. As a precaution, it should be noted that these individuals are at high risk for choking.

Slide 34

Challenges for Caregivers of Adults with Cerebral Palsy

- Earlier onset of age-associated diseases
  - Osteoporosis
  - Osteoarthritis
  - Increased risk for seizures
  - Respiratory infections, pneumonia
  - Difficulty moving joints

ADRC Training   36

Osteoarthritis makes it very painful to move. There is a high prevalence of pain due to osteoarthritis in adults with cerebral palsy that may not be verbally expressed due to communication difficulties. Again, the pain may be expressed through behavior such as becoming agitated if moved. This is important for the caregiver to understand in order to avoid frustration because of behavior changes.

Slide 35

Meeting the Needs of Aging Persons with Developmental Disabilities
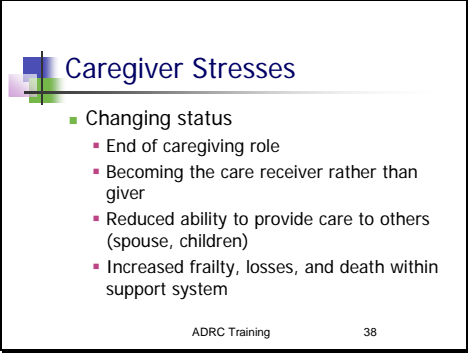
Cross Network Collaboration for Florida

Increased Caregiver Stress

ADRC Training   37

Transition slide...The last section describes how the caregiver responds to the accumulation of stress identified in this module.

Slide 36
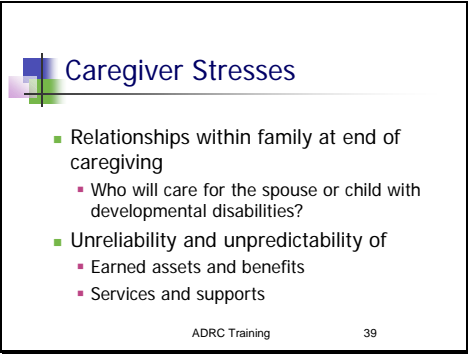
Caregiver Stresses

- Changing status
  - End of caregiving role
  - Becoming the care receiver rather than giver
  - Reduced ability to provide care to others (spouse, children)
  - Increased frailty, losses, and death within support system

ADRC Training   38

Because of the decline in the ability to provide an adequate level of care, the caregiver may begin to feel guilty. This is especially true if the adult child with developmental disabilities starts to provide reciprocal care to the parent. Many times the adult child may be able to provide more assistance than what was expected until the occasion arose.

Slide 37

Caregiver Stresses

- Relationships within family at end of caregiving
  - Who will care for the spouse or child with developmental disabilities?
- Unreliability and unpredictability of
  - Earned assets and benefits
  - Services and supports

ADRC Training   39

Providing life-long care to an adult with developmental disabilities increases the multi-role responsibilities of the aging caregiver. This may result in a collapse of care provision near the end of the caregiving role. Guilt, worry about the future, declining health of family members and changes in services all add to the family's stress. The supportive services that the ADRC provides are critical at this point.

Slide 38

Caregiver Stresses

- Lack of long-range planning
- Increased anxiety of future for spouse and child
- Own medical problems
- Possible dementia of self, spouse, child
- Multiple caregiving roles for two or more generations of family members

ADRC Training   40

Toward the end of the caregiver's role, the question that rises is: "Who will take over care of the adult with developmental disabilities?" This stress increases the strain within the family. The family needs a long-range plan developed with input from all family members and the adult with developmental disabilities.

Toward the end of the care giving role, the stressors on the caregiver multiply. Through the provision of supportive aging services, the ADRC may be able to help the caregiver deal with these stresses.

Slide 39

Caregiver Response to Stress

- Decline in mental health due to fatigue
- Increased depression
- Reduction in own social activities
- Increased anxiety
- Increased cognitive impairment
- Inability to provide care as in past

ADRC Training   42

The collapse of the caregiver initiates a crisis for the family. The crisis often occurs quickly and may result in a frantic call for help. Many times the collapse takes the form of the caregiver entering a hospital.

Slide 40

Caregiver Response to Stress

- Decline in physical health
- Disengagement or re-entrenchment in caregiving role
- Seeking services from the aging or disability network for the first time

ADRC Training   43

Disengagement is an early sign of collapse. When the caregiver does not seem to be involved in the care of the adult with development disabilities, with family members or social activities, it is usually a sign that the family or caregiver is in crisis. At this time, the provision of aging services may result in a reduction in the stresses that led to the crisis.

Slide 41

Summary of Module 4

- Caregivers are the bridging point for the aging and disability networks collaboration
- Aging brings increased stress to the caregiver

ADRC Training   44

The caregiver as the bridge between the two networks is the major point in Module 4. Collaboration between the networks can ensure that the caregiver receives the services that are needed to address the stressors brought on by aging of both the caregiver and the adult with development disabilities.

Slide 42

Summary of Module 4

- Multi-caregiving responsibilities result in the collapse of the caregiver and the supporting system
- Some adults with developmental disabilities will experience earlier aging
  - Adults with Down syndrome
  - Adults with cerebral palsy
  - Adults with very severe disabilities

ADRC Training   45

Emphasize that aging of the caregiver brings multi-role responsibilities and increases vulnerability to stress and crisis.

Slide 43

Summary of Module 4

- Caregivers and providers can
  - Minimize disease through early prevention
  - Work together to reduce stresses
- Importance of Planning Ahead

ADRC Training   46

The ADRC and the APD must work together to decrease the risk of crisis and collapse of the family support structure.

Slide 44

Exercise

- Scenarios
  - See handouts for scenarios and questions
- Group Discussion
  - Questions
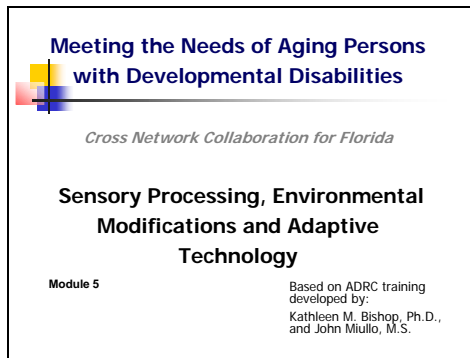
ADRC Training   47

See Appendix C for instructions on use of scenario exercises.

MODULE 5

Sensory Processing, Environmental Modifications and Adaptive Technology

Slide 1

Meeting the Needs of Aging Persons with Developmental Disabilities

Cross Network Collaboration for Florida

Sensory Processing, Environmental Modifications and Adaptive Technology

Module 5   Based on ADRC training developed by:
Kathleen M. Bishop, Ph.D., and John Miullo, M.S.

The environment can enhance or inhibit functioning and quality of life. Small environmental modifications and adaptive technology can assist the older person with developmental disabilities to maintain independence and health.
This module is an optional module. It can be used by itself or in conjunction with the previous four modules. This particular module includes information that can be helpful for anyone as they age. It is a common bridging topic for both networks.

Slide 2

Purpose of Module 5

- Detail how older adults and individuals with developmental disabilities:
  - Interact with the physical environment and adaptive technology
  - Have the same environmental/sensory issues

ADRC Training   2

Aging is aging is aging. The environment impacts all older persons. The slides will provide additional detail on sensory changes and impairments that affect all older persons. The physical environment can be modified to enhance the quality of life for caregivers and persons with developmental disabilities.

Slide 3

Purpose of Module 5

- Outline techniques for individuals and their families to:
  - Reduce the impact of sensory changes
  - Maintain independence
  - Address common challenges they share with each other
  - Experience quality of life through use of adaptive environment and technology

ADRC Training   3

Sensory processing is a complex process that can be understood through the use of this module. There are age-related sensory changes that are common to many older people as they age. The impact of sensory changes can be reduced through environmental modifications and adaptive technology. This can often be done in very inexpensive and cost effective ways to maintain skills for independence and quality of life. Additionally, two links for videos have been provided for trainers to view for further understanding of the benefits of adaptive technology.

Slide 4

Meeting the Needs of Aging Persons with Developmental Disabilities

Cross Network Collaboration for Florida

Sensory Processing

ADRC Training   6

Transitional slide for Sensory Processing.

Slide 5

Sensory Changes and Aging

- Increase in impairments with aging
- Increase in sensory changes
- Potential for reduction in quality of life and independence
- Common experience as people age regardless of pre-existing disabilities

ADRC Training   7

The risk for sensory impairments and a reduction in sensory information from the environment increase with age. The older each person is the more likely there will be some reduction or impairment. Often the result of sensory impairment is reduced social interaction and increased isolation. Communication can become more

difficult. People who have pre-existing disabilities have at least the same rate of sensory impairments and reduction in older age. Depending on how the factors of aging have been affected by the developmental disability, the risk factors for sensory impairments can be higher than for the general population.

Slide 6

Importance of the Environment

- Immediate environment increasingly important with aging
- Reduction of barriers to community participation and social interaction essential
- Balance of ease of use and challenge
  - Changing with age and increased impairments

ADRC Training   8

Humans need to balance the ease of use of objects in the environment with enough challenge so they do not become bored. As people age, it becomes more difficult to provide this balance. Additionally, pre-existing disabilities can complicate the ability to maintain this balance.

Sensory impairments can increase social isolation. A benefit of the federal senior meals program is to encourage older people to leave their homes for socialization while receiving a nutritional meal, thus increasing the likelihood for healthier aging.

Slide 7

Sensory Processing and Aging

- All information for functioning taken in from sensory information in the environment
- Brain must
  - Be aware of sensory stimuli
  - Receive the information accurately
  - Bring the information together through processing
  - Interpret information to determine response

ADRC Training   9

Sensory processing is a complex interaction that requires each of the steps of processing to work together. If there is impairment or information is received inaccurately, the older person cannot respond appropriately.

All behavior has meaning. Each older person's behavior reflects the information received from the environment. The resulting

response to the environment will be based on the individual's perception of the environment. When behavior is based on faulty interpretation of sensory information, the response may be perceived as paranoia, hallucinations, or dementia. Modifications can be made in the environment to minimize the negative effect of faulty sensory processing.

Slide 8

Sensory Processing and Aging

- Ongoing process 24 hours a day
- Too much information overwhelming
- Becomes more difficult with aging due to impairments and added perceived or actual environmental stress

ADRC Training   10

The process of taking information in from the environment never stops, not even during sleep. This can be exhausting and overwhelming for the older person with developmental disabilities especially if the individual or caregiver has sensory impairments such as visual or hearing.

Too much sensory information can interfere with sleep as well as with activities of daily living. The additional stress can also cause problems such as depression or perceived cognitive decline. When sensory processing impairments interfere with communication, there may be a subsequent reduction in social interaction. All of this can have negative affects on the older person.

Slide 9

Sensory Changes and Aging

- Although changes are age related, a combination of these changes may:
  - Increase risk of falls
  - Cause acute dementia
  - Reduce independence and quality of life
- Early onset aging of individuals with Down syndrome and cerebral palsy

ADRC Training   11

Age-related means these are commonly shared sensory changes. Acute dementia is a sudden loss of cognitive ability, including memory that can be reversed if the underlying cause for the loss is determined and treated. Sensory changes may increase the risk for losses as well as a reduction in independence and quality of life.

Slide 10

Sensory Changes in Older Adults

- Slowing of memory recall
- Interference with short-term memory
- Slowing of cognitive function
- Reduced ability to process multi-sensory input (confusion)

ADRC Training   12

Sensory changes or impairments can result in any or all of these negative effects.

Slide 11

Impact of Sensory Changes on Older Adults

- Reduced socialization
- Difficulty with directions and location
- Reduction in skills and interests
- Reduced ability to participate in interests and activities

ADRC Training   13

One or all of these can be the impact of sensory changes on older adults.

Slide 12

**Meeting the Needs of Aging Persons
with Developmental Disabilities**

Cross Network Collaboration for Florida

The Seven Senses and Aging

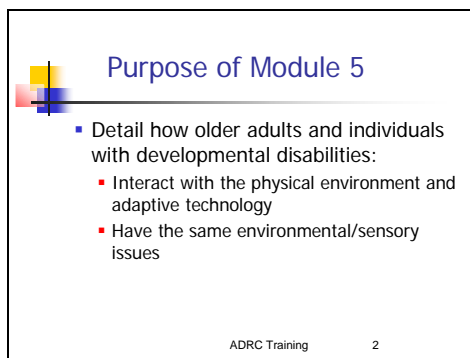ADRC Training   14
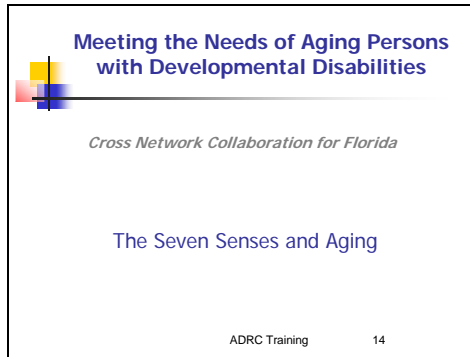
The transitional slide for The Seven Senses and Aging slides.

Slide 13

Seven Senses

- Hearing – Auditory
- Seeing – Visual
- Touch – Tactile
- Smell – Olfactory
- Taste – Gustatory
- Location in space – Proprioceptor
- Head moving through space – Vestibular

ADRC Training   15

These are the seven senses. The two least known by most people are proprioceptor and vestibular. These two senses work together to help with movement, fine motor skills and gross motor activities, and location in space. They are thought to be the ones most impaired by Alzheimer's disease.

Slide 14

Hearing and Aging

- Increased hearing impairments with aging
  - Presbycusis – Greek for 'Old hearing'
- Increased background noise interference
- Increased tinnitus – ringing in the ears

ADRC Training   16
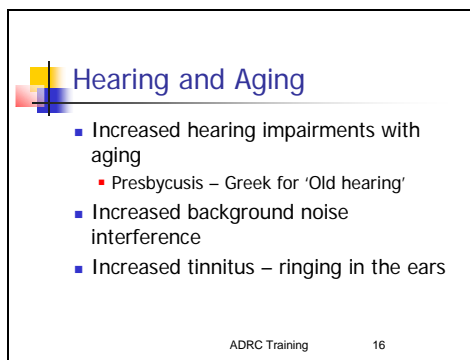
Hearing impairment can result in confusion and social withdrawal. The older individual affected can appear to have a form of dementia such as Alzheimer's disease when the symptoms are a result of hearing impairment. Simple modifications in the environment can reduce the negative impact.

Hearing aids do not restore the original hearing ability but magnify the remaining sounds. This can actually cause pain to the wearer, resulting in intentional loss of the hearing aids or storage in a drawer.

Slide 15

Environmental Modifications for Hearing Impairments

- Addition of soft materials to the environment
- Reduction of hard surfaces
- Reduction of background noises from appliances, conversation, street noise
- Increased lighting

ADRC Training   17

These easy and cost effective modifications to the environment can decrease the frustration of the older individual with the hearing impairment. For a person with a pre-existing cognitive impairment, the confusion from the hearing impairment may be considered to be a result of the cognitive impairment and therefore be overlooked.

Slide 16

Vision and Aging

- Increased visual impairments with age
- Central Vision Impairments – Difficulty with seeing in front affecting ability to read, see signage, recognize people
- Peripheral Vision Impairments – Narrowed visual field, affects ability to observe immediate environment

ADRC Training   18

These are common visual impairments in older persons. Most are a result of age-associated diseases.

Slide 17

Vision and Aging

- Increased glare sensitivity
- Decreased ability to see color contrasts
- Difficulty adjusting to changes in lighting
- Difficulty with busy patterns, increased background interference

ADRC Training   19

These are common changes that affect the quality of vision of the older person. For persons with cognitive impairments as a result of a developmental disability, they are more likely to be overlooked and misunderstood as part of the pre-existing disability.

Slide 18

Vision and Aging

- Increased risk for falls due to reduction in vision
- Increased risk for misdiagnosis of Alzheimer's disease due to visual changes/impairments

ADRC Training   20

These are common risks for any older person.

Slide 19

Environmental Modifications, Vision, and Aging

- Increase task lighting
- Decrease glare, avoid high gloss waxes, shiny surfaces
- Use consistent lighting to reduce shadows
- Use strong contrasting colors of furniture to floors and walls, objects to background colors

ADRC Training   21

Cost-effective and easy modifications such as these listed here can help the older individual with visual changes or impairments continue to function in the environment while reducing the risk for falls or confusion.

Slide 20

Touch and Aging

- Decreased tactile ability
- Loss in fine motor dexterity
- Increased tactile defensiveness
- Nerve reduction with inability to feel pain, sense danger
- Increased risk of skin breakdown

ADRC Training   22

Touch is what connects us to our environment and to each other. Tactile sensation of pain can also warn us so that we reduce the factor causing the pain in the environment.

Skin breakdown is common in older persons. Specific substances in the environment can increase the risk for skin breakdown.

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Slide 21

Environmental Modifications and Touch

- Be aware of textures that irritate skin
- Avoid synthetic fabrics
  - Use natural fabrics such as cotton to reduce skin breakdown
- Provide ample personal space and territory

ADRC Training   23

Personal space needs vary. For people who are tactile sensitive or defensive, there is usually a need for larger amounts of space. Lack of personal space may cause agitation, withdrawal from others, or refusal to participate in activities. Awareness of the need for personal space can help reduce these reactions.

Slide 22

Smell, Taste, and Aging

- Reduced taste and smell
- Increased sensitivity to noxious or dangerous odors
- Loss of appetite
- Changes due to medications

ADRC Training   24

These are common changes in smell and taste in older persons. For people with developmental disabilities who may have less control over their immediate environment, noxious smells may result in refusal to eat. Additionally, people with developmental disabilities are more likely to be on medications that will change the senses of taste and smell.

Slide 23

Environmental Modifications, Smell, and Taste

- Reduce noxious odors in environment if possible
  - Awareness that inappropriate behaviors may be related to noxious odors
- Bake before meals to stimulate appetite
- Conduct smell and taste exercises
  - Helps retain taste and smell

ADRC Training   25

These are ways to minimize the affect of increased or reduced taste and smell sensitivity.

ADRC Training   92

Slide 24

Proprioceptor & Vestibular

- Increased disorientation in space through disease process (i.e., Alzheimer's disease) or sensory loss
  - Inability to locate oneself in space
- Increased changes in the physical environment resulting in potential disorientation

ADRC Training   26

Disorientation can look like symptoms of dementia.

Slide 25

Possible Muscle Changes Affecting Mobility

- Moderate (15%) loss of muscle mass
  - Increase risk of loss for individuals who have not been weight bearing
- Moderate exercise will strengthen upper and lower body

ADRC Training   27

Muscle loss can be a common problem for older people, especially those that are non-weight bearing such as a person with cerebral palsy.

Slide 26

Possible Muscle Changes Affecting Mobility

- Severe (33%) loss of muscle
  - Increased falls
  - Reduced activities or interest in participating in activities
  - Weak upper body
  - Behavioral changes due to pain
  - Likely in persons not weight bearing (cerebral palsy)

ADRC Training   28

Severe loss of muscle can result in a significant reduction in quality of life.

Slide 27

Environmental Modifications for Mobility

- Increased cueing in the environment
- Marking of personal space and objects
- Chairs with arms
- Decreased accessibility barriers
- Adaptive equipment for ease of movement and independence
- Removal of throw rugs, thresholds

ADRC Training　　29

These modifications can help enhance opportunities for movement and thus reduce the risk for muscle mass loss.

Slide 28

Meeting the Needs of Aging Persons with Developmental Disabilities

Cross Network Collaboration for Florida

Assistive Technology and Aging

ADRC Training　　30

Transition slide for Assistive Technology and Aging.

Slide 29

Assistive Technology and Aging

- Enhance independence
- Improve quality of life
- Support functioning and daily living
- Cost effective
- A resource for both networks

ADRC Training　　31

Assistive technology can be used to help older people maintain a quality of life and functioning.

Slide 30

Assistive Technology

- *"Products, devices or equipment, … (from various sources), that are used to maintain, increase or improve the functional capabilities of individuals with disabilities…,"* Assistive Technology Act of 1998.

- From canes to voice recognition software

ADRC Training   32

This is the traditional definition of assistive technology. The technology can range from simple walking canes to complex voice recognition software that allows for control over one's immediate environment.

Slide 31

Assistive Technology Services

- Support individuals with disabilities and their caregivers to:
  - Select, acquire, or use adaptive devices
- Services include:
  - Functional evaluations and assessments
  - Training on devices
  - Purchasing or acquisition support

ADRC Training   33

Assistive technology can be used for all of these purposes.

Slide 32

Assistive Technology Products

- Enable accomplishment of Activities of Daily Living (ADLs)
- Assist in communication (augmentative communication devices)
- Support education, work or recreation activities
- Help achieve greater independence and enhance quality of life "off the shelf" or by special design

ADRC Training   34

As appropriate, off-the-shelf products can be used, ranging from already existing technology to those specially designed just for the individual. Many items are now available that provide solutions right off the shelf without modification while others can be fabricated from common articles and designed especially for a certain individual's needs. Assistive technology can support ergonomic needs at work, in school and facilitate the ability to participate in recreational activities.

Slide 33

Universal Design Approach

- For everyone
- Adapts to the individual
- Requires less updating and reassessment
- Generally requires less training
- Not always the best option

ADRC Training   35

Universal design is an approach of environments designed to meet the needs of individuals with disabilities.

Slide 34

Clinical Design Approach

- Specific for the disorder or individual
- May require updating and reassessment
- Generally requires more training
- Not always the best option

ADRC Training   36

Clinical design is an approach developed by a clinician with expertise in the area of assistive technology.

Slide 35

Combine Design Approaches

- Examples in aging:
  - "Bob's Room" in a long-term care facility Parkinson's Unit

- Examples in developmental disability group homes:
  - SmartSystems from Imagine!

ADRC Training   37

If the trainer has internet capability in the training room, videos can be shown to the participants by clicking on the underlined titles.

Slide 36

Collaboration Across the Networks

- Using technology to help us all work together
- A point at which we can all come together to maximize supports, independence, and quality of life
- Regardless of age or disability

ADRC Training   38

Both environmental modifications and assistive technology can be used to make a difference for consumers in the aging and developmental disabilities networks. The caregivers and individuals with developmental disabilities can benefit from the use of both.

Slide 37

Summary of Module 5

- Environmental modifications for sensory impairments can help maintain quality of life and functioning for the older person
- Assistive technology is a resource for both networks and can be another bridging opportunity

ADRC Training   39

The topics of this module, environmental modifications and assistive technology, can be a resource for both networks as a bridging opportunity.

Slide 38

Group Discussion

- Questions
- Survey Monkey

ADRC Training   40

Allow time for questions.

If you choose to use the survey monkey evaluation, you can inform participants when access to the evaluation will be sent.

APPENDIX A: Resources Related to Aging and Developmental Disabilities

Florida Organizations on Aging

Area Agencies on Aging (AAA)

Below is a listing of the 11 AAAs:

- **Northwest Florida Area Agency on Aging**
  5090 Commerce Park Circle
  Pensacola, FL 32505
  850-494-7100
  (Escambia, Okaloosa, Santa Rosa and Walton counties)
- **Area Agency on Aging for North Florida, Inc**.
  2414 Mahan Dr.
  Tallahassee, FL 32308
  1-866-467-4624or 850-488-0055
  (Bay, Calhoun, Franklin, Gadsden, Gulf, Holmes, Jackson, Jefferson, Leon, Liberty, Madison, Taylor, Wakulla and Washington counties)
- **Elder Options, the Mid-Florida Area Agency on Aging**
  5700 S.W. 34th St., Suite 222
  Gainesville, FL 32608
  352-378-6649or 1-800-262-2243
  (Alachua, Bradford, Citrus, Columbia, Dixie, Gilchrist, Hamilton, Hernando, Lafayette, Lake, Levy Marion, Putnam, Sumter, Suwannee and Union counties)
- **ElderSource, Area Agency on Aging for Northeast Florida**
  4160 Woodcock Drive, 2nd Floor
  Jacksonville, FL 32207
  904-391-6600 or 888-242-4464
  (Baker, Clay, Duval, Flagler, Nassau, St. Johns and Volusia counties)
- **Area Agency on Aging of Pasco-Pinellas**
  9887 4th Street North, Suite 100
  St. Petersburg, FL 33702
  727-570-9696727 or 570-5098 (Fax)
  (Pasco and Pinellas counties)
- **West Central Florida Area Agency on Aging, Inc.**
  5905 Breckenridge Pkwy., Suite F
  Tampa, FL 33610-4239
  813-740-3888
  (Hardee, Hillsborough, Highland, Manatee and Polk counties)

- **<u>Senior Resource Alliance</u>**
  988 Woodcock Rd., Suite 200
  Orlando, FL 32803
  407-514-1800
  (Brevard, Orange, Osceola and Seminole counties)
- **<u>Area Agency on Aging of Southwest Florida</u>**
  15201 N. Cleveland Avenue, Suite 1100
  North Fort Myers, FL 33903
  239-652-6900
  (Charlotte, Collier, DeSoto, Glades, Hendry, Lee and Sarasota counties)
- **<u>Area Agency on Aging of Palm Beach/Treasure Coast, Inc.</u>**
  4400 N. Congress Avenue
  West Palm Beach, FL 33407-3226
  561-684-5885
  (Indian River, Martin, Okeechobee, Palm Beach and St. Lucie counties)
- **<u>Aging and Disability Resource Center of Broward County</u>**
  5300 Hiatus Road
  Sunrise, FL 33351
  954-745-9567
  (Broward County)
- **<u>Alliance for Aging</u>**
  760 NW 107th Avenue, Suite 214
  Miami, FL 33172-3155
  305-670-6500
  (Miami-Dade and Monroe counties)

Florida Department of Elder Affairs (DOEA)

The Florida Department of Elder Affairs (DOEA) is the primary state agency responsible for administering human services programs to benefit Florida's elder population. These programs and services are primarily administered at the local level by Area Agencies on Aging, geographically located in 11 Planning and Service Areas (PSAs). Each Area Agency also operates as an Aging Resource Center offering coordinated access to information and assistance to help persons age 60 and above and their caregivers navigate available services, agencies and other long-term care options.

For further information:
Call: 850-414-2000
Elder Helpline: 1-800-963-5337
Email: information@elderaffairs.org
Web address: http://elderaffairs.state.fl.us/

National Organizations on Aging

U.S. Administration on Aging

The Administration on Aging (AoA), an agency in the U.S. Department of Health and Human Services, is the official Federal agency dedicated to policy development, planning and the delivery of supportive home and community-based services to older persons and their caregivers. The AoA administers the Older Americans Act and works through the national aging network of State Units on Aging, Area Agencies on Aging, Tribal and Native organizations representing 300 American Indian and Alaska Native Tribal organizations, and two organizations serving Native Hawaiians, plus thousands of service providers, adult care centers, caregivers, and volunteers.

For further information:
Call: 1-202-619-0724
Fax: 1-202-357-3555
Eldercare Locator (to find local resources): 800-677-1116
Email: aoainfo@aoa.hhs.gov
Web address: http://www.aoa.gov/

Florida Organizations on Disabilities, including Developmental Disabilities

Able Trust

The Able Trust, also known as the Florida Endowment Foundation for Vocational Rehabilitation, is a 501(c)(3) public-private partnership foundation established by the Florida Legislature in 1990. Its mission is to be the leader in providing Floridians with disabilities assistance through grant programs, public education, public awareness, and policy recommendations in the creation of fair employment opportunities.

To learn more about Able Trust:
Call: 850-224-4493 Voice or TDD
Fax: 850-224-4496
Email: info@abletrust.org
Web address: www.abletrust.org

Advocacy Center for Persons with Disabilities

The Advocacy Center for Persons with Disabilities, Inc. is the official, Governor-designated protection and advocacy system for the State of Florida. The Advocacy Center has authority and responsibility under eight federal programs. The Advocacy Center is a member of the National Disability Rights Network.

For more information:
Call: 1-800-342-0823
Web address: http://advocacycenter.org/

Agency for Persons with Disabilities (APD)

In October 2004, the Agency for Persons with Disabilities (APD) separated from the Department of Children and Families, where it was known as the Developmental Disabilities Program. The APD works in partnership with local communities and private providers to assist people who have developmental disabilities and their families.

To learn more about APD:
Call: 850.488.4877
Fax: 850.933.6456
Email: APD_info@apd.state.fl.us
Web address: http://www.apd.myflorida.com

The agency is divided into area offices by counties as listed below:

Area 1 - Escambia, Okaloosa, Santa Rosa, Walton
    160 Government Center, Room 412
    Pensacola, FL 32502
    (850) 595-8351

Area 2 - Bay, Calhoun, Franklin, Gadsden, Gulf, Holmes, Jackson, Jefferson, Liberty, Leon, Madison, Taylor, Wakulla, Washington
    2639 North Monroe Street, Suite B-100
    Tallahassee, FL 32399-2949
    (850) 487-1992

Area 3 - Alachua, Bradford, Columbia, Dixie, Gilchrist, Hamilton, Lafayette, Levy, Putnam, Suwannee, Union
    1621 Northeast Waldo Road, Building 1
    Gainesville, FL 32609
    (352) 955-6061

Area 4 - Baker, Clay, Duval, St. Johns, Nassau
    3631 Hodges Boulevard
    Jacksonville, FL 32224
    (904) 992-2440

Area 7 - Brevard, Orange, Osceola, Seminole
    400 West Robinson Street, Suite S430
    Orlando, FL 32801
    (407) 245-0440

Area 8 - Charlotte, Collier, Glades, Hendry, Lee
    2295 Victoria Avenue
    P.O. Box 60085
    Fort Myers, FL 33906
    (239) 338-1370

Area 9 - Palm Beach
    111 South Sapodilla Avenue, Suite 204
    West Palm Beach, FL 33401
    (561) 837-5564

Area 10 – Broward
    201 West Broward Blvd., Suite 305
    Ft. Lauderdale, FL 33301
    (954) 467-4218

Area 11 - Dade, Monroe
    401 NW 2nd Avenue, Suite South 811
    Miami, FL 33128
    (305) 349-1478

Area 12 - Flagler, Volusia
    210 N. Palmetto Avenue, Suite 312
    Daytona Beach, FL 32114
    (386) 947-4026 or (386) 238-4607

Area 13 - Citrus, Hernando, Lake, Marion, Sumter
    1601 West Gulf Atlantic Highway
    Wildwood, FL 34785
    (352) 330-2749

<u>Area 14</u> - Hardee, Highlands, Polk
    200 North Kentucky Avenue, Suite 422
    Lakeland, FL 33801
    (863) 413-3360

<u>Area 15</u> - Indian River, Martin, Okeechobee, St. Lucie
    337 North US Highway 1
    Fort Pierce, FL 34950
    (772) 468-4080

<u>Suncoast</u> - De Soto, Hillsborough, Manatee, Pasco, Pinellas, Sarasota
    1313 North Tampa Street, Suite 515
    Tampa, FL 33602
    (813) 233-4300

Center for Autism and Related Disorders (CARD)

The Center for Autism and Related Disorders, Inc. (CARD), a worldwide organization, provides services for children and their families with autism, Asperger's Syndrome, PDD-NOS (Pervasive Developmental Disorder - Not Otherwise Specified, an autism spectrum disorder), and related disorders.

For further information:
Call: 818-345-2345
Fax: 818-758-8015
Email: info@centerforautism.com
Web address: www.centerforautism.com

Centers for Independent Living (CILs)

The Centers for Independent Living are federally mandated under Section 725 of the 1973 Rehabilitation Act as amended in 1998. They are funded with federal and state dollars, and through local community grants and private donations. In Florida, CILs fall under the authority of the state Division of Vocational Rehabilitation and serve as the pre-employment readiness component to that program. CILs also provide services such as housing referral and adaptation, personal assistance referral, or legal aid.

The Florida network of 17 CILs serve persons with all types of disabilities. CILs serve all ages from children to seniors. Fifty-one percent of the staff and boards of CILs are person with disabilities, who play significant roles in the decision-making responsibilities of the Centers. Every Florida county is served by this network.

Ability1st
1823 Buford Court
Tallahassee, FL 32308
Call: 850-575-9621; 850-575-5245 TDD
Fax: 850-576-5740

Caring And Sharing CIL, Inc.
12552 Belcher Rd. South
Largo, FL 33773
Call: 727-539-7550; 727-539-7550 TDD
Fax: 727-539-7588
Web address: http://www.cascil.org

Center For Independent Living Of Broward
4800 N. Street, Rd. 7, Bldg. F, #102
Fort Lauderdale, FL 33319
Call: 954-722-6400; 954-735-1598 TDD
Fax: 954-735-0963
Email: cilb@cilbroward.org

Center For Independent Living Of North Central Florida
222 Sw 36th Terrace
Gainesville, FL 32607
Call: 352-378-7474; 352-378-5582 TDD
Web address: http://www.cilncf.org

Center For Independent Living Of North Florida
1823 Buford Ct.
Tallahassee, FL 32308
Call: 850-575-9621; 850-575-5740 TDD
Web address: http://www.cilnf.org
Email: cilnf@nettally.com

Center for Independent Living of South Florida, Inc.
6660 Biscayne Blvd.
Miami, FL 33138
Call: 305-751-8025; 305-751-8891 TDD
Fax: 305-751-8944
Web address: www.soflacil.org

Center for Independent Living of Southwest Florida, Inc.
2321 Bruner Lane
Fort Myers, FL 33916
Call: 239-277-1447; 239-277-3964 TDD
Fax: 239-277-1647
Web address: http://www.cilfl.org

Cil In Central Florida, Inc.
720 North Denning Drive
Winter Park, FL 32789
Call: 407-623-1070; 407-623-1185 TDD

Web address: http://www.cilorlando.org

Cil Of Northwest Florida, Inc.
3600 N Pace Blvd
Pensacola, FL 32505
Call: 877-245-2457; 850-595-5566 TDD

Coalition For Independent Living Options
6800 Forest Hills Blvd
West Palm Beach, FL 33413
Call: 561-966-4288; 561-641-6538 TDD
Fax: 561-641-6619
Email: cilo2000@bellsouth.net

Disability Solutions for Independent Living
119 South Palmetto Avenue, Suite 180
Daytona Beach, FL 32114
Call: 386-255-1812; 386-252-6222 TDD
Fax: 386-255-1814
Email: info@dsil.org

Independent Living Resource Center Of Ne Florida
2709 Art Museum Drive
Jacksonville, FL 32207
Call: 904-399-8484; 904-396-0859 TDD
Web address: http://www.cilj.com
Email: cilj@fdn.com

Sccil At Titusville
725 Deleon Avenue
Titusville, FL 32780
Call: 407-268-2244; 706-724-6324 TDD

Self-reliance, Inc.
8901 N. Armenia Ave
Tampa, FL 33604
Call: 813-375-3965; 813-375-3970 TDD
Web address: http://www.self-reliance.org

Space Coast Center For Independent Living
803 N Fiske Blvd, Suite B
Cocoa, FL 32922
Call: 321-633-6011; 321-633-6011 TDD
Fax: 321-633-6472
Web address: spacecoastcil.org

Suncoast Cil
2989 Fruitville Road, Suite 101
Sarasota, FL 34237
Call: 941-351-9545; 941-351-9545 TDD
Fax: 941-351-9875

Web address: http://www.scil4u.org

Victory Lane Center For Independent Living, Inc.
475 South Nova Rd.
Ormond Beach, FL 32174
Call: 386-671-1960; 386-671-1961 TDD
Web address: http://www.victorylanecil.org

Clearinghouse on Disability Information

The Clearinghouse operates a statewide toll-free information and referral system for all disability related services, programs, assistance, and resources. The Clearinghouse's information and referral service connects people with disabilities and advocates of people with disabilities to the resources they need.

Areas of resource information include but are not limited to:
- Accessibility
- Americans with Disabilities Act (ADA)
- Assistive Technology
- Basic Needs
- Benefits
- Community Resources
- Education
- Employment
- Health Care
- Housing
- Service Animals
- State and Local Government Issues
- Telecommunications
- Transportation

Contact the Clearinghouse:
Call: 1-877-232-4968
Email: clearinghouse@dms.myflorida.com.

Department of Management Services – Governor's Commission on Disabilities

The Governor's Commission on Disabilities was designed, by Executive Order, to be a policy advising body, collecting, analyzing, advocating, and advising on issues involving persons with disabilities. The Commission receives input from various sources including

the public as well as universities, state agencies, and non-profit organizations. The Commission publishes an annual report, July 1st, to the Governor with recommendations to remove barriers and improve services to persons with disabilities.

For further information, go to the web address:
http://dms.myflorida.com/other_programs/governor_s_commission_on_disabilities

Florida Alliance for Assistive Services & Technology, Inc. (FAAST)

The mission of FAAST is to improve the quality of life for all Floridians with disabilities through advocacy and awareness activities for further access to assistive services and technology. The following resources are available through FAAST:

Emergency Preparedness –
Links, Videos, Articles, and Other Helpful Information Regarding Emergency Preparedness

Housing –
General Housing Resources and Self-Help Guide

General Resources –
General Resource and Self-Help Guide for Children with Disabilities and Their Families
General Resource and Self-Help Information for Older Individuals with Disabilities

The above resources can be attained by:
Calling: 1-850-487-3278, 1-888-788-9216, TDD: 1-877-506-2723
Fax: 1-850-487-2805
Email: faast@faast.org

For further information go to the web address: http://www.faast.org/resources/library

Florida Family Care Council

The mission of the Florida Family Care Council is to advocate, educate, and empower individuals with developmental disabilities and their families, partnering with the Agency for Persons with Disabilities, to bring services to individuals for dignity and choice.

For further information:
Contact Person: Betty Kay Clements, 352-753-1163
FCC Telephone: 1-800-470-8101

Email: info@FCCFlorida.org
Web address: www.fccflorida.org

Florida Diagnostic & Learning Resources System (FDLRS)

The Florida Diagnostic & Learning Resources System provides diagnostic, instructional, and technology support services to district exceptional education programs and families of students with disabilities. Service centers include 19 centers that directly serve school districts in the areas of Child Find, Human Resource Development (HRD), Parent Services, and Technology. Additional statewide and regional services support the use of assistive technology, instructional technology, Universal Design for Learning, and AIM/NIMAS Florida services, as well as statewide HRD and FDLRS Administration.

For further information, go to the web address: http://fdlrs.com/

Florida Developmental Disabilities Council, Inc. (FDDC)

The mission of the FDDC is to advocate and promote meaningful participation in all aspects of life for Floridians with developmental disabilities. Resources available through FDDC include:

Emergency Preparedness –
Disaster Ready

Etiquette –
Disability Etiquette
People First Language

General Resources -
Building Bridges: A Guide to Understanding the Needs of Children with Developmental Disabilities and Their Families
What Do I Need and How Do I Get It?
Choosing and Planning Your Supports and Services
Planning Ahead
Your Life Your Way
Working with Your Support Coordinator

Housing -
A Place Where I Belong
Finding a Home
There's No Place Like Home

Stress -
Coping with Disability-Related Stress
Transportation - Let's Go – A Guide to Getting Around Your Community in Florida

Waitlist -
APD Waitlist Survey – Final Report (2008)

For further information:
Call: 850-488-4180; 850-488-0956 (TDD)
1-800-580-7801 (toll free); 1-888-488-8633 (TDD toll free)
Fax: 850-922-6702
E-mail: fddc@fddc.org
Web address: www.fddc.org

Florida Family Network on Disabilities

The Florida Family Network on Disabilities is part of a national network of individuals of all ages who may be at-risk, have disabilities, or have special needs and their families, professionals, and concerned citizens. The mission of Family Network on Disabilities is to ensure that individuals have full access to support, education, information, resources, and advocacy.

For further information:
Call: 1-800-825-5736
1-727-523-1130 (Pinellas County)
Fax: 1-727-523-8687
Web address: www.fndfl.org

National Organizations on Developmental Disabilities

American Association on Intellectual and Developmental Disabilities (AAIDD)

AAIDD (formerly AAMR -- American Association of Mental Retardation) is an interdisciplinary organization of professionals and citizens concerned about intellectual and developmental disabilities. Many resources and publications are available through the AAIDD, such as the following:

Aging and End of Life Webinar Series. Information about upcoming Webinars as well as archives of materials and presentations from past Webinars in this series are available on the website of the American Association on Intellectual and Developmental Disabilities (AAIDD). This series, sponsored by AAIDD, the Association of University Centers on Disability, The Arc of the United States, ANCOR, and the RRTC on Aging with Developmental Disabilities (University of Illinois at Chicago) has included the following presentations, among others:

Dementia among Adults with Down syndrome: Individual Differences in Risk and Progression

Aging and End of Life: Crisis or Opportunity for Individuals and Service Providers?

Key Issues in Healthcare Decision Making and Care at End of Life: How to Use Person-Centered Practices to Support Quality Planning with People with Critical, Chronic and/or Terminal Illnesses

End of Life through a Cultural Lens

For further information on publications and resources:
Call: 1-800-424-3688 or 1-202-387-1968
Fax: 1-202-387-2193
Email: books@aaidd.org

Kaiser Health News

Kaiser Health News (KHN) is a nonprofit news organization providing on-line coverage of health care policy and politics. In addition, KHN covers trends in the delivery of health care and in the marketplace.

For additional information go to the web address: http://www.KaiserHealthNews.org

National Association of Councils on Developmental Disabilities (NACDD)

The National Association of Councils on Developmental Disabilities (NACDD) is a national membership organization representing the 54 State and Territorial Councils on Developmental Disabilities. Its mission is to assist members in developing and sustaining inclusive communities and self-directed services and supports for individuals with developmental disabilities.

For further information:
Call: 1-202-506-5813
Fax: 1- 202-506-5846
E-mail: info@nacdd.org

National Disability Rights Network

The National Disability Rights Network is the nonprofit membership organization for the federally mandated Protection and Advocacy (P&A) Systems and Client Assistance Programs (CAP) for individuals with disabilities.

For additional information on disability resources:
Call: 1-202-408-9514
Fax: 1-202-408-9520
TTY: 1-202-408-9521
Email: info@ndrn.org

National Down Syndrome Society

The website of the National Down Syndrome Society has an on-line bookstore, information on education and research programs, and information and referral functions. Web links include sites offering information in Spanish, information on support groups, and links to other persons with Down syndrome.

For further information:
Call toll-free: 1-800-221-4602
Email: info@ndss.org

Strong Center for Developmental Disabilities' (UCEDD) Program in Aging and Developmental Disabilities (PADD) at the University of Rochester's School of Medicine and Dentistry

Curriculums, resources, and manuals available include:

Understanding Aging and Developmental Disabilities: An In-Service Curriculum Part I, 2nd Edition,

Intellectual Disabilities: A Caretaker's Guide to Aging and Dementia Rochester

Clinical Assessment Training, the Rochester Clinical Assessment Training Curriculum

For more information:
Call: 1-585-275-6604

The Alzheimer's Association

The Alzheimer's Association offers information for individuals and families who are struggling to live with the disease. There are many local chapters that provide support groups, reading materials, assist with locating resources and provide advocacy for people with Alzheimer's and their families.

For additional information:
Call: 1-703-359-4440 or 1-800-272-3900
Email: www.alz.org

The Arc National Headquarters

The Arc of the United States is an organization of and for people with developmental disabilities and their families. Its website offers a number of links as well as an on-line store for books and videos and information on policy issues, conferences, and news items.

For further information:
Call: 1-301-565-3842 or 1-301-565-3842
Web address: www.thearc.org

U.S. Administration on Developmental Disabilities

The Administration on Developmental Disabilities (ADD) is the U.S. government organization responsible for implementation of the Developmental Disabilities Assistance and Bill of Rights Act of 2000, known as the "DD Act." ADD, its staff and programs are part of the Administration for Children and Families in the U.S. Department of Health and Human Services.

For further information:
Call: 1-202-690-6590
Fax: 1-202-690-6904 or 202-205-8037

Web address: http://faq.acf.hhs.gov/cgi-
bin/acfrightnow.cfg/php/enduser/std_alp.php?p_cat_lvl1=69

U.S. Office on Disability

The Office on Disability (OD) in the U.S. Department of Health and Human Services oversees the implementation and coordination of programs and policies that enhance the health and well-being of people with disabilities across all ages, races, and cultures.

For additional information on disability resources:
Web address: http://www.napas.org/.
Email: ODInfo@hhs.gov

Articles on aging with developmental disabilities

Ansello, E. and T. Rose (1989). *Aging and Lifelong Disabilities: Partnership for the Twenty-first Century.* University of Maryland Press, University Park, Maryland.

Factor, A. "Aging with developmental disabilities: an information packet on understanding age-related changes and supporting successful aging." Chicago, IL: RRTC Clearinghouse on Aging and Developmental Disabilities, 1997.

Hammel, J., & Nochajski., S.M. (Eds.). (2000). *Aging and developmental disability: Current research, programming, and practice implications*. New York: Haworth Press. (Call Number: 20.9 .A454)

Herr, S. S., & Weber, G. (Eds.). (1999). *Aging, rights, and quality of life: Prospects for older people with developmental disabilities*. Baltimore: Paul H. Brookes. (Call number: 20.9 .A456)

Impact (Winter 2010). *Feature Issue on Aging and People with Intellectual Disabilities.* Published by Institute on Community Integration (UCEDD) Research and Training Center on Community Living. Vol. 23, No.1.

Janicki, M.P., Dalton, A.J., Henderson, C., & Davidson, P. (1999). "Mortality and morbidity among older adults with intellectual disability: Health services considerations." *Disability and Rehabilitation, 21*(5/6), 284–294.

Prasher, V. P., & Janicki, M. P. (2002). *Physical health of adults with intellectual disabilities.* Malden MA: Wiley-Blackwell

Articles on long range planning for families and individuals with developmental disabilities

DeBrine, E.J. (2003). *The future is now [electronic resource]: A future planning training curriculum for families and their adult relatives with developmental disabilities (2nd ed.)*. Chicago: Rehabilitation Research and Training Center on Aging with Developmental Disabilities, University of Illinois at Chicago. (Call Number: 54. F48)

Gaventa, W.C., & Coulter, D.L. (2005). *End-of-life care: Bridging disability and aging with person-centered care*. Binghamton, NY: Haworth Pastoral Press. (Call Number: 33 .G3) .

Sutton, E., T. Heller, H.L. Sterns, A. Factor & S. Miklos. "Person-centered planning for later life: a curriculum for adults with mental retardation." Chicago, IL: RRTC Clearinghouse on Aging and Developmental Disabilities, 1993.

Articles on coalition building and community planning for older individuals with developmental disabilities

Janicki, M.P. (et al) (1991) "Building the Future: Planning and Community Development in Aging and Developmental Disabilities." New York State Office of Mental Retardation and Developmental Disabilities, Albany, New York.

Janicki, M. & E. Ansello, eds. "Community supports for aging adults with lifelong disabilities." [S.l.] : Brookes Publishing, 2000. Order directly from the publisher at: www.brookespublishing.com/ or 1-800-638-3775.

Articles on dementia and developmental disabilities

Janicki, M. P., & Dalton, A. J. (Eds.). (1999). *Dementia, aging, and intellectual disabilities: A handbook*. Philadelphia, PA: Brunner/Mazel. (Call number: 20.9 .D45)

McCarron, M., Gill, M., McCallion, P., & Begley, C. (2005). "Health co-morbidities in ageing persons with Down syndrome and Alzheimer's dementia." *Journal of Intellectual Disability Research,* 49(7), 560-566.

Manuals

"Help for Caring for Older People Caring for an Adult with a Developmental Disability" is a 137-page manual for area agencies. Chapters include "Why Should Older Carers be Targeted for Assistance?," "Organizing Your Community," "Developing Your Agency's Initiative," "Cultural Aspects to Working with Carers," and "Key Issues in Working with Carers." The document also contains a number of appendices of resources and sample materials.

Aiding Older Caregivers. This 55-page toolkit, "*Aiding Older Caregivers of Persons with Intellectual and Developmental Disabilities,*" is an accumulation of materials, resources and best practices in the topic, produced as a direct result of three years of collaboration-building workshops in 33 different states. Sections include Demographics, Collaborations, Legislation, Best Practices, References, Resources, and Quick Reference Fact Sheets.

Rochester Environmental and Sensory Processing Awareness (RESPA) Checklists. Guidelines for environmental modifications based on sensory needs of the individual

with developmental disabilities. Available through the Program on Aging and Developmental Disabilities, Rochester, NY, 585-275-6604.

The Wit to Win:. How to Integrate Older Persons with Developmental Disabilities into Community Aging Programs, http://www.uic.edu/ orgs/rrtcamr/witowin.htm

Understanding Aging and Developmental Disabilities: A Training Curriculum (1997). Bishop, Davidson, Lucchino, Machemer, Overeynder, & Turk. Available through the Program on Aging and Developmental Disabilities, 585-275-6604.

Videos

Alzheimer's Disease and Adults with Down Syndrome
      Contact - Randy Costales, Associate Director
      The Arc of New Mexico 505-883-4630
      Free PowerPoint training program

Dementia and Adults with Intellectual Disabilities
18 minutes - Alzheimer's Disease and a Down Syndrome Individual
      New York State Developmental Disabilities Planning Council
      155 Washington Avenue, Albany, New York 12223
      www.ddpc.state.ny.us

Assessment tests for dementia in adults with Down syndrome or other adults with cognitive impairment

Dementia Scale for Down syndrome [DSDS]
Dr. A. GEDYE
P.O. Box 39081 Point Grey
Vancouver, BC V6R 4P1
Canada

Dementia Questionnaire for Mentally Retarded Persons [DMR]
Prof. Dr. Heleen M. EVENHUIS
Erasmus University Rotterdam
Intellectual Disability Medicine - Room Ff 317
Department of General Practice
P.O. Box 1738
3000 DR Rotterdam

The Netherlands
EMAIL: h.evenhuis@debruggen.nl

Assessment for Adults with Developmental Disabilities [AADS]
Dr. Sunny KALSY
Clinical Psychologist
Psychology Service
66 Anchorage Road
Sutton Coldfield
West Midlands
England B74 2PH
EMAIL: Sunny.Kalsy@bscht.wmids.nhs.uk

APPENDIX B: Glossary of Terms and Acronyms

Activities of Daily Living (ADLs) – Activities usually performed for oneself in the course of a normal day including bathing, dressing, eating, walking, transferring , and toileting.

Adaptive Behavior – Adaptive behavior is a collection of conceptual, social and practical skills that have been learned by people in order to function in their everyday lives. Significant limitations in adaptive behavior impact a person's daily life and affect the ability to respond to a particular situation or to the environment.

ADRCs – Aging and Disability Resource Centers. The State of Florida received its first ADRC multi-year grant from the U.S. Administration on Aging and the Centers for Medicare & Medicaid Services in 2004. The purpose of the grant was to create visible and trusted places in the community where people can receive consistent and unbiased long-term care information and community resources. The ADRC is designed to improve entry into the long-term care system and make services more accessible.

In 2005, the Department of Elder Affairs designated the first three ADRC sites in the Area Agency on Aging Planning and Service Areas (PSAs) based in Orlando, St. Petersburg and Fort Lauderdale. In addition to serving elders and their caregivers, these three ADRCs provide access services to adults with severe and persistent mental illness.

The ADRC has co-location arrangements with organizations that provide eligibility determination for services, namely staff of the Department of Elder Affairs CARES (Comprehensive Assessment and Review for Long-term Care Services) Unit and the Department of Children & Families ACCESS (Automated Community Connection to Economic Self-Sufficiency) Program. As a client advocate, the ADRC works with these state systems to ensure eligibility is determined as efficiently and expeditiously as possible.

As part of their Information and Referral responsibility, the ADRCs have developed a statewide internet-accessible database of resource information about long-term care and other community services. It is located at the following web address: http://www.agingresourcecentersofflorida.org/resource_dir.html.

With support from the recent ADRC expansion grant funded again by the U.S. Administration on Aging, the Department is partnering with the developmental disability community and the Agency for Persons with Disabilities to offer ADRC services in two of Florida's PSAs to persons with developmental disabilities age 50 or older and their family caregivers age 55 or older. This new initiative will support the expansion of the ADRC based in St. Petersburg and the transition from an Aging Resource Center to an ADRC of the Area Agency based in Fort Myers.

APD — Agency for Persons with Disabilities. The agency in the State of Florida responsible for oversight of services for persons with developmental disabilities.

Adult Day Care — Adult day care centers offer social, recreational and health-related services to individuals who cannot be left alone during the day because of health care and social need, confusion or disability.

Alzheimer's Disease — A disease marked by the loss of cognitive ability, generally over a period of 10 to 15 years, and associated with the development of abnormal tissues and protein deposits in the cortex of the brain. This is the most common type of later life onset of dementia.

Age into Medications — Medications taken over a long period may start to increase a person's risk for adverse effects with negative impact on the older individual.

Area Agency on Aging — Under the federal Older Americans Act, the U.S. Administration on Aging distributes funds for various aging programs through state units on aging, which in turn fund local area agencies on aging. Area Agencies on Aging are responsible for assessing the needs of older Americans in their designated Planning and Service Areas and coordinating the local aging service system. They administer programs that provide supportive and nutritional services to older people in communities where they live. In most cases, Area Agencies on Aging do not provide direct services. Instead, they subcontract with other organizations to ensure a full range of services is available for older people.

AoA – Administration on Aging. The Administration on Aging, an agency in the U.S. Department of Health and Human Services, is the official Federal agency dedicated to policy development, planning and the delivery of supportive home and community-based services to older persons and their caregivers. The AoA administers the Older Americans Act and works through the national aging network of State Units on Aging, Area Agencies on Aging, Tribal and Native organizations representing 300 American Indian and Alaska Native Tribal organizations, and two organizations serving Native Hawaiians, plus thousands of service providers, adult care centers, caregivers, and volunteers.

AoA has provided funding for Aging and Disability Resource Centers to almost all 50 states. Florida received funding in 2004. According to the AoA website, "The Aging and Disability Resource Center Grant Program, a cooperative effort of the Administration on Aging (AoA) and the Centers for Medicare & Medicaid Services (CMS), was developed to assist states in their efforts to create a single, coordinated system of information and access for all persons seeking long-term support to minimize confusion, enhance individual choice, and support informed decision-making." For a current list and map of states with ADRC funding, see the AoA website.

ARCs – Aging Resource Centers. Florida's 11 Area Agencies on Aging also function as ARCs, offering long-term care access services targeted to elders, their families and persons planning for future long-term support needs. The state's three ADRCs are also operating as ARCs. The only distinction is that ARCs do not have a disability population focus.

In each Planning and Service Area, the ARC forms a single, coordinated system for all persons seeking long-term care resources by providing information and referral through multiple entry points and streamlined access to public and private long-term care services. They also have co-location arrangements with state staff responsible for eligibility determination and they participate in the statewide internet-accessible database of resources.

<div align="center">OR</div>

ARC/Arc – Refers to not-for profit agencies in the disability network across the nation. Some are acronyms representing terms such as Association for Retarded Citizens. Others have changed their name to The Arc as a word and no longer an acronym. The Arcs were originally founded by parents who were developing alternative services to institutional/residential care. It is a national organization with chapters in every state.

Area Office – The local Agency for Persons with Disabilities (APD) office responsible for managing one of the agency's 14 service areas.

Assisted Living Facilities – A facility that provides a combination of housing and personalized health care in a professionally managed group-setting designed to respond to the individual needs of persons who require assistance with activities of daily living. The facility provides care to residents who cannot live independently, but who do not require 24-hour nursing care.

Assistive Technology – Assistive technology is any service or tool that helps the elderly or disabled do the activities they have always done but must now do differently. These tools are also sometimes called "adaptive devices." Such technology may be something as simple as a walker to make moving around easier or an amplification device to make sounds easier to hear (for talking on the telephone or watching television, for instance).

Auditory – One of the seven senses, taking in information from the physical environment through hearing.

Autism – A spectrum of neuropsychiatry disorders characterized by deficits in social interaction and communication, and unusual and repetitive behavior. This is one of the five developmental disabilities as defined by Florida Statutes.

Breaking Down the Silos – This term refers to the lack of integration and communication between service delivery networks. Each network, including mental health, developmental disabilities, and aging, has operated separately in most areas of the state of Florida and the U.S. The expansion of the ADRCs is intended to eliminate barriers to working together and provide "seamless" access to services for individuals and their families, regardless of which network delivers the services. Other terms used for this process include creating a Single Entry System, unbundling the services, and collaborative service delivery.

Caregivers – Caregiving is the act of providing unpaid assistance and support to family members or acquaintances that have physical, psychological, or developmental needs. Caring for others generally takes on three forms: instrumental, emotional, and informational caring. Instrumental help includes activities such as shopping for someone who is disabled or cleaning for an elderly parent. Caregiving also involves a great deal of emotional support, which may include listening, counseling, and companionship. Finally, part of caring for others may be informational in nature, such as learning how to alter the living environment of someone in the first stages of dementia. The reference throughout this curriculum is to unpaid caregivers, often family members of the individual in need of assistance.

Caregiver Support – Through the funded services of the Department of Elder Affairs, training and support is available to caregivers to help them reduce stress, increase coping skills, learn strategies for effective management of caregiving tasks, and enable them to provide high quality care to recipients within the home. Caregiver training and support is offered through community workshops, seminars, support groups and other organized local, regional, or statewide events. For more information, contact the Elder Helpline at 1-800-963-5337.

Central Office – Central Office is a reference to the Agency for Persons with Disabilities' headquarters located in Tallahassee.

Cerebral Palsy – Cerebral palsy is an umbrella term encompassing a group of non-progressive, non-contagious motor conditions that cause physical disability in human development, chiefly in the various areas of body movement. This is one of the five developmental disabilities as defined by Florida Statutes.

Clinical Design – Design of the physical environment that is prescribed by a clinician, often Occupational or Physical Therapist, specifically for the individual or a group of individuals with similar needs.

Cognitive Function – This term refers to the intellectual capacity of an individual.

Congregate Meals – These meal programs provide older individuals with free or low cost, nutritionally sound meals served five days a week in easily accessible locations.

Besides promoting better health through improved nutrition, meal programs provide daily activities and socialization for participants to help reduce the isolation of old age.

Cueing – Environmental prompts that will help confused people know where they are in space.

DCF – Florida Department of Children and Family Services. The Agency for Persons with Disabilities was formerly a part of this agency.

Dementia – Dementia is a condition in which there is a gradual loss of brain function; it is a decline in cognitive/intellectual functioning. The main symptoms are usually loss of memory, confusion, disorientation, problems with speech and understanding, changes in personality and behavior and an increased reliance on others for the activities of daily living. It is not a disease in itself but rather a group of symptoms which may result from age, brain injury, disease, vitamin or hormone imbalance, or drugs or alcohol. A person with dementia may also exhibit changes in mood, personality or behavior. The loss of mental functions must be severe enough to interfere with daily living.

Diagnostic Overshadowing – Diagnostic overshadowing refers to the tendency to inaccurately diagnose people with developmental disabilities. The developmental disability or aging of the individual is blamed rather than pursuing a possible underlying disease causing the decline. The tendency to ignore possible disease or adverse side effects from medications is more common in people with developmental disabilities.

DOEA – Florida Department of Elder Affairs, the state unit on aging as designated by the Administration on Aging.

Down Syndrome – A genetic disorder, in which a child is born with forty-seven rather than forty-six chromosomes, that results in developmental delays, retardation, low muscle tone, and other possible effects.

Elder Abuse – Elder abuse is a term referring to any knowing, intentional, or negligent act by a caregiver or any other person that causes harm or a serious risk of harm to a vulnerable adult. The specificity of laws varies from state to state, but broadly defined, abuse may be physical, emotional, sexual, exploitation, neglect, and abandonment.

Elder Abuse Prevention Programs – Allegations of abuse, neglect and exploitation of senior citizens are investigated by highly trained protective service specialists. Intervention is provided in instances of substantiated elder abuse, neglect or exploitation.

Elder Helpline (800-963-5337) – Information regarding elder services and activities is available through the statewide Elder Helpline Information and Assistance service

managed by the Department of Elder Affairs. By calling the toll-free number, the caller is routed to the local Helpline serving the area where the caller is located.

Energy Assistance – These programs can provide low-income households with elderly residents with funds to help pay home utility costs. Eligibility requirements may vary from state to state.

Epilepsy – Epilepsy is a sign of a disorder of the central nervous system characterized by loss of consciousness and convulsions.

Guardian – An individual appointed by a court of law to manage a person's financial and/or personal affairs because the court has found that the person is not competent to manage his or her own affairs. A conservator is similarly appointed, but only for financial affairs.

Guardianship – The process in which an individual is appointed by a court of law to manage a person's financial and/or personal affairs because the person is not able to or is not competent to manage his/her own affairs.

Gustatory – One of the seven senses, taking in information from the physical environment through taste.

Home and Community-Based Services (HCBS) – A variety of supportive services delivered in community settings or in a person's home designed to help the person remain at home and avoid institutionalization.

Home Delivered Meals – Sometimes referred to as "meals on wheels," home delivered meals are hot and nutritious meals delivered to homebound persons who are unable to prepare their own meals and have no outside assistance.

Home Health Care – Home health care is recognized as an increasingly important alternative to hospitalization or care in a nursing home for patients who do not need 24-hour a day professional supervision. Many people find it possible to remain at home for the entire duration of their illness or at least to shorten their hospital stay. In many cases readmission to the hospital can be prevented or delayed. A variety of health services are provided in a home health care program in the patient's home, under the direction of a physician.

ICF – Intermediate Care Facility. A residential setting which is federally funded through Medicaid dollars.

ICF/DD – Intermediate Care Facility/Developmental Disabilities. A residential setting which is federally funded through Medicaid dollars. Residents of the facility must meet the criteria for developmental disability and be Medicaid eligible.

ICP – Institutional Care Program. A Medicaid program that helps people in nursing facilities pay for the cost of their care plus provides general medical coverage. ICP eligibility is determined by the Florida Department of Children and Families.

Information and Referral – In the aging network, Information Specialists are available through the Elder Helpline to provide assistance and linkage to available services and resources.

Intergenerational – Being or occurring between generations.

LTC – Long term care. A continuum of services enabling an individual to receive services in the least restrictive setting. This may range from remaining at home to residing in an assisted living facility to placement in a nursing home.

Medicaid – Medicaid is a health benefit program administered by states for people with low incomes who meet other eligibility requirements. Federal and state governments finance the health insurance program. Medicaid may also pay for nursing home care if the individual's income and assets are within certain limits.

Medicare – The national health insurance program for eligible people 65 and older and some disabled individuals. Part A covers hospital costs. Part B covers doctor bills and other medical costs. Part C (supplemental health care coverage to Medicare) is designed specifically to supplement and complement Medicare's benefits by filling in some of the gaps of Medicare coverage. These insurance policies are non-group policies that may pay for Medicare deductibles, prescription drugs, or other services not covered by Medicare. Part D is the prescription drug program.

Olfactory – One of the seven senses, taking in information from the physical environment through smell.

Person-Centered – This concept refers to the practice and policy in the developmental disabilities network of placing the individual first in language, intake, and service delivery. The individual is the center of the process of choosing services. This concept is also the basis for client participation in care planning and service provision in the aging network.

Prader-Willi Syndrome (PWS) – A genetic condition caused by the absence of chromosomal material from chromosome 15. Characteristics of the syndrome include developmental delay, poor muscle tone, short stature, small hands and feet, incomplete sexual development, and unique facial features. Insatiable appetite is a classic feature of PWS. This uncontrollable appetite can lead to health problems and behavior disturbances. Prader-Willi Syndrome is one of the five developmental disabilities as defined by Florida Statutes.

Proprioceptor – One of the seven senses, used for movement and locating oneself within space so that activities of daily living can be performed effectively.

Protective Services – The program in the Department of Children and Family Services that responds to reports made to the department's central abuse hotline alleging abuse, abandonment, neglect, or exploitation, per Chapter 39 or 415, Florida Statutes.

Planning and Service Areas (PSAs) – In 1973, Area Agencies on Aging were established to provide services to seniors at the local level. The Florida State Unit on Aging divided the state into 11 local Planning and Service Areas (PSAs). Each has the responsibility of planning and coordinating resources in its local service area. An Aging and Disability Resource Center will be developed in each of the 11 PSAs.

ReferNET – A centralized web-based software application from RTM Designs for information and referral networks with multiple member organizations, used by all of Florida's ADRCs and ARCs.

Retardation – Retardation is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. It is one of the five developmental disabilities as defined by Florida Statutes.

Senior Centers – A vital link in the service delivery network, senior centers are functioning as meal sites, screening clinics, recreational centers, social service agency branch offices, mental health counseling clinics, older worker employment agencies, volunteer coordinating centers, and community meeting halls. Senior centers provide a sense of belonging, offer the opportunity to meet old acquaintances and make new friends, and encourage individuals to pursue activities of personal interest and involvement in the community.

Sensory Processing – A term related to the ability of the central nervous system to receive and interpret stimuli using the seven senses.

State Units on Aging (SUAs) – The Older Americans Act mandates that each state designate a state unit on aging as part of its state government structure. The state unit on aging is the designated focal point within the state government responsible for administering a complex service system designed to complement and support other human service systems in meeting the needs of the elderly. In Florida, the Department of Elder Affairs is the state unit on aging.

Spina Bifida – A medical diagnosis of Spina bifida cystica or myelomenigocele refers to a condition where a portion of the spinal cord fails to develop or close properly but the spinal cord remains in place. The individual affected may have a secondary condition

such as retardation. This is one of the five developmental disabilities as defined by Florida Statutes.

Support Coordinators – Every person enrolled in the Medicaid waiver program of the Agency for Persons with Disabilities receives a service called Support Coordination, which is a form of case management. Support Coordinators assist individuals and their families to access supports and services on their own.

Tactile – One of the seven senses, taking in information from the physical environment through touch.

Universal Design – Universal design refers to a broad-spectrum solution that produces buildings, products and environments that are usable and effective for everyone, not just people with disabilities.

Vestibular – One of the seven senses, used for movement. The vestibular system works closely with the proprioceptor system and is being used anytime the head moves through space. The brain requires hydration and movement for best functioning.

Visual – One of the seven senses, taking in information from the physical environment through seeing.

Vitality – The term vitality refers to the strength or stamina of the older individual to continue to participate in activities of daily living as well as survive. The more vitality a person has the increased likelihood of a good quality of life and function.

Waitlist – "Waitlist" is the prioritized list maintained by the APD Central Office of persons with developmental disabilities who have been determined eligible for APD services and eligible to receive waiver services when funding is available. In the aging network, the waitlist is called "Assessed Priority Consumer List" (APCL) and is also a prioritized list of individuals waiting for funded services to become available.

Waitlist Priority Checklist – Waitlist Priority Checklist is the tool completed at the time an eligible individual applies for APD waiver-funded services and consists of an indication of the category that the individual will be placed on the wait list. This checklist identifies services needed and current services received and requests information about the individual's current and short-term life situation, condition and circumstances. The checklist is reviewed on an annual basis and is updated when the APD is notified that the individual's needs and circumstances have changed.

Waiver – Refers to an APD Medicaid waiver authorized by 42 U.S.C. 1396n(c) of the Federal Social Security Act and Section 409.906, F.S., that provides Medicaid funding for home and community based services (HCBS) to eligible persons with developmental disabilities who live at home or in a home-like setting. The APD currently operates four HCBS waivers: Tier One, Two, Three and Four in accordance with Section 393.0661(3),

Florida Statutes, and Rules 65G-4.0026 through 65G-4.0029, Florida Administrative Code.

DOEA also operates the following Medicaid home and community-based services waivers through the Area Agencies on Aging: Aged and Disabled Adult and Assisted Living for the Frail Elderly.

APPENDIX C: Handouts for Meeting the Needs of Aging Persons with Developmental Disabilities

Handouts and instructions included:
- o Worksheet for Module 1
- o Worksheet for Module 2
- o Worksheet for Module 4

Instructions for Worksheet for Module 1:

After introduction of the project, project objectives, and trainers, the Worksheet for Module 1 should be presented as part of the packet given to participants. Organization of the activity should include –
- o Break up the participants into an approximate equal number within each group. Four groups will work best. If possible each group should have representatives from both the aging and developmental disabilities networks. Use the same groups for the entire training day. If the modules are not going to be presented on the same day, different groups can be formed for each of the modules as they are presented.
- o Instruct each group to identify a facilitator who will introduce each of the participants in the group as well as encourage completion of the questions for the Module 1 Worksheet.
- o Give the groups about 10 - 15 minutes to work on the Module 1 worksheet.
- o Check in with the groups at about 9 minutes to determine progress and need for an additional few minutes.
- o Ask each facilitator of the groups to introduce the participants in his/her group including the agency each participant represents.
- o Ask for a brief discussion on completing the worksheet. Indicate training material in Module 1 will include maps that identify each of the regions. Ask them to check back on their work after Module 1 to see if they have accurate information for contacts.
- o After each group has been introduced and there has been brief discussion on the different regions represented, move on to presenting Module 1.
- o At the end of Module 1 ask them to recheck their contact information.

Meeting the Needs of Aging Persons with Developmental Disabilities

Worksheet for Module 1

Name: _____ Date: _____
Location of Training: _____

1. List the name(s) and contact information for the local representatives from the Agency for Persons with Disabilities (APD) in your workgroup.

Name/Position	Area/Region Office #	Phone	Email

2. List the counties covered by each APD office represented.

Area/Region Office#	Counties

3. List the name(s), agency and contact information for Aging Resource Center, Aging and Disability Resource Center, or Area Agency on Aging representatives in your workgroup

Name/Position	PSA #	Phone	Email

4. List the counties in each ARC/ADRC/AAA service area represented.

PSA #	Counties

5. List the name(s), agency and contact information for other members of your workgroup

Name/Position	Agency	Phone	Email

6. List at least 3 benefits for working together after this training.

1.

2.

3.

Instructions for Worksheet for Module 2 – Exercise: Scenarios for Module 2

- o Use the same workgroups as for Module 1. If you are presenting Module 2 separately from Module 1, then break up the participants into four groups. If possible each group should have representatives from both the aging and developmental disabilities networks.
- o Assign half of the groups Scenario #1 and the other half of the groups Scenario #2. Give the groups approximately 8 - 10 minutes to discuss the assigned scenario and to answer the questions at the end of the scenario. Explain that each of the scenarios is based on real-life examples. There are no right and wrong answers to the questions. What is important to learn from each of the scenarios is the benefit of the networks working together.
- o Some important concepts that should be learned from Scenario #1 include:
  - o Caregivers are often the major common link between the networks.
  - o ADRC expansion and collaboration with APD may assist in meeting the needs of both the caregiver and the individual with developmental disabilities.
  - o It is important to work with the caregiver, especially if the caregiver is an elderly parent, to pull together any available documentation that can help determine if the individual is eligible for developmental disabilities services in Florida.
  - o Because John's chronological age was 65, it was actually easier to work together as he was eligible for services in both networks.
  - o Attaining documentation is usually much easier when the primary caregiver is still living.
  - o John would benefit from expanding his own social network.
- o Some important concepts that can be learned from Scenario #2 include:
  - o Caregivers are the major common link between the networks.
  - o As caregivers age, there is usually an increasing necessity to address their own needs and those of their spouse.
  - o It is common to find grandparents who are the primary, if not legal, caregivers for their grandchild with developmental disabilities.
  - o There will be caregivers from states with different eligibility criteria for developmental disabilities. It is important to work with the APD network to determine eligibility in every instance.
  - o Work with the grandparents to locate available documentation to determine eligibility in the state of Florida.
  - o This is an ideal time to determine if Wendy's siblings may be interested in re-connecting with Wendy. They may be interested in future caregiving assistance for Wendy.

Meeting the Needs of Aging Persons with Developmental Disabilities
EXERCISE: Scenarios for Module 2

The following scenarios are based on true situations with the names and any identifying information changed.

Scenario #1

John is 65 years old. He lives with his mother, 92 years old, who was widowed 25 years ago. John does the outside maintenance of their shared trailer while Mom cooks and cleans for him. They live off of her Social Security, a very small pension from John's father, and the odd jobs John does around the neighborhood. He has never applied for assistance.

John's mother recently fell while getting her newspaper on the front step. She has been hospitalized for a week. The hospital discharge planner recommends she go to a rehabilitation facility but she refuses. She does not think John can live independently.

John's mother reports that he only went to school until the 3rd grade. John would not sit still in class and was expelled from school due to poor attendance and disruption of the classroom. Mom kept him home after that and has never pursued a developmental disability diagnosis or assistance of any kind for John. She reports that he has always been "slow" and "different acting" than the other children of the neighborhood.

The discharge planner called the number for the local AAA asking for assistance with John and his mother.

Questions for Scenario #1:

1. If you received this phone call, what would you first do?

2. What further information do you need to know about John and his mother?

3. Who would you call from APD for assistance?

4. What are some of the issues that need to be resolved to help John and his mother?

Scenario #2

Wendy is 32 years old. She lives with her grandparents who are in their early 70s. While she lived in the state of Ohio with her mother she attended special education classes and was diagnosed with retardation of unspecified origin. Her mother was a drug abuser. The apartment the mother shared with Wendy and her two other children was considered unsafe by the child protective services in Ohio. The grandparents were asked to assist. Her grandparents became her legal guardians when Wendy was 16 and Wendy has lived with them since that time. She works in the local grocery store and helps out minimally at home.

Wendy's grandparents are concerned they are getting older and will be unable to care for Wendy in the future. The grandfather is scheduled for open heart surgery in a few weeks. Her grandmother wants to stay over at the hospital when her husband has the surgery and is afraid to leave Wendy alone. A neighbor suggested she call the local APD office for assistance with Wendy.

Questions for Scenario #2

1. What are the concerns for Wendy and her grandparents?

2. What additional information do you need about Wendy?

3. How would you follow up this phone call for assistance?

Instructions for Worksheet for Module 4 – Exercise: Scenarios for Module 4

- o Use the same workgroups as for Module 1. If you are presenting Module 4 separately from Module 1, then break up the participants into four groups. If possible each group should have representatives from both the aging and developmental disabilities networks.
- o Assign half of the groups Scenario #3 and the other half of the groups Scenario #4. Give the groups approximately 8 - 10 minutes to discuss the assigned scenario and to answer the questions at the end of the scenario. Explain that each of the scenarios is based on real-life examples. There are no right and wrong answers to the questions. What is important to learn from each of the scenarios is the benefit for the networks working together.
- o Some important concepts to learn from Scenario #3 include:
  - o We have to be careful not to make judgments about individuals' living situations as long as they are deemed not to be a danger to themselves or others.
  - o Neighbors may be offended by Bradley's living situation. If it is not violating local codes or legal regulations, the neighbor may not have much say in how Bradley lives.
  - o There are other networks that may also be helpful in this situation such as the local Animal Humane Society.
  - o While Bradley may be eligible for both aging and developmental disabilities services, he may not want them. He has the right to refuse assistance and services.
  - o While this may be a difficult situation, if the networks work together it is more likely a reasonable solution may be found.
- o Some important concepts to learn from Scenario #4 include:
  - o Eligibility for developmental disabilities services needs to be determined, even if the individual was eligible in another state. This can best be accomplished by working with the APD.
  - o Both the caregivers and individual need some service assistance in this situation. Again, this is an opportunity for coordination between the networks.
  - o Expanding available resources can help healthy aging for the caregivers and the individual with developmental disabilities.

Meeting the Needs of Aging Persons with Developmental Disabilities
EXERCISE: Scenarios for Module 4

The following scenarios are based on true situations with the names and any identifying information changed.

Scenario #3

Bradley is 75 years old and lives alone in the small home he inherited from his father. Recently, Adult Protective Services received a report about the filthy conditions of the house, the smells coming from the house, and the 25+ cats Bradley allows to run the rural neighborhood. The initial caller indicated they used to see a local Arc van pick Bradley up in the morning and return him home in the evening. They have not seen the van in many months.

Bradley was reluctant to allow the Adult Protective Service counselor to come in his house. While they were able to talk with Bradley and determine he was not immediately a danger to himself or others, they are concerned about the quality of his life. Additionally, the neighbor who made the first report continues to call to ask what has been done.

The APS investigator followed the terms of the interagency agreement with the ADRC and made a referral through the ARTT (APS Referral Tracking Tool) to the designated aging network contact.

Questions for Scenario #3

1. Since Bradley has been determined not to be a danger to himself or others, is there anything else the Aging and Disability Resource Center could or should do?

2. Is this a situation where the aging and disability networks could work together to assist Bradley?

3. How would you approach this situation?

Scenario #4

Alice is 41, lives at home with her mother and father and works at the local super market. They moved here from Michigan 5 years ago. While in Michigan, Alice received services from the developmental disabilities network. She was diagnosed with Down syndrome with mild mental retardation at a young age. Her father, 78, has been diagnosed with mid-stage Parkinson disorder. Her mother, 72, is the primary caregiver, has severe osteoarthritis and needs hip replacement. They live on the father's Social Security and a small pension. When they moved to Florida, they did not apply for services for Alice.

The mother has told her pastor that she is at her wit's end. Over the last 12 months, she has noticed subtle changes in her daughter. She says she has to fight with her daughter to go to work; she just wants to sit in the house and watch television. She also noticed that her normally sunny nature has turned to frustrated outbursts and she has difficulties finding words. She has started to hoard her clothes and possessions. Alice does not seem to care how she looks, another change from her past behavior.

The mother's concern is now for her own health care needs and the future needs of her husband and her daughter.

The pastor was given the Aging and Disability Resource Center's (ADRC) number to seek help for the family.

Questions for Scenario #4

1. As an employee of the ADRC what would you recommend for Alice and her mother?

2. What other agency could you contact for assistance in this situation?

3. What additional information do you need?

4. Is Alice automatically eligible for APD assistance?

5. What are at least 3 shared concerns across the disability and aging networks in this situation?