Cross Network Collaboration for Florida

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

PRESENTER’S MANUAL

ADRC Training
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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.

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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:

- Five modules of the curriculum,
  - 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.
  - 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.
Cross Network Collaboration for Florida

- **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.

- **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.

- **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.

- Summaries providing additional information for each slide for the trainer
- Handouts with instructions for use
- References for further information on aging with developmental disabilities
- Glossary of acronyms and terms
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.
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.
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

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.

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

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

Exercise

Worksheet

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.

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).

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.

The transitional slide for the next section ‘Breaking Down Silos.’

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.
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

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.

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

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

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.
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.

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.

Details of the Florida Aging and Disability Resource Center Expansion Grant.
Cross Network Collaboration for Florida

Slide 16

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

Details on the purpose of the grant and ADRC expansion.

Slide 17

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

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

Slide 18

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

Additional information on APD.
Cross Network Collaboration for Florida

Slide 19

A map of the 13 area offices and one regional office: Point out the office(s) represented by attendees in this session.

Slide 20

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

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.
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.

Transitional slide for commonalities and differences between the networks.

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.
Commonalities

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

Differences

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

Additional differences listed.
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Slide 28

Meeting the Needs of Aging Persons with Developmental Disabilities

Changing Dynamics for Adults with Developmental Disabilities

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

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

The typical lifespan for persons with developmental disabilities across the nation.
An overview of the known life situations throughout the nation with Florida's statistics similar to the rest of the nation.

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

Transitional slide for Stress in Caregivers of Adults with Developmental Disabilities.
Why Are Caregivers at Risk?

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

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

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

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.

Meeting the Needs of Aging Persons with Developmental Disabilities

Transitional slide for Referral and Intake.
Collaborative Referral

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

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.

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

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.

Meeting the Needs of Aging Persons with Developmental Disabilities

Transitional slide for Common Truths About Aging.
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.

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.

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.
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.

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

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.
Purpose of Module 2
- Understand Florida eligibility criteria for developmental disabilities services
- Foster cooperation between networks

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.

Meeting the Needs of Aging Persons with Developmental Disabilities

Transition slide for Referral and Intake.

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

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.
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.

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.

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.
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

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

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

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

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.

The 11 PSAs are grouped according to counties.
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.

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.

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.
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.

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 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
Transition slide for the Developmental Disabilities Network.

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.

APD operates through local offices, serving geographical areas designated by counties.
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 through the contact information below:

- **Area 1** - Escambia, Okaloosa, Santa Rosa, Walton - (850) 595-8351
- **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
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).

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.

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

- 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
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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

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)

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)
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Slide 29

Transitional slide for Developmental Disabilities Eligibility Criteria.

Slide 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

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.
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.

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.

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

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.
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.

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.

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.
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

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.

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

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.

Meeting the Needs of Aging Persons with Developmental Disabilities

Commonalities and Differences Between the Networks

Transition slide for network comparisons.
Slide 43

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

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

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

Slide 47

Area Comparison Maps

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

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

Meeting the Needs of Aging Persons with Developmental Disabilities

What is Aging?

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

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

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

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

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.
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.

This slide identifies the consequences when these myths are prevalent.

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

Myth 1 – Early Onset of Aging (Continued)

- The older adult with Down syndrome or cerebral palsy also experiences:
  - Same aging changes but earlier onset
  - Same rate of change but compressed due to shorter longevity

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.

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.
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.

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.
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.

Transition to Aging in Individuals with a Developmental Disability.
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.

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

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

Age-Related Changes Everyone Experiences

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

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.

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.
How is Vision Affected by Aging?

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

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.

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

The combination of hearing and vision changes usually does not interfere with independence but if the decline is severe it could result in sensory “deprivation.” 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.
Age-related 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.

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.
A 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.

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).

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.

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.

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

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.
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.

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.
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.

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.
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.

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.

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.
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.

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

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.
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.
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

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

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

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.

Meeting the Needs of Aging Persons with Developmental Disabilities

Caregiver Characteristics

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

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.
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.

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.  

Meeting the Needs of Aging Persons with Developmental Disabilities

Cross Network Collaboration for Florida

Changing Focus of Caregivers

Transition slide for Changing Focus of Caregivers.

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

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.

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

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.

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.
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.

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

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.
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.

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.

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.
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.

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.

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.

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.
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.

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.

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.

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.

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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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.

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.
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.

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.
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.
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.

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

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.

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.
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 caregiving 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.

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.
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.

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.

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

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

See Appendix C for instructions on use of scenario exercises.
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.

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.
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

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.

Transitional slide for Sensory Processing.

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.

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.

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.

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

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)

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

One or all of these can be the impact of sensory changes on older adults.
The transitional slide for The Seven Senses and Aging slides.

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.

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.
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

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.

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

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

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

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

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

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

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.
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.

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.

These are ways to minimize the affect of increased or reduced taste and smell sensitivity.
Disorientation can look like symptoms of dementia.

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

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

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

Meeting the Needs of Aging Persons with Developmental Disabilities

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

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

Assistive technology can be used for all of these purposes.

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

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

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

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

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
  1-866-467-4624 or 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
  352-378-6649 or 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
  727-570-9696 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)
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- **Senior Resource Alliance**
  988 Woodcock Rd., Suite 200
  Orlando, FL 32803
  407-514-1800
  (Brevard, Orange, Osceola and Seminole counties)

- **Area Agency on Aging of Southwest Florida**
  15201 N. Cleveland Avenue, Suite 1100
  North Fort Myers, FL 33903
  239-652-6900
  (Charlotte, Collier, DeSoto, Glades, Hendry, Lee and Sarasota counties)

- **Area Agency on Aging of Palm Beach/Treasure Coast, Inc.**
  4400 N. Congress Avenue
  West Palm Beach, FL 33407-3226
  561-684-5885
  (Indian River, Martin, Okeechobee, Palm Beach and St. Lucie counties)

- **Aging and Disability Resource Center of Broward County**
  5300 Hiatus Road
  Sunrise, FL 33351
  954-745-9567
  (Broward County)

- **Alliance for Aging**
  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
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**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
Cross Network Collaboration for Florida

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

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

Suncoast - 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.
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**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
Cross Network Collaboration for Florida

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

Sccl 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
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
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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 Information for Older Individuals with Disabilities

The above resources can be attained by:
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
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 -  

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.
Cross Network Collaboration for Florida

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

**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


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


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


Articles on dementia and developmental disabilities


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
Cross Network Collaboration for Florida


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.

**OR**

**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 myelomeningocele 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),

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:
- Worksheet for Module 1
- Worksheet for Module 2
- 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 -

- 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.
- 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.
- Give the groups about 10 - 15 minutes to work on the Module 1 worksheet.
- Check in with the groups at about 9 minutes to determine progress and need for an additional few minutes.
- Ask each facilitator of the groups to introduce the participants in his/her group including the agency each participant represents.
- 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.
- After each group has been introduced and there has been brief discussion on the different regions represented, move on to presenting Module 1.
- At the end of Module 1 ask them to recheck their contact information.
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.

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<th>Area/Region Office #</th>
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2. List the counties covered by each APD office represented.

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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

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Meeting the Needs of Aging Persons with Developmental Disabilities

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

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

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<th>Name/Position</th>
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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

- 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.

- 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.

- Some important concepts that should be learned from Scenario #1 include:
  - Caregivers are often the major common link between the networks.
  - ADRC expansion and collaboration with APD may assist in meeting the needs of both the caregiver and the individual with developmental disabilities.
  - 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.
  - Because John’s chronological age was 65, it was actually easier to work together as he was eligible for services in both networks.
  - Attaining documentation is usually much easier when the primary caregiver is still living.
  - John would benefit from expanding his own social network.

- Some important concepts that can be learned from Scenario #2 include:
  - Caregivers are the major common link between the networks.
  - As caregivers age, there is usually an increasing necessity to address their own needs and those of their spouse.
  - It is common to find grandparents who are the primary, if not legal, caregivers for their grandchild with developmental disabilities.
  - 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.
  - Work with the grandparents to locate available documentation to determine eligibility in the state of Florida.
  - 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

- 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.

- 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.

- Some important concepts to learn from Scenario #3 include:
  - 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.
  - 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.
  - There are other networks that may also be helpful in this situation such as the local Animal Humane Society.
  - 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.
  - While this may be a difficult situation, if the networks work together it is more likely a reasonable solution may be found.

- Some important concepts to learn from Scenario #4 include:
  - 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.
  - Both the caregivers and individual need some service assistance in this situation. Again, this is an opportunity for coordination between the networks.
  - 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?