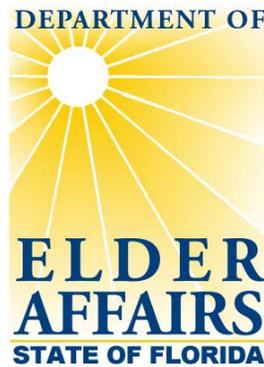


# **Meeting the Needs of Aging Persons with Developmental Disabilities and Their Families**

## ***Participant's Handbook<sup>1</sup>***



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<sup>1</sup> A publication created by RTSC, LLC

*Cross Network Collaboration for Florida*

Location

AGENDA

Contacts

## **Overview of the Five (5) Modules of “Meeting the Needs of Aging Persons with Developmental Disabilities and Their Families”**

### **Module 1: Introduction**

This module includes a brief overview of the aging and developmental disabilities networks in Florida, the commonalities of aging, and information regarding the expansion activities for the Aging and Disability Resource Centers (ADRCs) in Florida.

### **Module 2: Aging and Developmental Disabilities Systems**

This module includes additional information on the aging and developmental disabilities networks in Florida, expanded information on aging and aging with developmental disabilities.

### **Module 3: Aging in Individuals with a Developmental Disability**

This module includes more extensive information on risk factors for persons who are aging with developmental disabilities as well as pertinent demographics. Discussion about potential adverse affects of medications, especially in older persons with developmental disabilities, is also included.

### **Module 4: Bridging the Networks-Needs of Older Caregivers of Individuals with Developmental Disabilities**

The caregivers are often the bridge between the aging and developmental disabilities networks. Information on the issues commonly experienced by caregivers of individuals with developmental disabilities is included in this module.

### **Module 5: Sensory Processing, Environmental Modifications and Adaptive Technology**

Environmental modifications and adaptive technology can be used to enhance quality of life and function as people with developmental disabilities and their caregivers' age. Included in this module are typical sensory impairments and changes that increase as people age and possible modifications or adaptive technology that can enhance independence and quality of life.

## Meeting the Needs of Aging Persons with Developmental Disabilities

### Worksheet for Module 1

Name: \_\_\_\_\_ Date: \_\_\_\_\_

Location of Training: \_\_\_\_\_

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

Name/Position	Area/Region Office #	Phone	Email

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

Area/Region Office#	Counties

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

Name/Position	PSA #	Phone	Email

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

PSA #	Counties

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

Name/Position	Agency	Phone	Email

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

1.

2.

3.

## **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**

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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 3<sup>rd</sup> 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**

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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?

## **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**

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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**

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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?

## **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](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),

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

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

## **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  
727-570-9696/727 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)

- **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](mailto: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](mailto: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](mailto:info@abletrust.org)

Web address: [www.abletrust.org](http://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](mailto:APD_info@apd.state.fl.us)

Web address: <http://www.apd.myflorida.com>

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

### Area 1 - Escambia, Okaloosa, Santa Rosa, Walton

160 Government Center, Room 412

Pensacola, FL 32502

(850) 595-8351

### Area 2 - Bay, Calhoun, Franklin, Gadsden, Gulf, Holmes, Jackson, Jefferson, Liberty, Leon, Madison, Taylor, Wakulla, Washington

2639 North Monroe Street, Suite B-100

Tallahassee, FL 32399-2949

(850) 487-1992

### Area 3 - Alachua, Bradford, Columbia, Dixie, Gilchrist, Hamilton, Lafayette, Levy, Putnam, Suwannee, Union

1621 Northeast Waldo Road, Building 1

Gainesville, FL 32609

(352) 955-6061

*Cross Network Collaboration for Florida*

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

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

## *Cross Network Collaboration for Florida*

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](mailto:info@centerforautism.com)

Web address: [www.centerforautism.com](http://www.centerforautism.com)

### **Centers for Independent Living (CILs)**

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

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

#### **Ability1st**

1823 Buford Court

Tallahassee, FL 32308

Call: 850-575-9621; 850-575-5245 TDD

Fax: 850-576-5740

**Caring And Sharing CIL, Inc.**

12552 Belcher Rd. South  
Largo, FL 33773  
Call: 727-539-7550; 727-539-7550 TDD  
Fax: 727-539-7588  
Web address: <http://www.cascil.org>

**Center For Independent Living Of Broward**

4800 N. Street, Rd. 7, Bldg. F, #102  
Fort Lauderdale, FL 33319  
Call: 954-722-6400; 954-735-1598 TDD  
Fax: 954-735-0963  
Email: [cilb@cilbroward.org](mailto: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](mailto: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](http://www.soflacil.org)

**Center for Independent Living of Southwest Florida, Inc.**

2321 Bruner Lane  
Fort Myers, FL 33916  
Call: 239-277-1447; 239-277-3964 TDD  
Fax: 239-277-1647  
Web address: <http://www.cilfl.org>

**Cil In Central Florida, Inc.**

720 North Denning Drive  
Winter Park, FL 32789  
Call: 407-623-1070; 407-623-1185 TDD  
Web address: <http://www.cilorlando.org>

**Cil Of Northwest Florida, Inc.**

3600 N Pace Blvd  
Pensacola, FL 32505  
Call: 877-245-2457; 850-595-5566 TDD

**Coalition For Independent Living Options**

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

**Disability Solutions for Independent Living**

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

**Independent Living Resource Center Of Ne Florida**

2709 Art Museum Drive  
Jacksonville, FL 32207  
Call: 904-399-8484; 904-396-0859 TDD  
Web address: <http://www.cilj.com>  
Email: [cilj@fdn.com](mailto:cilj@fdn.com)

**Sccil At Titusville**

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

**Self-reliance, Inc.**

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

**Space Coast Center For Independent Living**

803 N Fiske Blvd, Suite B  
Cocoa, FL 32922  
Call: 321-633-6011; 321-633-6011 TDD  
Fax: 321-633-6472  
Web address: [spacecoastcil.org](http://spacecoastcil.org)

**Suncoast Cil**

2989 Fruitville Road, Suite 101  
Sarasota, FL 34237  
Call: 941-351-9545; 941-351-9545 TDD  
Fax: 941-351-9875  
Web address: <http://www.scil4u.org>

**Victory Lane Center For Independent Living, Inc.**

475 South Nova Rd.

Ormond Beach, FL 32174

Call: 386-671-1960; 386-671-1961 TDD

Web address: <http://www.victorylanecil.org>

**Clearinghouse on Disability Information**

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

Areas of resource information include but are not limited to:

- Accessibility
- Americans with Disabilities Act (ADA)
- Assistive Technology
- Basic Needs
- Benefits
- Community Resources
- Education
- Employment
- Health Care
- Housing
- Service Animals
- State and Local Government Issues
- Telecommunications
- Transportation

Contact the Clearinghouse:

Call: 1-877-232-4968

Email: [clearinghouse@dms.myflorida.com](mailto:clearinghouse@dms.myflorida.com).

**Department of Management Services – Governor's Commission on Disabilities**

The Governor's Commission on Disabilities was designed, by Executive Order, to be a policy advising body, collecting, analyzing, advocating, and advising on issues involving persons with disabilities. The Commission receives input from various sources including the public as well as universities, state agencies, and non-profit organizations. The

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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](http://dms.myflorida.com/other_programs/governor_s_commission_on_disabilities)

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

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

#### **Emergency Preparedness –**

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

#### **Housing –**

*General Housing Resources and Self-Help Guide*

#### **General Resources –**

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

The above resources can be attained by:

Calling: 1-850-487-3278, 1-888-788-9216, TDD: 1-877-506-2723

Fax: 1-850-487-2805

Email: [faast@faast.org](mailto:faast@faast.org)

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

### **Florida Family Care Council**

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

For further information:

Contact Person: Betty Kay Clements, 352-753-1163

FCC Telephone: 1-800-470-8101

Email: [info@FCCFlorida.org](mailto:info@FCCFlorida.org)

Web address: [www.fccflorida.org](http://www.fccflorida.org)

## **Florida Diagnostic & Learning Resources System (FDLRS)**

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

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

## **Florida Developmental Disabilities Council, Inc. (FDDC)**

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

**Emergency Preparedness –**  
*Disaster Ready*

**Etiquette –**  
*Disability Etiquette*  
*People First Language*

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

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

**Stress -**  
*Coping with Disability-Related Stress*

*Transportation - Let's Go – A Guide to Getting Around Your Community in Florida*

**Waitlist -**

*APD Waitlist Survey – Final Report (2008)*

For further information:

Call: 850-488-4180; 850-488-0956 (TDD)

1-800-580-7801 (toll free); 1-888-488-8633 (TDD toll free)

Fax: 850-922-6702

E-mail: [fddc@fddc.org](mailto:fddc@fddc.org)

Web address: [www.fddc.org](http://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](http://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@aidd.org](mailto:books@aidd.org)

### **Kaiser Health News**

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

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

### **National Association of Councils on Developmental Disabilities (NACDD)**

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

For further information:

Call: 1-202-506-5813

Fax: 1- 202-506-5846

E-mail: [info@nacdd.org](mailto: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](mailto: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](mailto: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](http://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](http://www.thearc.org)

### **U.S. Administration on Developmental Disabilities**

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

For further information:

Call: 1-202-690-6590

Fax: 1-202-690-6904 or 202-205-8037

Web address: [http://faq.acf.hhs.gov/cgi-bin/acfrightnow.cfg/php/enduser/std\\_alp.php?p\\_cat\\_lv1=69](http://faq.acf.hhs.gov/cgi-bin/acfrightnow.cfg/php/enduser/std_alp.php?p_cat_lv1=69)

**U.S. Office on Disability**

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

For additional information on disability resources:

Web address: <http://www.napas.org/>.

Email: [ODInfo@hhs.gov](mailto:ODInfo@hhs.gov)

## **Articles on aging with developmental disabilities**

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

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

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

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

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

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

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

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

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

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

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

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

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

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

## **Articles on dementia and developmental disabilities**

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

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

## **Manuals**

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

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

*Rochester Environmental and Sensory Processing Awareness (RESPA) Checklists.*

Guidelines for environmental modifications based on sensory needs of the individual with developmental disabilities. Available through the Program on Aging and Developmental Disabilities, Rochester, NY, 585-275-6604.

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

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

## **Videos**

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

*Dementia and Adults with Intellectual Disabilities*

18 minutes - Alzheimer's Disease and a Down Syndrome Individual  
New York State Developmental Disabilities Planning Council  
155 Washington Avenue, Albany, New York 12223  
[www.ddpc.state.ny.us](http://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

*Cross Network Collaboration for Florida*

The Netherlands

EMAIL: [h.evenhuis@debruggen.nl](mailto: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](mailto:Sunny.Kalsy@bscht.wmids.nhs.uk)