

***Aging with Dignity:
Supporting
Persons with ID/DD
Presentation at DDNA
& AADMD
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Aging: What are the Questions?

- › Why is this important now?
- › What do the numbers tell us?
- › What are the effects of aging on people with I/DD?
- › What program changes are needed?

Said Theodore Roosevelt....

Old age is like everything else. To make a success of it, you've got to start young.

Some Myths - ID/DD & Aging

- › All people with ID/DD age early
- › People with ID/DD age *differently*
- › All people with Down's syndrome get Alzheimer's
- › "Old age" care is the same as "nursing care"
- › All aging is the same
- › No new learning takes place as we age

Some Numbers...

General population over 65:

- ▶ 1900 = 4% population
- ▶ 2000 = 14% population
- ▶ 2050 = 20/25% population
- ▶ 2150 = 33% population

Baby Boomers:

Born b/t mid 1940's and mid 1960's
- one turns 50 every 14 seconds!!

People with ID/DD Also Aging

- ▶ 2000 -- 641,000 people with ID/DD 60+
- ▶ 2030 -1,242,800 people with ID/DD 60+

Life Expectancy for:

▶ **People with DD:** **People with Down's:**

1930's - 19	1920 - 9 yrs old
1970's - 59	1993 - 56 yrs old
1993 -- 66	

Demographics

- ▶ The mean age at death for persons with ID/DD rose from 19 in the 1930s to 66 years in 1993, **an increase of 247%**
- ▶ There were an estimated 641,161 adults age 60 and older in 2000 in the US; this group is projected **to nearly double** by 2030 when last of Baby Boomers reach age 60

Where Folks are Coming From

- ▶ Closure of institutions
- ▶ Families aging out of care – looking for services for first time
 - 35% live with someone 40 – 60
 - 25% live with someone over 60
- ▶ Independent living failures – alternatives needed
- ▶ Diversions from nursing home settings
- ▶ Waiting Lists – over **88K** – 41 states (4.5%+)

NOTE: This is first generation to outlive their parents

From literature review...

- ▶ People with Down's Syndrome...
 - Grow old at a much younger age
 - Have Alzheimer's Disease at higher rates than general population, develop it earlier with a shorter duration (on average 8 years), sometimes dramatically shorter (2 – 3 years)
- ▶ There is an increased risk for Alzheimer's Disease among people with developmental or other disabilities in general (e.g., those with head injuries)

Quote on Aging

“Age is opportunity no less than youth itself, though in another dress, and as evening twilight fades away the sky is filled with stars, invisible by day”

Henry Wadsworth Longfellow

Challenges

- ▶ Unprepared as a society for aging
- ▶ Parents who are caregivers are aging
- ▶ Services have not always adapted to changing needs
- ▶ Staff and families need education on aging
- ▶ Lack of partnerships across provider settings

Challenges for Providers

We Must Adapt

- ▶ The service needs of those we serve will change as they age
- ▶ Health and stamina will become harder to maintain
- ▶ We must consider for each person:
 - Health
 - Interests
- ▶ More folks needing services!

Aging – Some Principles

Aging is a part of the normal developmental process. As people age:

- ▶ Interests, needs and life conditions change
- ▶ People continue to need stimulation, challenge and social contact
- ▶ Physical changes may require modifications to their environments and the nature of their supports and services

Aging – Some Fundamentals

Aging is ---

- ▶ Normal and Inevitable
- ▶ A cross cutting issue – across all programs and settings
- ▶ A life event – and can be planned for either *reactively* or *proactively*

What are some effects of aging?

- ▶ Alzheimer's/Dementia
- ▶ Frailty – increasing weakness/diminishing capacity
- ▶ Decreasing vision and hearing
- ▶ Impaired mobility
- ▶ Terminal illness – eventually leads to death

Dementia – What is it?

- ▶ Widespread loss of mental skills and abilities so that capability to care for oneself is lost
- ▶ Involves cognitive decline from “organic” cause (head injury, stroke...)
- ▶ Causes in old age – Alzheimer’s, strokes, neurological such as Parkinson’s
- ▶ Loss of memory, language skills, sense of time & place, ADL’s and change in personality

Alzheimers and Downs Syndrome

- ▶ Having Down's syndrome *does not* mean person will have Alzheimer's
- ▶ Only 1 / 3 of adults with ID/DD who have Alzheimer's also have Down's syndrome
- ▶ For those with Down's who do get Alzheimer's - will have symptoms earlier than rest of population
- ▶ Downs is associated with early aging

Three stages of diagnosis

- ▶ *Possible dementia* - Initial diagnosis, some certainty supported by tests
- ▶ *Probably dementia* - Relatively certain diagnosis - supported by behavior
- ▶ *Definite dementia* - No question remaining, supported by neuropathology in brain (confirmed in autopsy)

Dementia - Alzheimer's disease

- Progression thru stages
Early Stage - start of onset:
- ▶ Some recent memory loss
 - ▶ Language difficulties
 - ▶ Work performance deteriorates

Dementia – Alzheimer’s disease

- Progression thru stages
Mid-Stage – progression:
- ▶ More language losses
 - ▶ More memory losses
 - ▶ Disorientation, confusion
 - ▶ Loss of some self-care skills
 - ▶ Severe changes in personality
 - ▶ Disturbed social behavior (suspiciousness)

Dementia – Alzheimer’s disease

- Progression thru stages
Late Stage –terminal:
- ▶ Substantial dysfunction
 - ▶ Basic skills forgotten
 - ▶ Loss of body weight
 - ▶ Mobility dysfunction
 - ▶ Long term memory loss
 - ▶ Bedridden
 - ▶ Increased risk of infection and pneumonia
 - ▶ Death

Dementia – Alzheimer’s Disease

- ▶ Progressive and terminal – people die from associated conditions (e.g. pneumonia)
- ▶ Generally long course (10 – 20 yrs) – for people with Down’s shorter course (4 – 7 years)

Dementia – Alzheimer's disease

Important to rule out reversible conditions:

- ▶ Stroke, depression, medication reaction, thyroid disease, brain tumor, nutritional deficiencies
- ▶ Vital to have baseline information on behavioral skills
- ▶ **AAMR/AAIDD** recommends screening after age 40 for people with ID/DD

Dementia – Provider expectations

- ▶ Early baseline screening is vital
- ▶ Diagnosis/Assessment difficult therefore need “personal best” baseline
- ▶ Exam every 6–12 months for changes
- ▶ Assess anytime concerns noted
- ▶ Maintain nutrition and hydration

Dementia – Programming Focus

- ▶ Modify IPP to anticipate changing ADL's and supervision needs
- ▶ Provide closer supervision to minimize confusion
- ▶ Maintain independence by increasing staff, prompts and hands-on care
- ▶ Monitor behavior and document episodes of confusion and memory lapse
- ▶ Look for triggers of inappropriate or dangerous behavior

Programming Ideas

- ▶ Keep Routines (predictable & simple)
- ▶ Emphasize maintaining skills, rather than teaching new skills.
- ▶ Limit choices: reduces anxiety & frustration
- ▶ Engage in meaningful activities – Use their name
- ▶ Patience & redirection – Reassure
- ▶ Familiar & Safe Environments
- ▶ Focus on reality
- ▶ Team Approach: Long-term planning

Communication & Dementia

- ▶ Interaction Style
 - Take time
 - Make eye contact
 - Communicate with simple but meaningful sentences
 - Use gestures
 - Use person's name frequently
- ▶ Talk to the person and with the person; not to others around them. Keep the focus on the person.

Other Challenges – Aging with ID/DD

- ▶ Strength
- ▶ Health
- ▶ Hearing
- ▶ Vision



Frailty - Losing Strength

- ▶ Aging affects:
 - Muscle Strength and endurance
 - Flexibility
 - Body composition (body fat)
 - Cardiovascular endurance
- ▶ Research indicates people with ID/DD have very low levels of cardio endurance
- ▶ Strength levels also very poor

Obesity - adults with ID/DD

- ▶ Adults living in the community have the highest rates of obesity
- ▶ Individuals with particular syndromes have a higher prevalence of being overweight and obese
- ▶ Persons with Down Syndrome are 1.5 times more likely to be obese

Physical activity

- | | |
|--|---|
| <p><i>General Pop</i></p> <ul style="list-style-type: none">▶ 15% of adults participate in regular physical activity for 30 minutes 5+ days/week▶ 40% do not participate in any regular physical activity | <p><i>Adults with ID/DD</i></p> <ul style="list-style-type: none">▶ 10% of adults with ID/DD engage in physical activity a minimum of three days a week▶ Most leisure-time activities are sedentary, such as watching television or listening to the radio |
|--|---|

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Fitness Levels Very Poor

- ▶ One third Americans overweight – almost 50% of people with ID/DD overweight
- ▶ Many more women with ID/DD overweight than men
- ▶ Pose higher risk of many diseases (diabetes, hypertension, stroke, arthritis, respiratory and cancer)
- ▶ All this = *“A Population at Risk”*

Physical activity, diets, & health

- ▶ For adults with ID/DD the combination of:
 - Sedentary lifestyles
 - High fat diets
 - Low fruit and vegetable diets
- ▶ Major contributor to increased risk factors for CVD and other chronic health conditions

Nutrition

- ▶ Our knowledge of disability and nutrition is next to nothing!
 - ▶ 93% adults with ID/DD living in the community have a high fat diet
 - ▶ 63% of adults do not consume enough fruits and vegetables
- Source: Draheim, et al. (2002)

Investing in Health Promotion

- ▶ People with disabilities account for only 17% of US population but 47% of medical expenditures
- ▶ Partly due to chronic health conditions
- ▶ Investing in *health promotion activities* improves health and reduces medical costs

What Can You Do?

- ▶ Support individuals to become more active NOW
- ▶ Provide Structured Program
 - Get Dr approval first
 - Increase physical activity throughout day
 - Choose the right exercise program
 - Exercise a minimum of three days a week
 - Keep program fun and rewarding

What Can You Do?

- ▶ Offer to exercise together
- ▶ Give encouragement to stick with it
- ▶ Plan for exercise on recreational outings
- ▶ Discuss ways to get more exercise
- ▶ Ensure transportation
- ▶ Identify ways of paying
- ▶ Shows him/her how to exercise

Exercise Daily

- ▶ Short walks – start slow 5/10 minutes
- ▶ Stretch together while watching TV
- ▶ Play catch or beach ball volley ball
- ▶ Encourage use of therapy, massage, balance exercises
- ▶ Take advantage of community resources

Hearing/Vision

Decreased capacity starts in our 30's

Hearing:

- ▶ 22% who are 35+ have diminished hearing
- ▶ 40% by 60 and 62% by 80

Vision:

- ▶ 25 % who are 35+ have some loss of vision
- ▶ 40 % by 59
- ▶ 50% over 80
- ▶ Same for all of us!!!!



Vision

- ▶ Regular exams are key – recommended annually for women over 35 and men over 40
- ▶ How do you know if there is a problem?
 - Ask!!!
 - Observe – changes, rubbing, squinting, tilting head, etc.
 - Anticipate Changes
- ▶ Adults with ID/DD may have same eye diseases as others
- ▶ High risk for Cataracts and swelling
- ▶ Individuals with Down's at higher than avg. risk for eye diseases

What Can You Do?

- › Modify environments
- › Provide additional lighting
- › Use contrast (light dinner plate dark placemat)
- › Reduce glare
- › Organize – make it easy to find items
- › Be consistent in environment



Planning for Aging

- › Reactive – Address issues for people who are already old
- › Proactive – Prepare and plan for people who will be aging



Prevention – Some Tips

- › Calcium & vitamin D can be preventatives to Osteoporosis
- › Appropriate screening and preventative care
- › Persons taking Dilantin may need dietary supplements
- › Exercise assists with maintaining physical activity, balance, flexibility
- › Low intensity exercise has been shown to decrease death rates
- › Exercise – safest & least expensive ways to lose body fat, decrease blood pressure, increase glucose tolerance, and maintain long long-term independence.
- › Buddy system builds community capacity

Potential Barriers Community Living

- ▶ Attitudes of staff about aging
- ▶ Knowledge of staff
- ▶ Regulations
- ▶ Need to increase staffing or provide specialized training (behavior/dementia/frailty)



Aging – Supports and Services

- ▶ *Clinical* – Screenings and Diagnostic Services
- ▶ *Housing* – barrier free accommodations
- ▶ *Day Services* – Retirement focus
- ▶ *Special supports* for adults with dementia, age-associated cognitive or functional decline
- ▶ Support for *death and dying*

Planning for Transition

- ▶ Shift in life focus and activities
- ▶ Change in program orientation
- ▶ Developmental vs. successful aging
- ▶ Build friendships/social circle
- ▶ Model after “normal” retirement
- ▶ BUT – Still need Active Treatment

Transition Issues

- › Programs need to reflect age of person
- › Staff training – aging process and changing needs of elderly ind's
- › Consistency more important
- › Focus on helping to keep skills

Program Issues – Aging in Place

- › Aging in Place means enabling people to stay in their homes and programs as they age
- › We must therefore adapt our services so that people can stay in their homes and still have their needs met

Aging in Place Issues

- › Whose choice is retirement?
- › How can the home be modified to accommodate changes?
- › What programmatic changes can be made to accommodate aging adults?
- › What can agency do to accommodate the frail elderly and those with declining functional abilities?
- › Access to appropriate healthcare

Programs for Aging Ind's

- ▶ Part-time work or volunteering
- ▶ Specialized day retirement programs
- ▶ Older age activities within current programs
- ▶ Participation in community activities for older adults
- ▶ Wellness programs



Can People Retire?

- YES! People can retire – from work but not from life (or programming/AT)
- ▶ Less structure may be needed – But Increase in other interests:
 - ▶ Social activities
 - ▶ Hobbies
 - ▶ Volunteering
 - ▶ Part-time work
 - ▶ Wellness – Health Related Activities

Should someone retire???

- ▶ Decision should be based on Individual's desire and preferred daily activities
- ▶ Based on current comprehensive functional assessment
- ▶ Include opportunities for leisure activities, social activities in community, exercise, etc.

Aging and the IPP

- Reflect Individual is older adult AND that staff are aware of changing needs
- By age 50 include education re: retirement
- Include skill development for choice/range of options
 - Indicate increased need for certain assessments for age related conditions
 - Reflect awareness that stamina, health & choices may affect daily routines and incorporate accommodations
 - If nap needed - Incorporate into Plan

Provider Expectations

- Individuals should still receive programming to meet their needs
- Individuals must participate to fullest extent of their capability
- Choice must be based on viable alternatives
- Focus may be on prevention of regression rather than just skill development
- For ICFs/MR - Active Treatment still required

Evaluation Questions

- Is the person aging?
- Have medications and health assessments adapted to age?
- What is the person's physical status?
- Does comprehensive assessment reflect changes?
- If the person is regressing, how is agency addressing?

Increasing National Focus

- ▶ AAIDD
- ▶ ARC
- ▶ Conferences
- ▶ Publications
- ▶ Discussions
- ▶ Web resources
- ▶ Awareness!!!



The Arc Position Statement

- ▶ As they age, our constituents must be recognized as respected members of the community. Services to people who are older must accommodate the supports needed by this population.
- ▶ Our constituents who are growing older should:
 - Be afforded the same rights, dignity, respect, and opportunities as other older people in their communities.
 - Have access to housing, health care, social services, transportation, and other services available to older Americans in their communities.
 - Receive supports to live, work, play, and retire when, where, and how they prefer.

The Arc Position Statement

- Be free from the fear of inappropriate institutionalization due to age-associated decline or infirmity.
- Have access to pension plans that include the same payment provisions afforded other retirees or to alternative financial supports available to older persons who no longer work.
- Legislation and regulations affecting older Americans should refer distinctly to the eligibility of our aging constituents.

The Arc Position Statement

- ▶ Public policy considerations include:
 - Programs that support caregivers of older people with disabilities should include support of older parents who are the primary caregivers for their adult children.
 - Federal and state resources should vigorously support research and best practices to meet the needs of older persons with disabilities.
 - Professionals should be prepared to deal with the issues related specifically to our aging constituents.

AAIDD & IASSID

Dementia Documents

- ▶ TEST BATTERY for the Diagnosis of Dementia in Individuals With Intellectual Disability
- ▶ PRACTICAL GUIDELINES for the Clinical Assessment and Care Manager of Alzheimer and other Dementias among Adults with Mental Retardation
- ▶ DIAGNOSIS OF DEMENTIA in Individuals with Intellectual Disability
- ▶ Evaluation Procedures for Establishing Diagnostic Criteria
- ▶ Epidemiology of Alzheimer Disease in Mental Retardation

http://www.aamr.org/Reading_Room/docs_dementia.shtml

What can nurses do to support ID/DD aging population?

- ▶ Develop systems to raise awareness and provide education on aging issues
- ▶ Improve health screenings and assessments – encourage use of baselines
- ▶ Implement an interdisciplinary approach to supporting the aging population
- ▶ Promote appropriate living options with supports
- ▶ Identify ways to provide community based supports

What can your agency do to support ID/DD aging population?

- ▶ Develop an "Agency Policy for Aging"
- ▶ Include:
 - Mission Statement
 - When to conduct assessments
 - Staff and client education
 - Wellness program focus and expectations
 - Legal issues - wills, directives, etc.
 - More!

Contact Information

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Dementia and intellectual disabilities

Why the concern about dementia among people with intellectual disabilities?

Everyone has to face the prospects of the increasing health risks that are associated with the expectation of living longer than ever before. Increased life expectancy is the result of discoveries that have led to major improvements in health over the past several decades. However, with longer life the risk of dementia is expected to show a corresponding increase in the general population. Ageing individuals with intellectual disabilities (ID), a condition of lifelong limited intellectual, social and vocational capabilities, are also living longer and healthier lives because they share in the same benefits of medical discoveries. Consequently, they are also at increased risk of developing dementia.

How many people with intellectual disabilities are affected by dementia?

Population studies show that the prevalence of dementia among people with ID appears to be about the same as in the general population, which is about 5% of people aged 65 and older. However, the prevalence of Alzheimer's disease, the most common cause of dementia, among adults with Down's syndrome is about 25% for those who are 40 years of age and older and about 65% for those who are 60 years of age and older. Thus, people with Down's syndrome are especially vulnerable to developing dementia. This can be explained by the fact that people with Down's syndrome have three copies of the portion of chromosome 21 which can contain a gene for amyloid precursor protein (APP). Overproduction of APP leads to its breakdown in such a way that amyloid and plaques are formed, and eventually Alzheimer's disease is manifested.

How are people with Down's syndrome affected differently by Alzheimer's disease?

Although only a fraction of people with Down's syndrome show the symptoms of Alzheimer's disease, upon autopsy nearly all older adults with Down's syndrome show the brain lesions that are characteristic of Alzheimer's disease. Men and women seem to be equally affected. The disease lasts on average for about eight years, with a range from one to twenty years. Average age of onset is about 50, followed by death at an average age of about 58 years. The natural history of Alzheimer's disease in people with Down's syndrome is similar to that of people from the general population with the notable exception that it starts about 20 years sooner in people with Down's syndrome.

The symptoms of Alzheimer's disease show wide differences between people with Down's syndrome. In the early stage of the disease, memory loss is not always seen, and not all the symptoms associated with Alzheimer's disease will be recognisable. Generally, changes in activities of daily living and work habits are noticed first. Epileptic seizures may occur early or late in the course of the disease. Cognitive changes are frequently present but they are difficult to evaluate because of limitations in the individual's language, communication and related intellectual abilities.

How is dementia diagnosed in people with intellectual disabilities?

There is no test for dementia that can be used for ageing people with ID who are showing deterioration in function. They face the same situation as ageing

people from the general population who are suspected of developing dementia. Diagnosis requires the exclusion of every other possibility. Many of the standard tests used on the general population are inappropriate for people with ID, particularly for those with severe deficits in intellectual function. It is recommended that comprehensive physical, medical, neurological, radiological and laboratory studies be combined with assessments of cognitive functions. Diagnosis of dementia should be reserved until after the evaluation of a similarly comprehensive follow-up examination six to twelve months later. Only the observation of significant changes during this six to twelve month period should be used for making a diagnosis of possible or probable dementia. Such evaluations are necessary to rule out conditions other than dementia and reversible causes of dementia. Complete evaluations are the same as for other people suspected of having dementia. It is also important to discuss the individual's symptoms with members of his or her family or others who are in regular contact with them. Detailed guidelines are available from the American Association on Mental Retardation (AAMR) at www.aamr.org/Reading_Room. These guidelines have been adopted by the AAMR and the International Association for the Scientific Study of Intellectual Disabilities (IASSID).

What services do individuals affected by dementia need?

People with ID who are diagnosed with dementia can continue to live in the community if the right support and assistance are provided. A resource list is available at www.uic.edu/orgs/rrtcamr/dbiblio.htm. Some service

providers have effective specialist teams that set up individually tailored care services. They also provide essential home care. Since people with ID affected by dementia may not be able to continue to live on their own, 'dementia capable' housing and support need to be provided. Use of daycare (or day activity services) is recommended to maintain quality of life and adequate supervision. Home services can reduce the need for, and delay the time of, admission to expensive nursing facilities or other intensive care institutions.

Principles that should guide the care decisions of people with ID and dementia

The main principle guiding decision-making should be that services should be aimed at meeting the individual needs of each person. This principle is summarised in the concept of 'person-centered planning' which has been widely promoted as an effective framework for service delivery. The focus is on making decisions based on the individual strengths, capabilities, skills, and wishes of each person. The individual's family, relatives and closest friends should be engaged with the person in all decisions with the aim of helping the person remain in his or her chosen home and community. The *Edinburgh Principles* were developed with these goals in mind. The principles, available at www.alz.co.uk/edinburghprinciples, have been adopted by the IASSID (www.iassid.org) and circulated by Alzheimer's Disease International.

Resources

Booklets

Janicki, M.P. (1995). *Developmental Disabilities and Alzheimer's Disease: What You Should Know*. The Arc of the United States. 48pp

A booklet covering some of the fundamentals concerning adults with intellectual disabilities and Alzheimer's disease, including what is Alzheimer's disease, its course and outcome, diagnostic suggestions, care considerations, and how to obtain assistance. Contains resource list and glossary. Available from: The Arc of the United States, 1010 Wayne Avenue, Suite 650, Silver Spring, MD 20910 USA. <http://209.183.228.233>

Kerr, D. & Innes, M. (nd). *What Is Dementia? - A booklet about dementia for adults who have a learning disability*. 16pp.

This booklet is designed to explain dementia and its nuances to people with intellectual disabilities (termed "learning disabilities" in Scotland). Using drawings and easy language, this booklet covers many of the symptoms and behaviours classically associated with Alzheimer's disease.

Available from: Down's Syndrome Scotland, 158/160 Balgreen Road, Edinburgh, Scotland EH11 3AU www.dsscotland.org.uk. A downloadable version is available at www.uic.edu/orgs/rrtcamr/dementia

Journal articles and books

Wilkinson, H.A. & Janicki, M.P. IASSID. (2002). The Edinburgh Principles with accompanying guidelines and recommendations. *Journal of Intellectual Disability Research*, 46, 279-284. www.blackwell-science.com/uk/journals.htm

Dalton, A.J. (1995). Alzheimer disease: A health risk of growing older with Down syndrome. In L. Nadel and D. Rosenthal (Eds.) *Down Syndrome: Living and Learning in the Community* (pages 58-64). New York: Wiley-Liss.

Janicki, M.P. & Dalton, A.J. (Eds.). (1999). *Aging, Dementia and Intellectual Disabilities: A Handbook*. Philadelphia: Taylor & Francis. www.taylorandfrancis.com

Janicki, M.P. & Dalton, A.J. (2000). Prevalence of dementia and impact on intellectual disability services. *Mental Retardation*, 38, 277-289. www.aamr.org

Janicki, M.P., Heller, T., Seltzer, G. & Hogg, J. (1996). Practice guidelines for the clinical assessment and care management of Alzheimer's disease and other dementias among adults with intellectual disability. *Journal of Intellectual Disability Research* 40, 374-382. Also available from the American Association on Mental Retardation www.aamr.org/Reading_Room

Kerr, D. (1997). *Down's Syndrome and Dementia*. Birmingham, UK: Venture Press

Internet

Dementia and intellectual disabilities-related resources and technical information are available at the University of Illinois at Chicago's website at www.uic.edu/orgs/rrtcamr/dementia

Dementia and intellectual disabilities-related discussion group is available at <http://groups.yahoo.com/group/Dementia-IDlistserv>

Videos/CD-ROMs

Dementia and People with Intellectual Disabilities - What Can We Do?

An instructional video which covers the basics of how dementia affects adults with intellectual disabilities, and provides information on diagnostics and suggestions on providing supports and services in community care settings. Available in VHS and CD-ROM formats.

Available from: New York State Developmental Disabilities Planning Council, 155 Washington Avenue, Albany, New York 12222 USA - www.ddpc.state.ny.us

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Alzheimer's Disease International

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Interdisciplinary Training Center on Gerontology and Developmental Disabilities (ITC)

IHD Priority Area: Aging and Developmental Disabilities

Project Contact Person: Michelle Reynolds

Funding Source: Administration on Developmental Disabilities,
Administration on Aging

Project Period: 07/97 - 06/06

Description: The goal of this project is to maintain an effective interdisciplinary training center on gerontology and developmental disabilities. The Center's purposes are to address personnel preparation needs and to provide a centralized mechanism for the integration and advancement of knowledge in the area of aging and developmental disabilities.

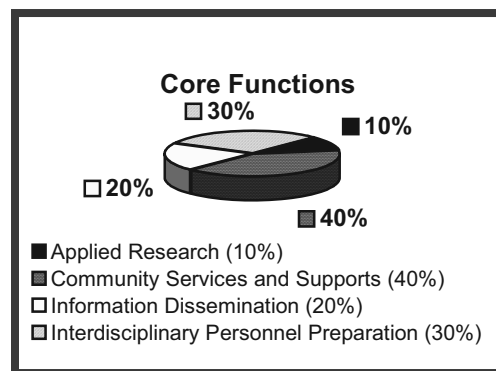
Core Functions

Applied Research: Evaluations are conducted to assess appropriate care of aging people with disabilities in settings such as nursing homes and Down syndrome and Alzheimer's disease networks.

Community Services and Supports: Training sessions have been conducted for service providers throughout the state in both aging and developmental disabilities networks. The Center has conducted workshops in Alzheimer's disease and Down syndrome, medical decision making, retirement, assistive devices, physical aspects of aging, person-centered planning, and psychotropic medication. A current project on advanced directives will provide an Advanced Directive in the person-centered planning process.

Information Dissemination: Newsletters are distributed on a national scale, and teleconferencing has been used to disseminate information.

Interdisciplinary Personnel Preparation: A core course is offered within the UMKC Gerontology program. University courses are infused with information on aging and developmental disabilities. Student trainees participate in all aspects of the Center.



Program Need and Historical Context

The Institute began its involvement in aging in 1984 with an Administration on Aging grant to enhance case management approaches. Following those efforts, the Institute began to address issues of community integration and long-term care. The Institute was then invited to participate on the AAUAP task force on aging and developmental disabilities.

Consumer and Community Involvement

- Many people with disabilities have participated in this project.
- A focus group of older people with developmental disabilities meets monthly to provide guidance to the program.
- Consumers assist in planning, implementation and evaluation programs.
- The ITC collaborates with many state and community agencies, such as Division of Aging, Division of MR/DD, Association on Aging with Developmental Disabilities in St. Louis, and the Midwest Bioethics Center in Kansas City.

Significant Project Activities and Outcomes

- Developed a retirement package that is used in St. Louis for approximately 100 consumers annually
- Conducted training statewide on aging and developmental disabilities
- Co-sponsored statewide conferences in St. Louis with the Association of Aging and Developmental Disabilities and the Minority Conference on Aging in Jefferson City with Lincoln University
- Collaborated with the Center on Aging Studies on a Certificate in Aging and Developmental Disabilities
- Presented statewide to older families of individuals with disabilities on future planning

Institute's Role

A special training center was established with the Institute's assistance through collaboration with the Missouri Gerontology Institute, UMKC Center on Aging Studies, and the UMKC Center on Rural Elderly.

Products

- Retirement planning tools
- University course infusion modules
- Informational fliers and brochures
- Various articles published in newsletters
- Aging related curricula
- Video on medical decision making
- Video on advance directives
- Video on grief and bereavement
- Video on assistive devices
- Fast Facts on Aging
- Information on web site
www.ihd.umkc.edu/ITC/default.htm

Impact

Systems Change: There has been an increased interagency collaboration between aging and DD systems.

Personnel: Institute trainees and pre-service students provide cross-cutting initiatives.

Leveraging: Through ITC, the Institute has directly received \$380,000 in additional grants/contracts. An additional \$150,000 has been leveraged with other agencies to enhance programs for older people with developmental disabilities.

WEB RESOURCES

Provided by H&W Independent Solutions

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DDNA – Developmental Disabilities Nursing Association	<p>www.DDNA.org</p> <p>A nationally focused organization with the goal to <i>foster the growth of nursing knowledge and expertise about optimal care of persons with I/DD, thereby improving their care, services, and quality of life.</i></p>
H&W Independent Solutions	<p>www.hwisolutions.com</p> <p>A nationally focused training and consultation firm, offering individually tailored services to agencies in the disability community. Web site has toolboxes and other resource materials available to assist you to improve services.</p>
ANCOR – American Network of Community Options and Resources	<p>http://www.ancor.org</p> <p>ANCOR is a national network of providers offering quality supports to people with disabilities.</p>
HCBS – The Community Living Exchange Collaborative	<p>www.hcbs.org</p> <p>This site is intended to facilitate sharing information, tools, and practical resources across the many states and local entities that are reexamining and redesigning how they provide supports. A special focus is on organizations that have received Real Choice Systems Change (RCSC) and Medicaid Infrastructure grants (MIG) from the Centers for Medicare and Medicaid Services (CMS).</p>
Self Advocates Becoming Empowered	<p>www.sabeusa.org</p> <p>A national self-advocacy organization including chapters the United State.</p>
AAIDD	<p>www.aaid.org</p> <p>American Association of Intellectual and Developmental Disabilities – a national organization for professionals in the field of developmental disabilities. AAIDD web site has extensive resources on aging. Look in Reading Room for <i>Aging</i> and Special Initiatives for <i>Aging and End of Life Issues</i>.</p> <p>For various resources and test batteries. This is found under the old AAMR web site.</p> <p>http://www.aamr.org/Reading_Room/docs_dementia.shtml -</p>

College of Direct Support	<p>www.nadsp.org</p> <p>The NADSP is a coalition of organizations and individuals committed to strengthening the quality of human service support by strengthening the direct support workforce.</p>
The Quality Mall	<p>www.qualitymall.org/main/</p> <p>A place where you can find lots of free information about person-centered supports for people with developmental disabilities. Serves as a portal to many other web sites.</p>
Research & Trng Center on Aging with DD	<p>http://www.uic.edu/orgs/rrtcamr/</p> <p>Rehabilitation Research and Training Center on Aging with Developmental Disabilities Department of Disability and Human Development University of Illinois at Chicago</p>
The Arc	<p>www.thearc.org</p> <p>The Arc – A national association for people/families. Has extensive information on aging. Go to web site and use search word “aging”</p>
Journal	<p>Living and Aging with a Developmental Disability: Perspectives of Individuals, Family Members and Service Providers <i>By Penny Salvatori, Mary Tremblay, and Joyce Tryssenaar</i></p> <p>JOURNAL ON DEVELOPMENTAL DISABILITIES, VOLUME 10, NUMBER 1, 2003</p>
Report	<p>Promoting Healthy Aging, Family Support, and Age-Friendly Communities for Persons Aging with Developmental Disabilities Report of the 2001 Invitational Research Symposium on Aging with Developmental Disabilities (2002)</p> <p>www.uic.edu/orgs/rrtcamr/gsa.pdf</p>
Books	<p><i>Health Management of Aging Adults with Mental Retardation: A Practical Guide.</i> Poindexter, A. R. (2002). The NADD Press. Kingston: New York.</p>
Books	<p><i>Dementia, Aging, and Intellectual Disabilities</i> Janicki, MP & Dalton, AJ</p> <p>Publisher: Brunner Mazel (Philadelphia, PA) bkorders@taylorandfrancis.com</p>
Other	<p><i>Use Google or other search engine and find additonal resources out there!!!</i></p>