Alzheimer’s Disease and People with Down Syndrome

A training for Everyone
Family Members and Support Staff

Developed With Funding Support from the Arizona Developmental Disabilities Planning Council
Learning Objectives

• At the end of this training participants will be able to:
  – Describe Alzheimer’s disease and the disease process
  – Explain how Alzheimer’s disease impacts people with intellectual and developmental disabilities
  – Identify at least 3 strategies to provide effective supports
Aging and Alzheimer’s disease
What is Alzheimer’s Disease?

• A progressive, degenerative, neurological disease of the brain

• A steady decline in memory and intellectual functioning severe enough to interfere with everyday life

• It is not reversible
What does Alzheimer’s look like?
General Warning Signs

- Memory changes
- Challenges in planning or problem solving
- Difficulty completing familiar tasks
- Confusion with time or place
- Trouble with visual or spatial relationships

- Problems with words
  - Misplacing things
  - Decreased or poor judgment
  - Withdrawal from activities
  - Changes in mood and personality
Aging With a Developmental Disability

- Life style effects
- Limited access to quality health care
- Lack of knowledge about aging for people with DD
- Inadequate funding for health care
- Effects of the disability and its treatment
- Normal effects of aging
- Negative attitudes about people with disabilities

Results in decreased quality of life for the person with a disability
Intellectual Disabilities (ID) and Dementia

• Increased life expectancy in ID population result of constructive public policies, focus on health and better community support services

• Greater numbers of aging people are result of ‘baby boom’ cohort, and increased life expectancy including those with ID

• The population of persons with ID and dementia will double in the next twenty years.
Down Syndrome and Dementia

- It is estimated that 6% of adults with an ID will be affected by some form of dementia after the age of 60 (with the percentage increasing with age).

- There is a genetic propensity for adults with Down syndrome to develop early onset Alzheimer’s disease.

- For adults with Down syndrome, studies show that at least 25% will be affected with dementia after age 40 and at least 50 to 70% will be affected with dementia after age 60.

- A significant percentage of the older ID population will be adults with Down syndrome, who usually make up about 10% of most ID providers’ service populations of adults age 40 and older.
The Relationship of Alzheimer’s Disease and Down Syndrome

- **Consequence of accelerated aging process**
  Accelerated progression of disease in those with Down Syndrome

- **Overexpression of amyloid precursor protein** (integral membrane protein expressed in many tissues and concentrated in the synapses of neurons) **on chromosome 21 in both**

- **Acetylcholine** (organic molecule that acts as a neurotransmitter) levels low in both Down syndrome and Alzheimer's patients

- **Degeneration of the hippocampus** (plays important roles in the consolidation of information from short-term memory to long-term memory and spatial navigation) **in both**
How many people with down syndrome get Alzheimer’s?

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>30’s</td>
<td>2%</td>
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<tr>
<td>40’s</td>
<td>10-15%</td>
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<tr>
<td>50’s</td>
<td>33%</td>
</tr>
<tr>
<td>60’s</td>
<td>50-70%</td>
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</tbody>
</table>

Warning Signs for Adults with Down Syndrome/IDD

- Development of seizures
- Changes in personality
- Long periods of inactivity or apathy
- Hyperactive reflexes
- Loss of activity of daily living skills
- Loss of speech
- Disorientation
- Increase in stereotyped behavior
- Abnormal neurological signs
Warning Signs for Adults with Down Syndrome/IDD

- Changes in activities of daily living skills are noted most often
- Seizures may occur in individuals who have not had them in the past
- Cognitive changes may be present although they may not be apparent
Aging Issues that Mask Alzheimer’s in Adults with Down Syndrome/IDD

• Visual and hearing impairments
• Thyroid disorders
• Depression
• Physical health problems
• Medication effects
• Nutritional deficiencies
Stages of the Disease
Stages of Alzheimer’s Disease

Generally described as having three stages:

• Mild (early)
• Moderate (middle)
• Severe (late)
Changes in Adults with Mild to Moderate Developmental Disabilities

Early Stage

• Loss of activity of daily living skills
• Behavioral Changes
• Personality changes
• Development of seizures
• Slow movement or alertness
Changes in Adults with Mild to Moderate Developmental Disabilities

Early Stage (cont.)

- Disorientation to time and place
- Easily frustrated, loss of familiarity with activities
- Visual problems
- Apathy or inactivity
- Preference for familiar things
Changes in Adults with Mild to Moderate Developmental Disabilities

Middle stage

• Symptoms of early stage increase
  – ADL markedly deteriorate
• Confusion and frustration increased
• Sleep disturbances
• Changes in appetite
Changes in Adults with Mild to Moderate Developmental Disabilities

Middle stage (cont.)

• Recognition of self and others begins to decline
• Severe change in personality
• Restlessness, wandering
• Communication reduced
Changes in Adults with Mild to Moderate Developmental Disabilities

Late Stage
• Severe disorientation to time and place
• Difficulty swallowing
• Loss of speech
• Difficulty walking
• Incontinent
Changes in Adults with Mild to Moderate Developmental Disabilities

Late Stage (cont.)

• No longer recognizes family members
• Inability to survive without total care
• Death occurs most commonly from pneumonia and kidney failure
Changes in Adults with Severe to Profound Developmental Disabilities

- Socially withdrawn, reduced responsiveness
- Apathy
- Impaired attention
- Almost seem to be in a coma
Nonpharmacological Strategies For Support

• Remember the four S’s
  – Maximize Safety and Limit the Risks
  – Promote Structure and Consistency
  – Enhance Serenity and Limit Confusing Stimuli
  – Nuture Sanity and Supports for All Caregivers
Pharmacologic Strategies

• For Depression and Anxiety and Psychosis and agitation
  – Continually re-assess effects of treatment
  – Avoid polypharmacy
  – Determine short and long term goals
  – Continually reassess response and need for medication(s)
Diagnostic Tools

• Focused medical and family history
• Physical exam and laboratory tests
• Dementia Screening Questionnaire for Individuals with Intellectual Disabilities – DSQIID
  – Can be used by staff and families if they are worried an individual is developing dementia.
• Neuropsychological tests
Diagnostic Tools (cont.)

• Functional status exam – for disease progression

• Mental status exam (adapted for ID/DS)

• Assessment for delirium/depression

• Brain scans (CT or MRI)
Prepare for Appointments

• Gather pertinent information
• Know past pertinent medical history
• Always compare the person to who she or he has been throughout a lifetime, not to others of similar chronological age
• Different shifts and perspectives of team/family
• Symptoms as specific as possible, time of day, what behaviors, patterns, who is present
• Prioritize symptoms
• Share the information with advocate who will be going
• Know what recent therapies have been given and assessments and be prepared to discuss changes
Benefits of Early Diagnosis

• Manage symptoms of dementia
• Maintain daily activities to the extent possible and preserve quality of life
• Anticipatory guidance
• Help offset caregiver stress
• Maintain ‘aging-in-place,’ whenever possible and appropriate
Consider substituting Community Living and Person Centered Services
Cynthia Vargo, 7/22/2013
The Ripple Effect
Need to Create a Dementia Friendly Community With Dementia-capable Care for Everyone
Because dementia is a condition that lessens an individual’s ability to self-direct and be left alone, long-term continued independent living is not an option.
The Ripple Effect

Friends/Housemates

Direct Support Staff

Jane/Jack

Aging Parents/Siblings

Doctors/Nurses
What kinds of services are needed for aging people with ID and Dementia?

• Supports for continued living with families when available and appropriate
• Engaging activities in community settings
• Health reviews and surveillance
• Appropriate screening and assessments for aging-related conditions
• Health maintenance – nutrition and exercise
• Supports for ‘dementia-capable’ care in community care settings that can change as the disease progresses; including education and training
Edinburgh Principles

• Questions raised by various service providers organizations across the world
• Involved key international researchers and service providers in the field of aging and intellectual disabilities
• Edinburgh Working Group on Dementia Care Practices: University of Stirling (Scotland), the State University of New York at Albany (USA), and the University of Illinois at Chicago (USA)
Edinburgh Principles

1. Adopt an operational philosophy that promotes quality of life.
2. Affirm that individual strengths guide decision-making
3. Involve the individual and family in all planning and service
4. Ensure availability of appropriate diagnostic and service resources
Edinburgh Principles

5. Plan and provide supports to optimize remaining in the community

6. Ensure that people with developmental disabilities have access to the same dementia services provided to others in the population

7. Ensure that community planning involves focus on adults with developmental disabilities
‘Aging in Place’: Goals

• What is ‘aging-in-place’ for people with ID and dementia and their families?

• What do we consider best practices?

• Supporting family caregivers
  – Recognize the challenges faced by the aging caregiver
  – Support sibling and parent care providers

• Change of care focus
  – Going from making gains to that of maintaining as much function as possible and dealing with eventual loss and decline

• Develop and emulate current models of care that anticipate the increasing support needs as dementia progresses
Addressing the dementia-related community care needs of adults with ID

• Diagnostic and intervention assistance
• Dementia care training for caregivers (family or staff)
• Support groups for caregivers (family or staff)
• Dementia capable community housing (group homes)
• Dementia capable day care programs and respite
• Health care and social supports
Team Approach to Care

- Improving outcomes
- Respect for need and opinions of team members
- Helps anticipate and prepare for decline
- Who is the team??

Tom

DSPs

Aging Svcs

IDD Agency

Family

Healthcare Team

alzheimer's association
Desert Southwest Chapter

800.272.3900
alz.org/dsw
Care Management for Adults with Alzheimer’s Disease and Down Syndrome

• Support the individual to feel safe and secure
• Emphasize maintaining abilities rather than teaching new skills
• Simplify routines and reduce choices
• Use patience and redirection and offer supportive care
Suggested Interventions

Early stage

• Routine and familiarity are important
• Continue activities with structure, more guidance and supervision
• Simplify directions
• Give multiple clues
Suggested Interventions

Middle Stage

• Create a calm environment
• Allow for rest periods
• Anticipate needs
• Simplify tasks
• Respond to the feeling behind the action
Suggested Interventions

Late stage

• Anticipate physical needs
• Consider palliative/comfort care
• Consider hospice care
Palliative and End of Life Care

• The realization that Alzheimer’s disease progresses with increasing risks of health complications impacting ones lifespan
• Respecting ones wishes for level of care and quality of life
• Defining, anticipating, and preparing for end of life
• Appreciate how the impact is felt upon everyone around them
• Celebrating ones life
Where to get help/supports?

• Local Alzheimer’s Association chapter
  – Alz.org/dsw

• National Alzheimer’s Association website
  – Alz.org
  – www.alz.org/library/downloads/downsyndrome

• University of Illinois at Chicago website

• Dementia assessment clinics
Guidelines for Structuring Community Care and Supports for People With Intellectual Disabilities Affected by Dementia

http://aadmd.org/NTG

Nancy Jokinen, Matthew P. Janicki, Seth M. Keller, Philip McCallion, Lawrence T. Force, and the National Task Group on Intellectual Disabilities and Dementia
Alzheimer’s Disease Education and Referral (ADEAR) Centers National Institute on Aging

NIA-funded Alzheimer’s Disease Centers (ADCs):

• ADCs conduct research to improve diagnosis and care and test treatments

• Help with obtaining diagnosis and medical management

• Opportunities to participate in research
Examples of Organizational Supports

- Administration on Community Living [http://www.hhs.gov/acl/]
  - Administration on Aging [http://www.aoa.gov/]
- State Planning Councils on Developmental Disabilities [http://www.nacdd.org/site/home.aspx]
- University Centers for Excellence in Developmental Disabilities Education, Research & Service [http://www.aucd.org/]
- Alzheimer's Association [www.alz.org]
- National Task Group on Intellectual Disabilities and Dementia Practices [www.aadmd.org/ntg]
Examples of Community Supports

- Community support provider agencies
  - Private/parent based (e.g., Arc chapters)
  - Public – state/local government entities
- Area Agencies on Aging (AAAs)
  - Aging and Disability Resource Centers (ADRCs)
- Alzheimer's Association chapters
  - Other local dementia care groups
- State and local Protection and Advocacy Networks
- Faith-based organizations
- Statewide or Community-based Respite/Caregiver Coalitions
Certainties vs. Uncertainties

What we can expect…
• Incidence of Alzheimer’s disease in adults with Down syndrome is 60% or more
• Average age for onset is 52 some as young as 40s or 30s
• Life expectancy 5-8 yrs from recognized symptom onset
• Mid-stage dementia involves most staff time to manage
• Late-stage dementia changes the caregiving relationship
• Costs increase with dementia care
Certainties vs. Uncertainties

What we don’t know…
• Who will be affected
• How long will an individual be affected
• What will be the particular behavioral expressions
• What will be the long-term effects on staff and friends
• What can prevent or slow down progression
• Burn out factors associated with long-term dementia care
Ensuring Healthier Aging for People with ID and Dementia

• Promote a better understanding of people aging with ID and dementia and their needs
• Work to make communities “disability and dementia friendly”
• Assure that services and supports have “quality” as a defining factor
• Promote greater education of personnel
• Involve people with ID and dementia in decision making
• Ensure availability of dementia capable community services and assistance for families
Most Important – Get Diagnosis!

• No cure but medications can help
  -- Early diagnosis provides better chance of benefitting from available treatments for symptoms of dementia
  -- Medications help treatment of coexisting behavioral changes – psychosis, anxiety, or depression
  -- Opportunities for treatment trials
• Allows for adjustments to long term care plans
• Time to develop a relationship with potentially new doctors and care partners
Desired Outcomes

• Maintenance of daily activities and quality of life
• Effective of behavioral and pharmacologic therapies
• Reducing possible LTC placement
• Reducing secondary health consequences including falls, injuries, emergency department/hospital care, polypharmacy
• Reducing challenging behaviors
• Prevention and awareness of abuse and neglect
• Securing supports for families and care providers
• Increased research to find cure
• Awareness of and implementation of economics of care and supports
The Philosophy and Values of Dementia Care

- People are unique
- Maintain and enhance personhood
- Respect for personhood
Thank you!

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Research Resources

alzheimer's association

trialmatch

Web Address: http://www.alz.org/trialmatch
Phone: 1.800.272.3900