

Aging and Dementia in People with Intellectual and Developmental Disabilities: Assessments and Care Practices



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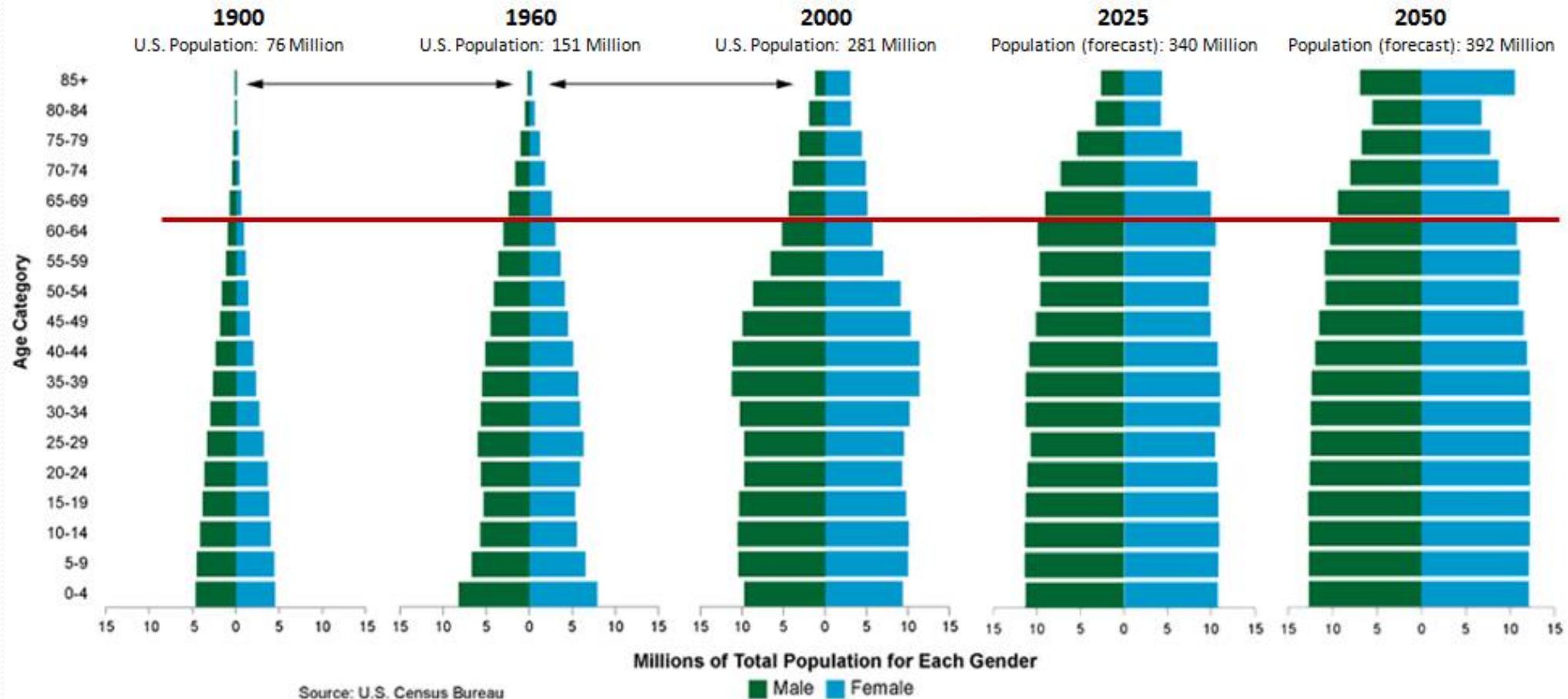
Nov 4, 2022



Changing US Population Demographics

By 2050, People Age 65 and Older Will Equal 20% of the Population

U.S. Population (and Forecast) by Age Category and Gender



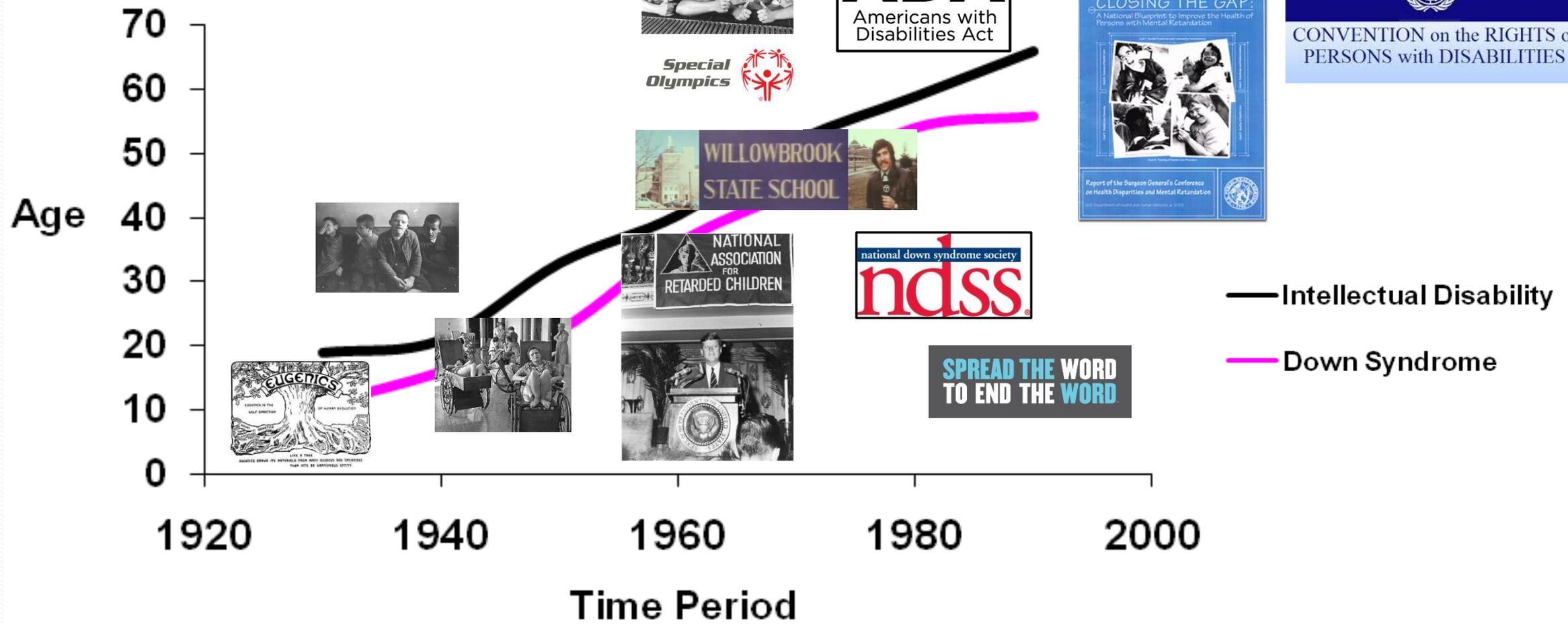
Aging and Intellectual and Developmental Disabilities

- In 2002, an estimated 641,000 adults with IDD were older than 60.
- In 2002 about 75% of all older adults with IDD were in the 40–60 year old age range.
- The number of adults with IDD age 60 years and older is projected to nearly double from 641,860 in 2000 to 1.2 million by 2030 due to increasing life expectancy and the aging of the baby boomer generation





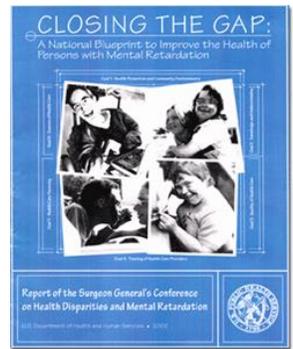
Life Expectancy



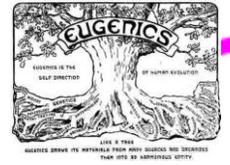
Life Expectancy



ADA
Americans with Disabilities Act



SPREAD THE WORD TO END THE WORD



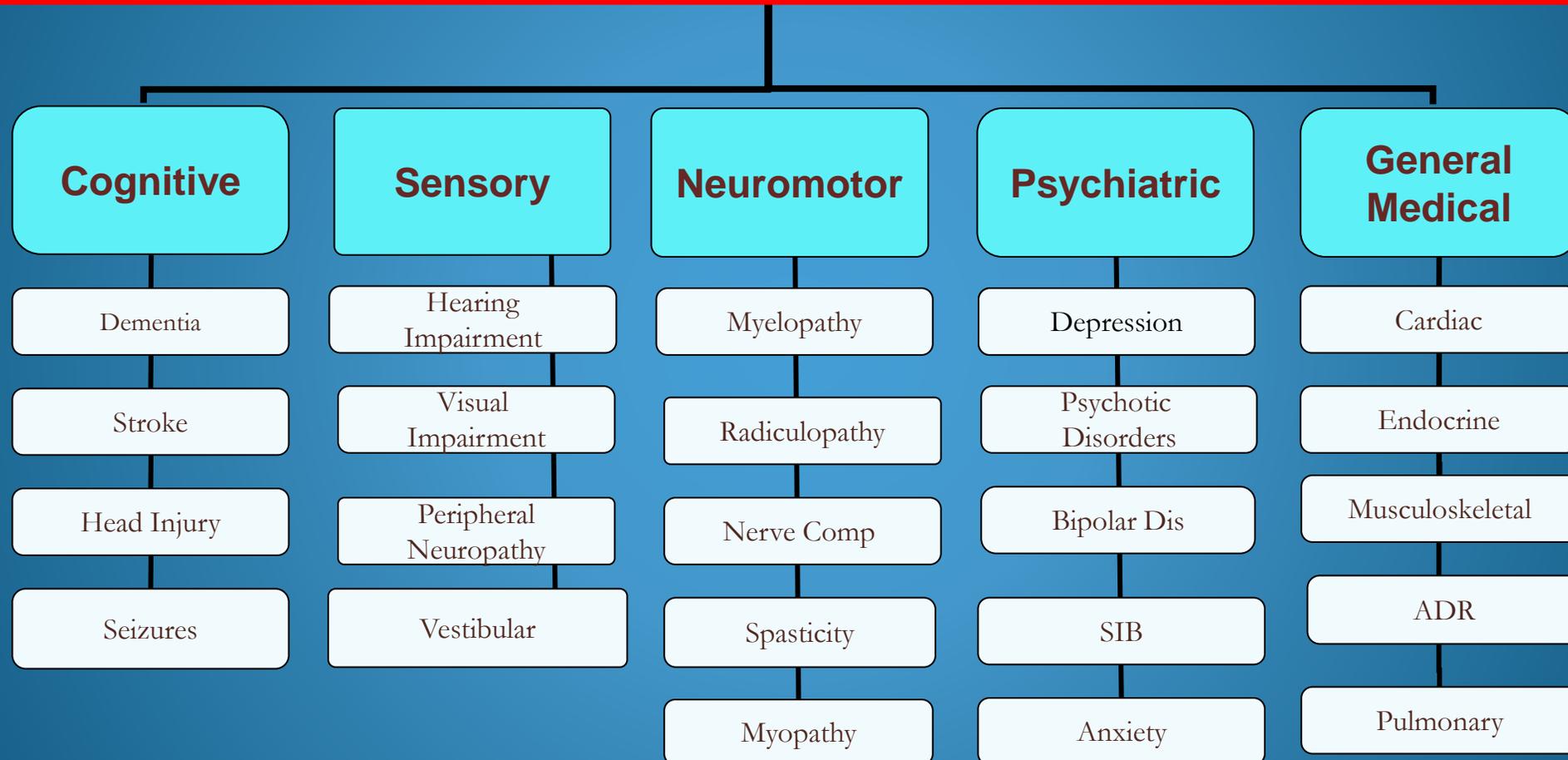
Source: Carter & Jancar, 1983, Janicki, Dalton, Henderson & Davidson, 1999

Expected Physical Changes of Aging

- **Osteopenia/Osteoporosis** - normal aging-related bone loss
- **Sarcopenia** - progressive loss of muscle mass
- **Presbyopia**: the lens of the eye becomes stiffer and less flexible – affecting the ability to focus on close objects (accommodation)
- **Presbycusis** – aging related change in the ability to detect higher pitches – more noticeable in those age 50+
- **Gustation** (i.e. the sense of taste) decrements become more noticeable beyond 60+
- **Olfaction** (i.e. the sense of smell) decrements become more noticeable after age 70+
- **Somatosensory System** - Reduction in sensitivity to pain, touch, temperature, proprioception
- **Vestibular** – Reduction in balance and coordination
- **Cognitive** – Reduction in short term memory loss, attention, and retrieval
- **Homeostenosis** -- Narrowing of reserve capacity



Functional decline is the decrement in physical and/or cognitive functioning and occurs when a person is unable to engage in activities of daily living



DD Specific Aging and Health Complications

Down Syndrome

- Sleep disturbances, depression, sensory loss
- Obesity
- Thyroid dysfunction, B12/folate deficiency
- Sleep Apnea
- Gait dysfunction
- Seizure Disorder
- Early onset Alzheimer's Disease

Cerebral Palsy

- Chronic Pain
- Dysphagia, aspiration, Esophageal strictures, gastritis
- Dental caries, erosion
- Motor dysfunction, inc spasticity and spinal cord dysfunction
- Osteoporosis
- Worsening bladder/bowel dysfunction

Autism

- Lifespan outcomes with Autism are unpredictable: some improve, some plateau, some lose skills
- Restrictive behaviors such as ritualistic, compulsive or self injurious behaviors tend to become more infrequent with age
- Seizures, accidental deaths (drowning, suffocation), earlier death from heart disease, aspiration pneumonia

When Change Occurs

- Normative or a sign of disease
- Life Stories
- Health Co-morbidities
- Psychosocial changes
- Dementia/Alzheimer's disease
- Biases/stereotypes/Diagnostic Over Shadowing



Cognitive Changes with Aging in Adults with Down Syndrome

Who I Am: My Stories, My Memory, My Life History

- Regression
- Medical
- Psychological
- Normal aging
- Mild cognitive impairment
- Early-onset Alzheimer's dementia; 60% by age 60!!



Cognitive Changes with Aging

- Normal changes = more forgetful & slower to learn
- MCI – Mild Cognitive Impairment =
 - Immediate recall, word finding, or complex problem solving problems (1/2 of these folks will develop dementia in 5 yrs)
- Dementia = Chronic thinking problems in > 2 areas
- Delirium = Rapid changes in thinking & alertness
- Depression = *chronic unless treated, poor quality, I “don’t know”, “I just can’t” responses, no pleasure*
can look like agitation & confusion

Making the Diagnosis of Dementia

- Having enough information; Life Story
- Differential diagnosis
 - Hypothyroidism, B12/folate, Sleep Apnea, Depression/Adjustment
 - ADR's, Neuromuscular
- Neuropsychological Assessment
- Imaging
- Biomarkers

NTG-Early Detection Screen for Dementia' (NTG-EDSD)

- Usable by support staff and caregivers to note presence of key behaviors associated with dementia
- Picks up on health status, ADLs, behavior and function, memory, self-reported problems
- Available in multiple languages
- Use: to provide information to physician or diagnostician on function and to begin the conversation leading to possible assessment/diagnosis



NTG-EDSD

v.1/2013.2

The NTG-Early Detection Screen for Dementia, adapted from the DSQIID*, can be used for the early detection screening of those adults with an intellectual disability who are suspected of or may be showing early signs of mild cognitive impairment or dementia. The NTG-EDSD is not an assessment or diagnostic instrument, but an administrative screen that can be used by staff and family caregivers to note functional decline and health problems and record information useful for further assessment, as well as to serve as part of the mandatory cognitive assessment review that is part of the Affordable Care Act's annual wellness visit for Medicare recipients. This instrument complies with Action 2.B of the US National Plan to Address Alzheimer's Disease.

It is recommended that this instrument be used on an annual or as indicated basis with adults with Down syndrome beginning with age 40, and with other at-risk persons with intellectual or developmental disabilities when suspected of experiencing cognitive change. The form can be completed by anyone who is familiar with the adult (that is, has known him or her for over six months), such as a family member, agency support worker, or a behavioral or health specialist using information derived by observation or from the adult's personal record.

The estimated time necessary to complete this form is between 15 and 60 minutes. Some information can be drawn from the individual's medical/health record. Consult the NTG-EDSD Manual for additional instructions (www.aadmd.org/ntg/screening).

(1) File #: _____ (2) Date: _____

Name of person: (3) First _____

(4) Date of birth: _____

(5) Sex:

Female	
Male	

(6) Best description of level of intellectual disability

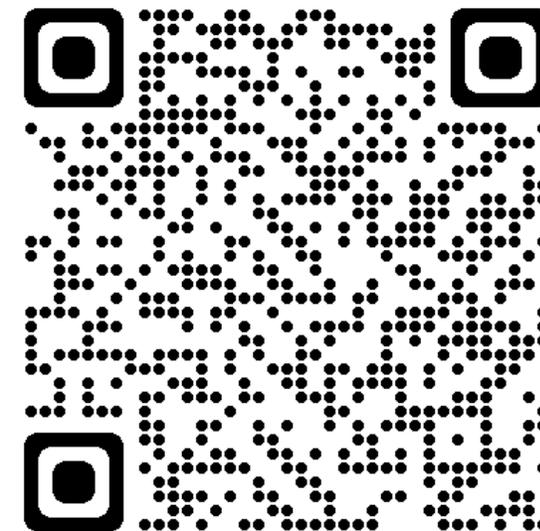
No discernible intellectual disability
Borderline (IQ 70-75)
Mild ID (IQ 55-69)
Moderate ID (IQ 40-54)
Severe ID (IQ 25-39)
Profound ID (IQ 24 and below)
Unknown

(7) Diagnosed condition (check all that apply)

Autism	
Cerebral palsy	
Down syndrome	
Fragile X syndrome	
Intellectual disability	
Prader-Willi syndrome	
Other:	

NTG-EDSD - page 4

	Always been the case	Always but worse	New symptom in past year	Does not apply
(8) Memory				
Does not recognize familiar persons (staff/relatives/friends)				
Does not remember names of familiar people				
Does not remember recent events (in past week or less)				
Does not find way in familiar surroundings				
Loses track of time (time of day, day of the week, seasons)				
Loses or misplaces objects				
Puts familiar things in wrong places				
Problems with printing or signing own name				
Problems with learning new tasks or names of new people				
(9) Behavior and Affect				
Wanders				
Withdraws from social activities				
Withdraws from people				
Loss of interest in hobbies and activities				
Seems to go into own world				
Obsessive or repetitive behavior				
Hides or hoards objects				
Does not know what to do with familiar objects				
Increased impulsivity (touching others, arguing, taking things)				
Appears uncertain, lacks confidence				
Appears anxious, agitated, or nervous				
Appears depressed				
Shows verbal aggression				
Shows physical aggression				
Temper tantrums, uncontrollable crying, shouting				
Shows lethargy or listlessness				
Talks to self				
(10) Adult's Self-reported Problems				
Changes in ability to do things				
Hearing things				
Seeing things				
Changes in "thinking"				
Changes in interests				
Changes in memory				
(11) Notable Significant Changes Observed by Others				
In gait (e.g., stumbling, falling, unsteadiness)				
In personality (e.g., isolated when was outgoing)				
In friendliness (e.g., now socially unresponsive)				
In attentiveness (e.g., misses cues, distracted)				
In weight (e.g., weight loss or weight gain)				
In abnormal/voluntary movements (head, neck, limbs, trunk)				



[NTG-EDSD \(the-ntg.org\)](http://the-ntg.org)

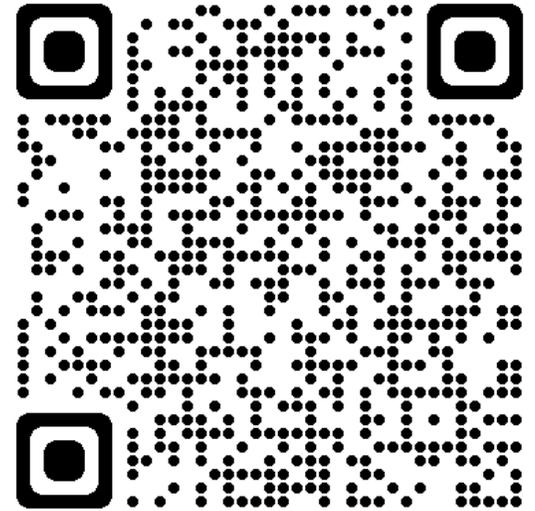
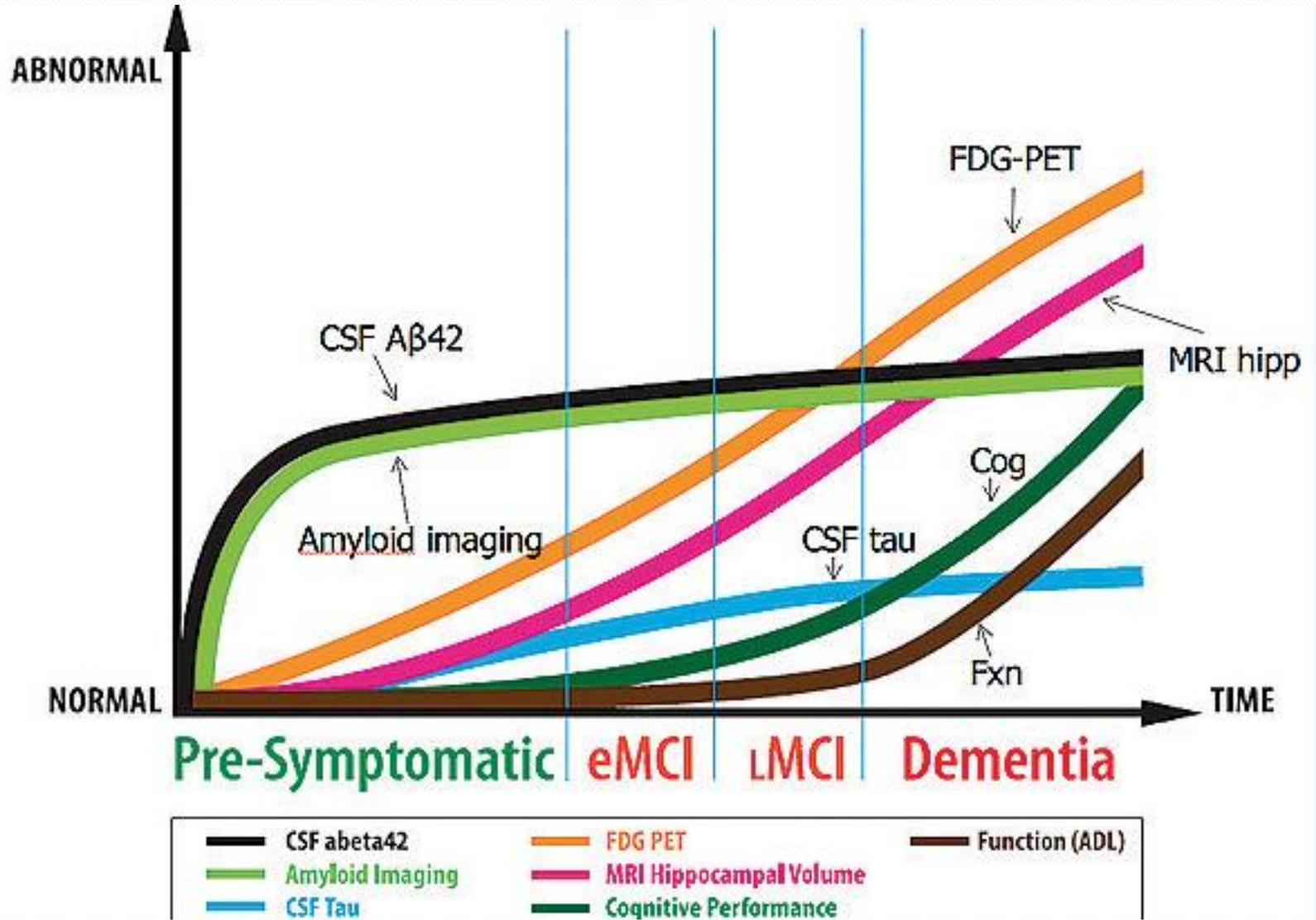
Neurocognitive Assessments

Informant-report and objective measures for clinical assessment of dementia in people with intellectual disabilities

- Adaptive Behaviour Dementia Questionnaire (ABDQ), Prasher et al. (2004)
- Assessment for Adults with Developmental Disabilities (AADS), Kalsy et al. (2000); Oliver et al. (2011)
- Dementia Questionnaire for People with Learning Disabilities (DLD)*, Evenhuis (1992); Evenhuis (1996); Eurlings, Evenhuis & Kengen (2006); Evenhuis et al. (2007)
- Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID), Deb et al. (2007)
- Prudhoe Cognitive Function Test (shorter versions), Kay et al. (2003)
- Test for Severe Impairment (Modified), Albert & Cohen (1992)
- Dementia Scale for Down Syndrome (DSDS), Gedye (1995)
- Fuld Object Memory Evaluation (1990)

*Originally named the Dementia Questionnaire for Mentally Retarded

Alzheimer's Disease Biomarkers

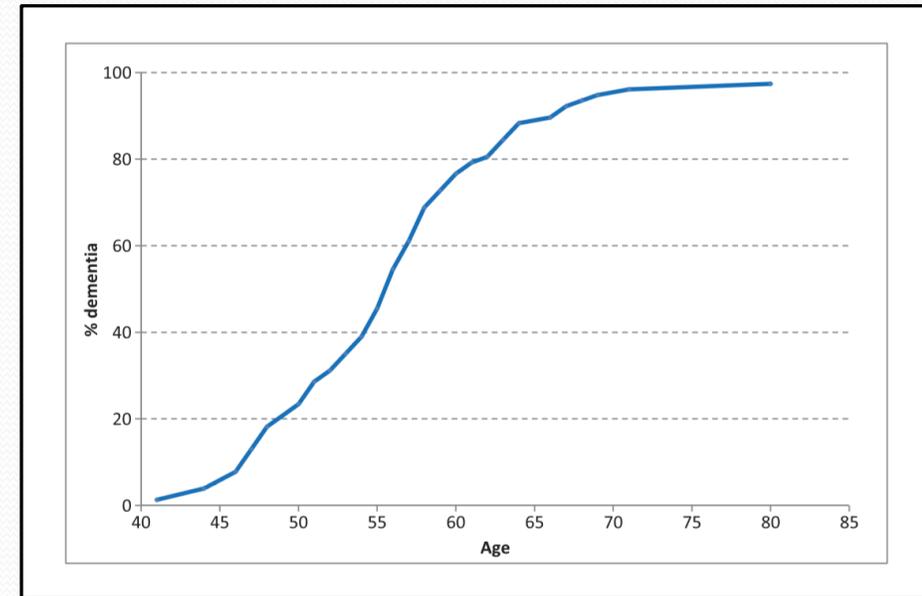


Report of the task force on designing clinical trials in early (predementia) AD
 P.S. Aisen, S. Andrieu, C. Sampaio, M. Carrillo, Z.S. Khachaturian, et al,
 Neurology Jan 2011, 76 (3) 280-286

Alzheimer's Disease in Down Syndrome

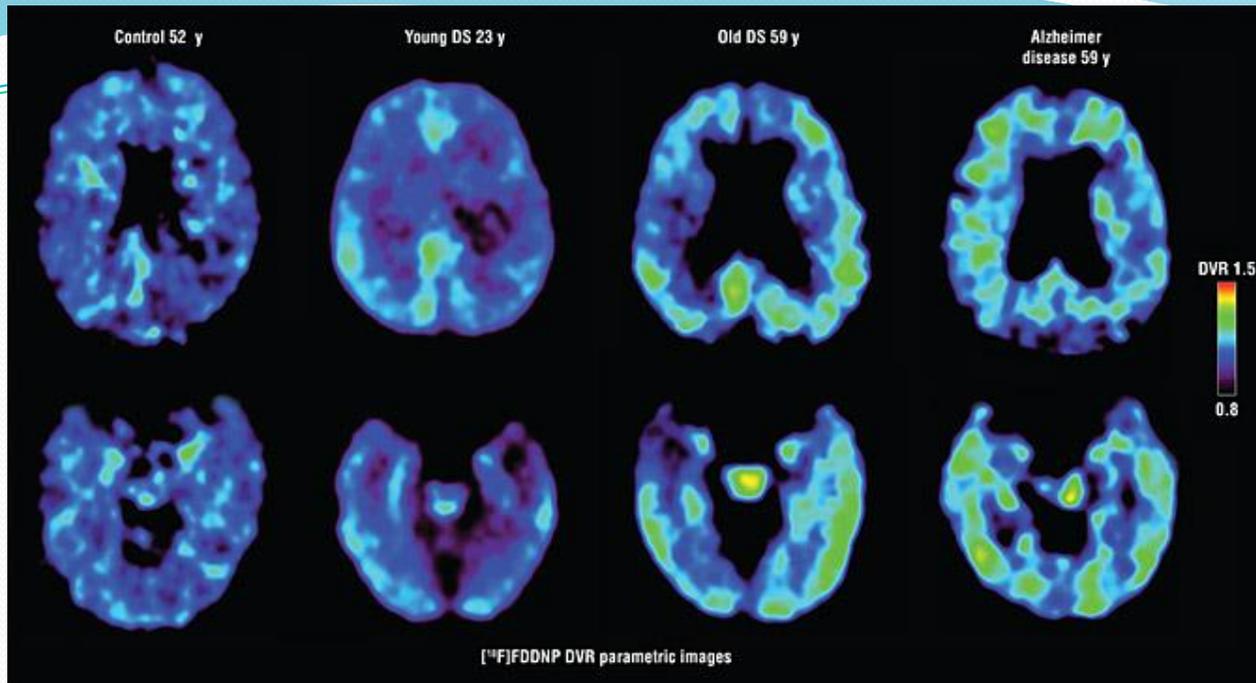
- Women with Down's syndrome are more at risk of developing Alzheimer's disease than men in the 40 to 65 age group
- People with Down's syndrome who develop Alzheimer's disease live, on average, 4-10 years from first symptoms; median 7 years
- Rapid decline can occur
- Sensory impairments (vision: 93.3%; hearing: 61.3%) were evident in adults with dementia
- Late onset seizures were evident in 73.9%; with epilepsy dx at mean age of 55.4, and interval of about ½ year following dx of dementia.

McCarron et al., (2017). A prospective 20-year longitudinal follow-up of dementia in persons with Down syndrome
Journal of Intellectual Disability Research Sep;61(9):843-852



Percentage of people with Down syndrome who develop dementia at different ages:

30's	2%
40's	10-15%
50's	20-50%
60's	60-90%

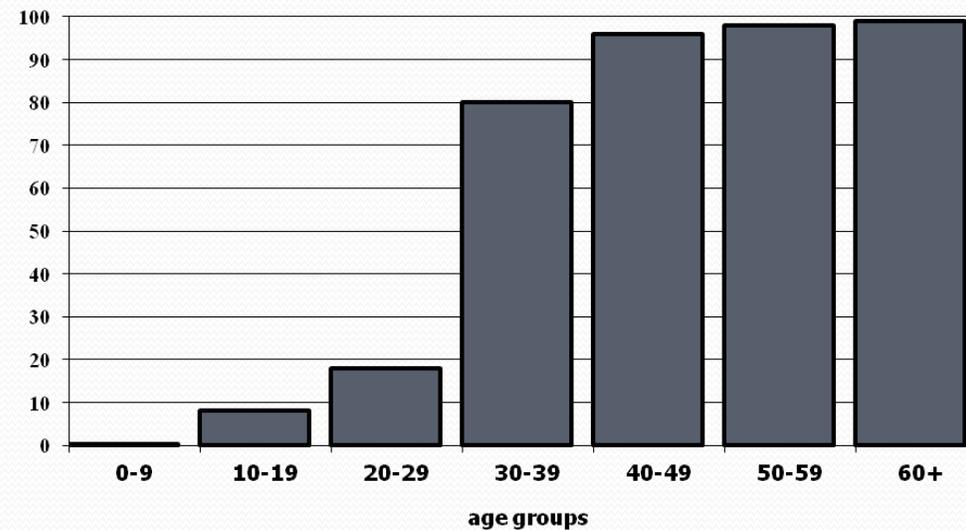


Representative Amyloid Scans in DS and AD

Nelson, L. D. et al. Arch Neurol 2011;68:768-774.

Percent persons with Down syndrome showing evidence of neurofibrillary tangles (NFT) and senile plaques (SP) at autopsy

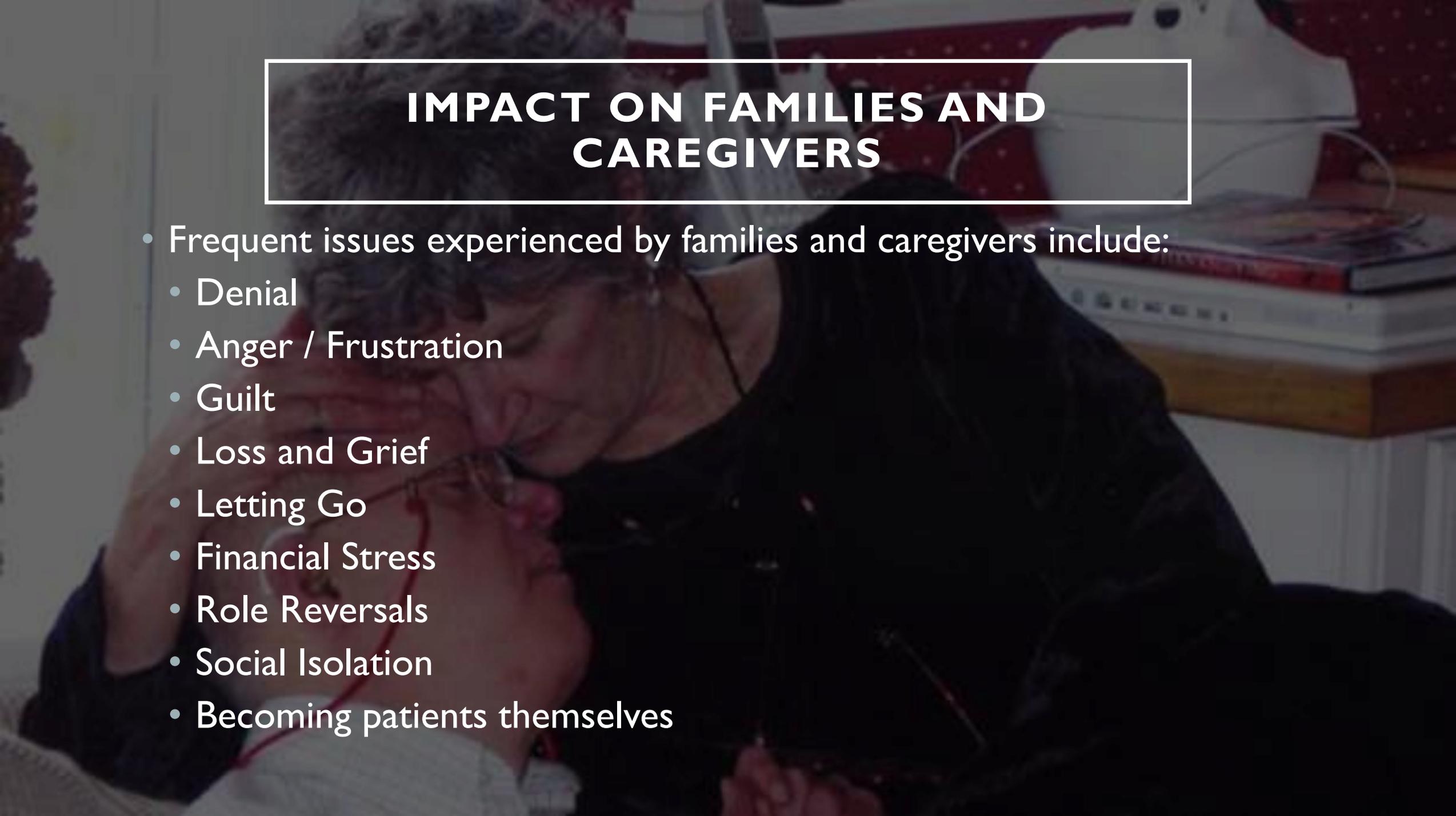
Mann, D.M.A. (1993). Association between Alzheimer disease and Down syndrome: Neuropathological observations. In J.M. Berg, H. Karlinsky, & A.J. Holland (Eds.), Alzheimer disease and Down syndrome and their relationship (pp. 71-92). Oxford University Press



Caring

- “Caring” with empathy and sensitivity
- Cognitive therapeutics
- Behavioral care and supports
- Health and wellness
- Concomitant health complications; seizures, sleep apnea, falls, etc.
- Anticipating progression and its various needs
- Palliative and end stage supports
- Research opportunities
- Financial and legal supports
- Transition of care

**SEE THE PERSON
NOT THE DEMENTIA**



IMPACT ON FAMILIES AND CAREGIVERS

- Frequent issues experienced by families and caregivers include:
 - Denial
 - Anger / Frustration
 - Guilt
 - Loss and Grief
 - Letting Go
 - Financial Stress
 - Role Reversals
 - Social Isolation
 - Becoming patients themselves

Potential Roadblocks affecting IDD & Aging

- Aging related disorders are superimposed on pre-existing social, mental & physical challenges:
 - Diagnosis is more challenging; Diagnostic Overshadowing
 - Interventions may be more challenging
 - Expectations and focus has been on gains and not loss
 - Fewer health care providers have expertise in both aging & ID
 - Service delivery may be a challenge because of political issues between the aging & the ID care systems
 - Parents/sibling age with associated challenges
- Persons with IDD often have more trouble dealing with normal age related changes because of their pre-existing disabilities, secondary conditions and associated medical problems.

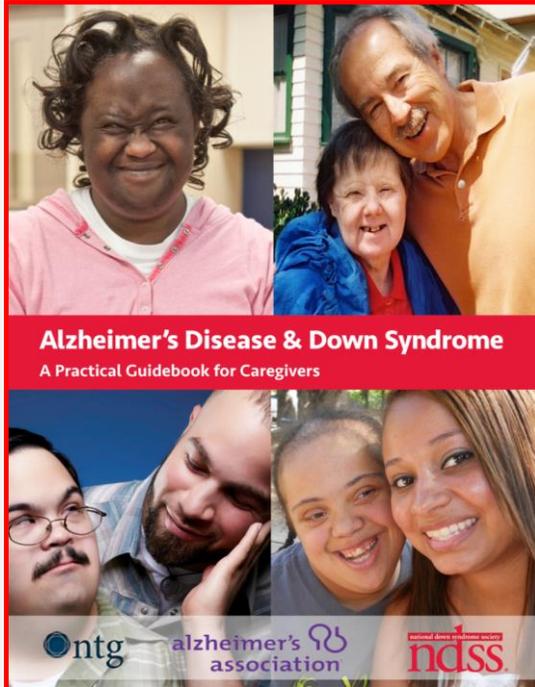
PERSON/FAMILY CENTERED RESOURCES

Aging and Down Syndrome

A HEALTH & WELL-BEING GUIDEBOOK



<http://www.ndss.org/wp-content/uploads/2017/11/Aging-and-Down-Syndrome.pdf>



http://www.ndss.org/wp-content/uploads/2017/11/NDSS_Guidebook_FINAL.pdf

Intellectual Disability and Dementia: A Caregiver's Resource Guide for Rhode Islanders



Seven Hills
Rhode Island

ntg
National Tech Group
on Intellectual Disabilities
and Dementia Practices

<http://www.sevenhills.org/uploads/SHRI-IDD-ADRD-Resource-Guide.pdf>

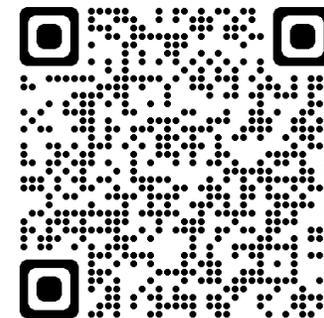
Jenny's Diary



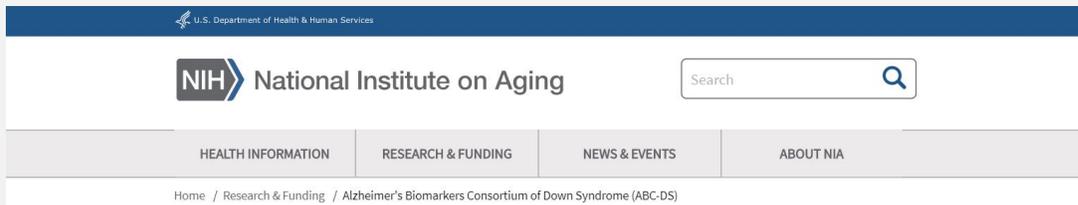
A resource to support conversations
about dementia with people who
have a learning disability

Karen Watchman,
Irene Tuffrey-Wijne, Sam Quinn

www.learningdisabilityanddementia.org/jennys-diary.html



ALZHEIMER'S BIOMARKERS CONSORTIUM OF DOWN SYNDROME (ABC-DS)

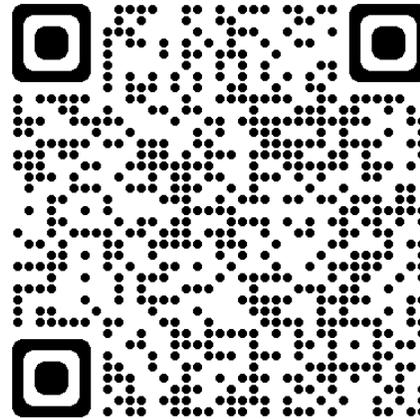


Alzheimer's Biomarkers Consortium of Down Syndrome (ABC-DS)



Exploring the Connection Between Down Syndrome and Alzheimer's Disease

The ABC-DS study is a joint study conducted by two groups of research collaborators—Neurodegeneration in Aging Down Syndrome (NiAD) and Alzheimer's Disease in Down Syndrome (ADDS)—and is supported by the National Institute on Aging (NIA) and the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), both part of NIH.



Goals and Measures

The overall goals of this study are to:

- Identify sensitive neuropsychological measures of cognitive decline, imaging, blood-based, and genetic biomarkers associated with transition from normal aging to mild cognitive impairment to clinical dementia in adults with DS
- Identify critical factors that link cerebral A β deposition to neurodegeneration and, ultimately, dementia
- Understand the relationships between biomarkers and pathways implicated in AD pathogenesis
- Provide rapid public access to all data, without embargo, and access to the biological samples by qualified scientific investigators

Recruitment

The NiAD sites will recruit 180 adults with DS (10% with dementia) and 40 sibling controls, age 25 years and older. The ADDS sites will recruit 225-300 adults with DS, 40 years and older.

<https://www.nia.nih.gov/research/abc-ds>

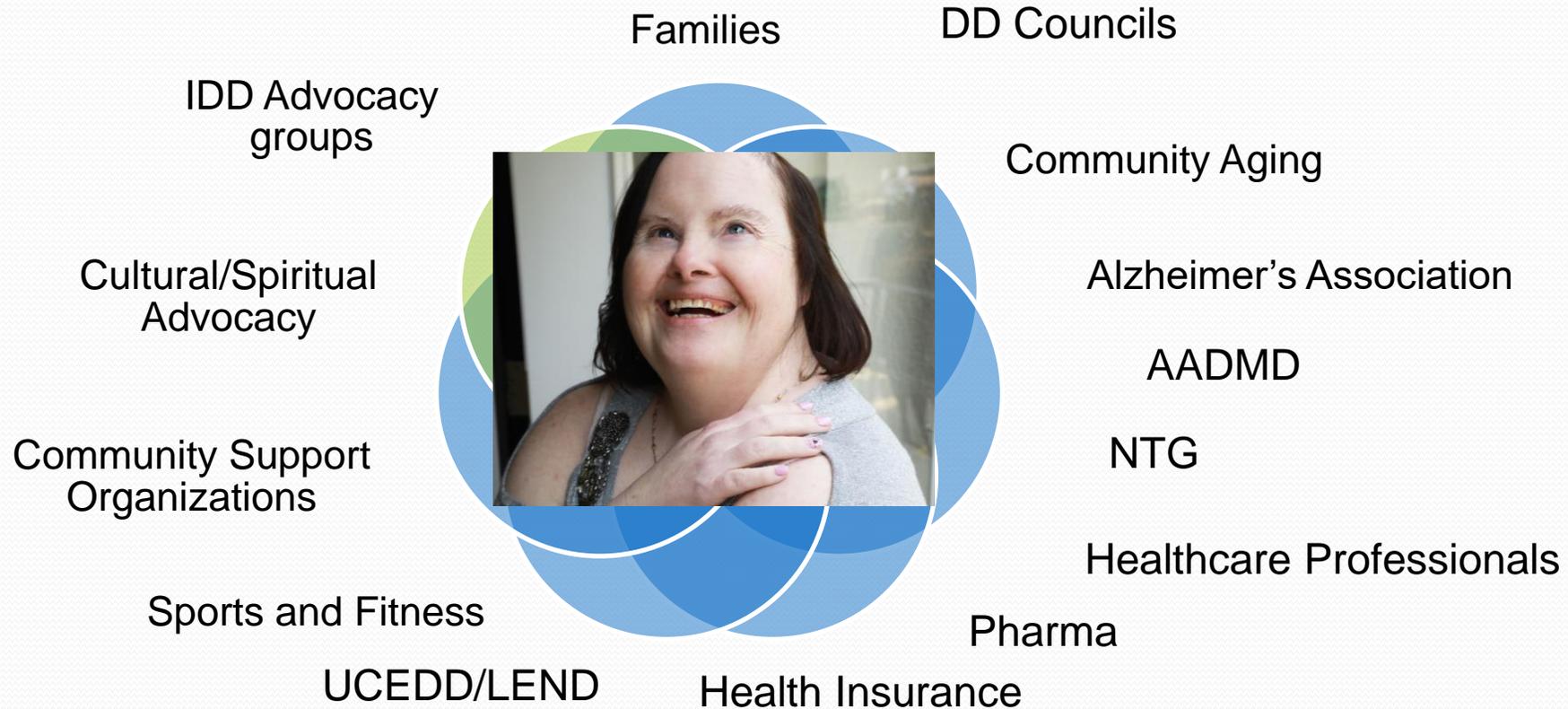
Neurodegeneration in Aging Down Syndrome (NiAD)

Site	Investigator & Study Coordinator
University of Pittsburgh (Coordinating Center), Pittsburgh, PA	Ben Handen, Ph.D., Co-PI William Klunk, M.D., Ph.D., Co-PI Cathy Wolfe, Study Coordinator
University of Wisconsin Madison, WI	Brad Christian, Ph.D., Co-PI Renee Makuch, Study Coordinator
Barrow Neurological Institute Phoenix, AZ	Marwan Sabbagh, M.D., Site PI Sandy Quintanilla, Study Coordinator
University of Cambridge Cambridge, UK	Shahid Zaman, M.D., Ph.D., Site PI Concepcion Padilla, Study Coordinator

Alzheimer's Disease in Down Syndrome (ADDS)

Site	Investigator & Study Coordinator
Columbia University (Coordinating Center) New York, NY	Nicole Schupf, Ph.D., Co-PI Deborah Pang, Study Coordinator
Kennedy Krieger Institute/Johns Hopkins Medical Center Baltimore, MD	Wayne Silverman, Ph.D., Co-PI
University of California, Irvine Irvine, CA	Ira Lott, M.D., Co-PI Eric Doran, Study Coordinator Alicia Hernandez, Study Coordinator
Harvard/Massachusetts General Hospital Boston, MA	Florence Lai, M.D., Site PI Diana Rosas, M.D., Site PI Nusrat Jahan, Study Coordinator Courtney Jordan, Study Coordinator
The New York State Institute for Basic Research in Developmental Disabilities Staten Island, NY	Sharon Krinsky-McHale, Ph.D., Site PI Deborah Pang, Study Coordinator
University of North Texas Health Science Center Fort Worth, TX	Sid O'Bryant, Ph.D., Site PI

Potential Aging and IDD Partners





Thank You!!

Intellectual Disabilities and Dementia (the-ntg.org)

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Aging in Community: A Sibling's Story

My experience with Pathfinder Village goes back many years; I had a vested interest as my brother had Down syndrome and I had trained as a Special Educator and worked in facilities in Connecticut before moving to New York.

So how did this small, upstate New York area progress in integrating residents into community programs and life? For the last 40 years I witnessed the changes implemented at Pathfinder to address the commitment that was made for broadening experiences for community members. The world changed for those with disabilities and Pathfinder met those changes, advancing their services to bring their residents into the community and the community into Pathfinder.

Surely Pathfinder Village creates a lovely country residential setting. However it is more than that. It is a diverse community offering the choice and opportunity for everyone who is there to be the best that they can be. To define community is important: It is not a place, a building or an organization. Community is both a feeling and a set of relationships. Members of a community have a sense of trust, safety and caring for each other. It's a sense of belonging that springs from feeling that other people accept you despite, not because of, who you are. For those who call Pathfinder home and for those who work there, there is a renewed sense of commitment to bringing neighbors and neighborhoods together.

Back to my story: My brother, Richard, lived at home for 50 years with our family. The onset of dementia required us to seek a safe environment for his care that would be the most home-like. His health required continued assisted care as his disease progressed. We turned to Pathfinder and received years of support and care, not only for him but for our entire family as well. Visits were always welcomed; we forged relationships with other members of "his" house, staff and the entire community — bonds that extended past his death and that will always be cherished. Richard's memorial service was held at Pathfinder's chapel. A full gathering of family, friends, and residents celebrated a life lived within this exceptional, caring community. Richard always felt that he had two families: his birth family and his Pathfinder family. Both were equally important and dedicated to him forever.

The supportive atmosphere at Pathfinder Village allows for all who go there to find the best there is for themselves. The message of Pathfinder, "that each life may find meaning," holds true for all.

Margaret Savoie
Cooperstown, New York
February 2020

