

Understanding Aging for Individuals with Intellectual and Developmental Disabilities

HCBS Conference
Wednesday, Sept 2
3-4:15 p.m. Georgetown East

Welcome and Thank You



DD Councils

- 56 DD Councils – 1 in every state and territory
- 60% of Councils members must be people with I/DD or a family member
- Funding for the DD Councils is appropriated by Congress and comes through the Administration on Intellectual and Developmental Disabilities (AIDD)

DD Councils

- Councils identify the most pressing needs of people with I/DD in their state or territory;
- Advance public policy and systems change that help individuals with I/DD live independently;
- Empower individuals to advocate for themselves and others

Aging and Intellectual and Developmental Disabilities

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- Aging and intellectual and developmental disabilities
- Supports needed when people with intellectual and developmental disabilities age
- Organizing and managing aging-related services for aging people with I/DD

***WHAT DO WE MEAN BY INTELLECTUAL
AND DEVELOPMENTAL DISABILITIES?***

Intellectual disability

Adults who:

- Have intellectual limitations that significantly limit their ability to successfully participate in normal day-to-day activities – such as self care, communication, work, or going to school, and
 - evolved or developed their intellectual limitation during the ‘developmental period’ (before approximately age 22), and
 - their limitations are anticipated to result in long term adaptive or functional support needs, and/or
- Are eligible for State or Federal public support programs because they have been diagnosed as having an intellectual disability



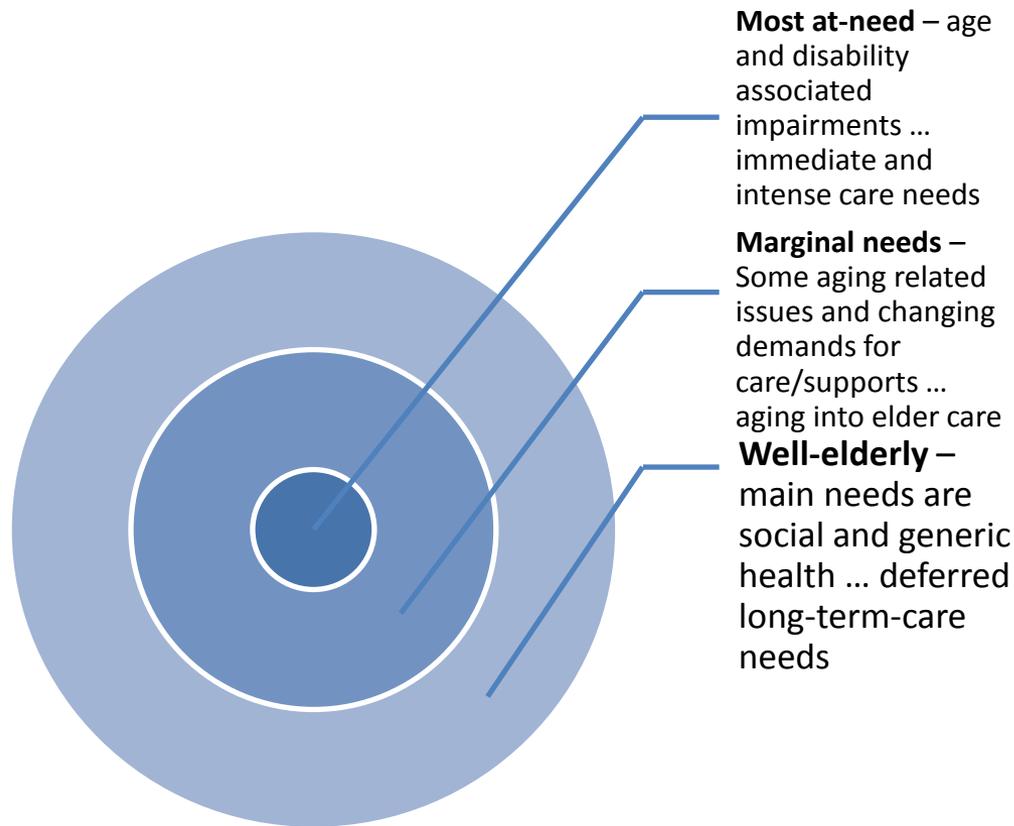
Developmental disabilities

- Include intellectual disability, but not always, and refer to conditions that originate prior to birth, in early infancy or during childhood, or before brain maturation (usually in the late teens)
 - Some impair senses, cognition, mobility, or severely compromise health and function
- An **intellectual disability** impairs cognitive and personal function (self-direction and self-care) over a lifetime
- A **developmental disability** is generally a neurodevelopmental condition (*which may include an intellectual disability, but does not always imply intellectual impairment*) which impairs normal growth, development, and function over a lifetime
 - Categorical vs. functional ☼ neurodevelopmental conditions (CP, epilepsy, ASD)
- In some jurisdictions these terms are used interchangeably. In some, only specific conditions are included under the terms

Aging & I/DD

- Aging refers to that segment of the lifespan that follows adulthood and usually involves shifts of focus from work to social activities
- Age-wise – generally after age 60/65
- Has many variations in autonomy and function
- Begins with a transition from work-age activities ends with advanced age (end-of-life)
- Can span some 40+ years!

Older people with ID with various levels of function and need



- Well elderly: Older adults lacking notable health problems
- Older persons with notable needs
 - Frailty & mobility problems
 - Sensory impairments
 - Cognitive pathologies
 - Profound and multiple disabilities
 - Major psychiatric co-conditions

SUPPORTS NEEDED WHEN PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES AGE

Impact of aging

- Changes in
 - cognitive capacities
 - physical abilities
 - social support networks
 - financial conditions
 - physical health
- Transitioning from ‘work age’ to ‘third age’
- Most older people transition into ‘aging’ without problems...
 - adults with intellectual and developmental disabilities may enter or re-enter specialized services when they age

- Changes in vision, hearing, mobility, nutrition, medication use, stamina, etc.
- Adaptations to living environment (vision, temperature, grasping, slipping, etc.)
- Losses of family, friends, peers, social network

Age-associated issues confronting providers

- Neurodegenerative diseases and conditions
 - Alzheimer's disease and related dementias
- Worsening of secondary conditions
 - Seizures, sensory losses, lifelong physical/mental health comorbidities
- Mobility/gait impairments
- Late onset cardiovascular and other diseases
- Frailty (loss of muscle mass, stamina, etc)
- Benign aging / cognitive decline / stamina

Key aging-related community supports for older adults with intellectual disability

- Supports for remaining at-home
- Physical and social barrier removal
- Access to community services for older adults
- Help with financial aid and benefits
- Medical/health services mediation
- Maintaining social supports/networks
- Advanced age and end-of-life supports

Focus – family or individual

Helping Families

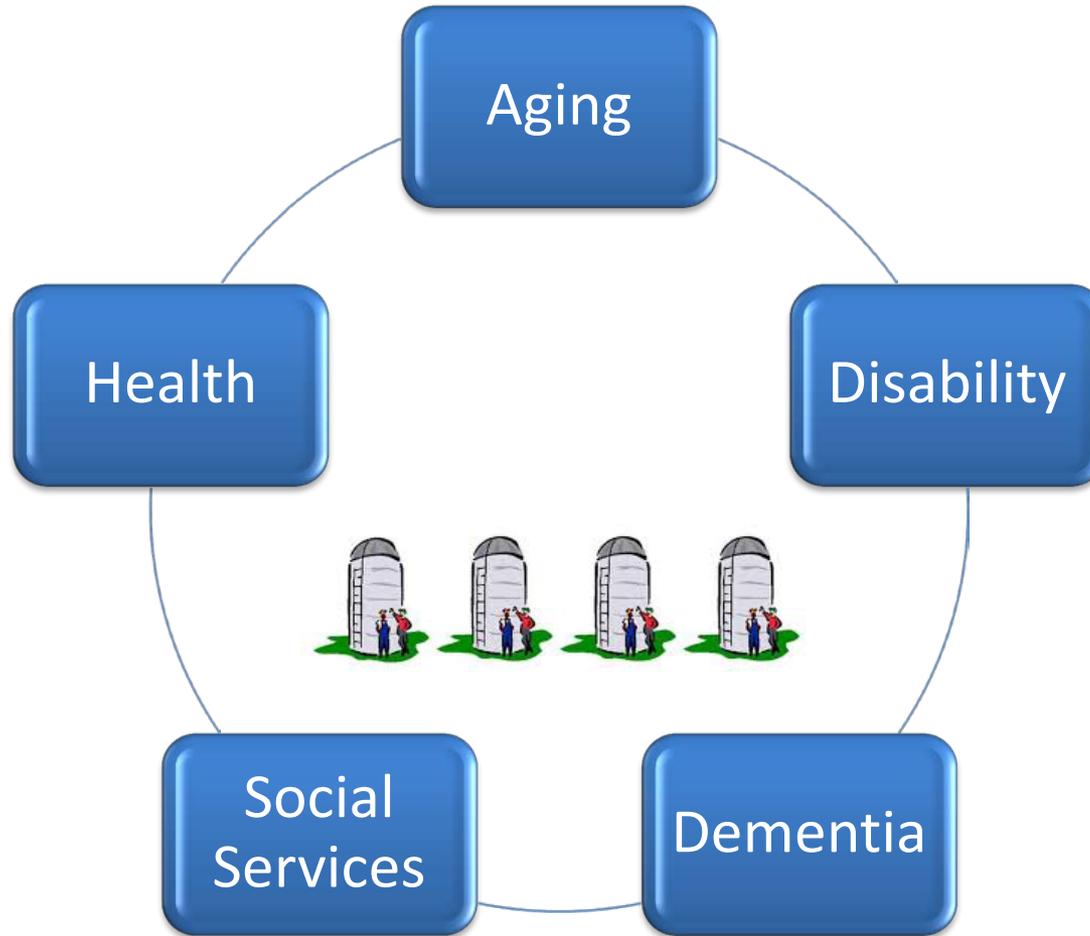
- Identify what they need
- Provide them with information
- Sort out who could best help
- Link them to the right provider (development disabilities agencies, health services, social services)
- Follow-up to make sure they have gotten what they need
- Shoring-up capacities

Helping Individuals

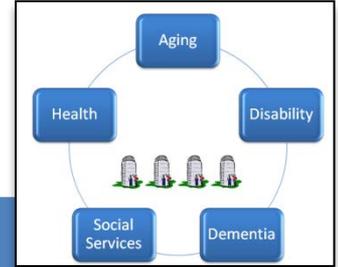
- Supporting at-home care
- Physical and social barrier removal
- Access to community services for pensioners
- Help with financial aid and benefits
- Medical/health services mediation
- Specialty housing/care for impairing secondary conditions
- End-of-life supports

ORGANIZING AND MANAGING AGING-RELATED SERVICES FOR AGING PEOPLE WITH I/DD

The silos



Silos or collaborators?

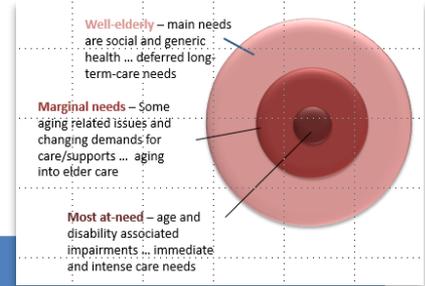


Silo 	Function
Aging	Older Americans Act services – senior centers, nutrition sites, adult day services, personal support/assistance services for older Americans – age 60+ (with some variations)
Disability	State I/DD agencies – supported by State funds and federal Medicaid – provide housing, day supports, casework and assistance and some specialized services (e.g., dementia)
Dementia	NGOs – provide information & referral, some direct care (day care, respite, caregiver aid/assistance)
Social Services	State social services agencies – public assistance, casework, adult protective, housing assistance...
Health	State health agencies, long term care facilities, medical providers – health care provision, long term care housing, disease control, diagnostic and assessment services ...

Focus of supports

- Most basic care/supports for older adults with intellectual disabilities and their families come from developmental disabilities agencies
 - When adults have been ‘part’ of the disability system *prior to aging*, services include
 - housing supports, respite for family caregivers, vocational assistance, training of staff, clinical assessments, social aid
 - When adults have not been ‘part’ of the disability system *prior to aging*, they may get services from
 - Public/social welfare (adult protective services), aging network, health care, and other generic resources

Aging needs - Supports



Problem/challenge	Options
Diminishing abilities	Screening/assessment, personal care, adaptive equipment, housing modifications
Retirement (<i>shift in daily routines</i>)	Local supports for transitioning from work to social involvements; lifestyle changes Use of senior center, meal sites, day care
Neurodegenerative conditions	Diagnostic services, caregiver assistance, specialty dementia care group homes
Families 'aging-out' of ability to care	Locating alternative housing, providing personal supports
Health changes/ Medical needs	Surveillance for primary/secondary medical conditions and age-related problems

Primary aging services/supports

- Effective and accessible health services
 - *Ensuring diseases and conditions are caught early*
- Nutrition and exercise
 - *Preventing obesity, deconditioning, and malaise*
- Prevention of secondary conditions
 - *Avoiding additional impairments from occurring*
- Geriatric assessments
 - *Diagnosing ills and physical problems of older age; polypharmacy*
- Mental health interventions
 - *Preventing depression and other ills*
- Continued social engagement
 - *Involvement in community activities and use of community amenities*

Bridging



- Aging adults with intellectual disabilities and their aging family caregivers may come in contact with following entities:
 - State developmental disabilities authority (the ‘state agency’)
 - Local intellectual disability provider agencies
 - The aging network
 - Health providers
 - Social/public welfare agencies
 - Alzheimer’s (or other dementia) groups
 - Volunteer organizations
- ‘Bridging’ is connecting diverse service networks...
 - Connecting or bridging ‘silos’ for a common purpose

Aging-related issues: Trending

– Transitioning to being ‘retirees’

- Supportive environments; linkages to senior system; alternative supports and services

– Advanced age and end-of-life situations

- Advanced age care; enabling a graceful death

– Dementia related care

- early detection and screening; DX services; aiding family caregivers; housing in specialty ‘dementia-capable’ group homes
- *The role of the National Task Group on Intellectual Disabilities and Dementia Practices*



National Task Group
on Intellectual Disabilities
and Dementia Practices

Matthew P. Janicki, Ph.D., & Seth M.
Keller, M.D.
Co-chairs, NTG

www.aadmd.org/ntg



Understanding Aging for Individuals with Intellectual and Developmental Disabilities

A Family Perspective

*Mary C. Hogan
Family Advocate
September 2,
2015*



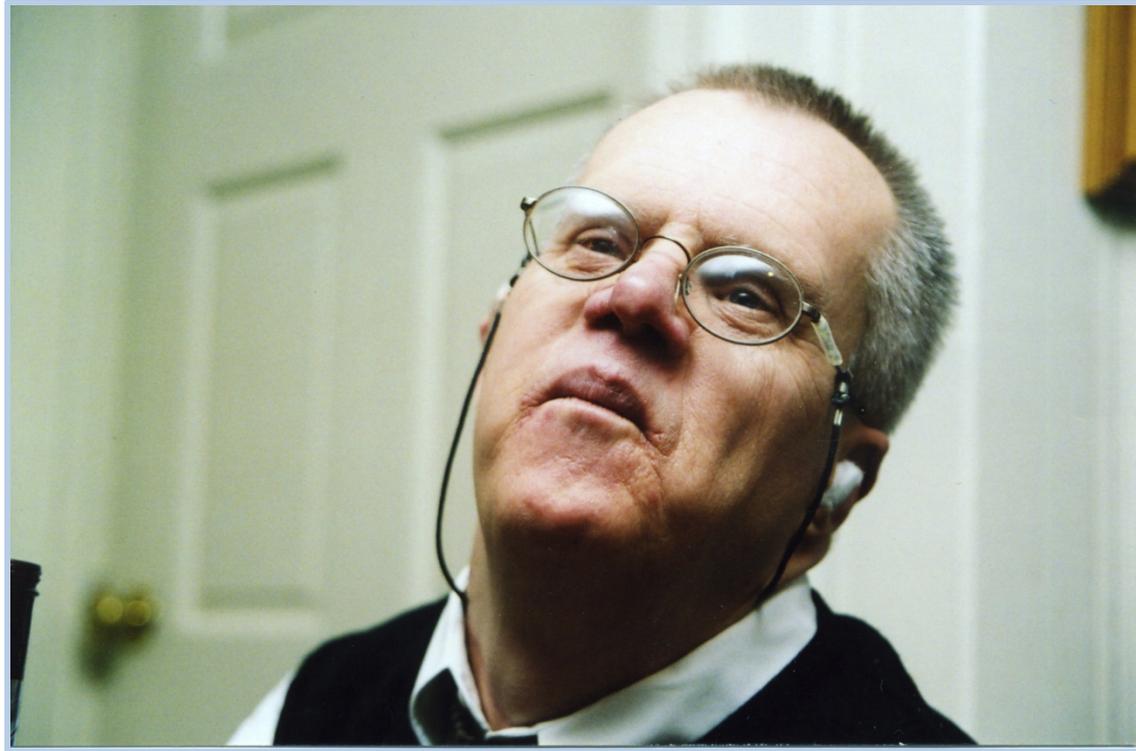
Advocacy across the life span



Lucy and Sarah

- Health is....a state of complete physical, mental and social wellbeing, and not merely the absence of disease.*
- Quality of life
- Quality of care

*World Health Organization 1946 as noted in *Health Disparities and Intellectual and Developmental Disabilities*, Gloria Krahn, MPH, CDC, May 16, 2010



“I be an old man.”

Accelerated Aging-A little understood phenomena

Coordination of Care

Model

Developed by
Kathleen Srsic-
Stoehr, MSN, MS,
RN, NEA-BC



UnitedHealthcare®
Community Plan



NACDD
National Association of Councils
on Developmental Disabilities

Challenges to Diagnosis and Care

- Decreased ability to self-report
- Overlooking subtle changes
- Conditions associated with I/DD maybe mistaken for symptoms of dementia
- Limited access to tools for diagnosis of people with I/DD
- Difficulty measuring change from previous level of functioning
- Diagnostic overshadowing
- Aging parents and siblings
- Lack of medical resources, research, education, and training

Courtesy of Seth Keller, MD

Aging in Place



- On-going caregiver training
- Increasing staff
- Creating a calm, safe, *“enabling”* environment
- Person centered planning
- Monitoring quality of life for all involved
- Supporting peers/family

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End of Life



Bill



Joey



Georgie



Carl

Gift of many families



Margaret



Joey

Aging Well



Margaret, Age 57, with sister Embry



Phoebe and sister Libby



Michelle at Shania Concert, Living her Dream



George, Age 62+

June-August 2015

Despite aging and slowing down, one can **Live life Fully**...Learning to ride a new *Amtryke* and performing in Music Therapy Concert



Caregiver Tools

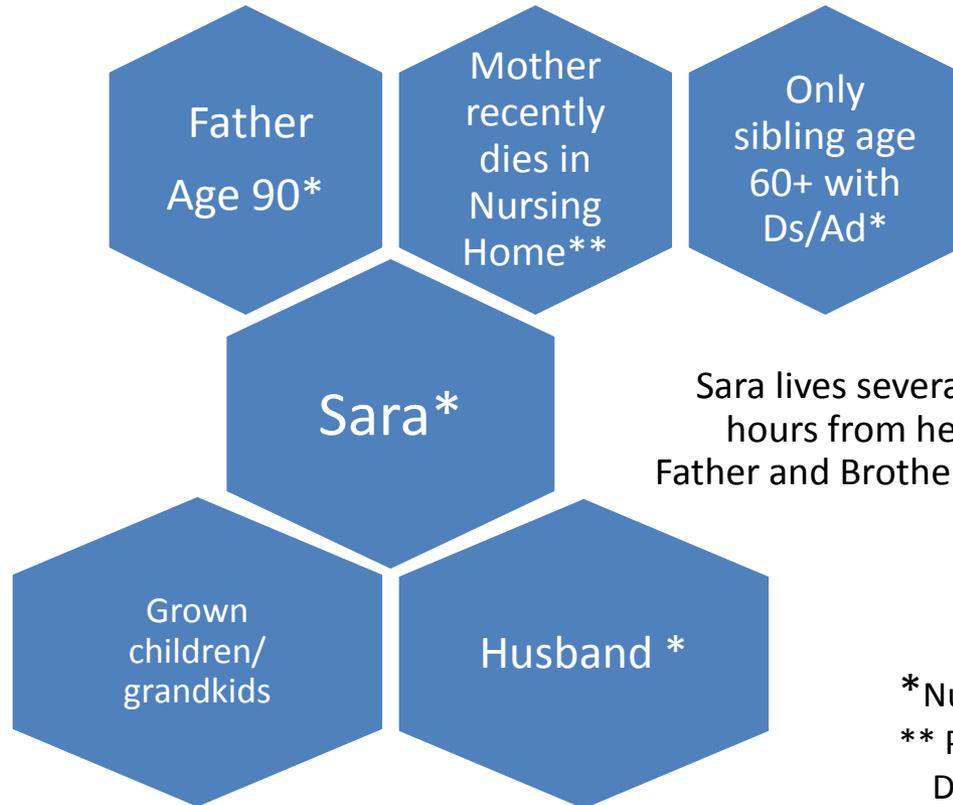
- Remember that ***“Behavior is communication.”***
- Value knowledge as “historian”
- Partner...partner...partner
- Weigh Risk vs. Benefit
- Think outside of the box.



Irma, Age 70

Siblings

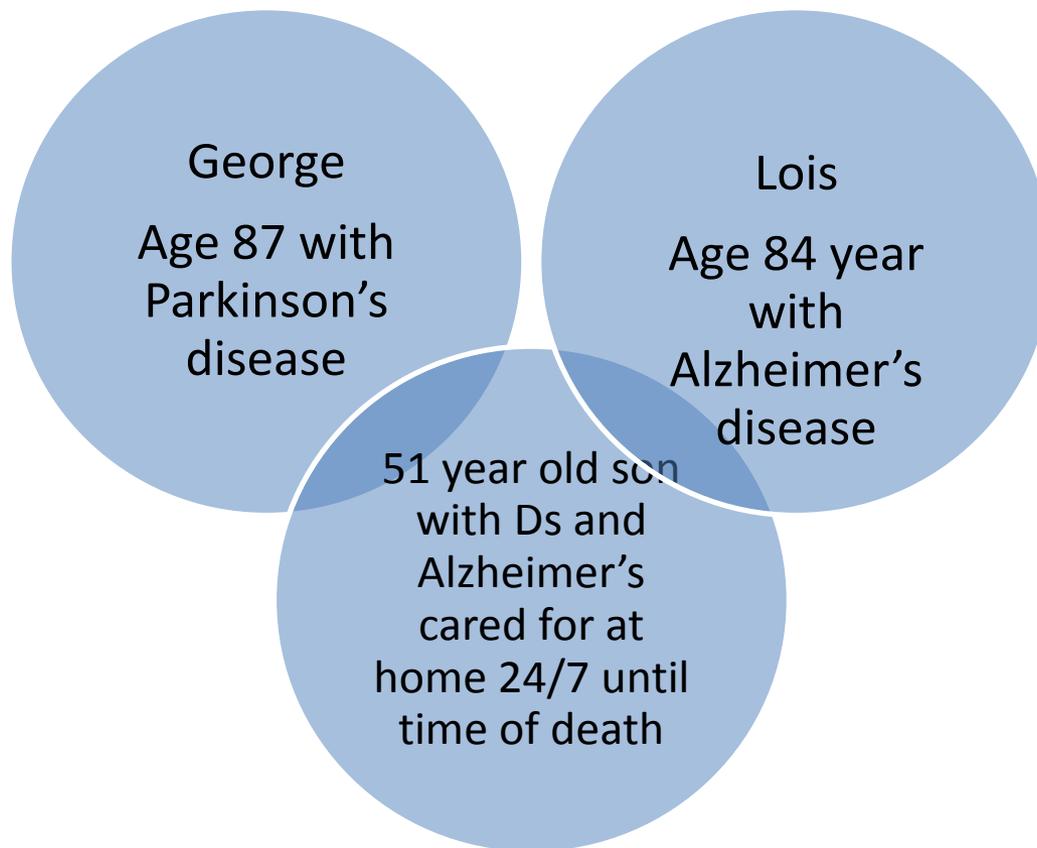
Complex Caregiving



How can I do this alone?

- *Numerous medical issues
- ** Parkinson's and Lewy Body Dementia

Caregiver Crises



Estimates suggest that roughly 75% of individuals age 40-60 with an ID live with aging family members

Provided by MP Janicki, PhD

Urgent needs of older caregivers...



Richard-age 49



Betty-age 85



Frank-age 90

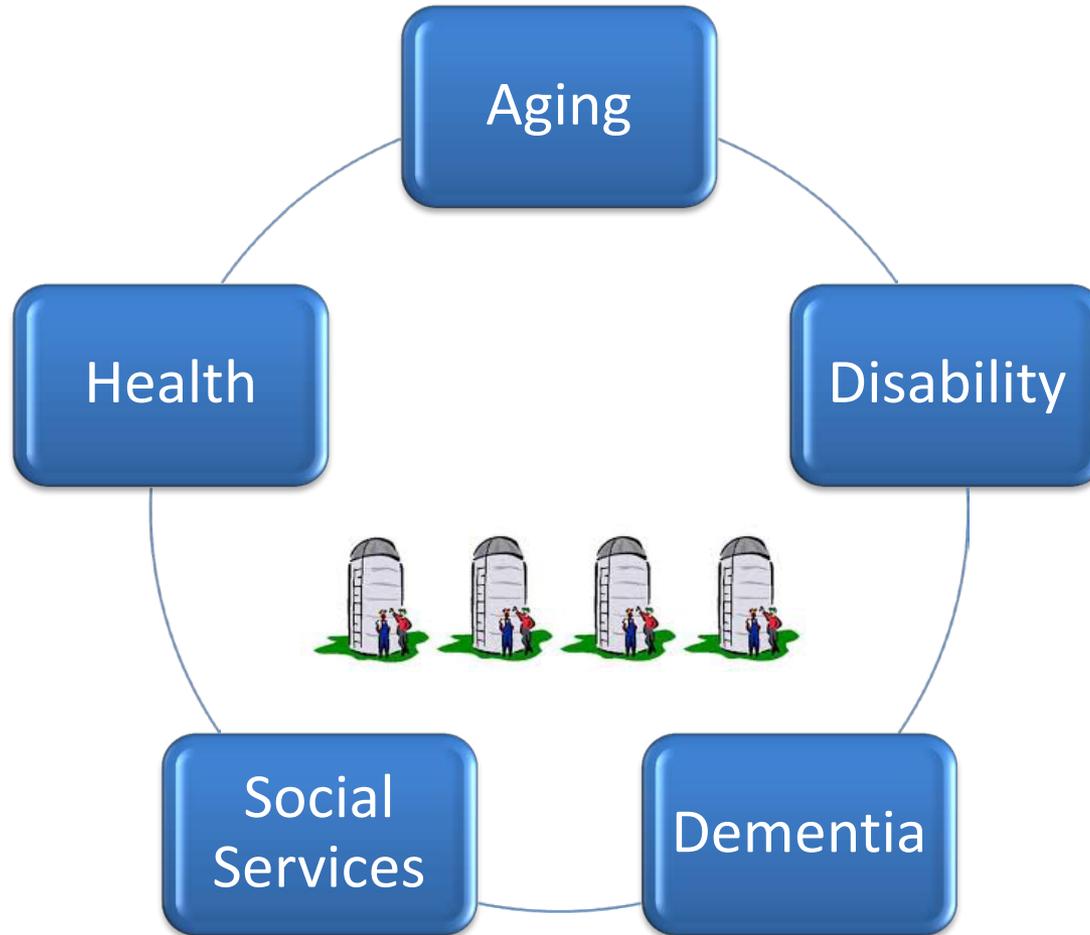
What families need...

- **A Support System**
 - Family, friends, community
 - Strong disability network
 - Informative Service Providers
 - Outreach from AAA and ADRC
 - Navigational Tools for the “system”
- **OPTIONS** for
 - **Long Term Care**
- Access to Specialty Resources
- **Respite Care**
- **HELP** finding the “Doors”



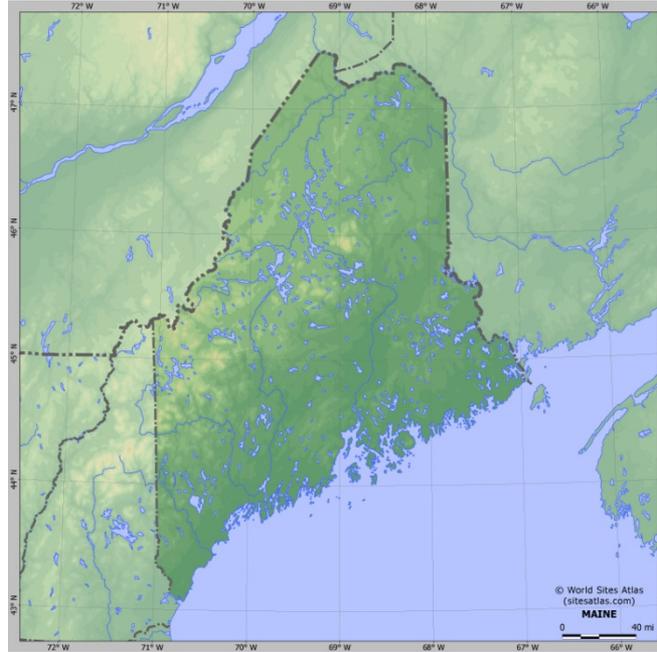
*Understanding
of the profound
sense of loss
experienced by
families...*

The silos





George, Age 62



Maine Developmental
Disabilities Council



Background to the Developmental Disabilities and Dementia Project

- “The Oldest State”:
Highest Median Age
- 2010: Dementia identified
as an issue of concern in
MDDC state plan
- 2012: MDDC was asked to
cosponsor an educational
event regarding DD and
Dementia. Anticipated
attendance was
estimated at 50; actual
registrations exceeded
200.
- 2013-14: MDDC contract
for report.



**Final Report
2015**



**Maine Developmental
Disabilities Council**

**SUPPORTS & SERVICES FOR
OLDER ADULTS WITH
DEVELOPMENTAL DISABILITIES
AND DEMENTIA IN MAINE**

Case Study



Developmental Disabilities Service System in Maine*

*Braddock, 2015

Community-based

State institution closed in 1996

Relatively low utilization of Nursing Facilities

Low levels of Family Support

Low utilization of Intermediate Care Facilities

Relatively high utilization of Out of Home residential

Eligibility

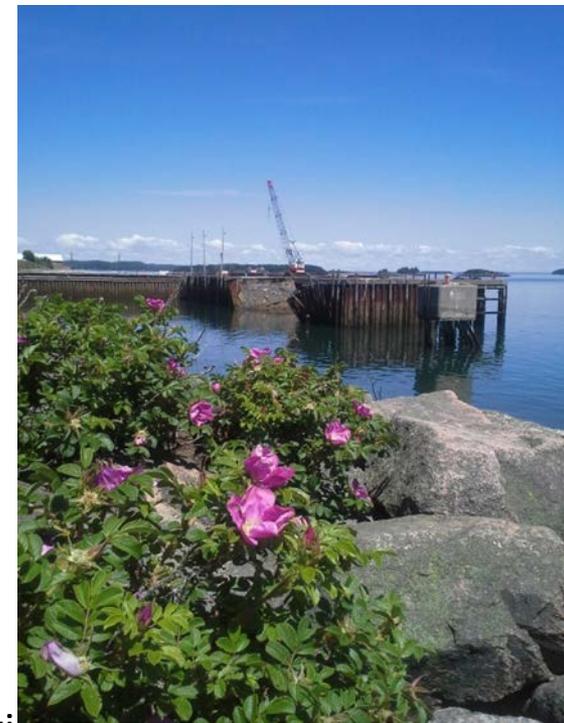
Relatively narrow, based upon diagnosis as well as function

Availability

From December 2008 to March 2015, the wait list for waiver services increased approximately 1500%.

Demographics

Reflect national trends of people with I/DD living longer and healthier lives.



Healthcare & Persons with Developmental Disabilities



- Low rates of preventive screening and primary care utilization
- High rates of chronic conditions such as obesity
- High prevalence of vision and oral health conditions



Difficulty with

- Access to specialists
- Physical access to care
- Feeling welcomed and understood
- Knowledge, training and perception of medical staff
- Patient-provider communication
- Quality of care

Healthcare & Older Adults with Developmental Disabilities



- Significant Challenges Accessing Specialty Care, especially in Rural Areas.
- Low awareness of age related issues



Developmental Services are not a great fit with the medical model

- Providers do not have a high level of clinical training
- Providers are not required to have clinical supervision
- The field does not have much experience with aging
- Rules may contraindicate commonly used dementia practices



Stakeholder



Feedback

Perceived Barriers to Accessing Healthcare

- Too few geriatricians
- Too few providers with expertise in developmental disability
- Lack of awareness of aging issues, including dementia
- Difficulty obtaining accurate diagnosis
- Difficulty obtaining differential diagnosis

Stakeholder Feedback

Perceived Barriers to Accessing Adequate Services and Supports

Developmental Services

- Waitlists for Developmental Services
- Some regulatory barriers
- Lack of awareness of aging related issues
- Lack of awareness or utilization of existing resources
- Difficult to adapt existing services to be dementia capable
- Staff skills
- “Reinventing the wheel”
- Limited availability of family supports
- Institutional care

Elder Services

- Difficulty accessing in-home services
- Inconsistent experiences with utilization of services
- Belief that people receive comprehensive services elsewhere
- Staff skills





Stakeholder Feedback

Perceived Barriers to Supporting Individuals and Families



- Difficult to reach families of persons who are “not in the system”
- Lack of flexible resources
- Need for immediate resources when caregiving families have a crisis
- Fear of the system
- Educating and supporting families
- Accessibility of programs and supports
- Age thresholds for eligibility

Sharing



Resources



In Action

- Training programs such as NTG, Savvy Caregiver and Direct Service Worker Online
- ADRC (Southern Maine Area Agency on Aging) Dementia Capable Service Network Grant
- Integration of Community Living programs at the state and federal level
- “No Wrong Door”
- Addressing Abuse, Neglect and Exploitation

Sharing



Resources

Opportunities

- Futures Planning
- Dealing with Risk
- Housing
- Transportation
- Reliable Home Care





Next Steps

Increase Awareness

- Persons with disabilities and families
- DD service providers
- Health and long term care professionals

Increase Integration of Services and Supports

- State agencies
- DD & aging service providers
- Research & education entities



Next Steps

Expand Systemic Capacity:

- Workforce development
- Enhance family support services

Adopt Evidence Based Screening Practices

Improve Data

Current Initiatives

- Dementia Capable Service Expansion Grant
-  Dementia Capable Grant

Maine Developmental
Disabilities Council

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Maine Developmental
Disabilities Council



Questions?

NTG Activities

A national early detection-screening instrument (NTG-EDSD)

Various language versions available

Access at www.aadmd.org/ntg

Practice guidelines

Community supports guidelines issued

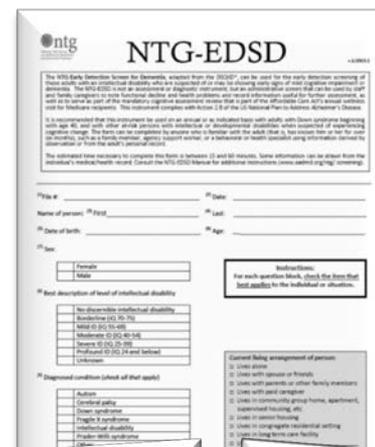
- Health practices, social care, day-to-day services and practices
- CARF & national program standards

Training and education activities

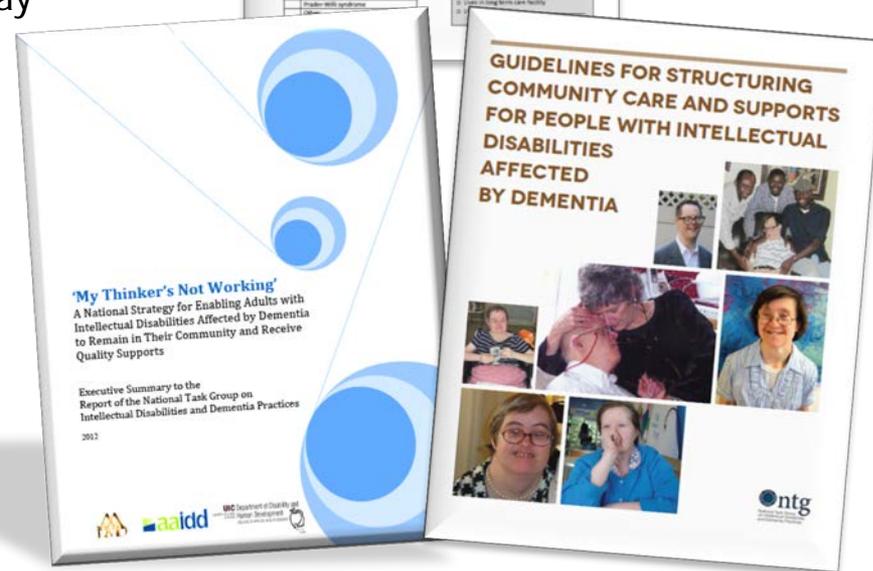
- Training workshops
- Meetings with professional groups
- Promotion of Family information

Linkages

- Administration on Community Living
- National Assoc. of State Directors of Developmental Disabilities Services
- National Assoc. of Area Agencies on Aging
- National Association of Councils on Developmental Disabilities



The NTG-EDSD form is a screening instrument for dementia. It includes a title 'NTG-EDSD' and a subtitle 'The NTG Early Detection Screen for Dementia, adapted from the 2002 NTG'. The form contains several sections: 'This is for...' (with fields for 'Date' and 'Name of person'), 'Date of birth' and 'Age', 'Sex' (with radio buttons for 'Female' and 'Male'), 'Best description of level of intellectual disability' (with checkboxes for 'No discernible intellectual disability', 'Borderline ID (IQ 70-75)', 'Mild ID (IQ 55-70)', 'Moderate ID (IQ 40-54)', 'Severe ID (IQ 25-54)', and 'Profound ID (IQ 20 and below)'), 'Disagreed condition (check off all that apply)' (with checkboxes for 'Alcohol', 'Developmental delay', 'Down syndrome', 'Epilepsy/epilepsies', 'Intellectual disability', 'Psychiatric conditions', and 'Other'), 'Bedroom(s)', 'Current living arrangement of person' (with checkboxes for 'Lives alone', 'Lives with spouse or partner', 'Lives with parents or other family members', 'Lives with adult caregiver', 'Lives in community group home, apartment, supervised housing, etc.', 'Lives in residential facility', and 'Lives in long-term residential setting or other long-term care facility'), and 'ntg' logo.



NTG Practice Guidelines for the Evaluation and Management of Dementia in Adults with ID

DIAGNOSIS AND TREATMENT GUIDELINES
Consensus Recommendations

The National Task Group on Intellectual Disabilities and Dementia Practices Consensus Recommendations for the Evaluation and Management of Dementia in Adults With Intellectual Disabilities

Julie A. Moran, DO, Michael S. Rafii, MD, PhD, Seth M. K. Baldev K. Singh, MD, and Matthew P. Jenike, PhD

Abstract

Adults with intellectual and developmental disabilities (IDD) are health care professionals with concerns related to growing older. A question is related to the evaluation of suspected cognitive decline (MCI), a question that most physicians feel ill prepared to answer. Intellectual Disabilities and Dementia Practices was convened to help address this largely underrepresented in the medical literature. The who work extensively with adults with IDD, has promulgated recommendations for the Evaluation and Management of Dementia in as a framework for the practicing physician who seeks to approach thoughtfully and compassionately.

The National Task Group on Intellectual Disabilities and Dementia Practices (NTG) was formed in a response to the National Alzheimer's Project Act, legislation signed into law by President Barack Obama. One objective of the NTG is to highlight the additional needs of individuals with intellectual and developmental disabilities (IDD) who are affected or will be affected by Alzheimer's disease and related dementias. The American Academy of Developmental Medicine and Dentistry, the Rehabilitation Research and Training Center on Aging With Developmental Disabilities—Lifetime Health and Function at the University of Illinois at Chicago, and the American Association on Intellectual and Developmental Disabilities convened their efforts to form the NTG to ensure that the interests and needs of people with intellectual disabilities and their families, when affected by dementia, are and continue to be considered as part of the National Plan to Address Alzheimer's Disease.¹ issued to address the needs of individuals with intellectual disabilities and their families, when affected by dementia, are and continue to be considered as part of the National Plan to Address Alzheimer's Disease.¹

Sanjay Gupta, MD, Editor
The Gupta Guide
Dementia in Mentally Disabled Hard to Identify

Published: Aug 26, 2013 | Updated: Aug 23, 2013
Download Complementary Source PDF

By Chris Kähler, Cardiology Editor, MedPage Today
Reviewed by P. Henry Wilson, MD, MACE, Instructor of Medicine, Professor, School of Medicine at the University of Massachusetts and Dorothy Casella, MA, BSN, RN, Nurse Planner

A new consensus statement addresses the challenges of evaluating and managing dementia in older adults with intellectual and developmental disabilities, such as Down syndrome or brain injury. These patients have an increased risk of poorer outcomes, compared with the general population, in part because healthcare professionals often lack training and preparedness to adequately respond to their special needs, according to Julie A. Moran, MD, previously with Beth Israel Deaconess Medical Center in Boston, and colleagues. Moran is now with Tewksbury Hospital in Tewksbury, Mass.

Even trying to establish a baseline decline in everyday activities in adults with intellectual disabilities can be challenging because cognitive functioning is highly individualistic, and also because of external factors such as poor record-keeping and contact with numerous healthcare professionals who often "presume that [the patient's] current level of ability represents [his or her] baseline level of functioning and, thus, miss signs of early decline," they wrote in the August issue of *Mayo Clinic Proceedings*.

"It's a relatively new phenomenon to have a large number of people with intellectual disabilities living into their 70s, 80s and beyond," Moran told *MedPage Today* in an interview. "Primary care and other general physicians typically didn't receive medical training specific to the needs of this patient population, particularly in terms of assessing their cognitive function. They need to be educated."

To address the multiple needs of these patients and their caregivers, the National Task Group on Intellectual Disabilities and Dementia Practices was formed. Its creation was a direct response to the National Alzheimer's Project Act that was signed into law in January 2013 by President Obama.

The recommendations for assessing patients with intellectual disabilities are intended to help provide healthcare professionals the information they need for the "detection of any cognitive impairment" — a requirement that appears in the Medicare Annual Wellness Visit component of the Affordable Care Act.

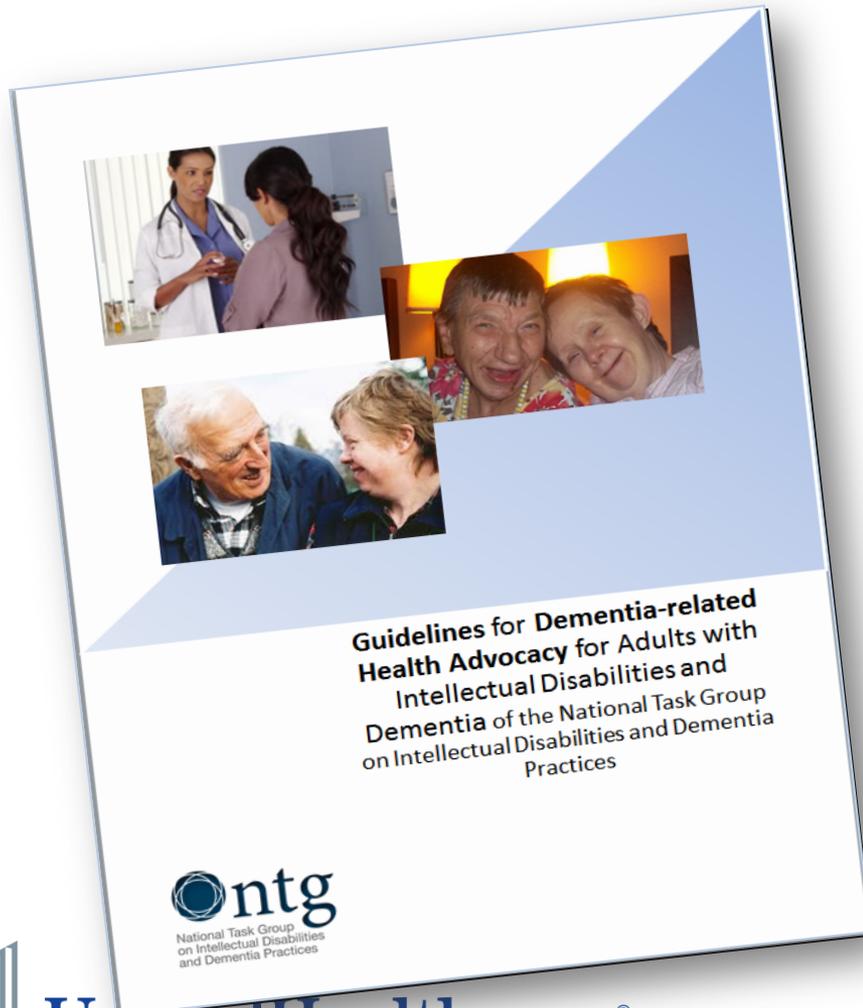
Researchers recommend a nine-step approach for assessing health and function. These include:

The NTG's recommended nine-step approach for assessing health and function.

- ✓ Taking thorough history, with particular attention to "red flags" that potentially indicate premature dementia such as history of cerebrovascular disease or head injury, sleep disorders, or vitamin B12 deficiency
- ✓ Documenting a historical baseline of function from family members of caregivers
- ✓ Comparing current functional level with baseline
- ✓ Noting dysfunctions that are common with age and also with possible emerging dementia
- ✓ Reviewing medications and noting those that could impair cognition
- ✓ Obtaining family history, with particular attention to a history of dementia in first-degree relative
- ✓ Noting other destabilizing influences in patient's life such as leaving family, death of a loved one, or constant turnover of caregivers, which could trigger mood disorders
- ✓ Reviewing the level of patient safety gleaned from social history, living environment, and outside support
- ✓ Continually "cross-referencing the information with the criteria for a dementia diagnosis"

Sources: Moran JA, et al "The national task group on intellectual disabilities and dementia practices consensus recommendations for the evaluation and management of dementia in adults With intellectual disabilities" *Mayo Clin Proc* 2013; 88(8): 831-840.
<http://www.medpagetoday.com/TheGuptaGuide/Neurology/41694>

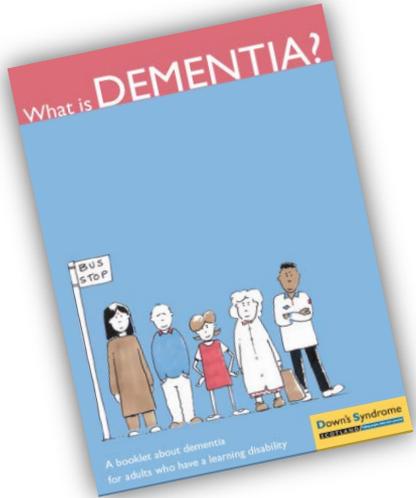
For Guidance...



- NTG Guidelines and recommendations for dementia-related health advocacy preparation and assistance that can be undertaken by provider and advocacy organizations.
- The guidelines help caregivers recognize and communicate symptoms, as well as find appropriate practitioners familiar with the medical issues presented by aging adults with lifelong disabilities.

www.aadmd.org/ntg

Other useful resources



What is DEMENTIA?

- ❑ Pamphlet created by Down's Syndrome Scotland to use with adults with intellectual disabilities and explain dementia and its effects on their friends, relatives and parents.
 - ✓ Download at: Download at: http://lx.iriss.org.uk/sites/default/files/resources/What%20is%20dementia_0.pdf

- ✓ The NTG FAQ: Some Basic Questions about Adults with Intellectual/Developmental Disabilities Affected by Alzheimer's Disease or Other Dementias



- ❑ Fact sheet in a question and answer format addressing common questions regarding dementia and intellectual disabilities.

- ✓ Download at <http://aadmd.org/sites/default/files/FAQ-Table-v9.pdf>

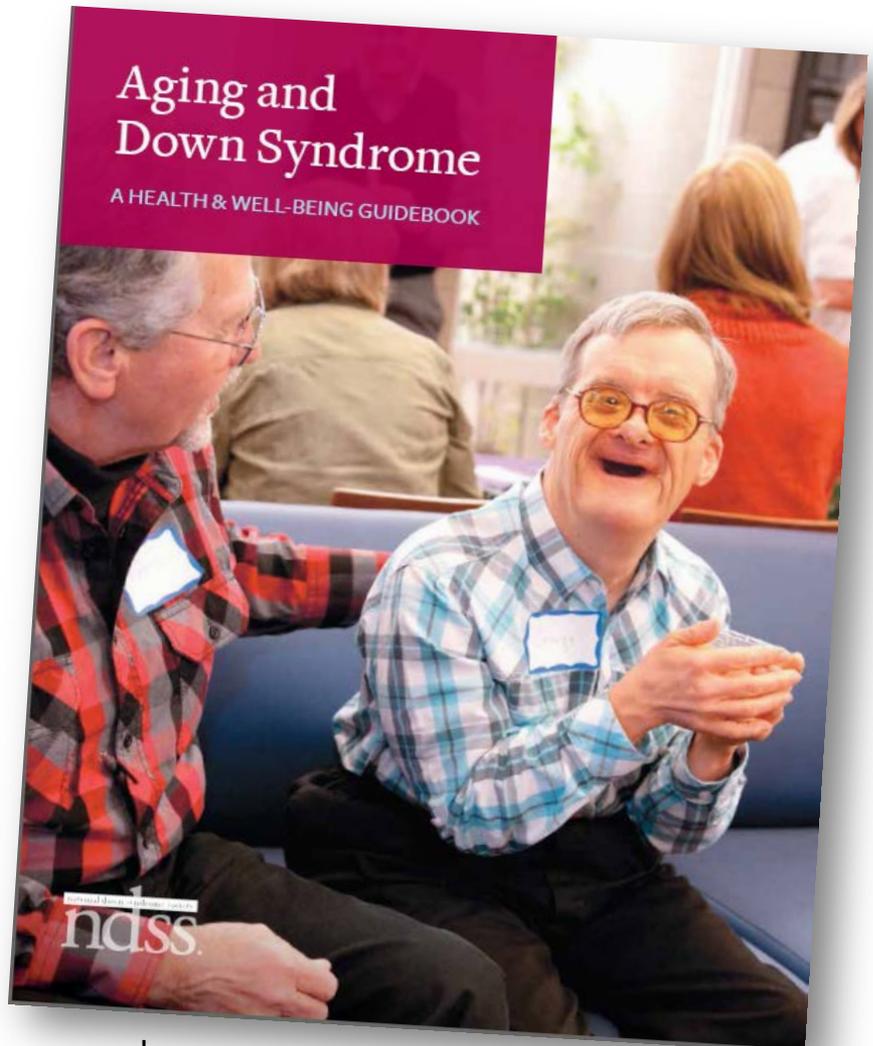
Aging and Down Syndrome: A Health & Well-being Guidebook

Adults with Down syndrome, along with their families and caregivers, need accurate information and education about what to anticipate as a part of growing older, so they can set the stage for successful aging.

The purpose of this guidebook is to help with this process... it is intended to be helpful to a variety of users: *families, professionals, direct caregivers or anyone concerned with the general welfare of someone with Down syndrome.*

The goals of this guidebook are to:

- Provide guidance, education and support to families and caregivers of older adults with Down syndrome
- Prepare families and caregivers of adults with Down syndrome for medical issues commonly encountered in adulthood
- Empower families and caregivers with accurate information so that they can take positive action over the course of the lifespan of adults with Down syndrome
- Provide an advocacy framework for medical and psychosocial needs commonly encountered by individuals affected by Down syndrome as they age



www.ndss.org

Additional Resources

Coping with Behavior Change In Dementia: A Family Caregiver's Guide by Beth Spencer and Laurie White, Whisppub.com 2015

The Guide to Good Health for Teens and Adults with Down Syndrome by Brian Chicoine, M.D. and Dennis McGuire, Ph.D., Woodbine House Press 2010

Mental Wellness in Adults with Down Syndrome: a Guide to Emotional and Behavioral Strengths and Challenges by Dennis McGuire, Ph.D. and Brian Chicoine, M.D., Woodbine House Press 2006

The 36-Hour Day by Nancy Mace and Peter Rabins, Johns Hopkins University Press, 2008

Picture Communication Systems, DynoVox, Mayer and Johnson LLC
Boardmaker