

## **Improving Alzheimer’s Diagnosis and Care for Adults with Down Syndrome**

*Resources for Clinicians and Community Members*

*For more information about our project or to suggest resources to add to this document, contact Megan Cvitanovic ([mcvitano@stanford.edu](mailto:mcvitano@stanford.edu)).*

*To stay up-to-date with upcoming virtual forums and research studies, subscribe to our mailing list at*

*<https://mailman.stanford.edu/mailman/listinfo/idd-transform-info>.*

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### General Information / Resources

#### [IDD-TRANSFORM website](#)

- Includes information about the IDD-TRANSFORM project and links to previous virtual forums.

#### [National Down Syndrome Society \(NDSS\)](#)

- NDSS empowers individuals with Down syndrome and their families by driving policy change, providing resources, engaging with local communities, and shifting public perceptions.

#### [Aging and Down Syndrome: A Health & Well-Being Guidebook](#)

- A resource for families, professionals, direct caregivers, or anyone concerned with the general welfare of an adult with Down syndrome with a specific focus on aging and health-related matters in an

individual with Down syndrome such as common medical conditions, Alzheimer's and Down syndrome, and mental health.

### [About Alzheimer's Disease and Down Syndrome](#) (NDSS)

- This webpage from the National Down Syndrome Society provides a general definition and overview of Alzheimer's Disease, its span, and how to recognize symptoms.

### [The National Task Group on Intellectual Disabilities and Dementia Practices](#) (NTG)

- The NTG is a not-for-profit organization charged with ensuring that the interests of adults with intellectual and developmental disabilities who are affected by Alzheimer's disease and other causes of dementia - as well as their families and friends – are taken into account.

### [NTG - Early Detection and 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

### [Dementia Care Planning and the EDSD](#) (NTG)

- Dementia care planning is a process that involves assessing the state of an individual who has been diagnosed with dementia and then considering what care and support practices should be implemented to help compensate for any losses or challenges being experienced. The NTG-EDSD can be an useful device for collective discussions and dementia care planning involving families and care providers.

### [NTG Serial Assessment of Function in Dementia](#) (SAFD)

- This tool, adapted from the NTG-Early Detection and Screen for Dementia (EDSD), assesses the functional decline in adults with ID over time post diagnosis of dementia.

### [NTG Resources on Down Syndrome and Alzheimer's](#)

- Many organizations have produced briefs about Alzheimer's and Down syndrome and guides for caregivers and others interested in knowing more. A brief list of the national organizations and links to their sites is provided on this webpage.

### [Advocate Medical Group Adult Down Syndrome Center](#)

This is a great resource library, with a variety of resources about different areas of health for adults with Down syndrome.

- [Resource Library](#): filter by topic on the left-hand side of the page
- [Email List](#)
- [Facebook](#)
- [Instagram](#)

### [The National Healthy Brain Initiative](#)

- The Healthy Brain Initiative aims to improve our understanding of brain health by providing the latest science and tools. The initiative also brings bringing partners together to support brain health across the lifespan. The Healthy Brain Initiative's Road Map series provides steps to address brain health, the needs of caregivers, and future road maps.

### [Global Down Syndrome Foundation](#)

- The Global Down Syndrome Foundation is a public non-profit dedicated to significantly improving the lives of people with Down syndrome through Research, Medical Care, Education and Advocacy. Formally established in 2009, GLOBAL's primary focus is to support the [Linda Crnic Institute for Down Syndrome](#), the first academic home in the United States committed solely to research and medical care for people with Down syndrome.

[Lucille Esralew, Senior Psychologist Supervisor at California Department of Developmental Services](#)

- Presentation: "[Brain Health Across the Lifespan for People with Intellectual and Developmental Disabilities](#)"

[Health Matters Webinar Series: Healthy Brain Initiative for People with Intellectual and Developmental Disabilities](#)

- Healthy Brain Webinar Series is presented by the HealthMatters Program, Department of Disability and Human Development, College of Applied Health Sciences, University of Illinois at Chicago in partnership with National Task Group on Intellectual Disabilities and Dementia Practices (NTG) and ENGAGE-IL.

## Person/Family Centered Resources

[Alzheimer's Disease & Down Syndrome: A Practical Guidebook for Caregivers \(NDSS\)](#)

- The National Down Syndrome Society, in partnership with the NTG and the Alzheimer's Association, released a guidebook specifically for those caring for an individual with Down syndrome diagnosed with Alzheimer's disease. [Also available in Spanish.](#)

[Jenny's Diary: A Resource to Support Conversations about Dementia with People who have an Intellectual Disability](#)

- This is a free to download booklet and set of postcards aimed at supporting conversations about dementia with people who have an intellectual disability.

[NTG Family/Caregiver Resources for Alzheimer's/Dementia](#)

- The NTG has compiled key news articles and a list of publications that may be helpful to family members and caregivers caring for individuals with an intellectual disability living with dementia.

[Support Groups for Caregivers of Individuals with Down Syndrome and Alzheimer's Disease](#)

- This webpage lists various support groups available to caregivers/family members.

### [Intellectual Disability and Dementia: A Caregiver's Resource Guide for Rhode Islanders](#)

- This is a resource guide for family caregivers, and others, that explains the basics of dementia, caregiving aids, and sources of help. The guide was developed for use in Rhode Island, but is applicable in any state. This is the main guide; see also the guide on 'health' and 'talking about dementia'.

## Resources for Health Care Providers

### [Down Syndrome Medical Interest Group](#)

- DSMIG-USA® is a group of health professionals committed to promoting the optimal health care and wellness of individuals with Down syndrome (DS) across the lifespan. Members of this DSMIG-USA are professionals from a variety of disciplines who provide care to individuals with Down syndrome and/or their families. This may include physicians, scientists, psychologists, nurses, genetic counselors, educators, therapists, clinic coordinators, and related health professionals. Members may also include individuals who engage in research or health policy relevant to Down syndrome.
- [Speaker Series](#)
- [Project ECHO](#)

### [Project ECHO® Growing Older with Lifelong Intellectual Disabilities: When Dementia is Suspected or Diagnosed](#)

- Taking place fall 2024. This Project ECHO series is a free, practical, case-based education program for health care and service providers who want to enhance their knowledge, competence, and performance related to the care of people with intellectual and developmental disabilities affected by dementia. Each ECHO session will include a short presentation by a topic expert, followed by a case study submitted in advance by an ECHO participant site, and then open discussion to learn from one another.

### [AADMD Chapters for Students and Residents](#)

- Students in many health-related fields receive little to no training about IDD. AADMD wants to change that. You can connect with an existing chapter or apply to start a new chapter here.

### [GLOBAL Medical Care Guidelines for Adults with Down Syndrome](#)

- The new GLOBAL Medical Care Guidelines for Adults with Down Syndrome (GLOBAL Adult Guideline) provide first in-kind, evidence-based medical recommendations to support clinicians in their care of adults with Down syndrome.

### [Examining Adults with Neuroatypical Conditions for MCI/Dementia During Cognitive Impairment Assessments: Report of the Neuroatypical Conditions Expert Consultative Panel](#)

- The NTG and the Lumind IDSC Foundation issued a comprehensive report on the barriers to determining MCI and dementia in adults with neuroatypical conditions, such as acquired brain injury, autism, cerebral palsy, Down syndrome, intellectual disability, serious mental illness, and significant sensory impairments.

### [Addressing Brain Health in Adults With Intellectual Disabilities and Developmental Disabilities: A Companion to the KAER Toolkit for Primary Care Providers](#)

- This toolkit is designed to address the needs of adults with intellectual and developmental disabilities (I/DD) who develop dementia. This companion document complements the [GSA KAER Toolkit for Primary Care Teams](#). It provides guidance for health workers, support personnel, and caregivers. It includes specific information on screening, assessment, and diagnosing dementia, resources for clinicians and caregivers, and information on brain health and risk reduction

### [Guiding an Improved Dementia Experience \(GUIDE\) Model](#)

- The GUIDE Model focuses on comprehensive, coordinated dementia care and aims to improve quality of life for people with dementia,

reduce strain on their unpaid caregivers, and enable people with dementia to remain in their homes and communities. It will achieve these goals through Medicare payments for a comprehensive package of care coordination and care management, caregiver education and support, and respite services.

### [Health Care for Adults with Intellectual and Developmental Disabilities: Toolkit for Primary Care Providers](#)

- The IDD Toolkit website provides information for the primary care of adults with intellectual and developmental disabilities. The Toolkit offers health care providers best-practice tools and information regarding specific medical and mental and behavioral health concerns, including resources for patients and families.
- [Down Syndrome Health Watch Table](#)

### [Diagnostic overshadowing among groups experiencing health disparities](#)

- This article by The Joint Commission describes the risks of diagnostic overshadowing and provides recommendations to help recognize and address diagnostic overshadowing among groups experiencing health disparities, including adults with intellectual and/or developmental disabilities.

## Information about Research

### [Alzheimer Biomarkers Consortium — Down Syndrome \(ABC-DS\)](#)

- The Alzheimer Biomarkers Consortium-Down Syndrome (ABC-DS) is a longitudinal study funded by the National Institute on Aging (NIA), the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), and the National Institutes of Health (NIH) INCLUDE (INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndromE) project. The goal of ABC-DS is to follow a cohort of adults with Down syndrome over time to identify early biomarkers that may herald the onset of Alzheimer's disease. The investigators hope that these biomarkers can be useful

to inform clinical trials and improve the quality of life in people with Down syndrome and for the general population.

### [LuMind](#)

- LuMind IDSC serves as a bridge between the Down syndrome community and the research community. Their mission is to accelerate research to increase availability of therapeutic, diagnostic, and medical care options and empower families through education, connections, and support.
- [Specific information about Alzheimer's.](#)

### [ABATE Study](#)

- The ABATE Study is testing a vaccine for Alzheimer's. We want to see if the vaccine is safe. We also want to see if it slows the progression of Alzheimer's disease in people with Down syndrome. About 80 people with Down syndrome will take part in the ABATE Study.

### [World Wide FINGERS \(WW-FINGERS\)](#)

- The Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER) trial is the first randomized controlled trial (RCT) showing that it is possible to prevent cognitive decline using a multidomain lifestyle intervention among older at-risk individuals. WW-FINGERS was established to support and convene global multidomain dementia prevention trials, share experiences and data, and harmonize methods