

## People with Intellectual or Developmental Disabilities and Dementia

### 1) “Overview” (Seth M. Keller, MD, Co-Chair NTG, Immediate Past President, AADMD)

- Seth M. Keller, M.D., AADMD, Advocare Neurology of South Jersey: [sethkeller@aol.com](mailto:sethkeller@aol.com)
- Neil, M. (2007). Alzheimer’s dementia: What you need to know, what you need to do. Understanding intellectual disabilities and health. <http://www.intellectualdisability.info/mental-health/alzheimers-dementia-what-you-need-to-know-what-you-need-to-do>
- Mann DMA. Association between Alzheimer disease and Down syndrome: neuropathological observations. In: Berg JM, Karlinsky H, Holland AJ, eds. Alzheimer disease, Down syndrome and their relationship. Oxford: Oxford University Press, 1993. <http://trove.nla.gov.au/work/10402887?q&versionId=45032042>
- Wilkosz et al., (2009). Trajectories of cognitive decline in Alzheimer’s disease. *International Psychogeriatrics*, 28, 1-10. doi: 10.1017/S1041610209991001 <http://www.ncbi.nlm.nih.gov/pubmed/19781112?dopt=AbstractPlus>
- NTG-Early Detection Screen for Dementia: <http://aadmd.org/ntg/screening>
- Guidelines for Structuring Community Care and Supports for People With Intellectual Disabilities Affected by Dementia (2013). *Journal of American Policy and Practice in Intellectual Disabilities*, 10 (1), 1-24.
- Online Help for DD and Dementia
  - For publications, screening tools, and other resources on dementia and I/DD: <http://aadmd.org/ntg>
  - For information on Down syndrome and dementia: <http://www.alz.org/dementia/down-syndrome-alzheimers-symptoms.asp>
  - Look for their new booklet: *Aging and Down Syndrome: A Health & Well-being Guidebook*: <http://www.ndss.org>
- State, regional, local contacts
  - Your state developmental disabilities agency
  - Your state aging agency
  - Your area agency on aging
  - Your state chapter of The Arc
  - Your state developmental disabilities planning council
  - Your state or local chapter of the Alzheimer’s Association
  - Your state’s Caregiver Support Program
  - Local dementia assessment clinics or centers
- American Academy of Developmental Medicine and Dentistry: <http://aadmd.org/NTG>
- Matthew P. Janicki, Ph.D., University of Illinois at Chicago, RRTC/Aging and DD, Chicago, Illinois USA: [mjanicki@uic.edu](mailto:mjanicki@uic.edu)

### 2) Overview of Research on Down Syndrome and Aging: Opportunities and Challenges (Ira T. Lott, MD, Professor Emeritus, University of California, Irvine)

- Haydar T.F., Reeves R.H. Trisomy 21 and early brain development. *Trends Neurosci.* 2011; 35:81–91. doi: 10.1016/j.tins.2011.11.001 <http://www.ncbi.nlm.nih.gov/pubmed/22169531>

- Down syndrome: the brain in trisomic mode (2012). *Nat Rev Neuroscience*, 13(12), 844-58. doi: 10.1038/nrn3314. <http://www.ncbi.nlm.nih.gov/pubmed/23165261>
- Lanfranchi, S., Jerman, O., DalPont, E., Alberti, A., & Vianello, R. (2010). Executive function in adolescents with Down syndrome. *Journal of Intellectual Disability Research*, 54, 308–319. <http://eric.ed.gov/?id=EJ877694>
- Ball, Sandra, L., Holland, Anthony, J., Treppner, Peter, Watson, Peter, C., & Huppert, Felicia, A. (2008). Executive dysfunction and its association with personality and behaviour changes in the development of Alzheimer's disease in adults with Down syndrome and mild to moderate learning disabilities. *British Journal of Clinical Psychology*, 47. DOI: 10.1348/014466507X23096 <http://onlinelibrary.wiley.com/doi/10.1348/014466507X230967/abstract?deniedAccessCustomisedMessage=&userIsAuthenticated=false>
- Adams, D., Oliver, C. (2010). The relationship between acquired impairments of executive function and behaviour change in adults with Down syndrome. *Journal of Intellectual Disability Research*, 54(Pt 5), 393-405. DOI: 10.1111/j.1365-2788.2010.01271.x <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2788.2010.01271.x/abstract>
- Nelson, L. D., Orme, D., Osann, K., & Lott, I. T. (2001). Neurological changes and emotional functioning in adults with Down Syndrome. *Journal of Intellectual Disability Research*, 45(Pt 5), 450-456. <http://www.ncbi.nlm.nih.gov/pubmed/11679050>
- Edgin, Jamie, O., Mason, Gina, M., Allman, Melissa, J., Capone, George, T., Iser DeLeon, Cheryl Maslen, Reeves, Roger, H., Sherman, Stephanie, L., and Nadel Lyinn (2010). Development and validation of the Arizona Cognitive Test Battery for Down syndrome. *J Neurodev Disord.*, 2(3), 149–164. doi: [10.1007/s11689-010-9054-3](https://doi.org/10.1007/s11689-010-9054-3) <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3026140/>
- Zigman, W.B., Devenny, D.A., Krinsky-McHale, S.J., Jenkins, E.C., Urv, T.K., Wegiel, J., Schupf, N., Silverman W. (2008). Alzheimer's Disease in Adults with Down Syndrome. *Int Rev Res Ment Retard*, 1 (36), 103-145. <http://www.ncbi.nlm.nih.gov/pubmed/19633729>
- Burt, D. B., & Aylward, E. H. (2000). Test battery for the diagnosis of dementia in individuals with intellectual disability. Working Group for the Establishment of Criteria for the Diagnosis of Dementia in Individuals with Intellectual Disability. *Journal of Intellectual Disability Research*, 44, 175–180. <http://www.ncbi.nlm.nih.gov/pubmed/10898382>
- Coskun, Pinar, E., & Busciglio, Jorge (2012). Oxidative Stress and Mitochondrial Dysfunction in Down's Syndrome: Relevance to Aging and Dementia. *Current Gerontology and Geriatrics Research*, 12. doi: <http://dx.doi.org/10.1155/2012/383170> <http://www.hindawi.com/journals/cggr/2012/383170/>
- TMI program UCI 2001-present
  - California Center for Connected Health <http://www.cchpca.org/>
  - California Telehealth Network <http://www.caltelehealth.org/>

### 3) “Federal Resources” (Andrew Morris, MPH, Administration on Intellectual and Developmental Disabilities, Administration for Community Living)

- Andrew Morris:
  - E-mail: [andrew.morris@acl.hhs.gov](mailto:andrew.morris@acl.hhs.gov)
  - Phone: 202-690-5985

- AIDD programs : University Centers for Excellence on Developmental Disabilities  
<http://www.acl.gov/programs/aidd/Programs/UCEDD/index.aspx>
- National Alzheimer's Contact Center:
  - Website with Information on Down-Syndrome:  
<http://www.alz.org/dementia/down-syndrome-alzheimers-symptoms.asp>
  - 24/7 Helpline: 1-800-272-3900
- Eldercare Locator: <http://eldercare.gov>
- Information on alzheimers.gov:
  - <http://alzheimers.gov/>
  - [http://alzheimers.gov/down\\_syndrome.html](http://alzheimers.gov/down_syndrome.html)
- ACL Alzheimer's Page:  
[http://www.aoa.gov/AoARoot/AoA\\_Programs/HPW/Alz\\_Grants/index.aspx](http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/index.aspx)
- NIA's Alzheimer's Disease Education And Referral Center (ADEAR):  
<http://www.nia.nih.gov/alzheimers>
  - [adear@nia.nih.gov](mailto:adear@nia.nih.gov)
- NIA-funded Alzheimer's Disease Centers (ADCs):  
<http://www.nia.nih.gov/alzheimers/alzheimers-disease-research-centers#adcs>
- NIA ADEAR Search for Alzheimer's Clinical Trials: <http://www.nia.nih.gov/alzheimers/clinical-trials>
- Alzheimer's Association TrialMatch: <http://www.alz.org/trialmatch>