

Annual Round Table Presentations

- 2011 Round Table, Dublin, Ireland - [presentations](#)
- 2010 Round Table, Prato, Italy - [presentations](#)

IASSID State of the Science Papers

- Haveman, M.J., Heller, T., Lee, L.A, Maaskant, M.A, Shooshtari, S., Strydom, A. (2009). [Report on the State of Science on Health Risks and Ageing in People with Intellectual Disabilities](#)
. IASSID Special Interest Research Group on Ageing and Intellectual Disabilities/Faculty Rehabilitation Sciences, University of Dortmund.
- Strydom, A., Lee, L.A, Jokinen, N., Shooshtari, S., Raykar, V., Torr, J., Tsiouris J.A., Courtenay, K., Bass, N., Sinnema, M., Maaskant, M.A. (2009). [Report on the State of Science on Dementia in People with Intellectual Disabilities](#)
. IASSID Special Interest Research Group on Ageing and Intellectual Disabilities.

Other Documents

- [The Irish Longitudinal Study on Ageing Intellectual Disability Supplement \(TILDA-IDS\)](#)
New Research From Ireland - This represents the first wave data from the TILDA-IDS and links to presentations of the one-day conference on findings and implications. □
- [Resources on Grief, Loss and End of Life](#)
compiled by Bill Gaventa
- **New DVD Resource on Supporting Retirement and Inclusion in Community Organisations.**

This DVD resource is based on participant stories from our recent *Transition to Retirement* research project. The research project was funded under the Australian Government's ARC-Linkage scheme. The project team comprised me, Professor Christine Bigby (La Trobe University), Professor Susan Balandin (University College Molde, Norway), Dr Nathan Wilson (The University of Sydney) and Diane Craig (La Trobe University). The research team supported older people with a lifelong disability to drop one day at work or day program and replace that day by joining a local community or volunteer group. The DVD resource includes the stories of six people who took part in the study. These stories provide a depiction of the

approach that can be used by practitioners to illustrate to other people with a disability, and their families, what is possible in retirement with the right level of support. The DVD also provides an excellent teaching resource on topics such as disability, ageing, retirement, volunteering and social inclusion. An Opinions and Perspectives paper in the *Journal of Intellectual and Developmental Disability* describes the theoretical basis behind the transition to retirement intervention.

Available on line or a hard copy from Australian Foundation for Disability Services Services http://www.afford.com.au/cms/index.php?option=com_content&view=article&id=51&Itemid=49

National Plan on Dementia and Adults with Intellectual Disabilities

The National Task Group on Intellectual Disabilities and Dementia Practices has issued a plan for improving the community care of adults with intellectual disabilities affected by dementia. "This is an issue that will only grow in intensity and the nation needs to address this challenge head on" said Dr. Seth M. Keller, the President of the AADMD and co-chair of the National Task Group. The Group's report, 'My Thinker's Not Working': A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports", summarizes and addresses some of the challenges facing the nation due to the increasing rate of dementia found in older people with intellectual disabilities. The report offers recommendations for the improvement of services and suggests that its findings and recommendations be considered and integrated into the reports and plans being developed by the federal Advisory Council on Alzheimer's Research, Care, and Services -- under the National Alzheimer's Project Act. The report notes that Alzheimer's disease mostly impacts adults with lifelong intellectual disabilities in the same ways as it does other people, but sometimes has a more profound effect due to particular risk factors - including genetics, neurological injury, and deprivation. Dr. Keller said that "families are often the main caregivers for adults with an intellectual disability and when Alzheimer's occurs they are profoundly impacted." Such families not only include parents, but also siblings and other relatives. The report notes that many such families have difficulties in providing extensive care at home once dementia becomes pronounced and care demands overwhelm them.

The report also notes that it is important to recognize signs of dementia-related changes early, and identified an instrument potentially applicable to adults with an intellectual disability. This instrument could also be used for the cognitive assessment provision of the annual wellness visit under the Affordable Care Act. The report recommends adoption of such an instrument by providers and regulatory authorities to identify those adults at-risk due to early signs of mild cognitive impairment or dementia. Dr. Matthew P. Janicki, of the University of Illinois at Chicago, the other co-chair, said that "generally there is little information on this issue and much needs to be done to make people more aware of it." He noted that the Group recommended an

intensified community education effort to enhance the capabilities of staff, clinicians, community providers, and administrators. Further, education is needed to raise awareness of dementia and how it affects adults with an intellectual disability among families and other caregivers.

The report notes that dementia has a devastating impact on all people – including people with an intellectual disability and their friends, families and the staff who may be involved with them as advocates and caregivers. The National Task Group wants its report to contribute to the work of the federal Advisory Council on Alzheimer's Research, Care, and Services. Plans are also in place to produce educational materials, develop guidelines for care, and hold training sessions across the country.

The report and its 'Action Plan' is available at these websites: aadmd.org/ntg/thinker and www.rtcadd.org

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