

# Caregiving and Intellectual and Developmental Disabilities and Dementia: Report of a Pre-Summit Workgroup

**Tamar Heller, Haleigh Scott, Matthew P. Janicki, and  
Pre-Summit Workgroup**

Organized by the National Task Group on Intellectual Disabilities and Dementia Practices (NTG), the Rehabilitation Research and Training Center on Developmental Disabilities and Health, and the Alzheimer's Association

Funded by the National Institute on Disability, Independent Living and Rehabilitation Research, Administration for Community Living,  
grant # 90RT5012-01-03, 90RT5032-01-00, and 90RT5007-02-02.



#DementiaCareSummit

## Purpose of Workgroup

- (1) Assess the current state of research, policy, and practice, and develop recommendations related to supports for older adults with intellectual and developmental disabilities (IDD)
- (2) Translate the contributions of these findings to the greater dementia care agenda
- (3) Promote inclusion of issues relevant to IDD and dementia for the Summit platform.

## Background: Similarities and Differences in Support Needs

- Different trajectories of dementia
  - Earlier age onset (particularly Down Syndrome in which 50-75% will have dementia after age 60)
  - Early signs difficult to diagnose
  - Some have shorter period of debilitation
- Require life-long supports and caregiving
  - Many live at home (estimate of 33,000 living with older caregivers) and twice as many in out-home settings
  - Greater role of siblings in assuming care
- Experience with group homes for dementia care

## Bridging the Two Service Networks

- *Toronto Declaration on Bridging Knowledge, Policy and Practice in Aging and Disability* (Bickenbach et al., 2012)
- Common issues of end of life care, abuse and neglect, residential supports, health declines, financial supports and assistive technology warrant inclusion of IDD in general studies
- NTG developed practice guidelines and national training curriculum drawing upon both fields
- Federal efforts can bridge (e.g., Administration on Community Living inclusion of IDD in dementia funding)

## Bridging Research in Aging and IDD

- Rich literature on career caregivers and family support models in aging and IDD
  - Provides opportunity to examine long-term impacts of caregiving and models of home based care
  - Examines impact of behavioral challenges on caregivers and optimal supports
  - IDD research also includes positive outcomes (e.g., family satisfaction, person-centered planning, consumer direction)
- Little cross-over in research
  - IDD family caregivers not included in generic research on dementia and families
  - Research across systems could inform family support practices, including financial support schemes.

## Recommendations

- 1) Integrate community education, outreach, research, and supports for caregivers of older adults and caregivers of adults with IDD and dementia to capitalize on the strengths of both programs and promote inclusion.
- 2) Increase research and community programming to support people with IDD and dementia in group homes.
- 3) Examine, acknowledge and respect the diversity of family values and caregiving practices.
- 4) Develop strategies for increasing early screening and public awareness of dementia and other aging related issues in people with IDD and their caregivers.
- 5) Conduct comparative effectiveness research to study different models integrating aging and IDD networks to provide quality continuous care.

For more information and access to the  
Report

**Caregiving and IDD and Dementia: Report  
of the Pre-Summit Workgroup on  
Caregiving and IDD**

theller@uic.edu

[www.aadmd.org/ntg](http://www.aadmd.org/ntg)

or

<http://rrtcadd.org/2017/08/11/caregiving-and-intellectual-and-developmental-disabilities-and-dementia-report-of-the-pre-summit-workgroup-on-caregiving-and-idd/>