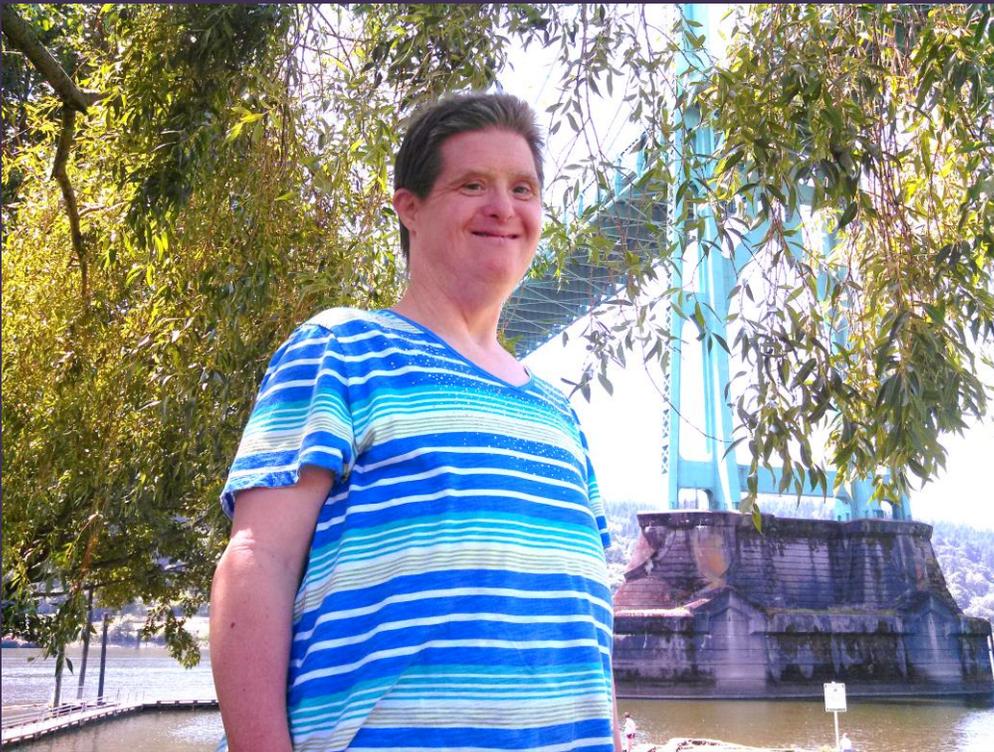


# Module 9 Companion Guide

## Discussion Questions & Resources

Supporting People with Intellectual Disabilities and Dementia



### ADRC Dementia Care Training

Aging Services and  
Supports for People  
Living with Dementia

*Last updated December 2015*

## **Module 9 Companion Guide: Discussion Questions & Resources**

This guide serves as a supplement to Module 9 of the ADRC dementia care training initiative. Module 9 builds on and enhances the information presented in the previous modules by focusing specifically on supporting people who have both intellectual disabilities and dementia. We encourage ADRC staff and partners to view modules 1-8 before viewing module 9.

Learning will be most effective if ADRC staff and partners watch this video together and then discuss the content. Discussion questions are provided in this guide to facilitate this process.

Links and resources related to dementia and intellectual disabilities are included as well. All of the resources described in the video are listed as are additional resource materials that may be helpful to ADRC staff, partners, and family members of people with developmental disabilities. Resources that are more technical or appropriate for ADRC staff are marked with an asterisk (\*).

Remember: the Alzheimer's Association's free 24/7 helpline is 1-800-272-3900 and Oregon's ADRC website section on Alzheimer's is [www.HelpforAlz.org](http://www.HelpforAlz.org)

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## Group Discussion Questions & Activities

### **Module 9: Supporting People with Intellectual Disabilities and Dementia**

1. People with intellectual disabilities who develop dementia have many similarities to and many differences from people in the general population who develop dementia.
  - a. Describe some of these similarities.
  - b. Describe some of the unique challenges that make them different from the general population.
  - c. How does your knowledge about person-centered care and dementia help you to work effectively with people with intellectual disabilities who develop dementia?
  - d. What specific knowledge and skills do service providers and other support persons need to provide optimal assistance to people with intellectual disabilities?

*Note: Think about life experiences, family and social context and a variety of personal and financial resources. Consider similarities and differences related to screening and diagnosis, family support, negotiating the service system (compare aging services with agencies serving those with developmental disabilities), health disparities and person-centered thinking.*

2. Bill West indicated that people with developmental and intellectual disabilities are underserved based on prevalence estimates and the number of people who are serviced through the DD system. In part, people with intellectual disabilities may be unknown in the service system because they have been supported by family members. As family members and the person with intellectual disabilities age, people may be entering the system for the first time. Talk with your colleagues about people with intellectual disabilities who have come into your system of care later in life.
  - a. How did these individuals and their families come to your agency's attention?
  - b. What were the presenting needs?
  - c. What else did you see?
  - d. Do you think you and your colleagues were prepared to provide person-centered support to these people?
  - e. After reviewing this video what, if anything, would you do differently now?

Talk with your colleagues about people with intellectual disabilities who remain unknown to the DD and aging services system.

- f. What kind of outreach services are needed to let families know that support services are available as family members age?
3. Think now about people who have been part of the DD system since they were young adults. Talk with colleagues who have worked with individuals supported both by DD who have used or would be candidates for aging services. How can knowledge about normal age-related changes and about aging services enhance support for individuals who have been served within the DD system?
    - a. What kind of relationships exist between these agencies in your community?
    - b. What has worked well and what have been challenges as these two different systems address the needs of a person with intellectual disabilities and dementia?
    - c. How can these relationships be developed and strengthened?
    - d. How can service providers share information with one another to improve continuity of care and meet individual needs?
  4. Gathering good baseline data early in life was emphasized throughout this module. How can options counselors or case managers compile this information to assist in planning long-term services and supports for people with intellectual disabilities who are showing symptoms of dementia?
    - a. How can DD and aging services providers gather information from aging family members to support understanding of who the person is and what is important to them?
    - b. How can DD and aging services providers gather historical information about a person with intellectual disabilities and dementia when family members are not available to provide this information?
    - c. How can DD and aging services providers support older family members who can no longer provide the level of support they and the person with the intellectual disability is accustomed to?

5. CJ Webb describes ways to adapt the environment to support people with intellectual disabilities who have dementia and other age-related changes.
  - a. Give examples of adaptations that can be made to the physical environment.
  - b. What are examples of adaptations that can be made to the social environment?
  
6. Jeanne represents a family member who is sandwiched between the needs of her sister with Down syndrome and her father. She has support through the DD system that provides a personal assistant to Ruth and the assisted living provide supports for housing and meals, among other supports. At the same time, Jeanne finds her role to be exhausting and overwhelming at times. She knows that the assisted living community where her sister lives now will not be an appropriate living situation long term.
  - a. How would you support Jeanne and Ruth to explore other options?
  - b. Consider first what is important for Ruth and what is important to Ruth as you help Jeanne to explore options?
  - c. How could you work with the provider to help assure that Ruth's dietary and social/emotional needs are met?

Link to Module 9 Feedback: <https://www.surveymonkey.com/r/BPKMS97>  
(please encourage each participant to complete this)

## Resources

### **National Task Group (NTG) on Intellectual Disabilities and Dementia Practices**

The NTG is a partnership of individuals and organizations working to support adults with intellectual and developmental disabilities who are affected by dementia. The coalition has produced a number of products including practice guidelines, screening tools, informational materials, and education curriculum. A selection of these resources are highlighted below, and the complete list can be found here: <http://aadmd.org/ntg/products>.

- The NTG-Early Detection Screen for Dementia (NTG-EDSD)  
<http://aadmd.org/sites/default/files/NTG-EDSD-Final.pdf>

“The NTG-Early Detection Screen for Dementia, adapted from the DSQIID\*, can be used for the early detection screening of those adults with an intellectual disability who are suspected of or may be showing early signs of mild cognitive impairment or dementia. The NTG-EDSD is not an assessment or diagnostic instrument, but an administrative screen that can be used by staff and family caregivers to note functional decline and health problems and record information useful for further assessment, as well as to serve as part of the mandatory cognitive assessment review that is part of the Affordable Care Act’s annual wellness visit for Medicare recipients. This instrument complies with Action 2.B of the US National Plan to Address Alzheimer’s Disease.

It is recommended that this instrument be used on an annual or as indicated basis with adults with Down syndrome beginning with age 40, and with other at-risk persons with intellectual or developmental disabilities when suspected of experiencing cognitive change. The form can be completed by anyone who is familiar with the adult (that is, has known him or her for over six months), such as a family member, agency support worker, or a behavioral or health specialist using information derived by observation or from the adult’s personal record.” (Note: this description can be found on the tool.)

- *Guidelines for Dementia-related Health Advocacy for Adults with Intellectual Disabilities and Dementia of the National Task Group on Intellectual Disabilities and Dementia Practices*  
<http://aadmd.org/sites/default/files/Bishop-document-web.pdf>
- *‘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*  
[http://aadmd.org/sites/default/files/NTG\\_Thinker\\_Report.pdf](http://aadmd.org/sites/default/files/NTG_Thinker_Report.pdf)

## National, state, and other resources

- Administration for Community Living [http://www.acl.gov/IDD and Dementia Report \(2015\)](http://www.acl.gov/IDD%20and%20Dementia%20Report%20(2015).pdf)  
[http://www.aoa.acl.gov/AoA Programs/HPW/Alz Grants/docs/IDD-and-Dementia.pdf](http://www.aoa.acl.gov/AoA_Programs/HPW/Alz_Grants/docs/IDD-and-Dementia.pdf)
- American Association on Intellectual and Developmental Disabilities – *People Planning Ahead: Communicating Healthcare and End-of-Life Wishes* (2009)  
<http://aaidd.org/publications/bookstore-home/product-listing/2013/06/24/people-planning-ahead-communicating-healthcare-and-end-of-life-wishes#.Via9uX6rS70>
- Alzheimer’s Disease International – *Dementia and intellectual disabilities*  
<http://www.alz.co.uk/adi/pdf/intellectualdisabilities.pdf>
- National Down Syndrome Society – *Aging and Down Syndrome: A Health & Well-Being Guide*  
<http://www.ndss.org/Global/Aging%20and%20Down%20Syndrome.pdf>
- Online discussion group for persons interested in issues related to dementia among persons with intellectual disabilities  
<https://groups.yahoo.com/neo/groups/Dementia-IDlistserv/info>

## Videos and media from YouTube and other sources

- [Extended Interviews from Bill, Jeannie, and CJ – TBD]
- “Dementia and People With Intellectual Disabilities” (Length – 23:37)  
<https://youtu.be/wrKLURsAy6Y>
- “Down Syndrome and Dementia” (Length – 4:56)  
[https://youtu.be/Clbg\\_j2o7tk](https://youtu.be/Clbg_j2o7tk)
- “When People with Developmental Disabilities Age” (Length – 18:18)  
<https://youtu.be/MEtkml2xEG8>

## Peer-reviewed publications\*

Jokinen, N., Janicki, M. P., Keller, S. M., McCallion, P., Force, L. T. and National Task Group on Intellectual Disabilities and Dementia Practices (2013), Guidelines for Structuring Community Care and Supports for People With Intellectual Disabilities Affected by Dementia. *Journal of Policy and Practice in Intellectual Disabilities*, 10: 1–24. doi: 10.1111/jppi.12016