ADRC Dementia Care Training

Module 9:
Supporting People with Intellectual Disabilities and Dementia

ADRC
Aging and Disability Resource Connection of OREGON

Dementia defined

It is a **set of symptoms** that may be caused by many different diseases or conditions.

Dementia effects:

- Memory
- Judgment
- Thinking
- Ability to do self-care
- Reasoning
- Problem-solving
- Mood and/or personality

Intellectual disabilities (ID) defined

- Limitations in
  - Intellectual functioning
  - Adaptive behavior (daily living skills)
- Originates before age 18
- A type of developmental disability

Intellectual Disabilities (ID) definition

Significantly subaverage general intellectual functioning defined as full scale intelligence quotient's (IQ) 70 and under as measured by a qualified professional and existing concurrently with significant impairment adaptive behavior directly related to an intellectual disability as described in OAR 411:320-0080 that is manifested during the developmental period prior to 18 years of age.

Intellectual Disabilities (ID) definition

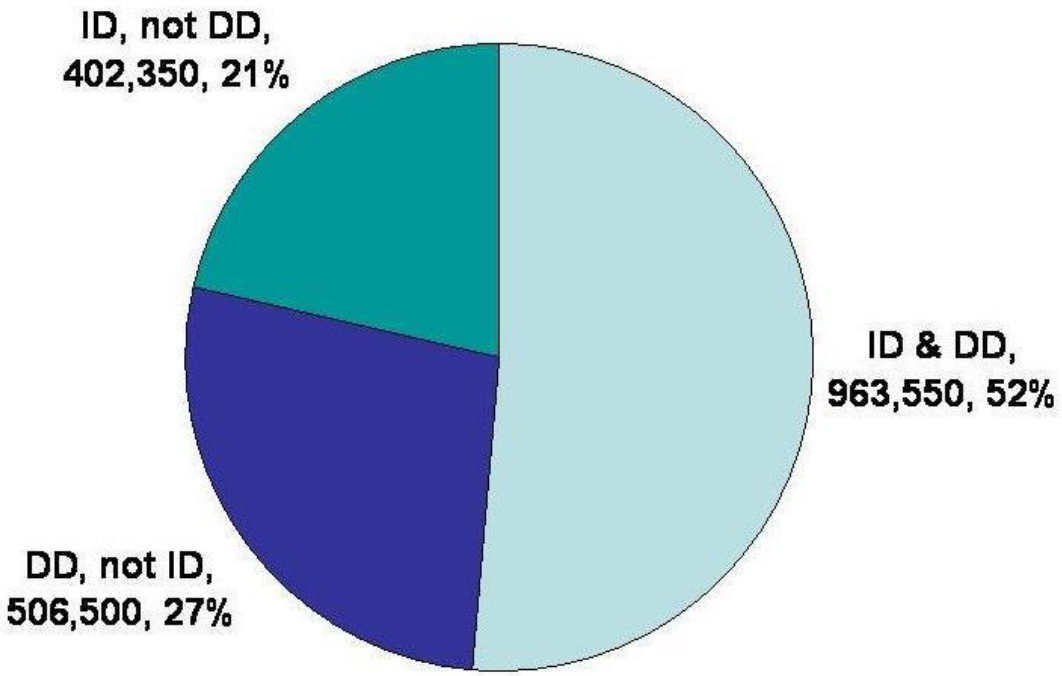
Individuals with full scale IQ's 71-75 may be considered to have an intellectual disability if there is also significant impairment in adaptive behavior as diagnosed and measured by a licensed clinical or school psychologist as described in OAR 411-320-0080. [OAR 411-320-0020(59)]

(Smallwood, 2015)

Developmental Disability

- A severe mental or physical impairment or combination of mental and physical impairments
- Begins in and directly affects the brain
- Begins prior to 22 years of age (18 years of age for an ID)
- Has continued, or is expected to continue, indefinitely
- Causes significant impairment of daily living skills (e.g., adaptive behavior – communicating, grooming, dressing, safety and social skills).
- Examples: Autism, cerebral palsy, epilepsy, traumatic brain injury, or other neurological disabling conditions.

Figure 1. Adults (18+ years) with Intellectual Disability (ID) and/or Developmental Disability (DD)



US DHHS, ASPE Office of Disability, Aging & Long Term Care Policy (2006)

Down syndrome – A type of ID

- The most frequently occurring chromosomal disorder
- The leading cause of intellectual and developmental delay in the U.S. and in the world.
- Occurs 1 in 671 live births

(Global Down Syndrome Foundation)

Down syndrome

- Life span is 60 years
- Population is unknown (estimates over 400,000)
- Wide variety of intellectual abilities
- Predisposed to certain medical conditions. Examples:
  - Congenital heart defects
  - Celiac disease
  - Sleep apnea
  - Alzheimer's disease

(Global Down Syndrome Foundation)

Image via Shutterstock, Copyright Marcel Jancovic

Prevalence of ID and dementia

- 650,000 over age 60 have ID (2015)
- 1,300,000 projected by 2030

- 8% affected by Alzheimer's disease and other dementias
  - 52,000 in 2015
  - 104,000 in 2030

(Bishop et al, 2015)

Down Syndrome and dementia

- Prevalence of dementia higher
- Not all will develop Alzheimer's disease

(Zigman, 2013; NDSS)

Why focus on people with ID?

- Underserved population

(Chicoine et al., 1999)

Why focus on people with ID?

- Underserved population
- Unique challenges
  - Symptoms of dementia may be missed
  - Assumptions of dementia – other causes may be missed

(Chicoine et al., 1999)

Why focus on people with ID?

- Parent caregiver support needs
  - 85% of people with ID live with families
  - Primary social network for people with ID

(Seltzer et al, 2000)

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(Seltzer et al, 2000)

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Why focus on people with ID?

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  - Primary social network for people with ID
  - Life long family care
  - Aging parents - unique challenges
  - Most have not made plans

(Seltzer et al, 2000)

Why focus on people with ID?

- Sibling caregiver support needs
  - Most families have a sibling who is involved
  - Sisters more likely than brothers
  - Families with involved siblings are more emotionally cohesively
  - About 25% of people with ID live with sibling after the death of their parents

Person-centered support

Person first!

- Person-centered thinking

Bill West

Arc of Multnomah County

Person first!

- Person-centered thinking
- Person-centered planning
- Person-centered care
- Patient-focused, family-centered

Jeannie

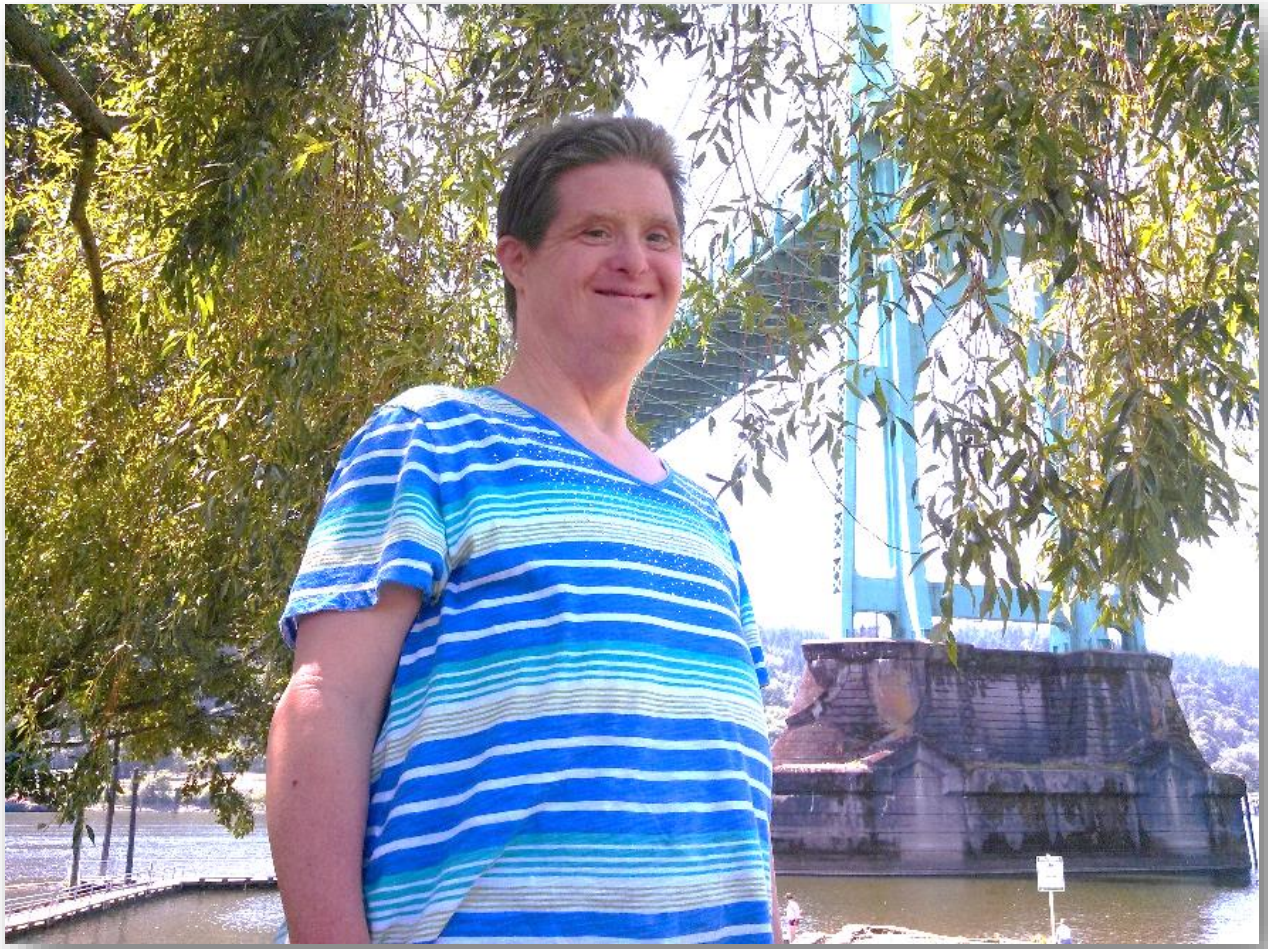
Family caregiver for sister, Ruth

Person-centered care

Early signs of dementia

- Behavior changes often subtle
- Down syndrome
  - Younger age onset
  - Rapid progression
  - Accelerated aging

Ruth



Early signs of dementia

- Common behavior changes
  - Getting lost, misdirected
  - Confusion in familiar situations
  - Memory problems
  - Difficulty with gait and balance
  - Late onset seizures
  - Changes in personality

Is it dementia?

- Symptoms that can be indicators of physical or psychological conditions.

Indicators of physical or psychological conditions

- Loss of adaptive skills
- Disruption of sleep cycle
- Appetite changes
- Apathy
- Moodiness
- Irritation
- Aggression
- Psychomotor agitation or retardation
- Memory loss
- Psychotic features

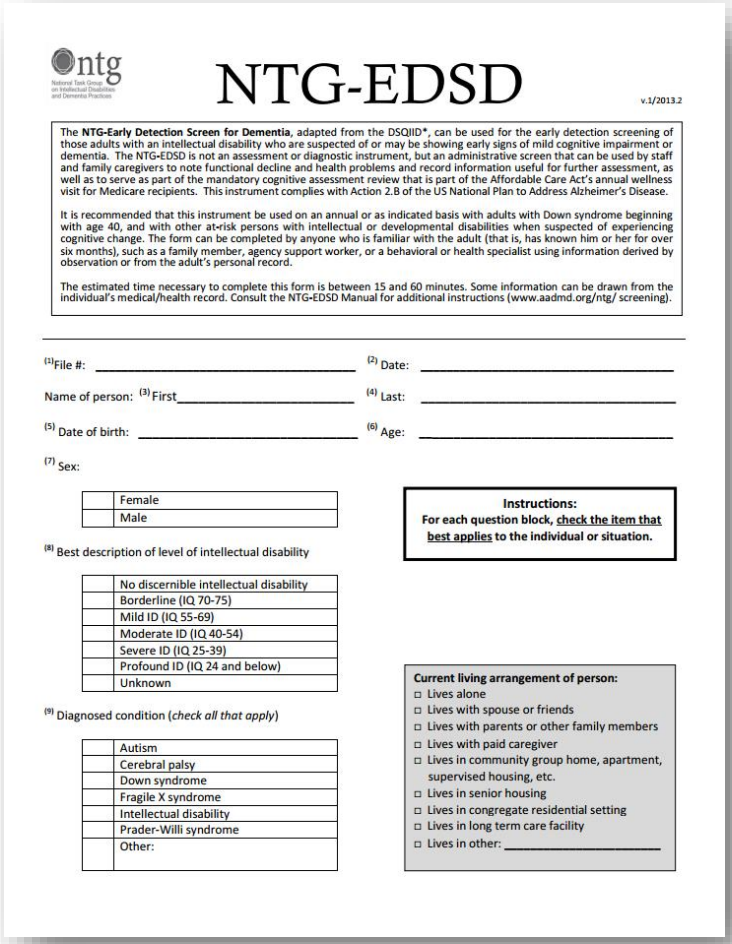
(Chicoine et al., 1999)

Conditions often missed

- Cardiovascular disease
- Seizures
- Hypothyroidism
- Hearing impairment
- Infections
- Medication side effects
- Sleep apnea
- Anemia

(Bishop et al., 2015)

National Task Group on Intellectual Disabilities and Dementia Practices



ntg

NTG-EDSD

v.1/2013.2

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.

The estimated time necessary to complete this form is between 15 and 60 minutes. Some information can be drawn from the individual's medical/health record. Consult the NTG-EDSD Manual for additional instructions (www.aadmd.org/ntg/ screening).

(1) File #: _____ (2) Date: _____

Name of person: (3) First_____ (4) Last: _____

(5) Date of birth: _____ (6) Age: _____

(7) Sex:

	Female
	Male

Instructions:
For each question block, check the item that best applies to the individual or situation.

(8) Best description of level of intellectual disability

	No discernible intellectual disability
	Borderline (IQ 70-75)
	Mild ID (IQ 55-69)
	Moderate ID (IQ 40-54)
	Severe ID (IQ 25-39)
	Profound ID (IQ 24 and below)
	Unknown

(9) Diagnosed condition (*check all that apply*)

	Autism
	Cerebral palsy
	Down syndrome
	Fragile X syndrome
	Intellectual disability
	Prader-Willi syndrome
	Other:

Current living arrangement of person:
- ☐ Lives alone
- ☐ Lives with spouse or friends
- ☐ Lives with parents or other family members
- ☐ Lives with paid caregiver
- ☐ Lives in community group home, apartment, supervised housing, etc.
- ☐ Lives in senior housing
- ☐ Lives in congregate residential setting
- ☐ Lives in long term care facility
- ☐ Lives in other: _____

- NTG early detection screen:
  - Completed by family member or caregiver
  - Used annually (beginning by age 40 for people with Down syndrome)

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NTG Early Detection Screen for Dementia

- Comparisons to the previous year:
  - Physical health
  - Mental health
  - ADLs
  - Language and communication
  - Sleep-wake change
  - Ambulation
  - Memory
  - Behavior and affect
  - Self-reported problems and problems noted by others

(Bishop et al., 2015)

NTG Early Detection Screen for Dementia

- Conditions that are present:
  - Sensory impairment
  - Significant recent life events
  - Chronic conditions, illnesses
- Medications and purpose:
  - For example – for chronic conditions, mental health or behavioral expressions, pain

(Bishop et al., 2015)

CJ Webb

Oregon Technical Assistance Corporation

Patient-focused, family-centered care

- Involving the individual and family in decision making
- Providing emotional support and freedom from physical discomfort
- Placing the focus on the individual
- Ensuring continuity and coordination of care
- Communication!

(Kirkendall, et al., 2012)

Diagnosing dementia

Diagnosis of exclusion

- Medical history
- Physical exam
- Blood work (e.g., thyroid function, vitamin B12, folic acid, CBC, chemistry profile)

Multidisciplinary teams

Ongoing relationships

Issues specific to Down syndrome

- Common medical issues
  - Sensory loss (vision and hearing)
  - Hypothyroidism
  - Obstructive sleep apnea
  - Osteoarthritis
  - Atlantoaxial instability and cervical spine concerns
  - Osteoporosis
  - Celiac disease

(National down syndrome society, 2013)

Person-Environment Fit

Abilities

Environmental Demands

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Person-environment fit

Abilities

- Adaptability
- Physical
- Sensory
- Cognitive

Environmental Demands

- Structure
- Tasks/activities
- Stimulation (noise, people)
- Illumination
- Accessible space

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Person-environment fit

Changing the focus of support

- Maintaining abilities
- Simplify routines
- Increase support

Changing the focus of support

Person-environment fit

Strengths/Abilities

- Physically active
- Social interaction
- Organizing things
- Helping people

Limitations/needs

- Hearing
- Celiac disease
- Easily bored

Optimal Environmental Demands

- Structure
- People
- Controlled access to food
- Meaningful activity

Adapting support

Balancing environmental demands

- Reduce sensory stimuli
  - Reduce noise levels
  - Serve one dish at a time

(Jokinen et al., 2013).

Balancing environmental demands

Balancing environmental demands

- Adapt the physical environment
  - Improve lighting
  - Focus on safety (e.g., grab bars, eliminate throw rugs)
  - Assist with way finding, visual cues
  - Access to safe outdoor space

(Jokinen et al., 2013).

Progression of the disease

- Maintain routines
- Support pleasurable activities

Family caregiver issues and needs

- Information
- Services
- Support from others
- Encouragement
- Respite

Family caregiver issues and needs

- Life-long caregiving
- May be unknown to the service system
- The caregiver is aging

Family caregiver issues and needs

- Sibling caregivers

Family caregiver needs

- Information
- Training
- Guidance
- Emotional support

Family caregiver needs

Supporting family caregivers

Progression of the disease

- Advance planning
- End-of-life planning

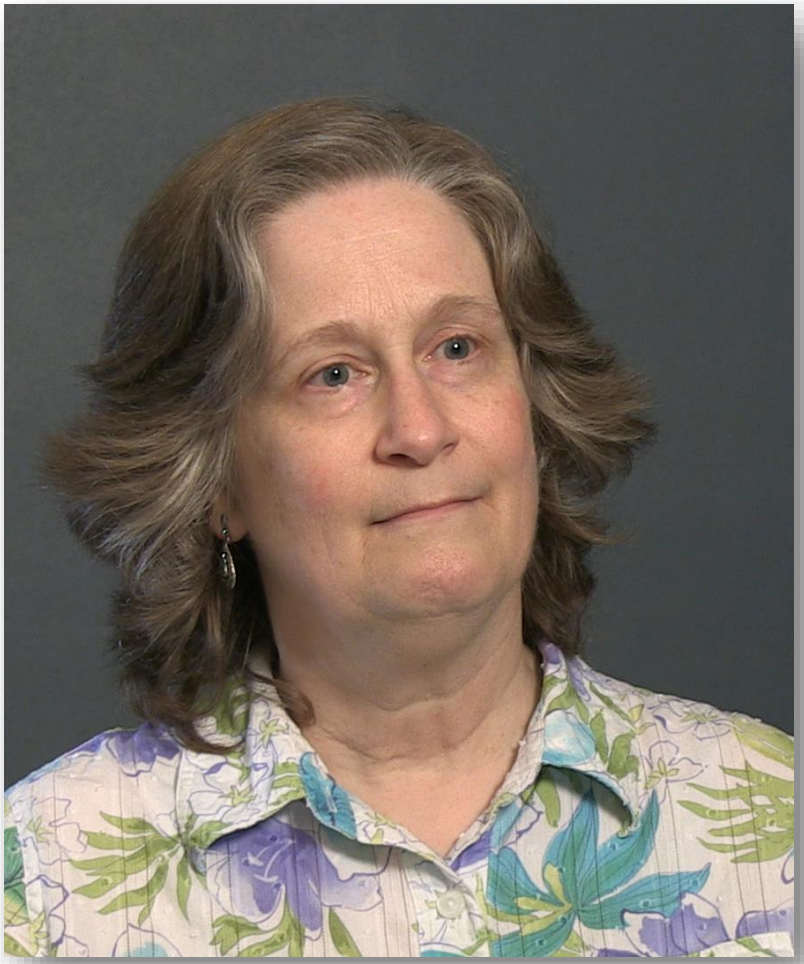
Advance planning

End-of-life care

- Person-centered care
- Optimize quality of life
- Anticipate, prevent, and treat suffering from any cause
- Coordinate support – team collaboration: family, caregivers, health care providers.

(Hogan, 2015 webinar)

End-of-life care



Supporting family caregivers

What the ADRC can do

- Become familiar with resources
- Add resources to ADRC data base
- Collaborate with other agencies to bridge service gaps
- Identify practitioners with specialized knowledge

What DD services can do

- Become familiar with resources
- Add resources to ADRC data base
- Partner with CILs, aging services, Alzheimer's Association, ARCs, and other organizations
- Identify practitioners with specialized knowledge

Resources

- National Task Group
- Administration for Community Living

Feedback Survey

Please give us your feedback on this training module

https://www.surveymonkey.com/r/BPKMS97

This training was developed by Portland State University on behalf of Oregon Department of Human Services – Aging & People with Disabilities. Funding for this project was provided by an Administration for Community Living grant (#90DS2001) and funding provided by the Oregon Legislature for mental health training.

Thank you for your participation!