

Aging & Developmental Disabilities

No One Left Behind

Janet L. Miller, M.S.
Dementia Awareness Outreach Specialist



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Presentation Objectives:

- To provide information about unique experiences.
- To illustrate how a lack of understanding can lead to barriers in availability of resources.
- To provide recommendations on best practices.
- To consider what might be best practices for future generations.



Definition of Developmental Disability

People with developmental disabilities have severe chronic disabilities that can be cognitive, physical, or a combination of both.

These disabilities appear before the age of 22 and are likely life-long conditions.

The term “developmental disability” is used to encompass intellectual disabilities as well as physical disabilities.







WHAT IS UNIQUE?



A Unique Population

- Persons with developmental disabilities are living longer and more meaningful lives, due in part to advances in medical science.
- The number of U.S. adults with developmental disabilities age 60 and older is projected to nearly double from 644,860 in 2000 to 1.2 million by 2030.
- Older adults with developmental disabilities can present clinicians with unique challenges related to appropriate assessment and treatment.



What are the Unique Experiences with Aging for this Population?

Most individuals with developmental disabilities are not able to live alone without some types of support:

Residential:

- An aging parent or sibling;
- Community-based group homes, in-home supports or in institutions.

Receiving Support Needs:

- In-home support services provided by direct support agencies;
- May be on long waiting lists to receive support services;
- May have never been in services provided by agencies;
- May experience difficulties if they have crisis placement due to death or illness of parent or sibling.



Unique Experiences Continued...

Socialization and Recreation

Programs and services for adults with developmental disabilities are frequently in segregated settings.

- Day programs and sheltered workshops;
- Group homes of two or more individuals all with disabilities;
- Specialized recreation programs like Special Olympics.



Unique Experiences Continued...

Privacy, Dignity, and Choice

Historically

- None of these were offered to persons residing in institutions across the United States and around the world

<https://www.youtube.com/watch?v=aWzaJdHh99g>

- 1950's – Some families who chose not to send their family members to institutions gathered in Omaha to open the Opportunities Center, a day program for persons with developmental disabilities.
- Principles of Normalization was brought to the U.S. by Wolf Wolfensberger in the early 70's. Prompted the development of services offered within the community.



Historical Perspective Continued...

- Public education not offered

Special education programs in the United States were made mandatory in 1975 when the United States Congress passed the Education for All Handicapped Children Act (EAHCA)

Public Law 94-142

- Most older individuals with developmental disabilities were never offered public education.

Present day

- Many improvements have been made
- More choice, but often limited options



SO WHAT IS THE IMPACT?



Aging services and supports for persons with developmental disabilities are available but not always utilized due in part to limited understanding of family and staff to address their unique needs.



Impact on this Population

- Services for persons with developmental disabilities have focused on the needs of younger adults.
- Limited research is available on the present needs of the older population.
- There are minimal services for persons with developmental disabilities at normal retirement age.
- Present assessments for dementia are often impractical for persons with developmental disabilities.



Impact on this Population

Inadequate Resources for Programs and Supports

- Local, state and federal funds
- Direct-support staff

http://dhhs.ne.gov/developmental_disabilities/Documents/DServices4thPriority.pdf

Monetary Resources for Individuals

Example:

- Income from SSI and SSDI = \$770.00
- Board and Room costs = \$698.00
- Remainder for month = \$ 72.00

Individuals receiving Supplemental Security Income can have no more than \$2,000 in assets.



Impact on this Population

Personal Experience

- 2013 face-to-face survey of five direct-support agencies found none had departments addressing needs of aging clients, and no training was offered in aging issues.
- Most nursing homes are not prepared to work effectively with individuals who have developmental disabilities.
- Individuals receiving Medicaid experience difficulties in accessing some health care providers due to low reimbursements and already met case loads.



Healthcare Disparities for Adults with Developmental Disabilities(DD)

No required training on DD in medical schools

No required training on aging unless you are going into the field of geriatrics

No medical textbooks on aging and Developmental Disabilities

Little available research

Few practitioners with expertise

Few patients in health care providers caseload with DD diagnosis



Families and Direct Support Staff Have Limited Knowledge of:

- the potential health conditions that may come with aging;
- the critical need for healthy diets and exercise;
- behaviors that may be indications of something more severe;
- training or aging support that may be available in their communities.



Adults with developmental disabilities may encounter

- Limited opportunities to engage in physical exercise.
- Limited understanding of healthy eating.
- Limited stimulating environments in day services.



Healthy Aging Challenges

Medical history is often incomplete or unknown.

1. Staff turnover
2. Family not available for information, historical documentation unavailable
3. Providers not understanding baseline functioning
4. Healthcare provider turnover.



Health Conditions to Consider

- Higher risk of having chronic health conditions and chronic pain at earlier ages.
- Many have pre-existing conditions such as neurological, functional, and physical impairments and demonstrate signs of aging in their 40's and 50's.



Other Considerations

- Approximately 30-60% of older adults with moderate to severe I/DD have a mental disorder” and many health providers lack knowledge in differentiating between preexisting behaviors, depression and dementia. (Wolfson et al 2013)
- The World Health Organization in a 2013 report stated that those **most vulnerable in deficiencies in healthcare services are those that experience disabilities.**



Dementia Prevalence: Developmental Disability vs. Down Syndrome

Developmental Disability

Age	Percentage
40+	3%
60+	6%
80+	12%

Down Syndrome

Age	Percentage
40+	22%
60+	56%

Matthew P. Janicki and Arthur J. Dalton (2000) Prevalence of Dementia and Impact on Intellectual Disability Services. *Mental Retardation*: June 2000, Vol. 38, No. 3, pp. 276-288.



Changes Noted



September 2016



November 2018



Recommendations

Strive to offer adequate assessments and intervention.

1. Document base-line functions (mid to late 20's).
2. Compare changes over time (at least annually).
3. Rule out all possible medical causes for changes in behaviors and don't rely on adding more medications.
4. Monitor use of prescription and over-the-counter medications.



Recommendations

- There is an urgent need for aging adults with developmental disabilities and their families to have access to quality supports that address their age-related health and social changes.
- As people age and require more supports for their activities of daily living, work or recreation they may require modifications to their homes and communities that allow them to remain in their current settings



National Task Group

The 'NTG' is a coalition charged with ensuring that the interests of adults with intellectual and developmental disabilities who are affected by Alzheimer's disease and related dementias – as well as their families and friends – are taken into account as part of the [National Plan to Address Alzheimer's Disease](#).

“My Thinker’s Not Working”

- 42-page summative report
- In response to the Alzheimer's National Plan
- 20 recommendations for the improvement of services nationally for persons with developmental disabilities

<https://aadmd.org/ntg/thinker>



NOW WHAT?

- Greater understanding of the community about persons with disabilities
- Inclusive education in the public schools
- Competitive employment opportunities
- Alternatives to group home living (supported apartments, family support homes)
- Services and supports are to be person-centered
- Self Advocacy groups such as People First of Nebraska

<https://www.peoplefirstnebraska.com/>



Best Practices

- Train family members, staff and the medical community on the needs of individuals with disabilities over their lifespan.
- Work to involve aging individuals with disabilities in their own aging and healthcare;
- Work with local advocacy organizations to develop health promotion policy / program specific to this population;
- Seek to expand the current research base to gain additional knowledge;
- Ensure that adequate data is collected on the number of persons with disabilities in the community and the numbers of individuals with disabilities dying from dementias.



National Task Group

- Offers a training curriculum on dementia capable care of adults with developmental disabilities and dementia which is evidence-based and includes information from the best of the research currently available.

Training will be offered in:

Norfolk, Nebraska April 24, 25 and 26, 2019

North Platte, Nebraska April 29, 30 and May 1, 2019

Contact Janet Miller, janet.miller@unmc.edu for details.




Screening Tools

Adapted from:

- Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (Deb et al., 2007), and
- Dementia Screening Tool (adapted by Philadelphia Coordinated Health Care Group from the DSQIID, 2010)

www.aadmd.org/ntg/screening

 **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 2.8 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

(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: _____

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

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: _____



Aging Coalition

In February, 2019 a Developmental Disabilities Aging Coalition was formed.

Group is made up of professionals from Psychiatry, Neurology, Nursing/Long Term Care, Gerontology, Education, the Aged and Disabled Resource Center, internal medicine, Physical therapy and the Alzheimer's Association.

Topics discussed as projects needed:

- Education on aging and developmental disabilities to medical and nursing students
- Education and support materials to current physicians
- Telehealth and other types of media training
- Dementia capable housing
- Annual dementia screenings at earlier ages
- Training in aging for all direct support provider agencies
- Flexibility in reimbursements for developmental disabilities services based on rapidly changing needs.



Presentation by Seth Keller MD

Thursday, April 11, 2019

6:30 to 8:30 pm

UNO Community Engagement Center

*Aging in Adults with Intellectual
And Developmental Disabilities:
Concerns and Hope*

<https://dsamidlandsorg.presencehost.net/events/event/2019/04/11/dses-dr-seth-keller-aging-in-adults-with-intellectual-and-developmental-disabilities-concerns-and-hope/232943>



THEN WHAT?



The Future

- Funding issues
- Community involvement
- Integrated education and activities
- Advancements in research
- Technological advances could increase levels of independence



In Memory of My Daughter, Jennifer Miller

February 10, 1977
to
November 26, 2018

Cause of Death:
Alzheimer's Disease



Resources

American Academy of Developmental Disabilities and Dentistry –

www.aadmd.org

National Task Group - www.aadmd.org/ntg

Association on Aging with Developmental Disabilities – www.agingwithdd.org

National Down Syndrome Society – www.ndss.org

National Down Syndrome Congress – www.ndscenter.org

The Arc: for persons with I/DD – www.thearc.org

Tamar Heller, PhD, Institute for Health Research and Policy -

<https://www.ihrp.uic.edu/researcher/tamar-heller-phd>

Adults with Intellectual and Developmental Disabilities: A Unique Population by Carolyn C. Tinglin, MSc, RN in Today's Geriatric Medicine, Vol 6 No. 3 P.22

Guidelines for Structuring Community Care and Supports for People with Intellectual Disabilities Affected by Dementia – Journal of Policy and Practice in Intellectual Disabilities, Vol. 10 Number 1 pp 1-24, March 2013

Growing Old with A Developmental Disability – 2012 presentation by Drs. A.M. Lane and S. Hirst

What conditions or disorders are commonly associated with Down syndrome?

<https://www.nichd.nih.gov/health/topics/down/conditioninfo/associated>





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