

Aging, Dementia, and I/DD: What You Can Do to Make a Positive Difference

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Training objectives

- ▶ Participants will be able to discuss characteristics and information on aging, dementia, and intellectual/developmental disabilities (IDD).
- ▶ Participants will be able to discuss the importance of health care advocacy for adults with IDD including screening, working with the health care providers, systems challenges, daily health advocacy, and support.
- ▶ Participants will be able to discuss and implement practices of quality caregiving and supports for older adults with IDD including health care advocacy.



What we will discuss today

- ▶ Overview of aging, dementia, and IDD
 - ▶ Overview of challenges and systems issues
 - ▶ Definition and discussion of systems issues related to dementia capable care and IDD
 - ▶ Suggestions of where do we go from here
- 



What is aging?

- ▶ Active process that occurs over an individual's lifespan
 - ▶ Generally considered progressive changes in the physiology of the body and mental processes – begins with birth and continues until death
 - ▶ Interaction of factors of aging with pre-existing conditions
 - ▶ Genetics
 - ▶ Lifestyle – Diet, exercise, smoking, support networks including family and friends
 - ▶ Environment – social and physical
 - ▶ Attitude
 - ▶ Unique to each individual within patterns of aging
- ▶ Gains and losses



Aging Across the Lifespan

- ▶ Similar patterns for all adults regardless of pre-existing disability.
 - ▶ Each adult ages uniquely within patterns of aging.
 - ▶ Personalities do not change, each adult becomes more of who she or he has been absent disease process.
- ▶ Factors of genetics, lifestyle, environment, and attitude influence health and well-being old age.
 - ▶ Risk factors for age related and associated diseases and conditions based on combination of factors across the lifespan.
- ▶ All adults need proper nutrition, hydration, and exercise across the lifespan.
 - ▶ As adults age there is a continued need for exercise and attention to stamina – generally involving periods of low activity interspersed with periods of high activity.



Introduction: Why a lifespan approach?

- ▶ We become more of who we are as we age.
- ▶ All of our diseases, experiences, pre-existing conditions come together to make a difference in aging.
- ▶ Regardless of the pre-existing conditions, people with disabilities can age successfully.
- ▶ Risk factors in aging can be minimized through preventive activities across the lifespan.



Personalities, Behavior, and Aging

- ▶ We become more ourselves as we age
- ▶ The older we are the more unique we are as a combination of factors of aging and our life experiences
- ▶ Personalities and behavior (how we exhibit our personalities) do not change substantially over a lifetime.
- ▶ Significant changes in personality and/or behavior usually indicate disease, side effects of medications, poor environmental fit, or mental health concerns.



Myths and Stereotypes about Aging and IDD

- ▶ Lifetime accumulation of assumptions of lack of competency with double jeopardy
- ▶ Higher risk for mental illness which also increases the myths about aging with IDD
- ▶ Automatic assumption of dementia as normal aging for adults with IDD
- ▶ Assumption when functioning and cognitive decline occurs it is normal aging and not disease process



Challenges to healthy aging in adults with IDD

- ▶ Lack of knowledge of medical history
 - ▶ Staff turnover
 - ▶ Family not available for information, historical documentation not kept or lost,
 - ▶ Health care provider turn over
- ▶ Lack of systems for advocacy in agencies and families
 - ▶ Information provided for the appointment



Health Care Disparities & IDD

- ▶ Lack of knowledge & research about aging in adults with IDD
- ▶ Lack of training & expertise for health care providers on IDD, even less known about aging
- ▶ Aging for everyone still one of the stereotypes and prejudice allowed to be voiced (watch late night talk shows for example)
- ▶ In a society in which material wealth is highly valued especially for quality of life in later years adults with IDD more likely to be in poverty, existing on minimal income, and less family supports



Down syndrome and other specific IDD & Aging

Higher risk but not automatic decline and disease process in adults with Down syndrome!!!



What is Down syndrome?

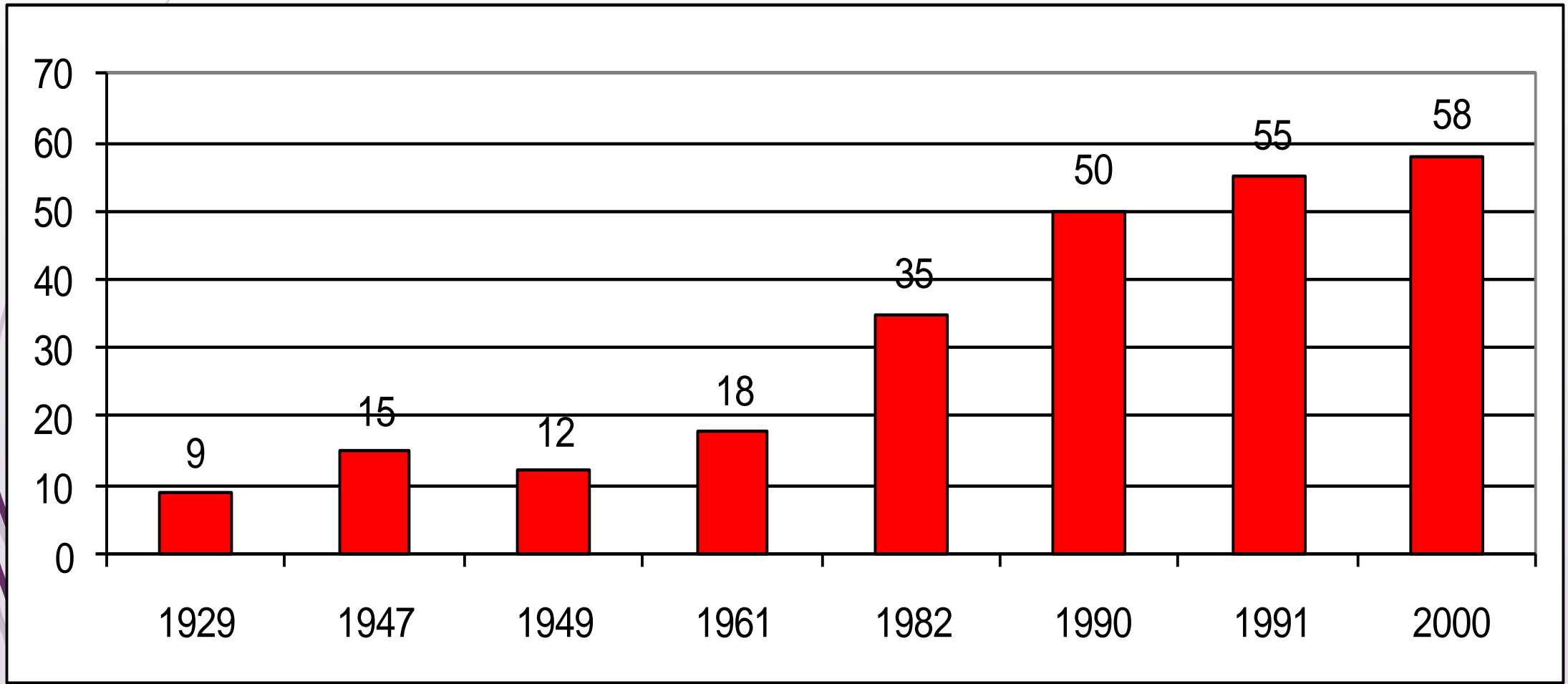
- One of the developmental disabilities, usually associated with Intellectual Disability (ID)
- 1 in 750 live births, genetic, older parent correlation,
- Trisomy 21 (Chromosomal defect)
 - All cells of the body (95%)
 - Some of the chromosomes in all cells (2 – 3%)
 - All chromosomes in some cells of body, mosaicism, (2 – 3%)



Down syndrome & Aging

- ▶ Longevity is shorter than the general population
- ▶ Earlier aging into risks for diseases and conditions
 - ▶ Hearing & vision loss
 - ▶ Congenital heart disease
 - ▶ Adverse Effects of medications
- ▶ Early changes may result in:
 - ▶ Behavioral changes including intensity of behaviors as compared to their previous behaviors
 - ▶ Loss in function or cognitive capacity
 - ▶ Assumption of Alzheimer's dementia

Down syndrome & Life Expectancy





Known risk factors for adults with Down syndrome

Down Syndrome

- Congenital heart disease
- Earlier onset for risk factors than the general population
 - Higher risk for Alzheimer's disease
- Aging into Adverse side effects of Medications
- Hearing impairment at birth, increased with age
- Adult onset Leukemia
- Secondary condition of Autism, autistic tendencies



Cerebral Palsy and Aging

Cerebral Palsy (CP)

- Eating and swallowing disorder affecting nutritional intake
- Scoliosis
- Tuberosus sclerosis
- Adverse Effects of Medications
- Arthritis/Osteoporosis
- Significant pain over the lifetime
- Respiratory



Potential Risk factors for persons with Autism:

- Genetics- Possible pre-dispositions for disease/neurological impairments.
- Lifestyle- Difficulty with adjusting to change and loss of routine. Difficulty with developing social networks necessary for healthy aging.
- Attitude- Inability to deal with life stressors including sensory overload and demands.
- Environment- Inability to adjust to variety and environmental changes sometimes necessary in aging.



Disability specific risk factors to rule out

- ▶ Autism
 - ▶ Sensory overload
 - ▶ Pain
 - ▶ Anxiety/depression
- ▶ Epilepsy
 - ▶ Osteoporosis
 - ▶ Arthritis
 - ▶ Seizures



Overview of dementia and IDD




What is Dementia?

➤ Dementia

- Loss of cognitive functions (such as memory, thinking and reasoning) severe enough to interfere with daily functioning
- Dementia is not in itself a disease, but is used to describe symptoms associated with certain diseases or conditions
- Dementia is NOT associated with normal aging
- Adults with IDD experience diagnosis of various dementias at the same rate as the general population



Alzheimer's disease

- ▶ The most common form of dementia related to older age
 - ▶ A progressive regressive disease with cognitive and functioning loss over time
 - ▶ Last skills lost first, going back in time with capacity to function
 - ▶ Inability to learn new skills, take in new challenges, make choices,
 - ▶ Often results in difficulty making decisions and good judgement
- 



Down syndrome and Alzheimer's disease

- ▶ Close to 100% of adults with Down syndrome exhibit the plaques and neurofibrillary entanglements upon autopsy
- ▶ However, longitudinal studies indicate that approximately 60% exhibit the cognitive or functioning loss or behavioral changes that are symptoms of the disease
- ▶ Major system issue as health care providers, advocates, and families do not understand this, automatic assumption of AD
- ▶ Many age related and associated conditions/diseases same symptoms as AD



The affect of AD

- ▶ Sensory challenges that often result in –
 - ▶ Being lost in space and time, not knowing where you are or what is expected of you
- ▶ Meaning deaf
- ▶ Meaning blind
- ▶ A slow loss of skills, memory, language, and cognitive functioning
- ▶ Difficulty with choices, communication, and overwhelmed with too much noise and movement



Systems Issues and aging, dementia capable care





What are systems issues?

- ▶ **Systems thinking** is the process of understanding how those things which may be regarded as systems influence one another within a complete entity, or larger system. In nature, systems thinking examples include ecosystems in which various elements such as air, water, movement, plants, and animals work together to survive or perish. In organizations, systems consist of people, structures, and processes that work together to make an organization "healthy" or "unhealthy".
- ▶ Systems thinking can get in the way of quality of care and maintaining the essence of each person with dementia



Examples of Systems thinking in the IDD field

- ▶ Achievement of independence is the goal and is good for adults with IDD
- ▶ Choices are always good for adults with IDD, the more the better
- ▶ Community outings should occur 2,3,4, times a week and be documented
- ▶ Aging in place is always the best option for everyone in the general population and should be the same for adults with IDD
- ▶ Challenging behaviors can be solved through a team approach using a behavior plan



Independence versus Autonomy through interdependence

- ▶ Is true independence possible?
- ▶ Western Psychological Theory that promotes the idea of separate nuclear families, moving away from parents home,
- ▶ Erik Erikson example
- ▶ Promotes the idea of personal responsibility without addressing the inequities in society or challenges as part of industrialized world
- ▶ Within the disease loss over time makes independence even less likely and not desirable



Systems Issues, dementia, and IDD

- ▶ Focus on childhood and young adults
- ▶ Transition defined currently as childhood to young adulthood, school to work or adult activities
- ▶ Progressive regressive dementias such as due to Alzheimer's disease and related dementia require a rethinking of how we provide supports, communicate, redefinition of active treatment and therapeutic activities, philosophy of care
 - ▶ Dementia means our goals, planning, and caregiver practice must change



Goals within system



Goals currently

- **Sensory stimulation & challenge**
- **Novelty & exposure to new information**
- **Skill building**
- **Increases independence**
- **Choices and opportunities**
- **Normalization**
- **Philosophy of care Age In Place**

Need to change to

- **Balance of ease of use with limited sensory stimulation**
- **Predictability and Consistency**
- **Maintain function and social interaction as much as possible**
- **Limited choices – may be one at a time**
- **Support and failure free activities**
- **Increased options for care, continuum which does not mean institutionalization**



Policy and Practices





Philosophy of Care

- ▶ Policies and practices
 - ▶ Caregivers with multiple caregiving responsibilities
 - ▶ Assumption of division of formal and informal caregiving as though life can be separated in compartments
- ▶ Terminology
- ▶ Environments based on assumptions of philosophy
- ▶ Health care provision



Environment and AD

- ▶ Environments designed for younger adults with IDD
- ▶ Assumption that noisy and stimulating environments are educational, necessary
- ▶ Change in the environment is common, with AD change should be as little as possible
- ▶ Environments are not designed to cue adults with AD



Terminology, policy, & Expectations

- ▶ Normalization

- ▶ What is normalization within the context of the disease of Alzheimer's disease
- ▶ What does it matter, who is hurt if someone wants to wear the same clothing every day?

- ▶ Choices

- ▶ Can be stressful and not possible to do

- ▶ Independence versus autonomy through interdependence



Caregivers



- ▶ Turn over of staff so few know the individual in earlier times
 - ▶ Pay for direct support staff in human services low in comparison to other industries, direct reflection of our societies valuing of human services
- ▶ Younger staff who often do not have training and experience with older adults with IDD
- ▶ Philosophy of aging in place without supports put into place or frank discussions about what it takes to support individuals especially in middle and end stages of the disease



Program and Activities



- ▶ Programs designed on a school model rather than adult learning
- ▶ Designed to have much movement and stimulation which does not meet the needs of adults with AD or often older adults in general
- ▶ Regulations often require active treatment, skill development, or advancement



Documentation and Program requirements

- ▶ Measurement of success currently how many times picks up a toothbrush and completes the task using the tools without assistance, folding five pieces of clothing
- ▶ Measurement of success may become walking in the bathroom with a caregiver or being in the laundry room while a caregiver folds the laundry
- ▶ Outcomes become just being in as peaceful or joyful way as possible, not always doing



Caregiver education and training in IDD system

- ▶ Expectation of sensory stimulation, movement, and continual activity as 'quality care'
 - ▶ Adults who may be meaning blind, meaning deaf, & not be able to distinguish details from the whole can be overwhelmed with sensory stimulation, not be able to respond appropriately
- ▶ Assumption of Choices are always good for adults with IDD, the more the better
 - ▶ Within AD the fewer choices and for some people with IDD one choice at a time yet this is the opposite of our training



Systems changes needed



- ▶ Overall goal is to keep people in own homes without recognition of supports that are needed to make that happen
- ▶ We in this culture are so focused upon human doing, not human being and value care or interventions only if they are measurable, quantifiable
- ▶ Feelings of safety, personal value, and purpose are communicated with a look, a tone, or a hug yet the current system discourages taking the time or being in the moment

Being in the moment challenge

- ▶ Multi tasking good, sitting quietly watching the birds together bad by our training





Health Care Advocacy and you

You can make a positive difference through health care advocacy



Health Care Advocacy: Why is it needed?

- Ageism by health care providers
- Assumption of automatic loss and decline as part of aging untrue but commonly believed
- Assumption of dementia, especially in persons with Down syndrome
- Importance of giving voice



Diagnostic Overshadowing

Definition: Blaming loss, decline, and changes on the pre-existing diagnosis

- ▶ Example – Decline assumed to be a result of intellectual disability rather than disease process
- ▶ Example – Reported chest pain ignored because of the pre-existing diagnosis of ID
- ▶ Assumption of lack of cognitive capacity due to diagnosis of ID in combination with aging
- ▶ Lack of experience or verbal capacity for the adult with ID to report symptoms



Other Pre-existing conditions

- All pre-existing conditions interact with the aging process and the factors of aging.
- Recommendations-
 - Know each individual
 - Develop lifespan activities that prevent disease and changes that affect quality of life in old age
 - Advocate to make sure the pre-existing conditions do not influence health care providers to ignore symptoms of disease or assume dementia



Where do we go from here?

- ▶ Health care advocacy systems over the lifespan through training
- ▶ Long range planning/Futures planning through the course of the disease
- ▶ Administrative support and understanding of the need to assist DS in the day to day caregiving
- ▶ Training on the disease at all levels of the organization
- ▶ Frank discussions on supporting caregivers and reassessing those concepts/policies we take for granted in our field
- ▶ Change the way we measure success!



Factors of Aging:

- Genetics- What pre-existing conditions and predispositions for diseases are genetically programmed for persons with Autism Spectrum Disorders?
- Lifestyle- How does the pre-existing disability affect lifestyles and opportunities?
- Environment- Does the pre-existing disability limit or shape the environmental choices?
- Attitude- How does the pre-existing disability affect attitude about aging and life? What adaptive behavior has been developed to deal with life stressors?



Behaviors as symptoms

- Behaviors as form of communication,
- All behavior has meaning
- Assume meaning and look for it, document when you find the underlying cause and share with others this information
- Resort to the behavioral plan last or as a reaction to a crisis situation but then look for the underlying cause(s)



Sensory processing and differential diagnosis

Rule out sensory impairments and challenges.

Seven senses: Responsible for our interaction with the external world.

1. Auditory (hearing)
2. Visual (sight)
3. Olfactory (smell)
4. Gustatory (taste)
5. Tactile (touch)
6. Proprioceptor (position) – the sensory feedback that informs us where the parts of our body are and how they are moving. Integrates input from the 5 senses.
7. Vestibular (balance) - related to and dependent on the proprioceptive system. The vestibular system is what gives us balance, allows us to stand and move through space without falling over.



Tips for Health Care Advocacy in your Agency

You are the expert!




Tips for Health Care Advocacy

- ▶ Be aware of myths and stereotypes about aging in persons with IDD
- ▶ Know the possible side effects and interactions for medications used by the individual
- ▶ Never assume it is the result of aging!
- ▶ Be persistent
- ▶ Develop systems of communication between residential, day program, and family or others in the adults life



Remember: Successful Aging involves:

- ▶ Connecting all the factors of aging across the lifespan
 - ▶ Building up reserves in body systems and factors such as a social support network
 - ▶ Minimizing the effects of the pre-existing disability and the age-associated disability over the lifespan.
 - ▶ Understanding potential risk factors and addressing them in childhood, young adulthood, before old age.
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Recommended Systems Changes:

- Discuss possible risk factors before they occur
 - Document this discussion,
 - Develop a formal process
- Develop aging committees, long range planning for future needs
- The system needs changing for individuals to age in place!



Lifespan Prevention

- Develop activities for healthy movement and weight bearing early in life
- Mentor good practices such as hydration, moderate diet, and exercise (You are the role model)
- Make the exercises fun and part of everyday life
- What you do will influence others around you.

Summary

NATIONAL TRAINING CURRICULUM
Dementia Capable Care of Adults with ID & Dementia



General Information for Potential Workshop Sites

- ▶ You can make a difference for you and others as each ages by understanding aging and developing prevention activities across the lifespan.
- ▶ Successful aging is possible for every person.
- ▶ Enjoy aging yourself and serve as a role model to others.
- ▶ Through health care advocacy and healthy practices across the lifespan
- ▶ **You can make a difference!**

Questions and Answers to help you make a difference

<https://aadmd.org/ntg/education-and-training>

