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Bridging the Gap: Adapting the 4Ms of Age-Friendly Health Systems for People with Intellectual and Developmental Disabilities

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Learning Objectives

- Understand the 4Ms framework: what is it, how it works, and its impact on healthcare for older adults.
- Understand how and why the 4Ms framework could be adapted to support individuals with disabilities as they age.
- Identify practical ways to apply the 4Ms framework to enhance person-centered care for adults with intellectual and developmental disabilities (IDD) as they age.

Defining Disability

What is a disability?

- **There is no one-size-fits-all**
  - Complex concept
  - Deeply personal
  - Fluid
  - May change overtime and across contexts
  - Largely determined by social factors

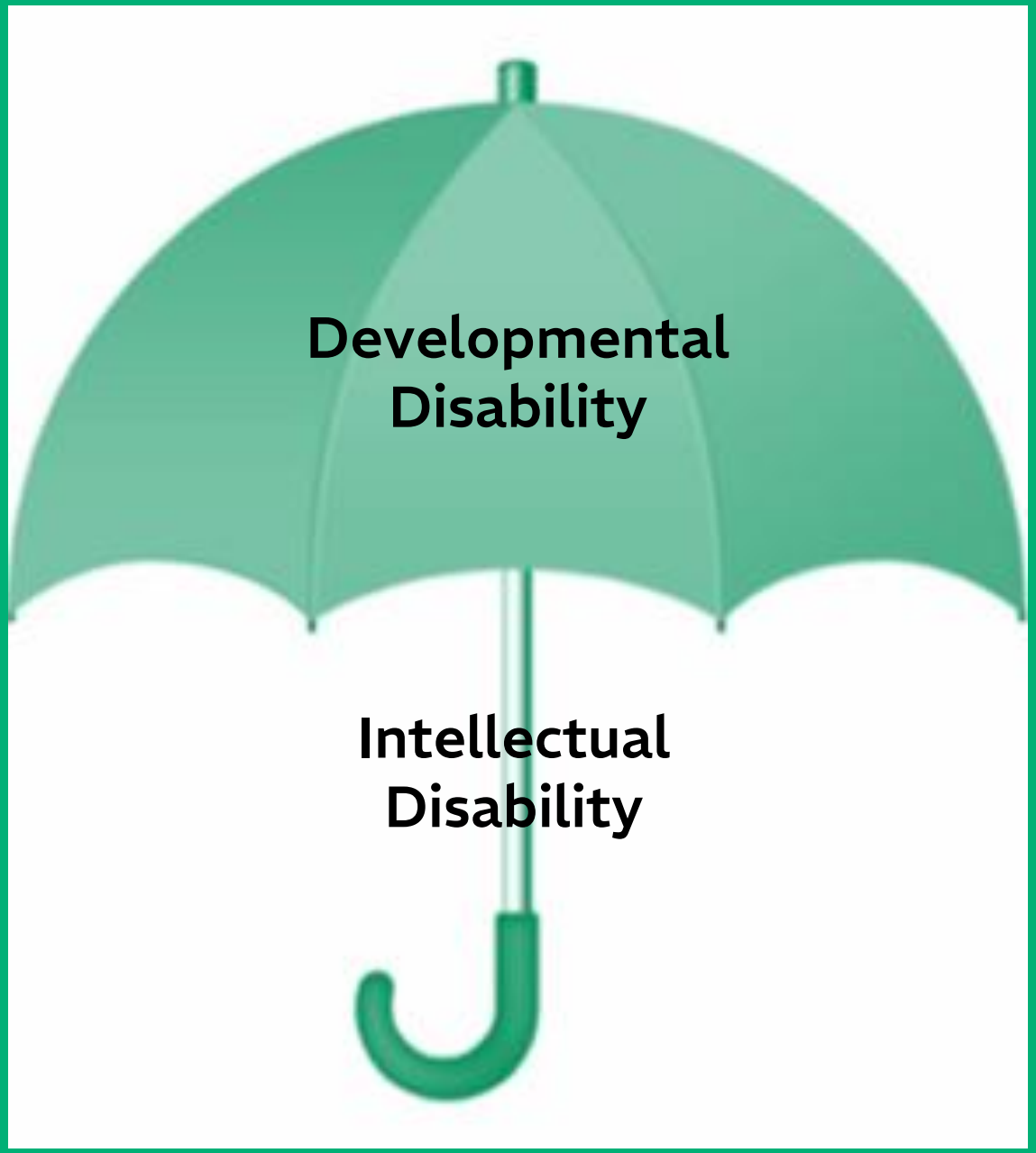
- **Under the Americans with Disabilities Act:**
  - A person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment" (U.S. Department of Justice Civil Rights Division Disability Rights Section, 2020).

Source: Brashler & Moro, 2019; Mackelprang et al., 2022; Moro & McGinley, in press; Moro, McGinley, & Ewald, 20025

Global and National Disability Data

- About 1.3 billion people (16%) worldwide live with significant disabilities
- In the U.S., 27% of adults report disabilities affecting cognition, mobility, hearing, vision, and daily living
- 20% of individuals with disabilities are aged 18 to 64
- Recognized as health disparities population by NIH in 2023

Source: CDC, 2023; Leppert & Schaeffer, 2023; Moro, McGinley, & Ewald, 2025; WHO, 2022



Select Developmental Disabilities

- Attention-Deficit/Hyperactivity Disorder (ADHD)
- Autism Spectrum Disorders (ASD)
- Cerebral Palsy
- Fragile X Syndrome
- **Intellectual Disability (ID)**
- Hearing Loss
- Learning Disorders
- Tourette Syndrome

Source: Centers for Disease Control & Prevention, 2025

Diagnosing Intellectual and Developmental Disability (IDD)

- Originates **before age 22** with **lifelong** presentation;
- Significant limitations in **intellectual functioning**; and,
- Significant limitations in **adaptive behavior**, including conceptual, social, and practical skills used in everyday life.

Source: AAIDD, 2025

Intellectual and Developmental Disability

- **1-3% of the world's population**

- In the US, approximately *7.39 million people* with IDD
  - 5.32 million are children age 21 or younger
  - 2.1 million are adults age 22 or older

- Classification of Severity:
  - Mild (85%)
  - Moderate (10%)
  - Severe (4%)
  - Profound (2%)

- Occurs among all demographic groups

Source: National Center for Health Statistics, 2023; Residential Information Systems Project, 2023; WHO, 2023

Health & Healthcare Disparities

Health Disparities

- Compared to peers without a disability:
  - Poorer overall health
  - Worse outcomes for the same conditions, including death
  - Higher rates of chronic illnesses (not related to disability)
    - Cardiac disease
    - Diabetes
    - Stroke
    - Osteoporosis
    - Arthritis
    - Asthma
    - Dental disease

Source: Moro, McGinley, & Ewald, 2025

Life Expectancy

- **U.S. Population:** 77 years old

- **IDD Overall:** 61.2-63 years old
  - Mild IDD: 74 years old
  - Moderate IDD: 67.6 years old
  - Severe IDD: 58.6 years old

- **Recent report from the NHS:**
  - Median age at death: 62.5
  - On average, adults with IDD die 19.5 years younger than the general population

Source: Landes, Stevens, & Turk, 2021; White, et al., 2024

Down Syndrome and Alzheimer's Disease

- Greatly increased risk of risk of dementia/Alzheimer's Disease
- Common Symptoms
  - Decrease in social behaviors
  - Increased sadness, fear, anxiety
  - Decreased interest in usual activities
- By age 40, most people with Down syndrome show brain changes
- More prevalent as people with Down syndrome age
  - Age 50 – 30% have Alzheimer's dementia
  - Age 60 – 50% have Alzheimer's dementia

Source: Alzheimer's Association, 2025

Healthcare Disparities: General

- Experienced at all level of healthcare
- Environmental Barriers
  - Physical barriers (inaccessible exam tables)
  - Communication barriers (lack of interpreters, jargon)
  - Sensory barriers (too bright, loud, overstimulating)
- Assumptions about capacity
- Lack of disability information in EHR
- Lack of provider training (biases, discomfort)
- Diagnostic overshadowing
- Over/under treatment
- Over/under medication
- Polypharmacy
- Limited/no access to care

Source: Moro, MvGinley, & Edwald, 2025.

Healthcare Disparities: COVID

ACUTE CARE

- Higher rates of hospital admissions for treatable conditions
- Higher rates of safety events while hospitalized
- Longer lengths of stay
- High-cost utilizers
- Higher rates of 30-day readmissions

COVID

- Leading cause of death among people with IDD in 2020
  - 3rd leading cause of death among people without IDD.
- Orders to ration care based on disability status
  - Required Office of Civil Rights (OCR) intervention.
- The long-term impacts still being explored, including the implications of delayed healthcare on health long-term

Source: Ailey et al., 2014, 2019; Balogh et al. 2011, 2018; Courtenay & Perera, 2020; Friebel & Maynou, 2022; Landes et al., 2020 & 2022; Lunsky et al., 2019

Healthcare Disparities: Fatal Five

People with IDD are more at risk than both disabled and non-disabled peers to experience one of these conditions:

- Aspiration
- Constipation
- Dehydration
- Seizures
- Sepsis

Source: Relias, n.d.; IntellectAbility, n.d.; WHO, 2022

Importance of Disability-Friendly Healthcare

Americans With Disabilities Act (ADA)

- Passed on July 26, 1990; ADA Amendments Act (ADAA) Signed 2008

- Provides a legal framework that enables people with disabilities to challenge discrimination in all aspects of public life:
  - Healthcare organizations (e.g., hospitals, doctor's offices, pharmacies, dental offices) that serve the public must provide full and equal care to people with disabilities, including
    - Accessible facilities
    - Reasonable modification to policies, practices, procedures
    - Effective communication that is understood by those receiving care

Source: ADA National Network, 2024; Staton et al., 2023

Principles and Applications of Universal Design

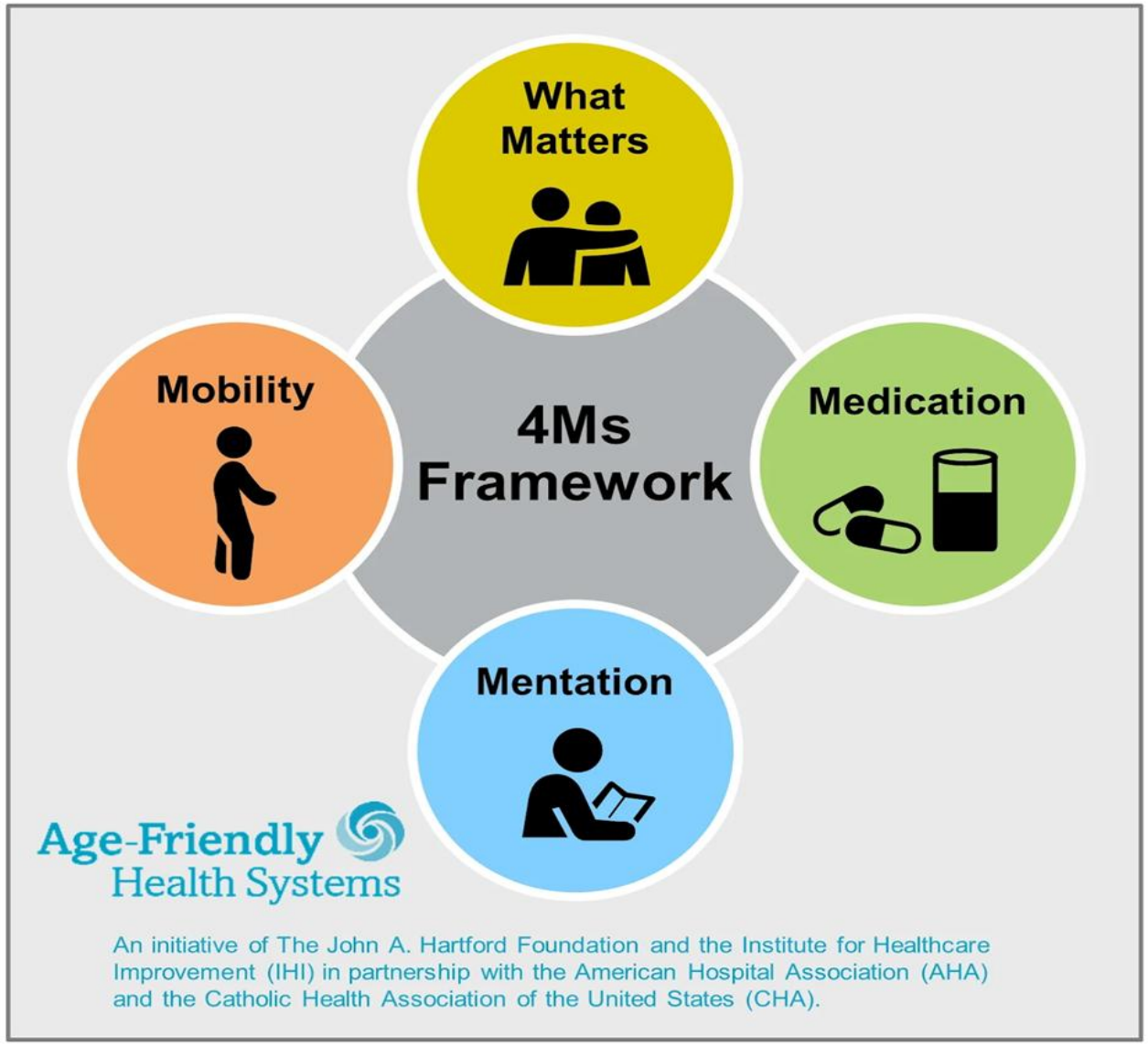
The 7 Principles of Universal Design include:

1) equitable use
2) flexibility in use
3) simple and intuitive use
4) perceptible information
5) tolerance for error
6) low physical effort
7) size and space for approach and use

- Application Involves: Designing healthcare environments so that are usable by everyone, regardless of mobility or other types of disability

Source: Baida & Ivanova, 2019; The Centre for Excellence in Universal Design, 2025; UC Regents, 2024

4Ms Framework



What Matters

Know and align care with each older adult's specific health outcome goals and care preferences including, but not limited to, end-of-life care, and across settings of care.

Medication

If medication is necessary, use Age-Friendly medication that does not interfere with What Matters to the older adult, Mobility, or Mentation across settings of care.

Mentation

Prevent, identify, treat, and manage dementia, depression, and delirium across settings of care.

Mobility

Ensure that older adults move safely every day in order to maintain function and do What Matters.

Age Friendly Health System (AFHS)

- Healthcare systems understand ADA and their obligation, but may struggle with implementation

- AFHS was developed and designed to promote better healthcare for adults age 65+ by implementing the 4Ms into care provision

- There are 5,477 AFHS nationally, including:
  - Rush University; United Health Services (UHS; Binghamton)
  - Stanford Health Care - Geriatric Trauma Program
  - Three in the Palo Alto area; Two in the Menlo Park area

Source: Moro, McGinley, & Ewald, 2025; Ordway et al., 2021; Staton et al., 2023

Applying the 4Ms in Practice

What Matters

- Care aligned to patient/ family health and personal goals
- Entire care team, across disciplines and settings, aligns care with goals over time/ across settings
- Includes: pain management, advance care planning, where care is received, and patient and caregiver concerns

Importance for people with disabilities:

- Learn valuable information about how a patient perceives their disability
- Understand and address barriers to health and healthcare
- Better prepare for future visits

Source: Emery-Tiburcio et al., 2021; Moro, McGinley, & Ewald, 2025

Medication

- Prescribing only necessary medications
- Medications do not interfere with what matters to the patient (including mobility and mentation)
- Establishing the simplest medication regimen
- Assess medical necessity and alternative medications with fewer side effects

Importance for people with disabilities:

- Decrease polypharmacy
- Decrease over/ under prescribing
- Prescribe the least amount of psychotropic medication necessary

Source: Emery-Tiburcio et al., 2021; Moro, McGinley, & Ewald, 2025

Mentation

- Preventing, identifying, treating, and managing across settings:
  - Dementia
  - Depression
  - Delirium
- Screen and educate patients and families about their symptoms and presentation

Importance for people with disabilities:

- Increased risk of dementia before age 60
- Decrease diagnostic overshadowing
- Timely referrals to specialists (may take time to locate)

Source: Emery-Tiburcio et al., 2021; Moro, McGinley, & Ewald, 2025

Mobility

- Assess fall risk and overall mobility and functional status goals regardless of fitness level
- Maximize activity and function, by encouraging ambulation and/or range of motion exercises
- Ensure the safety of home environment and safety getting to and from appointments

Importance for people with disabilities:

- Promote universal design to ensure accessible facilities and ensure a more disability-friendly healthcare system.

Source: Emery-Tiburcio et al., 2021; Moro, McGinley, & Ewald, 2025; United States Government Accountability Office, 2022

IDD Focused Clinical Tips and Examples of Tailored Programs

Preparing for Medical Appointments

Before the appointment:

- Identify a trusted support person
- Prepare the person if there will be blood tests, etc.
- Talk to the healthcare provider about accessibility

Monitor and keep track of changes in:

- Motor skills
- Cognition
- Sensory
- Mental Health
- Behavioral
- Use of medications

Source: Bathje, Keagle, Cooper, & Bannister, 2025; Man, Lacroix, & Lai, 2025; Moro & Brashler, 2019

Improving Communication

- Ensure providers direct attention and communication to the individual
- Before the Appointment: Write down questions
- During the Appointment: Ask questions using EHR
- After the Appointment: Write down any changes
- Be sure to bring relevant documents:
  - Health Resume
  - Health Passport
  - My Hospital Form
  - NTG-EDSD
  - DSRD Tools

Source: Emery-Tiburcio et al., 2021; Moro, McGinley, & Ewald, 2025; United States Government Accountability Office, 2022

Supporting Decision Making

Remember:

- People with IDD can discuss what matters to them and what they want if they are ill
- People with IDD can understand a life-limiting diagnosis
- People with IDD should be involved in making decisions to the best of their ability
- People with IDD grieve and need to be supported – grief may look a little different

Utilize Decision-Making Tools, including Advance Care Planning Tools, Adapted or Developed for People with IDD:

- Coalition for Compassionate Care of California
- Talking End of Life … with people with intellectual disability
- The ARC's Center for Future Planning
- The Victoria & Stuart Project

Source: Moro & McGinley, 2021 & 2024

Tailoring Healthcare

Neuro-Inclusive Oncology Care and Empowerment Program (Dana-Farber Cancer Institute)

Offers support services to people with intellectual and/or developmental disabilities (IDD):

- Provides support services throughout treatment
- Provides social work support
- Conducts comprehensive assessment of psychosocial needs
- Addresses treatment barriers

Life Transitions: The Mercy Doula Program (People Inc.)

Integrative care with an interdisciplinary focus:

- Proactive - initial diagnosis, assessment of current supports, services and needs, team discussions, build trust and rapport
- Active - direct support to the person/support network, care planning needs and updates
- Reactive - bereavement and after care supports, celebration of life, 1:1 opportunities to work through grief and loss

Source: Dana-Farber Cancer Institute, n.d.; People, Inc., n.d.

Additional Resources

- RUSH Center for Excellence in Aging
  - https://aging.rush.edu/professional-older-adult-family-care/age-friendly-health-system/4ms-framework/
- UCLA Health
  - https://www.youtube.com/watch?v=ojQTz9FlNt4
- Colorado Department of Human Services
  - https://www.youtube.com/watch?v=Zpn-zAp0cWI
- Special Olympics: Healthcare Provider Training
  - https://elearn.specialolympics.org/health/learn
- Dana-Farber Neuro-Inclusive Oncology Care
  - https://www.youtube.com/watch?v=P_K-ozD8B38

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Thank you!

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