



NOVEMBER 8, 2023

ENGAGING DIVERSE AND  
INCLUSIVE AUDIENCES WITH  
THE HEALTHY BRAIN ROAD MAP

GSA 2023, TAMPA, FL

# The Hidden Majority Beyond Our Silos

Disability is All of Us



UNIVERSITY OF  
**ILLINOIS CHICAGO**



## MEET *the* TEAM

**Component B**  
Healthy Brain Initiative for  
People with Intellectual and  
Developmental Disability



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# Addressing Structural / Social Determinants of Health to Promote Brain Health for People with Intellectual and Developmental Disability

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# Dementia is Covered through the Americans with Disability Act of 1990 (ADA) and 2008 ADA Amendment Act



**An individual with a disability is defined by the ADA as:**

1. a person who has a physical or mental impairment that substantially limits one or more major life activities,
2. a person who has a history or record of such an impairment, or
3. a person who is perceived by others as having such an impairment.



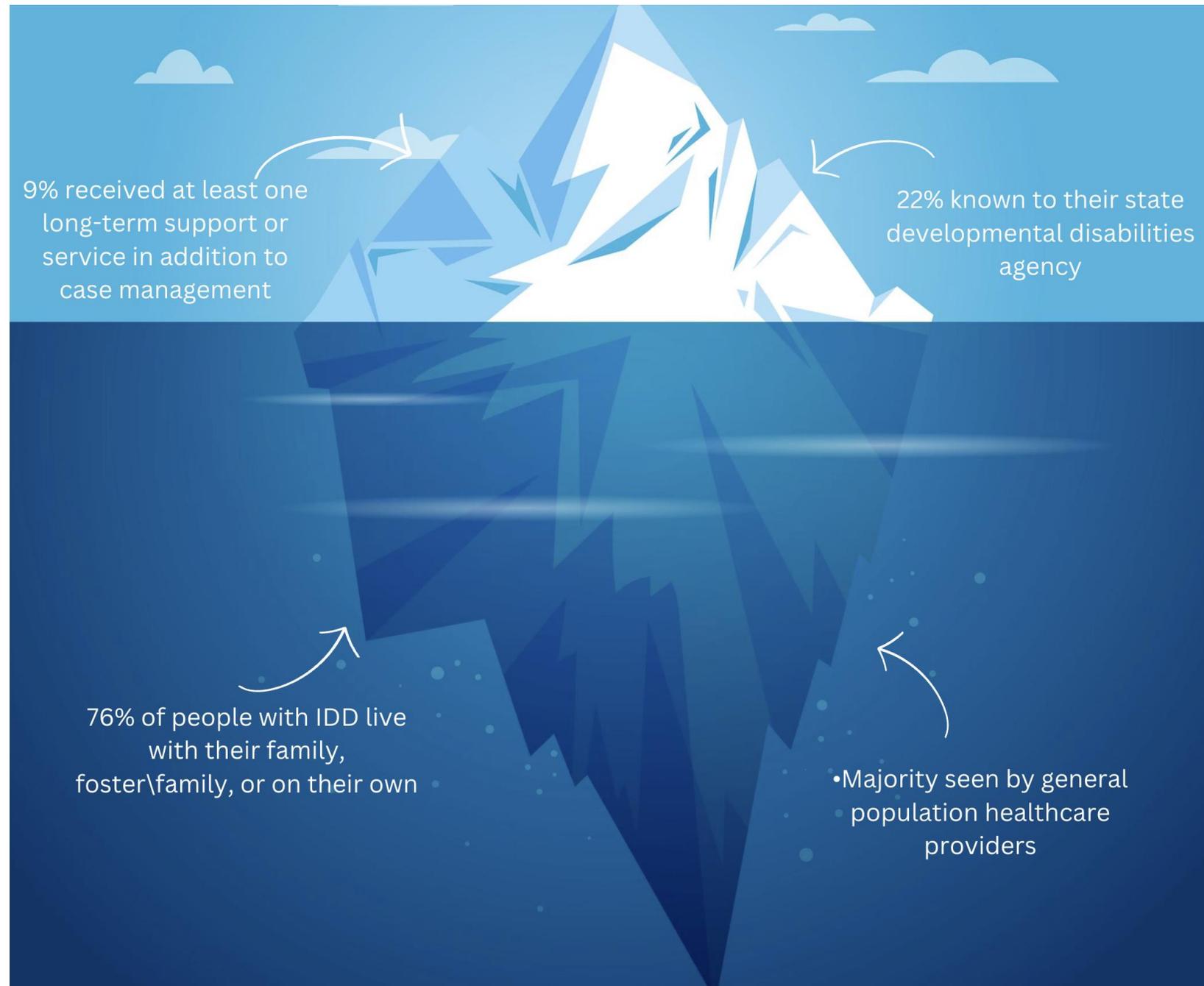
# Engaging and Educating the Public

- Dementia is a disability
- Disabled people get dementia
- Barriers people face when they try to have a healthy brain lifestyle
- Barriers people face when they get diagnosed
- Targeted brain health messages for people with intellectual and developmental disability(IDD) incorporating fairness, justice, empowerment, participation, and self-determination

# Intellectual Disability

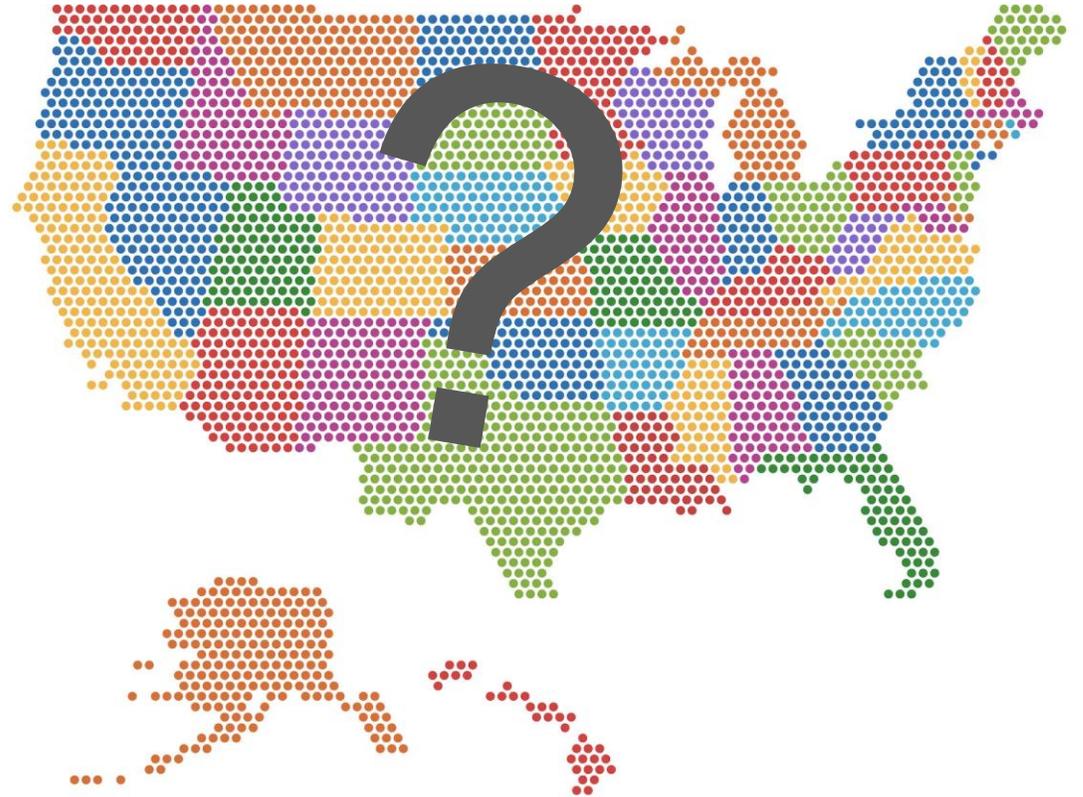
- Intellectual disability is a condition characterized by significant limitations in both intellectual functioning and adaptive behavior that originates before the age of 22.\*
- Approximately 6.5 million people in the United States have an intellectual disability (IDD). Approximately 1 – 3 percent of the global population has an intellectual disability—as many as 200 million people.
- Number of adults with IDD age 60 years and older may double from 641,860 in 2000 to 1.2 million by 2030 resulting in a need for more services.

# Multiprong Approaches For Healthy Brain



# Measuring, Evaluating and Utilizing the Data

- People with intellectual and developmental disability are not represented in national surveys (e.g. Behavioral Risk Factor Surveillance System (BRFSS), etc.).
- Challenging to understand disparities and opportunities for improving equity.



# People with Intellectual Disability and ADRDs

- About 11,000 (6%) of the 180,000 older people with IDD will experience a form of dementia (from Alzheimer's disease or another cause) after age 60; and the percent will increase with age.
- People with Down syndrome have a higher risk, with about 2 in 3 people over the age of 60 developing dementia, usually Alzheimer's disease (AD), with a mean age of onset or diagnosis of AD at 53.



When we think & act  
**UPSTREAM**  
we create a healthier,  
safer world.



## Changing the Paradigm

- People with intellectual and developmental disability (IDD) have healthy brains.
- ADRDs are NOT a natural course of aging for people with IDD.
- People with IDD like their non-disabled peers can optimize cognitive, emotional, psychological and behavioral functioning with or without dementia to cope with life situations.
- Healthy lifestyles among people with IDD can be supported by considering the impact of structural and social determinants on healthcare and health outcomes.

# Risk Factors for People with IDD

Hypertension

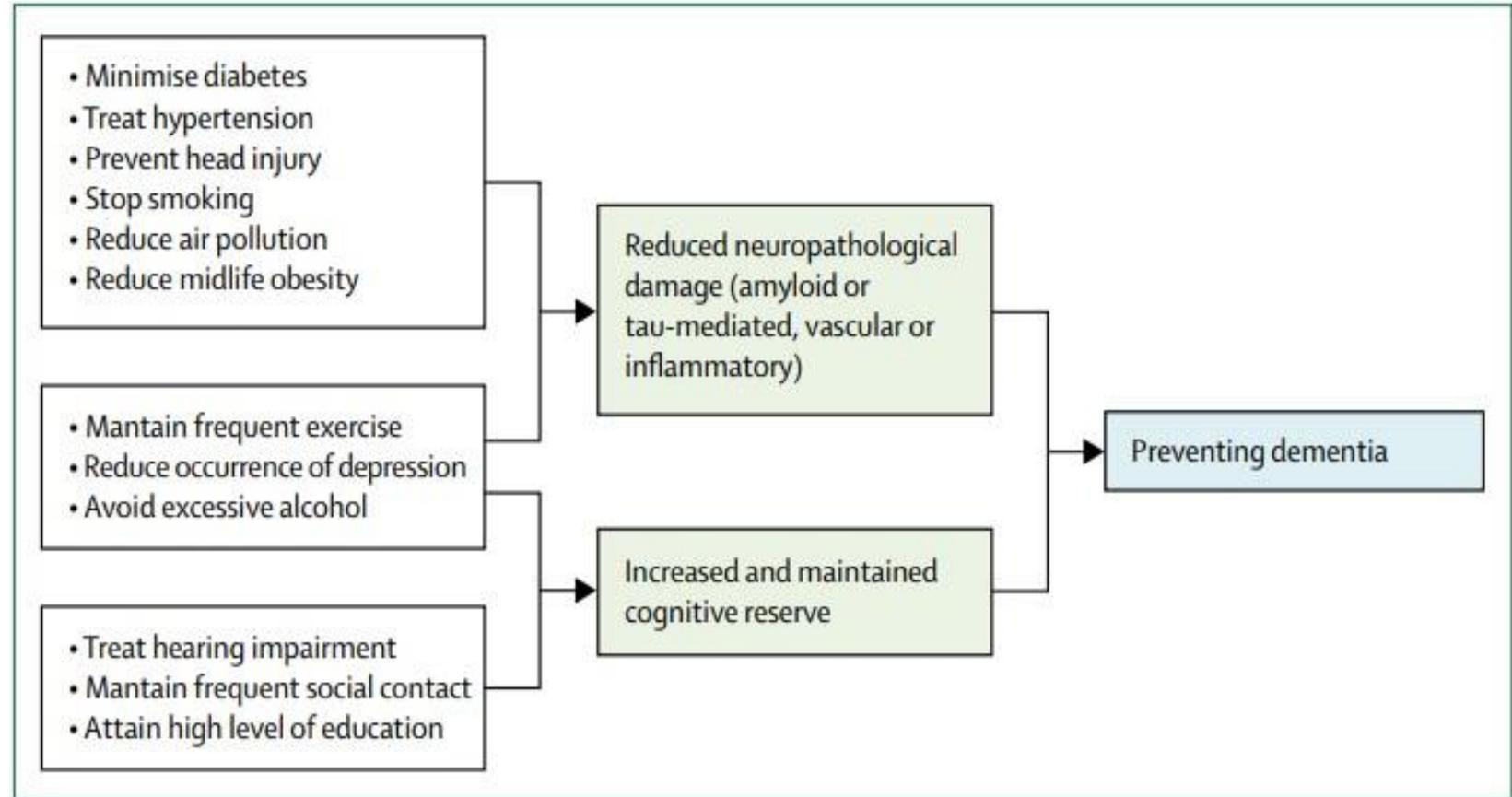
Obesity

Physical Activity

Smoking

Depression

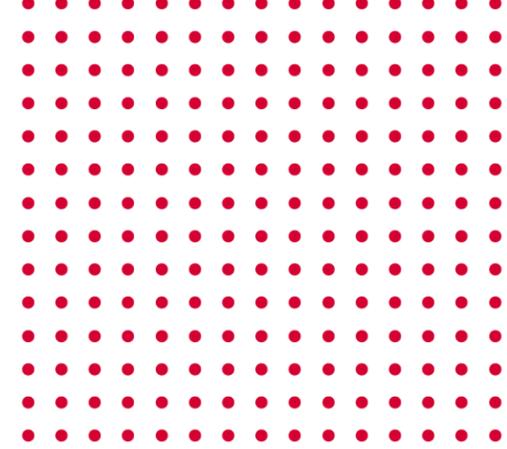
Hearing loss



**Figure 2: Possible brain mechanisms for enhancing or maintaining cognitive reserve and risk reduction of potentially modifiable risk factors in dementia**

# Intersectionality

## Disparities in Chronic Disease Outcomes: Race/Ethnicity/IDD



### Anstey et al (2020)

- Significant gaps in research in **ethnic and cultural diversity**
- Evidence-lacking on **specific population groups and cultures within populations**
- Little understanding **biological mechanisms** underlying **psychosocial factors**
  - Allostatic load (McEwen & Stellar, 1993)  $\leftrightarrow$  Weathering (Geronimus 1996)

### Yu et al (2023)

Nationwide longitudinal study on health among adults with IDD

Black adults with IDD were more likely to have chronic health conditions (\*\*HPT, Diabetes, Asthma\*\*)

# Strengthening Partnerships and Policies

Matthew P. Janicki, PhD

# Beyond Silos: Engaging Diverse State Stakeholders

## Taking on a 'lifespan' perspective



What happens in younger age influences what occurs in older age



### What can help?

**Reduce stressors** – improve mental health and consequently brain health

**Consider nutrition and weight** – avoid overweight – leads to disease

**Promote social inclusion and involvement** – stimulate cognitive capacities

**Look at total life situation** – who is involved, who helps, who influences

**Stimulate planning** – get systems involved to aid lifespan health and later-outcomes

# Silos or Collaborators?



Silo	Targeting
<b>Aging</b>	Older Americans Act services – senior centers, nutrition sites, adult day services, personal support/assistance services for older Americans – age 60+ (with some variations)
<b>Disability</b>	State IDD agencies – supported by State funds and federal Medicaid – provide housing, day supports, casework and assistance and some specialized services (e.g., dementia)
<b>Dementia</b>	NGOs – provide information & referral, some direct care (day care, respite, caregiver aid/assistance)
<b>Social Services</b>	State social services agencies – public assistance, casework, adult protective, housing assistance...
<b>Health</b>	State health agencies, long term care facilities, medical providers – health care provision, long term care housing, disease control, diagnostic and assessment services ...

# Interconnectivity

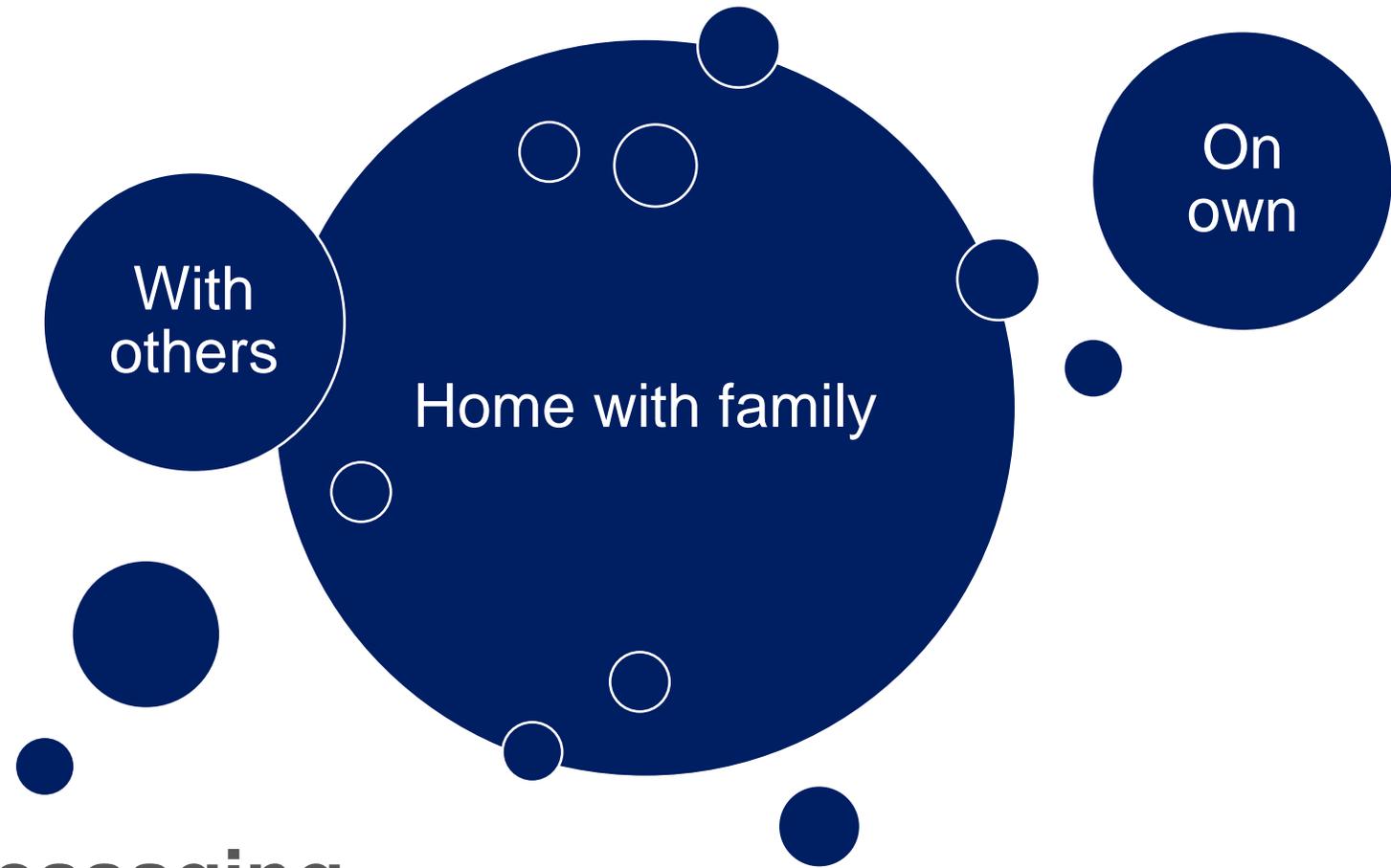


Persons with intellectual disabilities and their family caregivers may encounter the following entities:

- State developmental disabilities authority -- the 'state agency and its network of local intellectual disability provider agencies
- The aging network
- Public health organizations and providers
- Social/public welfare agencies
- Alzheimer's (or other dementia) groups
- Charitable and volunteer organizations

Connecting diverse service networks to work for risk reduction and brain health in a target population...

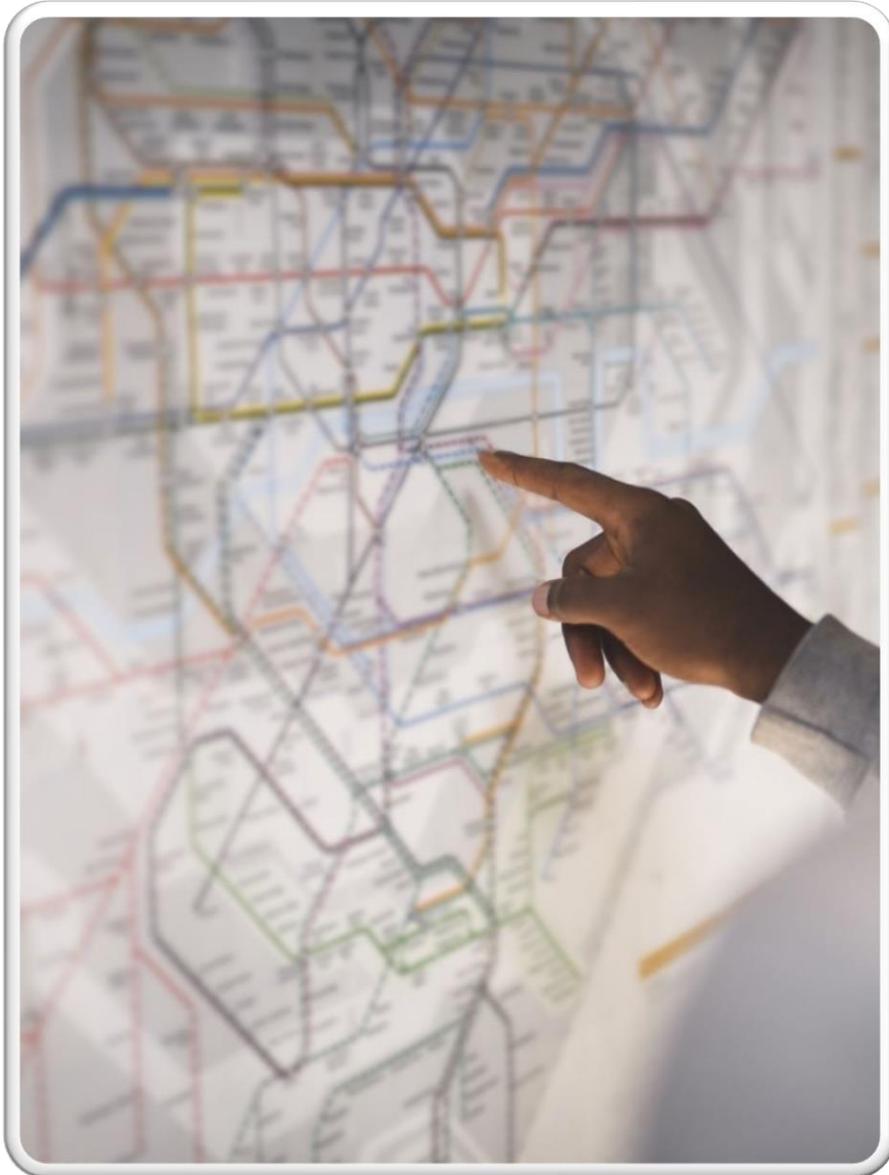
# Who Lives Where?



## Targeting brain health messaging

- Broad approach to reach all settings
- Narrow approach to work through intermediaries
- Engaging the disability community
- Cross-sectorial efforts (other groups)

# Addressing IDD Brain Health - Road Map Strategies



## State Councils on Developmental Disabilities (DD and Bill of Rights Act)

- Required to have a strategic plan and enable coordination among state agencies
- Council membership by agencies, petitioning Council for underwriting risk reduction efforts
- **Influence:** state developmental disabilities agency, education agency, health agency, etc.

## State Units on Aging (aging dept, elder affairs div, etc.) (Older Americans Act)

- Required to produce multi-year plan for receipt of federal funds
- Advisory councils help set framework
- **Influence:** state and local (AAA) efforts for targeting; funding initiatives

## State health departments/agencies

- Required to address public health issues
- **Influence:** physical and brain health initiatives

# National IDD organizations for networking, collaboration, and health initiatives

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The Arc of the United States

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National Association of State Directors of Developmental Disabilities Services

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National Down Syndrome Society

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National Task Group on Intellectual Disabilities and Dementia Practices

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American Association on Intellectual and Developmental Disabilities

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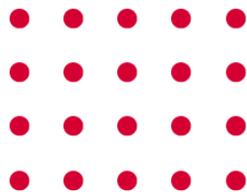
Association of University Centers on Disabilities

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ANCOR

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ACCSES



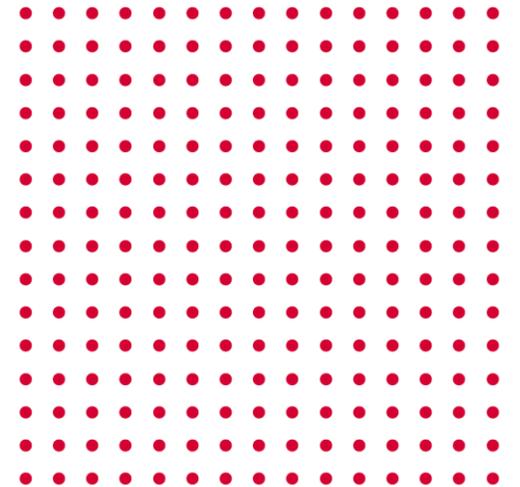
# Implementing the HBI Road Map: Content That Matters and Programs That Work

Jasmina Sisirak, PhD, MPH

# Addressing SDOH to Build a Diverse and Skilled Workforce – Healthcare and Public Health

Healthcare providers need training on how to provide inclusive and accessible healthcare.

- **ENGAGE-IL (GWEP)**  
**Geriatric CEU Modules 27 Learning Modules**
  - ✓ Healthy Brain Module 1: Health Advocacy
  - ✓ Healthy Brain Module 2: 6 Pillars of Brain Health for People with IDD
  - ✓ Address disability humility for people with intellectual and developmental disability
  - ✓ Identify SDOH, 2) uproot systemic bias, and 3) illustrate Universal Design.
  - ✓ Topics: diagnostic overshadowing, complex health conditions, accessible healthcare (buildings, equipment, communication)



# Addressing SDOH to Build a Diverse and Skilled Workforce – Dementia Capable Care of Adults with Intellectual Disabilities and Dementia

- Overview of dementia for direct support professionals in community-based residential programs supporting adults with IDD.
- Topics include:
  - what is dementia
  - types of dementia and stages,
  - planning for impact of dementia,
  - models for individual and group care,
  - communication techniques,
  - environmental adaptations,
  - managing BPSDs, and
  - creating a dementia care plan

<https://www.the-ntg.org>



National Task Group on Intellectual  
Disabilities and Dementia Practices



## Addressing social determinants of health within the 6 pillars of health

- **MOVE More**
- **LEARN More**
- **LIVE More**
- **EAT Well**
- **REST/SLEEP Well**
- **BE Well**

# Programs That Work

## VIRTUAL COACH

### HealthMatters Program\*

Research based, field tested health promotion program that provides service provider organizations strategies and materials to support healthy options and choices for people with intellectual and developmental disability (IDD).

\*Meets the Administration for Community Living OAA Title III-D Evidence-Based Requirements

#### 1 THE TRAINING

HealthMatters Program Train-the-Trainer Certified Instructor Workshop

- 6-hour online
- organize and start a tailored physical activity & health education program for people with IDD

#### 2 THE CURRICULUM

Health Matters: The Exercise and Nutrition Health Education Curriculum for People with Developmental Disabilities

- adaptable instructor scripts for each lesson
- participant handouts & worksheets
- 59 lessons on health, exercise, nutrition, choice-making, self determination



#### 3 THE PROGRAM

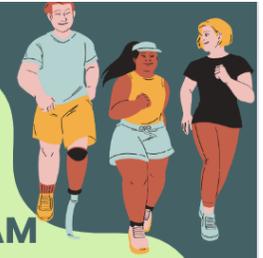
12-Week HealthMatters Program for People with IDD

- group physical activity and health education
- 36 lessons, 3x per week, 4-6 hours weekly

#### 4 THE CLASSROOM

Virtual Coach

- multimodal supplement to the Curriculum
- 36 lessons, resources, infographics, videos
- virtual support allows for an interactive communication, feedback, resource sharing, and collaborative learning



# Beyond Silos

- Community based service providers
- Special Olympics
- Project SEARCH
- MCO
- State and local departments of public health
- AAA
- SNAP-Ed
- USDA Cooperative Extension System
- Local Parks and Rec Services

# OUR REACH

Virtual Coach:  
HealthMatters Program

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**HealthMatters™**  
HealthMattersProgram.org

 UNIVERSITY OF  
**ILLINOIS CHICAGO**

SINCE ITS LAUNCH IN NOVEMBER 2020

**2150**

received health  
promotion  
programming

**PEOPLE WITH INTELLECTUAL  
DISABILITY**



**ORGANIZATIONS**

**147**

community based  
organizations took part in the  
HealthMatters Program



**512**

Trained and  
Certified

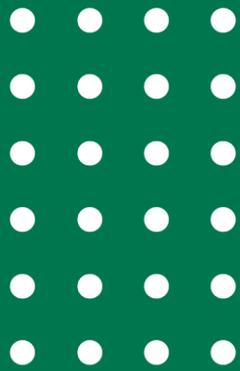
**STAFF  
MEMBERS**



**STATES 37**

Across the U.S., plus  
Canada, the Netherlands,  
and Portugal





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