The Hidden Majority Beyond Our Silos

Disability is All of Us
Component B
Healthy Brain Initiative for People with Intellectual and Developmental Disability

Meet the Team

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

Jasmina Sisirak, PhD, MPH
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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.

*American Association on Intellectual and Developmental Disabilities
Multiprong Approaches For Healthy Brain

9% received at least one long-term support or service in addition to case management

22% known to their state developmental disabilities agency

76% of people with IDD live with their family, foster family, or on their own

*Majority seen by general population healthcare providers*
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.
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

Lancet 2020; 396: 413–46 Published Online July 30, 2020 https://doi.org/10.1016/S0140-6736(20)30367-6
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
<table>
<thead>
<tr>
<th>Silo</th>
<th>Targeting</th>
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<tr>
<td>Aging</td>
<td>Older Americans Act services – senior centers, nutrition sites, adult day services, personal support/assistance services for older Americans – age 60+ (with some variations)</td>
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<tr>
<td>Disability</td>
<td>State IDD agencies – supported by State funds and federal Medicaid – provide housing, day supports, casework and assistance and some specialized services (e.g., dementia)</td>
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<tr>
<td>Dementia</td>
<td>NGOs – provide information &amp; referral, some direct care (day care, respite, caregiver aid/assistance)</td>
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<td>Social Services</td>
<td>State social services agencies – public assistance, casework, adult protective, housing assistance…</td>
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<tr>
<td>Health</td>
<td>State health agencies, long term care facilities, medical providers – health care provision, long term care housing, disease control, diagnostic and assessment services …</td>
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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
<table>
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<th>National IDD organizations for networking, collaboration, and health initiatives</th>
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<tr>
<td>The Arc of the United States</td>
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<td>National Association of State Directors of Developmental Disabilities Services</td>
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<td>National Down Syndrome Society</td>
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<td>National Task Group on Intellectual Disabilities and Dementia Practices</td>
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<td>Association of University Centers on Disabilities</td>
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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 SSDOH, 2) uproot systemic bias, and 3) illustrate Universal Design.
  ✓ Topics: diagnostic overshadowing, complex health conditions, accessible healthcare (buildings, equipment, communication)

https://engageil.com
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
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

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).

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

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

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

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

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