Healthy Brain Initiative for People with Intellectual and Developmental Disabilities
Webinar 1

Beth Marks, Matthew Janicki, Kathryn Service, Valerie Gruss, and Jasmina Sisirak

May 4, 2021
1:00 to 2:00 pm CDT
Welcome to our 2021 Healthy Brain Webinar Series for People with Intellectual and Developmental Disabilities (IDD)

- Today, we are presenting our new CDC-funded Healthy Brain Initiative and introducing our partners.
- We would like your input about brain health and the types of resources that would be helpful to you.
- As we go through our presentation today, please think about the following questions and put your feedback in the chat box.
  - Do you have any issues and needs for brain health?
  - What types of brain health resources/information would be useful?
- CEUs are not offered for the webinars.
- Webinars and materials will be recorded and archived on YouTube.
- Please use chat box for comments and questions!
Presented by

• **HealthMatters Program** (https://www.healthmattersprogram.org), Department of Disability and Human Development, College of Applied Health Sciences, University of Illinois at Chicago.

• In partnership with **National Task Group on Intellectual Disabilities and Dementia Practices** (NTG) and **ENGAGE-IL HRSA Geriatrics Workforce Enhancement Program** (GWEP).

• Funded by the Centers for Disease Control and Prevention (CDC), National Center for Chronic Disease Prevention and Health Promotion, The Healthy Brain Initiative Award #1 NU58DP006782-01-00. Contents are solely the responsibility of the authors and do not represent the official views of CDC.
Alzheimer’s Disease and Other Dementias

1. About 11,000 (6%) of the 180,000 older people with IDD will experience a form of Alzheimer’s disease and related dementias (ADRD) after age 60 (increases with age).

2. Dementia is **NOT** a natural course for people with IDD.

3. Strong evidence with evolving research showing that people can reduce their risk of cognitive decline by making key lifestyle changes (physical activity, socially engaged, good heart health).
Partnership

- HealthMatters Program, University of Illinois at Chicago (Beth Marks, PhD, RN, FAAN and Jasmina Sisirak, PhD, MPH)
- National Task Group on Intellectual Disabilities and Dementia Practices (NTG) (Matthew Janicki, PhD and Kathryn Service, RN)
- ENGAGE-IL HRSA Geriatrics Workforce Enhancement Program (GWEP) (Valerie Gruss, PhD, APN, CNP-BC, FAAN)
Aims - Support “populations with a high burden of Alzheimer’s disease and other dementias”

- Education and training program and resources for healthcare and public health professionals and caregivers to provide person-centered care for PwIDD and their supports
- Workforce development to expand and scale-up Healthy Brain Initiative Road Map Series (2018-2023) for people with IDD and their supports
- Policies and partnerships to implement public health strategies to promote brain health
Healthy Brain for Life: Changing Expectations

1. We are 1 of 3 Component B projects with CDC’s National Healthy 5-year Brain Initiative addressing dementia among groups with a high burden of Alzheimer’s disease and related dementias (ADRDs)
   - International Association for Indigenous Aging (IA2)
   - UsAgainstAlzheimer’s
   - Alzheimer’s Association (Component A)
HBI Collaborators

1. Alzheimer’s Association
2. American Academy of Developmental Medicine and Dentistry (AADMD)
3. American Association on Health & Disability
4. American Association on Intellectual and Developmental Disabilities (AAIDD)
5. Association of University Centers on Disabilities (AUCD)
6. Community Living Policy Center, Lurie Institute for Disability Policy at Brandeis University
7. Council on Quality and Leadership (CQL)
8. Down Syndrome Medical Interest Group (DSMIG)
9. ENGAGE-IL GWEP
10. Exceptional Parent (EP)
11. Global Down Syndrome Foundation (GDSF)
12. Golisano Institute for Developmental Disability Nursing
14. Midwest Roybal Center for Health Promotion and Translation
15. National Alliance for Direct Support Professionals (NADSP)
16. National Center on Health, Physical Activity and Disability (NCHPAD)
17. National Down Syndrome Congress (NDSC)
18. National Down Syndrome Society (NDSS)
20. Project SEARCH
21. Special Olympics (SO)
22. The ARC
Healthy Brain Initiative

Promote brain health for persons with IDD and their supports

Social Determinants of Health

1. **Health Behaviors**
   - Diet, Physical Activity, Alcohol, Tobacco, Drugs, Sexual Activity

2. **Clinical Care**
   - Access to Quality Care

3. **Social-Environmental Factors**
   - Education, income, Employment, Family & Social Support, Community Safety

4. **Physical Environment**
   - Air and Water Quality, Housing and Transit

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**1**WHO

**2**Cleveland Clinic Healthy Brain
COVID-19 and Brain Health

Live in congregate settings with higher spread of COVID-19:

- more likely to die from COVID-19 than those without IDD*
- higher death rates among people with IDD than without IDD at ages 0-17 and 18-74, but similar rates at ages 75 and older
- higher prevalence of comorbid circulatory, respiratory, and endocrine diseases across all age groups.

*Turk, et al., 2020
HBI Community of Practice for People with IDD and their Supports

- Create “one-stop space”

1. **Awareness of ADRDs** among PwIDD as a public health issue
2. **Public health strategies** to improve the quality of life of PwIDD
3. **Caregiver health and wellness** to optimize care for PwIDD with inclusive Healthy Brain resources and trainings

- **Improve health equity** for people experiencing ADRDs
- **Enhance opportunities** for PwIDD and supports to actively engage in **lifestyle goals, preferences, and options**
Healthy Brain Initiative Activities

- Interactive **HealthMatters website** + Healthy Brain **Messaging** and **Webinar Series** + Virtual Coach **HealthMatters Program**
- ENGAGE-IL **CEU Modules** + **Dementia Guide Expert** App
- NTG **Dementia Capable Care** of Adults with IDD + **Healthy Brain Curriculum**
  1. Dementia **Information Package** for people with IDD
  2. Nutritional and **Dietary Guidelines**
  3. Memory Care **Home Solutions**
  4. Project SEARCH’s **Employment Transition with Health**
  5. Brain **Health Screenings**
  6. Education and **Advocacy Package**
Virtual Coach: HealthMatters Program

• Bringing health promotion programming to your community
• Completing Virtual Coach pilot
  o 53 community organizations in 23 states
  o 41 continued both training and instructing (November to January 2021)
  o 274 staff - projected reach ~1700 of participants with IDD
• Adding extension modules to include healthy brain strategies
• Including health education information that can be used where people live, learn, work, and play
• Next FREE training September/October 2021. Continue to offer training twice a year.
ENGAGE-IL 2.0™
Enhancing Care for Older Adults

Geriatric Workforce Enhancement Program (GWEP)

Dr. Valerie Gruss, PhD, APRN, GNP-BC, FAAN
University of Illinois Chicago

HRSA Grant # U1QHP28730
Award # 2 U1QHP287300400
Engage-IL 2.0 Building Age-Friendly Health Systems & Workforce

9 Innovative Programs

4 primary objectives

**Objective 1:** Build Age-Friendly Health Systems & establish Dementia-Friendly Communities

**Objective 2:** Deliver community-based Wellness Education Programs Improving Safety and Quality and address the Health and Wellness of Vulnerable Populations

**Objective 3:** Educate and Train Interprofessional health care workforce, about geriatrics and working effectively in interprofessional collaborative teams.

**Objective 4:** Transform Primary Care Environments into Age-Friendly Systems providing value-based primary care geriatrics by strengthening partnerships with community-based organizations (CBOs) caring for underserved vulnerable populations

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**1. Age Friendly Systems: Dementia Friendly Communities**
- Vertical Independent Villages
- Dementia Friendly Prisons
- Dementia Guide Expert Mobile App

**2. Wellness, Safety & Quality**
- Health Fairs & Fall Prevention at Senior Centers
- H.O.M.E.

**3. Geriatric Education & Interprofessional Training**
- Online Training Program
- Interprofessional Student Fellowship Program

**4. Primary Care Age Friendly Communities**
- FQHC Primary Care Clinics: Miles Square Health Center & Access Network
- UI Health Home Visits Program with Telehealth
Vertical Independent Villages™

Collaborating partners, City of Chicago, Age-Friendly Commission and UIC Engage-IL has developed and implemented a city-wide dementia training program for building management staff caring for older adults residing in their buildings...

Creating Vertical Independent Villages which are age-friendly and dementia friendly communities

IRB Approved: UIC IRB # 2017-0182
Vertical Independent Villages™

IMPACT
Trained hundreds of building management staff who engage with thousands of older adults

COVID-19 IMPACT
• Transitioned to online webinar trainings
  Nov. 2020, Feb. 2021, May 2021
• Moving to dedicated website with online training modules available to all building management staff
Engage-IL 2.0 Building Age-Friendly Health Systems & Workforce
9 Innovative Programs
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Create Age-Friendly Communities
Creating Dementia Friendly Prisons

Illinois Department of Corrections (IDOC) was exploring options for training prison Correction Officers to recognize and address the changing health care needs of older inmates.

UIC Engage-IL developed a “Dementia-Friendly Training Program” for prison staff thereby creating IDOC “Dementia-Friendly Prisons”
Warden’s Needs Assessment indicating prisons are in need of training
Pilot: Taylorville Correctional Facility February 2020
Transitioning to virtual training due to COVID-19
Engage-IL 2.0 Building Age-Friendly Health Systems & Workforce

9 Innovative Programs

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Create Age-Friendly Communities Transforming the Alzheimer experience with a Mobile App

**Dementia Guide Expert™**

*Guia Experta Sobre La Demencia*  
치매 안내 전문가

**Download the FREE App now !!**
Available for iOS on Apple iTunes and for Android on Google Play

**IMPACT:**

App downloads/views: > 66,211

12 Countries: Australia, Brazil, Canada, China, Germany, Japan, Korea, New Zealand, Spain, Taiwan, U.K., U.S.

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Transforming the Alzheimer experience with a Mobile App

Dementia Guide Expert

2021 Accessible Inclusive design
Engage-IL 2.0  *Building Age-Friendly Health Systems & Workforce*

**9 Innovative Programs**

**4 primary objectives**

**Objective 1:** Build Age-Friendly Health Systems & establish *Dementia-Friendly Communities*

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Educate Interprofessional Healthcare Workforce with Online Technology and Student Fellowships

Online Accredited Learning in Interprofessional Geriatrics (OALIG)™

- Library of 27 Online geriatric training modules
- Our website (engageil.com) serves as a portal to our online program
- Modules offer Free continuing education credits to licensed professionals

IMPACT
- Total number of modules completed: **21,258**
- Total number of learner profiles: **5,956**

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Managing Chronic Conditions
Promoting wellness is integral to improving health and quality of life for older adults while assisting them to better self-manage their chronic illness. These modules promoting wellness Nutrition; Oral Health; Sleep Quality; Sexuality and manage common conditions: Common Acquired Hospital Complications; Managing Multiple Chronic Conditions; Pain Management; Drug Therapy in Older Adults; Dementia; Older Adults with Visual, Hearing and Cognitive Impairment in a variety of health care settings Transitional Care; Palliative Care.

Modules Addressing Psychosocial Needs
These modules address common negative consequences associated with psychosocial functioning and aging including Depression and Delirium of the Older Adult and Elder Abuse and Self-Neglect. The modules also promote wellness and improve quality of life by educating health professionals to address the psychosocial needs of older adults and families at the end of life End of Life and Hospice; The Dying Process.

Engaging Patients and Families
These modules connect the concepts of wellness with safety Fall Prevention, Driving Safety; Medication Management and community services Community Based Home Care. They educate health professionals to enhance patients’ relationships Health Literacy and Communication, while addressing the needs of families and caregivers Caregiver Burden.

Integrating Population Health
This module educates on the physiology of aging Process of Aging, changing healthcare systems Community Services; Access and Payment Solutions; Screening and Preventative Care and lifestyle Physical Activity and cultural aspects of aging LGBTQIA Older Adults and soon Addressing the Needs of Older Adult with Disabilities.
Summary

ENGAGE-IL has

- Assembled an **interprofessional team** of healthcare experts with the shared vision to enhance the care provided to **vulnerable populations and reduce health disparities**

- Developed **strong community partnerships** with government agencies, health care organizations, academic medical centers, and other stakeholders supporting programs to provide best care practices for vulnerable populations

- **Created multiple innovative products and programs** utilizing technology to reach a wide audience resulting in improved clinical proficiency and positive practice changes

- Shaped the future healthcare workforce through online interprofessional education, community healthcare programing to **address the needs of extremely vulnerable populations**

Valerie Gruss, vgruss@uic.edu

Visit: engageil.com

Thank You
National Task Group on Intellectual Disabilities and Dementia Practices (NTG)

Matthew P. Janicki, Ph.D.
University of Illinois at Chicago and the National Task Group on Intellectual Disabilities and Dementia Practices
mjanicki@uic.edu

Webinar segment
May 4, 2021
Speaker Background

*Research Associate Professor*, Department of Disability and Human Development, University of Illinois at Chicago

*Co-Chair*, National Task Group on Intellectual Disabilities and Dementia Practices

*Member*, Federal Advisory Council on Alzheimer’s Research, Care, and Services

*Principal investigator*, Longitudinal study of specialized dementia-related care group homes designed for adults with intellectual disability

*Formerly*, Director for Aging and Special Populations for the New York State Office for People with Developmental Disabilities
The National Task Group is a national non-profit organization with a charter to ‘advocate, provide technical and clinical assistance, disseminate information, aid with research, and create and provide educational and technical matter related to dementia among adults with intellectual disability’

- We aid in defining best practices that can be used by agencies when delivering supports and services to adults with intellectual disability affected the various dementias
- We developed ‘first-instance’ early detection / screening instrument and working on a treatment tracking instrument
- We produce educational materials of use to families, people with ID, and providers of services
- We engage in discussion on public policy with respect to dementia as it affects adults with intellectual disability
- We collaborate with federal and national organizations on matters related to ID and dementia

National Alzheimer’s Project Act
- NAPA - signed into law in 2011
- Required submission of an annual Alzheimer’s Plan to Congress – from 2012 to 2025

NTG Key Activities...
- ‘Thinker’ report
  - national plan for dementia and ID
- Early detection-screening instrument
  - NTG-EDSD
  - SAFD
- Practice guidelines
  - Community supports
  - Health advocacy
  - Assessment
- Training and education activities
  - National education curriculum on dementia and ID
  - Training workshops and webinars
- Family supports
  - Informational matter
  - Support group
- Participation
  - Federal NAPA Council
  - DS-Consortium (NICHD)
Activities of the NTG that relate to ‘brain health’

- Collaboration with leading US Down syndrome associations and organizations in developing COVID-19 and ID informational materials
- Studying impact of COVID-19 among providers
- Creating resource guides for family caregivers ... to improve care, health, and nutritional outcomes
- Producing informational materials to enhance supports and services to affect lifestyle
- Creating resources for families to better understand dementia and its impact
- Offering trainings for agency personal on dementia
- Being a partner in the Health Matters™ Program’s CDC grant on brain health
Socio/clinical findings about COVID-19 and Implications for brain health

• Reduction or removal of support, increased social isolation (compounded by digital exclusion), and mental health issues had an impact on people with ID (SCPLD, 2020)

• During lockdown periods and related social isolation, measures showed an increase of depressive symptoms and a worsening in functional status in adults with ID (Villani et al., 2020)

• Persons with ID experienced massive disruption in health, home, and community services, increasing existing inequities in health care (Nygren & Lulinski, 2020)

• Anecdotal data indicated high rates of infection among adults with ID and tests showed positivity for antibodies (even when symptoms were not noticed) – with possible residual effects

• General population research already reporting some post-infection adverse neurological and psychiatric outcomes (Taquet et al., 2021)

Implications for Brain Health

• Short term reactive effects due to lockdowns, dramatic changes in routines, stress from infection, and transfer of anxiety from others in home

• Long term effects still to be determined, but there may be some residual neurological effects that affect behavior and brain health (‘post-COVID stress disorder’)

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Policy and Practice implications

- Strengthening commitment among stakeholders to lifelong emphasis on health – with the commonality of mitigating dementia
- Cross-cutting collaborations across population sectors around intellectual disability and lifelong health focus
- Increasing understanding of lifelong lifestyle and lived experiences on enhancing later-life health and minimization of cognitive impairment
- Incorporating within practices, policies and regulatory environments emphasis on healthy lifestyle and related practices to affect brain health
- Enriching written and oral structures that can serve to inform and enhance positive lifelong practices by persons with intellectual disability
- Incorporating ‘brain health’ into national and state dementia plans
Healthy Brain Initiative for People with IDD and Dementia: A Lifespan Approach

Kathryn Service RN, MS, FNP-BC, CDDN
National Task Group on Intellectual Disabilities and Dementia Practices
What’s the Connection?

- BRAIN HEALTH
- Dementia
- Intellectual Disabilities
In practice:

• Lifespan approach
• Shift in “Philosophy” ≠ Shift in Respect & Dignity
• LIVING with dementia
• Person centered yet relationship centered = Partnership
• Value of Knowledge
The Lifespan

BRAIN HEALTH matters throughout!
It’s never too late!
Changing Focus in ID Support

BEFORE the Diagnosis
- Learning New Skills
- Independence & Autonomy Valued and Encouraged
- Behavior Modification
- MORE Choices, Stimulation, Community Outings
- Focus on Doing

AFTER the Diagnosis
- Maintain Function & Prevent Excess Disability
- "Hands-on" Personal Care
- Predictable, Consistent Routine
- Failure-free Choices
- Social Interactions!
- Focus on Feeling & Being

Service, 2002, 2017
Living with Dementia

- The Value of the Life Story
- Remaining Active and Engaged

1. Physical Exercise
2. Food & Nutrition
3. Medical Health
4. Sleep & Relaxation
5. Mental Fitness
6. Social Interaction
Brain Health is both person-centered yet relationship centered

- For the person with Intellectual Disabilities
- For the Care Partner
- When?
Educate and Empower, Policies and Partnerships, and Workforce Development

THE NTG WEBSITE:
MY THINKER'S NOT WORKING
FREQUENTLY ASKED QUESTIONS
GUIDELINES FOR EVALUATION AND MANAGEMENT OF DEMENTIA IN ADULTS WITH ID
GUIDELINES FOR STRUCTURING COMMUNITY CARE AND SUPPORTS FOR PEOPLE WITH ID AFFECTED BY DEMENTIA
GUIDELINES FOR DEMENTIA-RELATED HEALTH ADVOCACY FOR ADULTS WITH ID AND DEMENTIA

www.the-ntg.org
Person/Family Centered Resources

Aging and Down Syndrome

Alzheimer's Disease & Down Syndrome
A Practical Guidebook for Caregivers

Intellectual Disability and Dementia: A Caregiver's Resource Guide for Rhode Islanders

Jenny's Diary
A resource to support conversations with people who have learning disability
www.learningdisabilityanddementia.org/jennys-diary.html

Ann has Dementia
https://booksbeyondwords.co.uk/bookshop/paperbacks/ann-has-dementia
Questions?

- Do you have any issues and needs for brain health?
- What types of brain health resources/information would be useful?

For more information contact:
Jasmina Sisirak, PhD, MPH
jisirak@uic.edu
Join us for Webinar 2: May 25th, 2021 (1pm-2pm CT)

Brain Health Across the Lifespan for People with Intellectual and Developmental Disabilities

Lucille Esralew, PhD, NADD-CC
Office of Statewide Clinical Services, Clinical Services Branch for the California Department of Developmental Services