

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

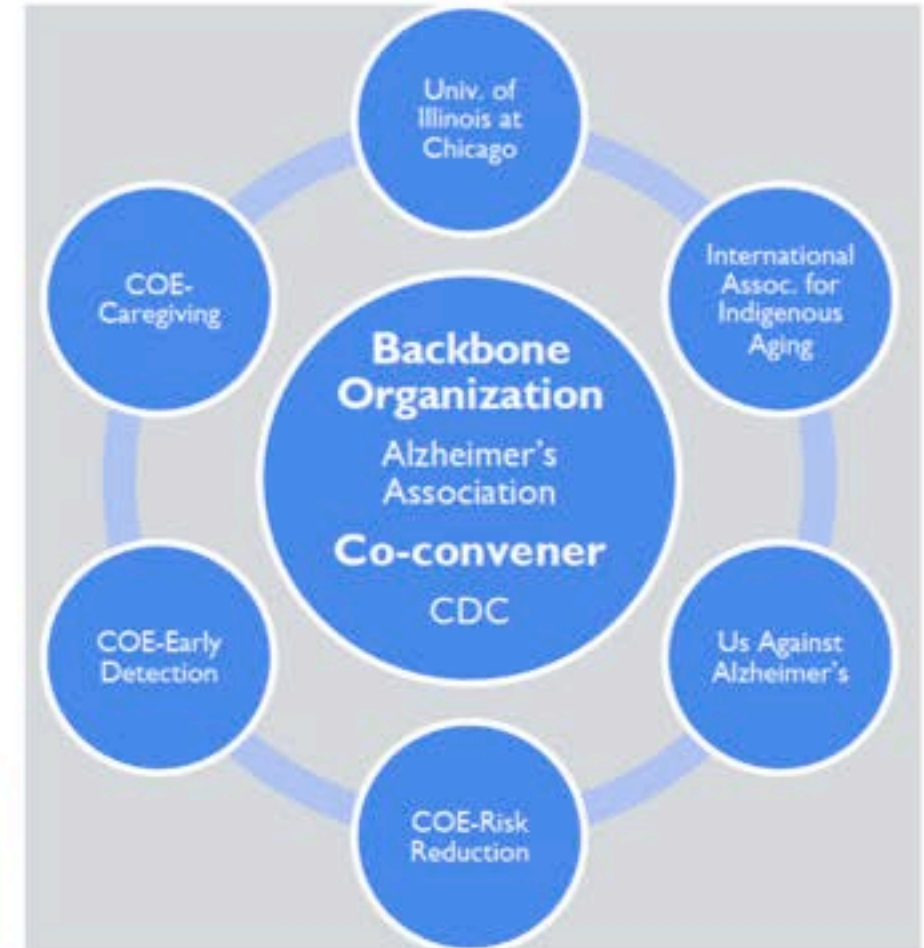
- HealthMatters Program, University of Illinois at Chicago (Beth Marks, PhD, RN, FAAN and Jasmina Sisirak, PhD, MPH)
- National Task Group on Intellectual Disabilities and Dementia Practices (NTG) (Matthew Janicki, PhD and Kathryn Service, RN)
- ENGAGE-IL HRSA Geriatrics Workforce Enhancement Program (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)



**HEALTHY BRAIN
INITIATIVE**



**CENTERS FOR DISEASE
CONTROL AND PREVENTION**

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
13. Illinois Council on Developmental Disabilities (ICDD)
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)
19. National Task Group on Intellectual Disabilities and Dementia Practices
20. Project SEARCH
21. Special Olympics (SO)
22. The ARC



Healthy Brain Initiative

Promote brain health for persons with IDD and their supports¹

Social Determinants of Health



¹WHO

²Cleveland 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.

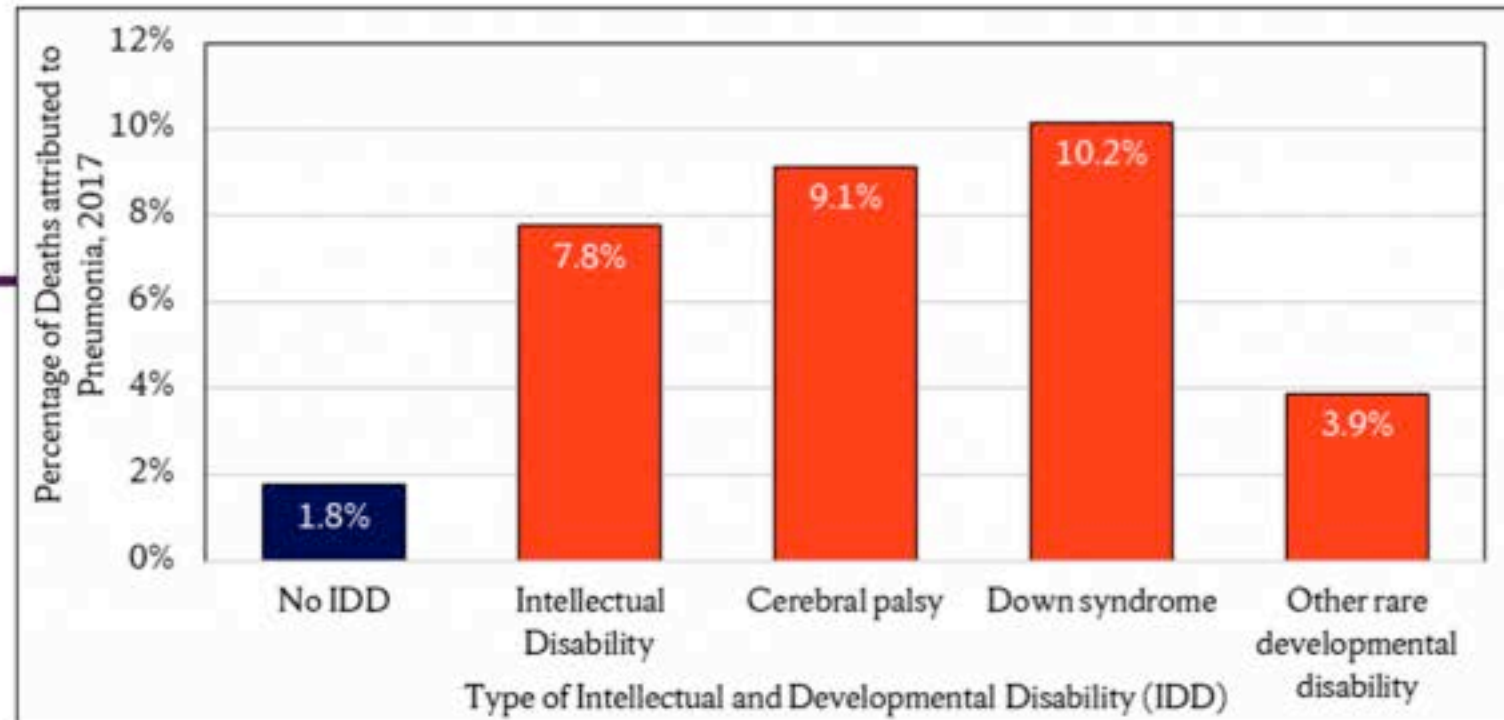
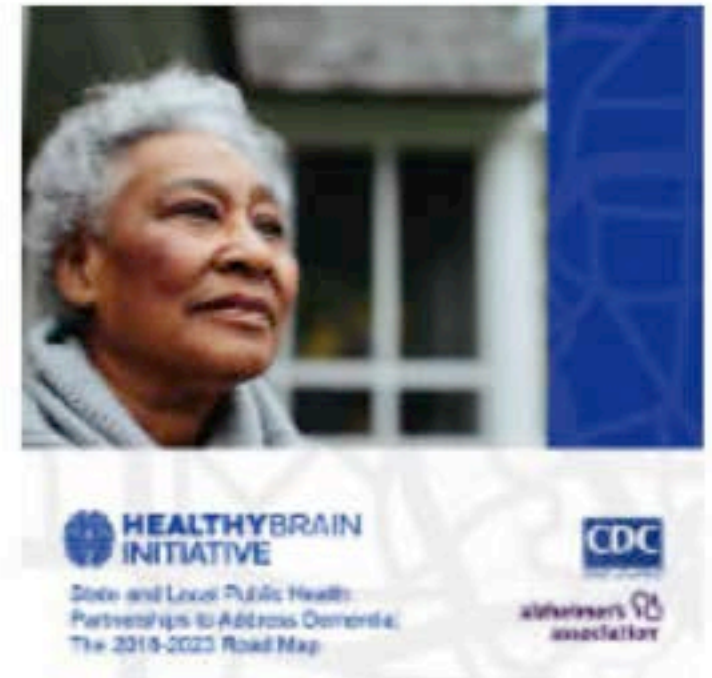


Figure 1. A Large Share of all deaths among Individuals with Intellectual and Development Disability are Attributable to Pneumonia

Data Source: National Center for Health Statistics, National Vital Statistics System, 2017 (among adults age 18 and older)

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



Brain Health
You Can Make a Difference!

- 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
 - 53 community organizations in 23 states
 - 41 continued both training and instructing (November to January 2021)
 - 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

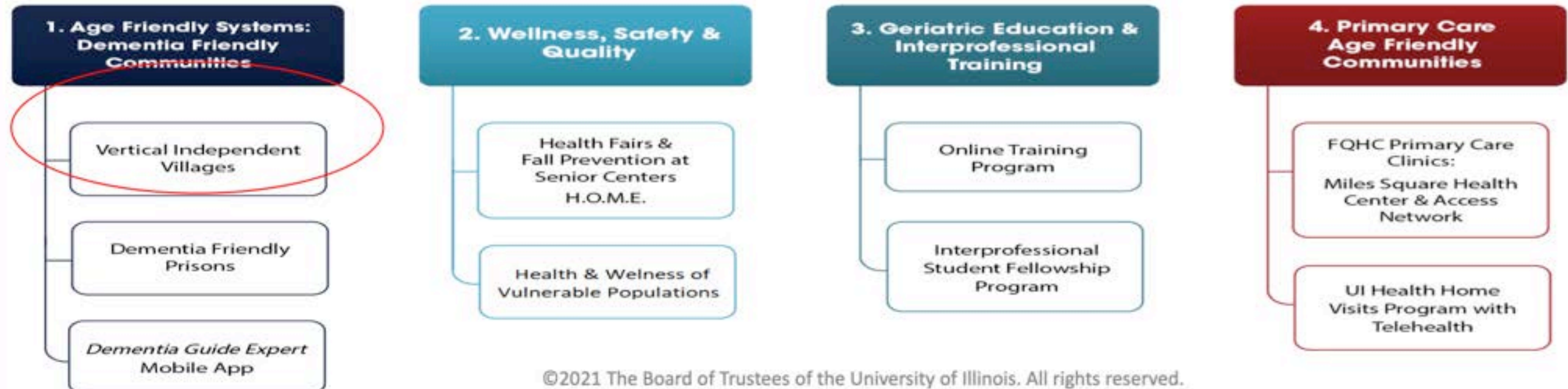
4 primary objectives

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



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

Create Age-Friendly and Dementia Friendly Communities



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

UIC

*Create Age-Friendly and
Dementia Friendly Communities*



Engage-IL 2.0 Building Age-Friendly Health Systems & Workforce

9 Innovative Programs

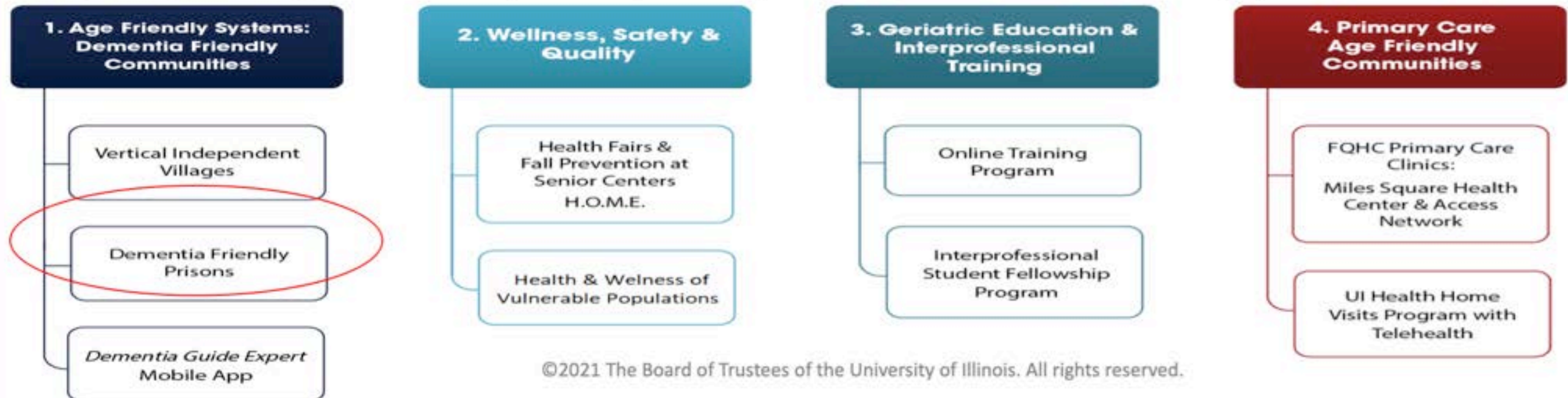
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Create Age-Friendly Communities

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*”

Wardens’ 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

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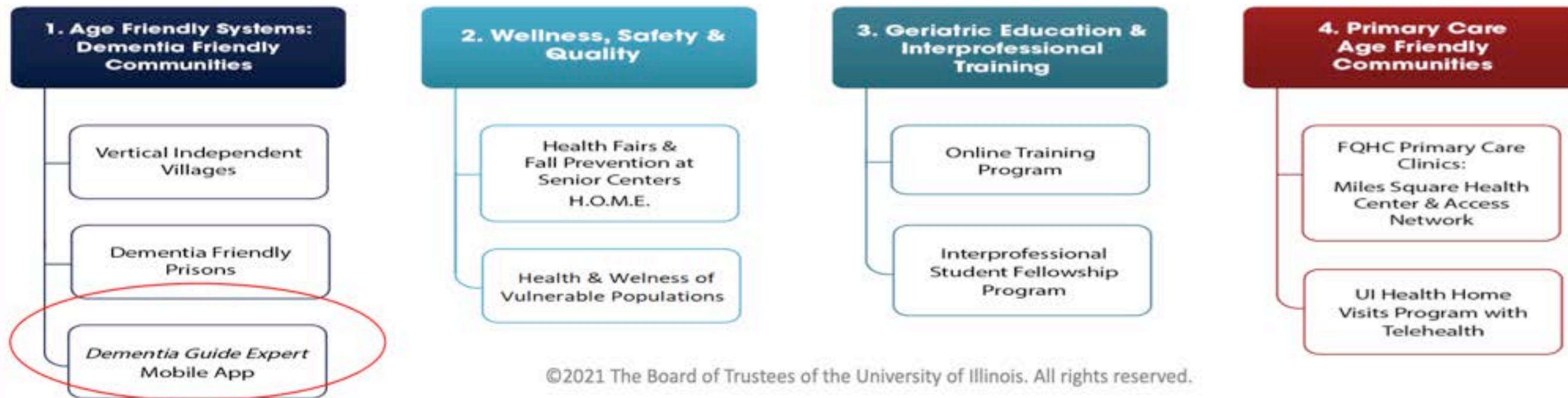
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Create Age-Friendly Communities Transforming the Alzheimer experience with a **Mobile App**

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.



Available in Spanish



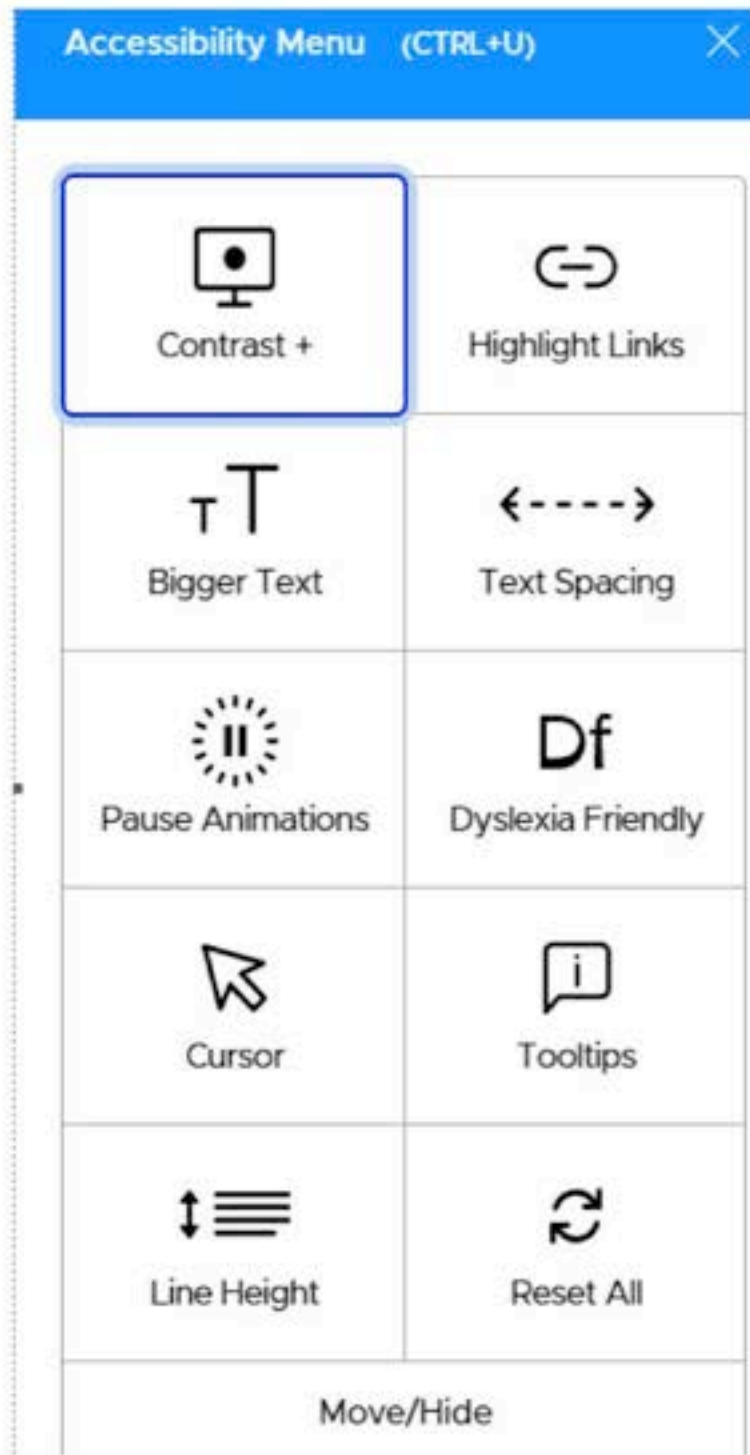
Available in Korean



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

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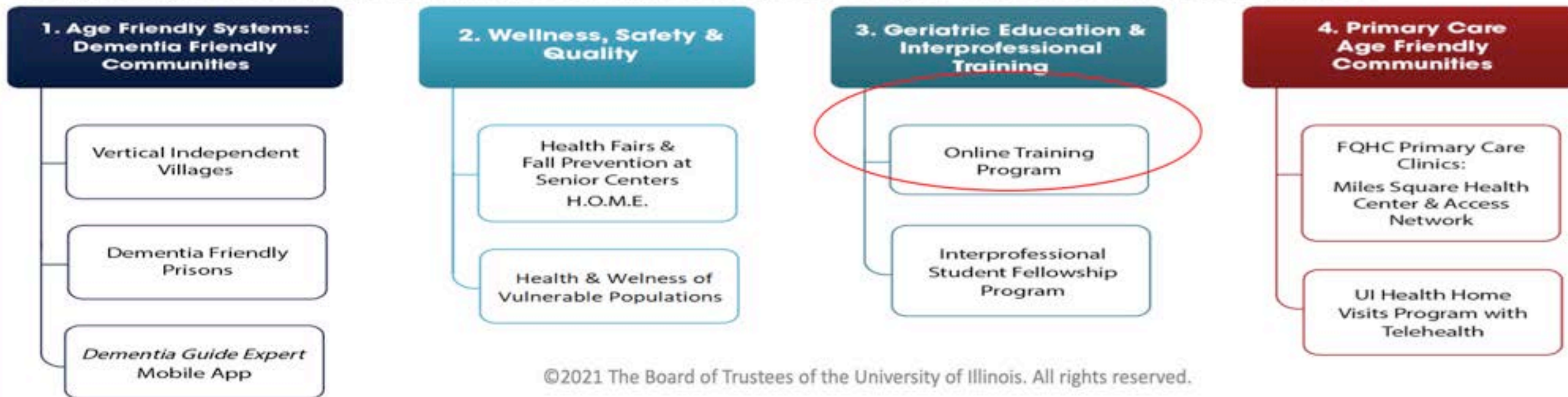
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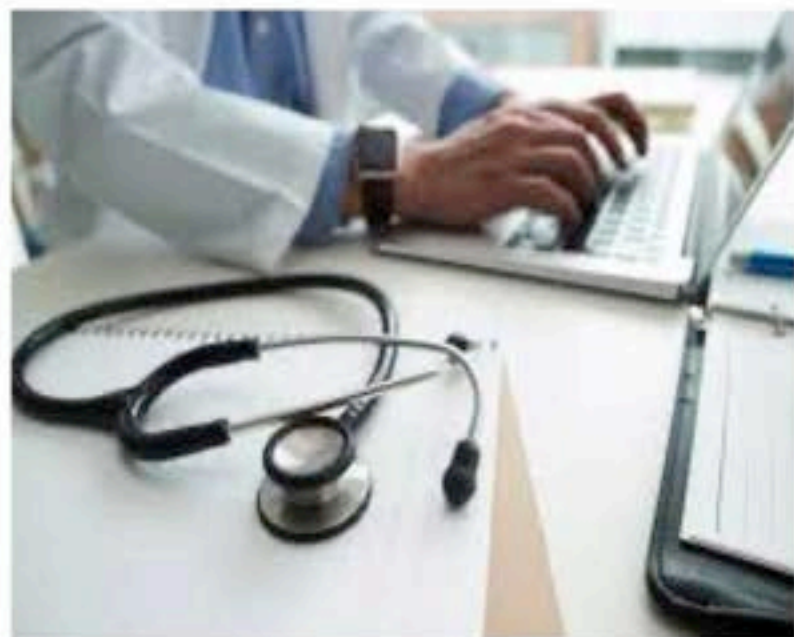
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Educate Interprofessional Healthcare Workforce with Online Technology and Student Fellowships



Online Accredited Learning in Interprofessional Geriatrics (OALIG)TM



- 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**



Online Accredited Learning in Interprofessional Geriatrics (OALIG)TM

engageil.com

27 Online Learning Modules Promoting Wellness:

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 programming 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



National Task Group
on Intellectual Disabilities
and Dementia Practices

www.the-ntg.org

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*')

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

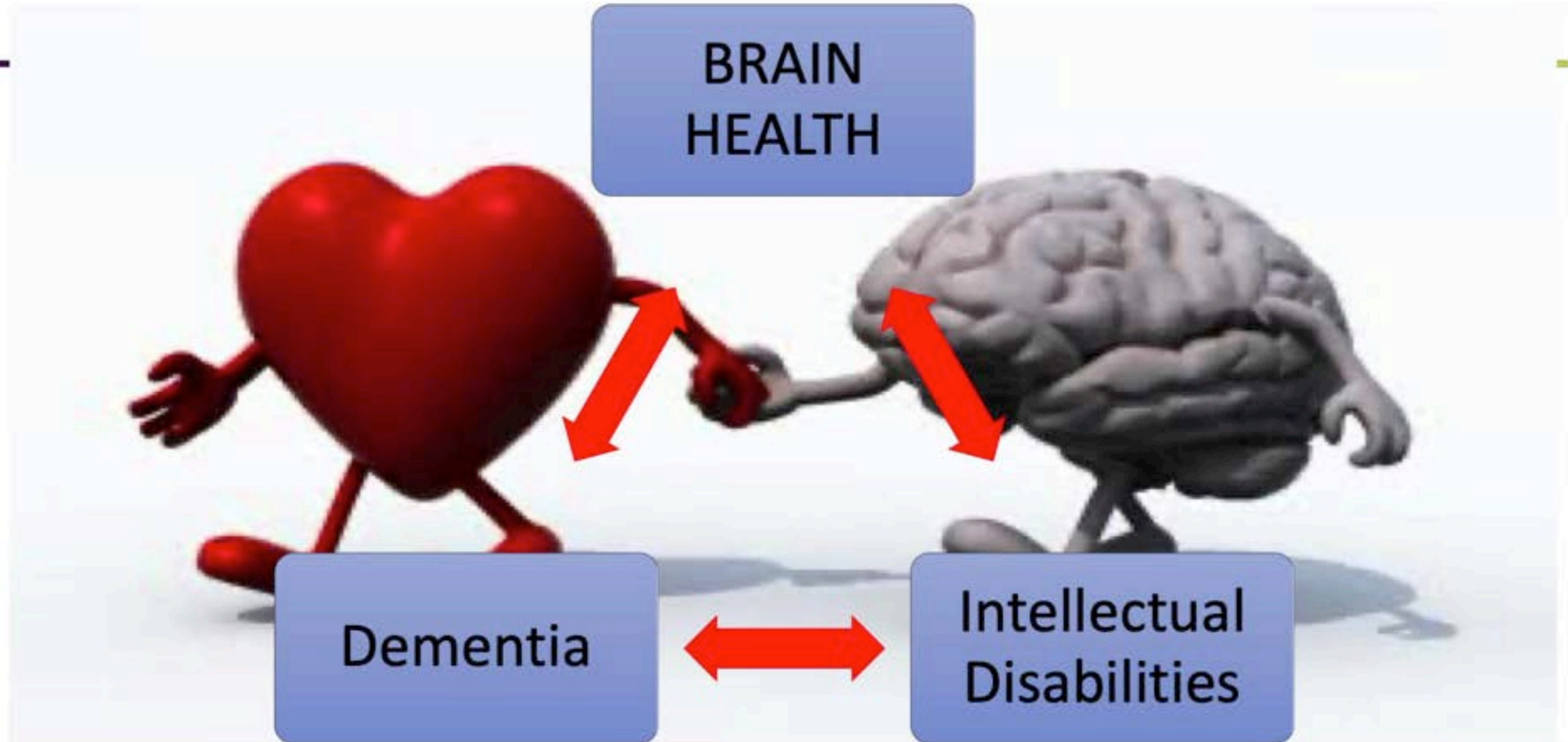
Incorporating 'brain health' into national and state dementia plans

Healthy Brain Initiative for People with IDD and Dementia: A Lifespan Approach

Kathryn Service RN, MS, FNP-BC, CDDN

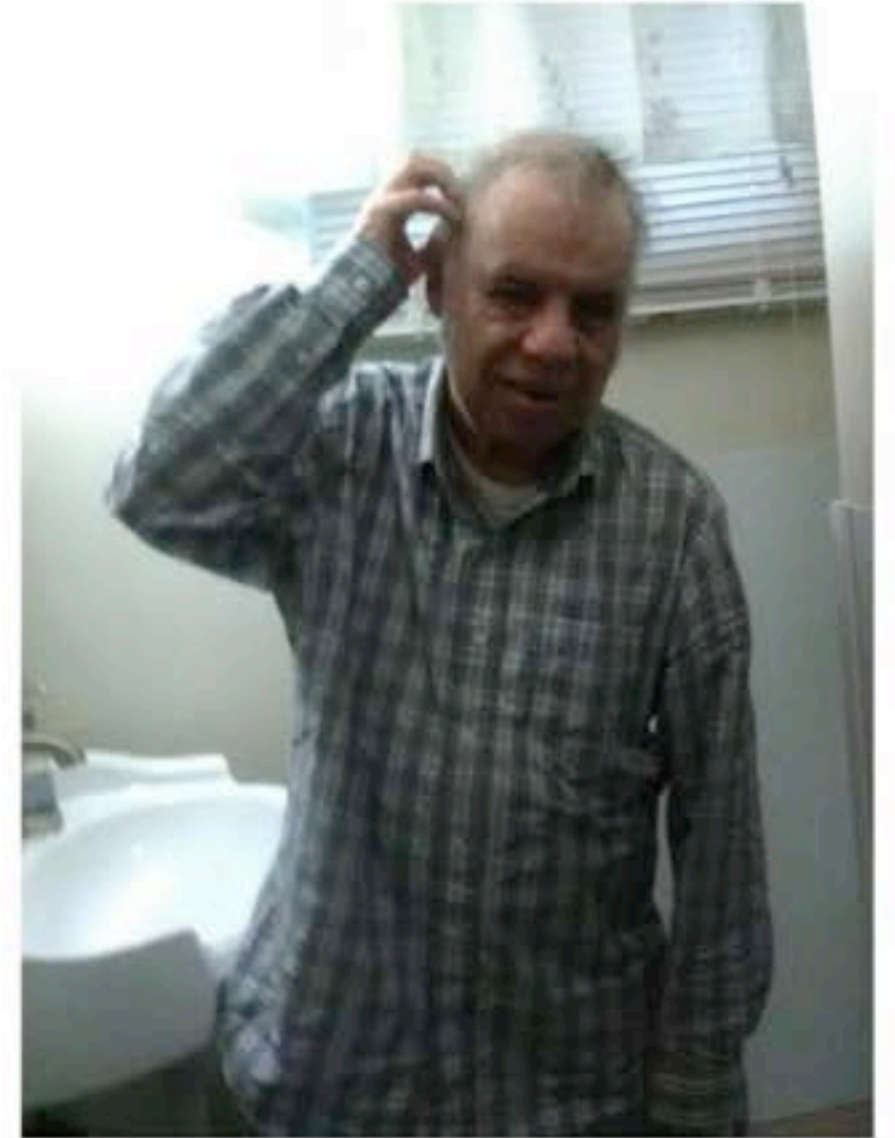
National Task Group on Intellectual Disabilities and Dementia Practices

What's the Connection?



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!



1 Physical inactivity

2 Smoking

3 Excessive alcohol consumption

4 Air pollution

5 Head Injury

6 Infrequent social contact

7 Less education

8 Obesity

9 Hypertension

10 Diabetes

11 Depression

12 Hearing impairment

12 dementia risk factors

Source: Livingston et al. A, et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission

www.alz.co.uk



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



Jenny's Diary



A resource to support conversations
about dementia with people who
have a learning disability

Karen Watchman,
Irene Tuffrey-Wijne, Sam Quinn

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

A HEALTH & WELL-BEING GUIDEBOOK



ndss

<http://www.ndss.org/wp-content/uploads/2017/11/Aging-and-Down-syndrome.pdf>



Alzheimer's Disease & Down Syndrome

A Practical Guidebook for Caregivers



ntg

alzheimer's association

ndss

http://www.ndss.org/wp-content/uploads/2017/11/NDSS_Guidebook_FINAL.pdf

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



Seven Hills
Rhode Island

ntg
National Task Group
on Intellectual Disability
& Dementia Prevention

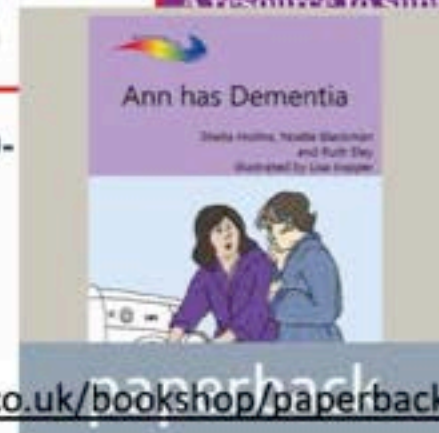
<http://www.sevenhills.org/uploads/SHRI-IDD-ADRD-Resource-Guide.pdf>

www.learningdisabilityanddementia.org/jennys-diary.html

Jenny's Diary



A resource to support conversations
with people who
have an intellectual disability



Ann has Dementia

Sheila Collins, Health Educator
and Ruth Day
Illustrated by Lisa Ingle

by
Liz Ingle, Sam Quinn

<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

jsisirak@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