

Enhancement of Geriatric Care for All: Resources for Older Adults with Intellectual and Developmental Disabilities

ENGAGE-IL 2.0™

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Dr. Gruss has no conflicts of interest

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- Health Resources and Services Administration (HRSA)
- Center for Disease Control (CDC)
- AWHONN
- National Institute of Health (NIH)





Land Acknowledgement

The University of Illinois System -- with its universities in Urbana-Champaign, Chicago, and Springfield -- rests on the land of multiple native nations. These lands were the traditional birthright of indigenous peoples who were forcibly removed and who have faced two centuries of struggle for survival and identity in the wake of dispossession. We hereby acknowledge the ground on which we stand so that all who come here know that we recognize our responsibilities to the peoples of that land and that we strive to address that history so that it guides our work in the present and the future.

The Land Acknowledgement Statement below is a respectful public acknowledgement of the traditional guardians of the land at events or gatherings, either by the host of ceremonies or a designee.

Land Acknowledgement Statement I would like to begin today by recognizing and acknowledging that the U of I System carries out its mission in its namesake state, Illinois, which includes ancestral lands of the Peoria, Kaskaskia, Piankashaw, Wea, Miami, Mascoutin, Odawa, Sauk, Mesquaki, Kickapoo, Potawatomi, Ojibwe, and Chickasaw Nations. We have a responsibility to acknowledge these Native Nations and to work with them as we move forward as a vibrant, inclusive institution.

Pronunciations:

Peoria (Pea-Or-E-ah)
Kaskaskia (Kahs-KAHS-kee-ah)
Piankashaw (Pea-AN-kah-shah)
Wea (Way-ah)
Miami (My-Am-E)
Mascoutin (Mah-SCOH-tin)
Odawa (Oh-DAH-wah)
Sauk (SAH-uk)
Mesquaki (Meh-skv-AH-kee)
Kickapoo (KICK-a-poo)
Potawatomi (Pot-tah-WAH-tah-mee)
Ojibwe (Oh-JIB-way)
Chickasha (Chi-KAH-shah)

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Learning Objectives

Upon completion of this session, participants will be better able to:

1. Define Brain Health Across the Lifespan
2. Describe the role of ENGAGE-IL as a Geriatrics Workforce Enhancement Program (GWEP) to increase access to care and improve health outcomes for older adults with IDD
3. Introduce the ENGAGE-IL 27 online education modules including new modules specific for people with IDD and describe who can benefit from taking these modules and how they can help to improve health outcomes of older adults with IDD
4. Review ENGAGE-IL strategies that can maximize engagement by people with IDD and their supports in Brain Health strategies



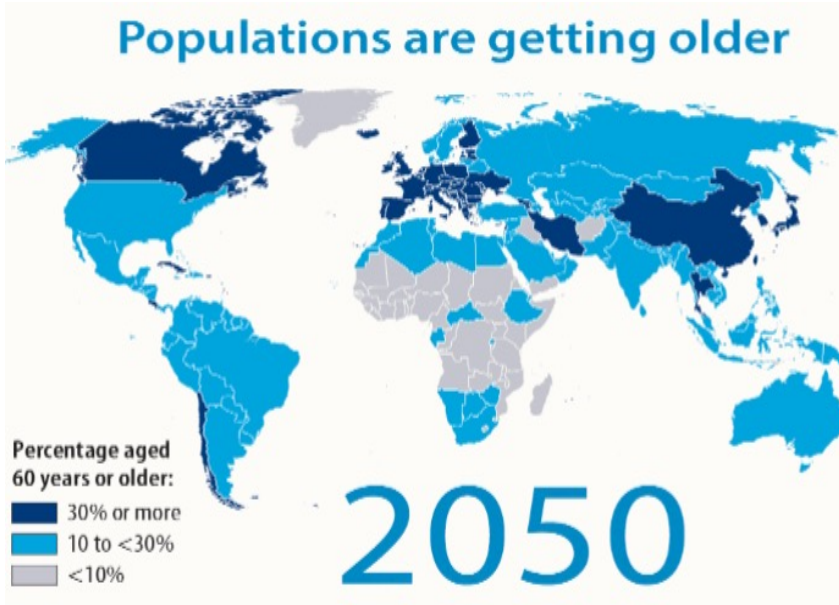
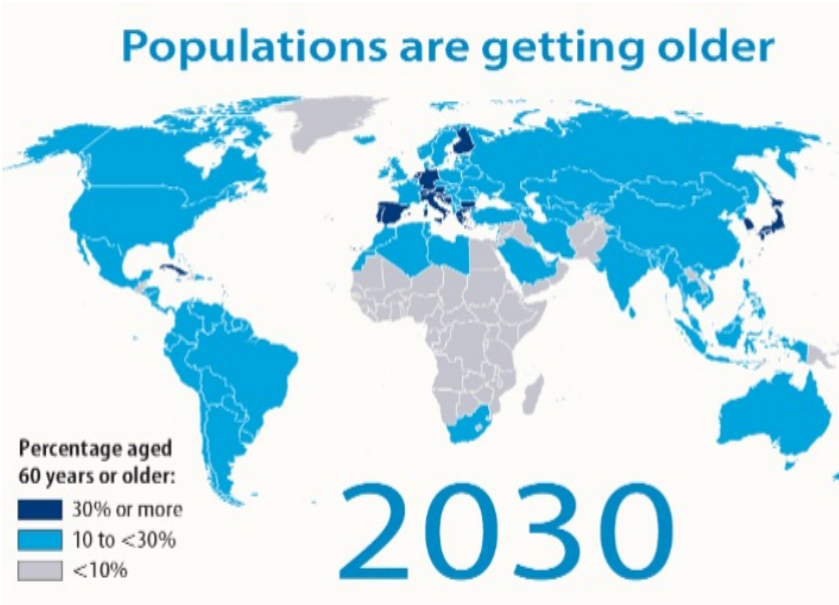
Learning Objective 1

Define Brain Health Across the Lifespan



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Populations are getting older

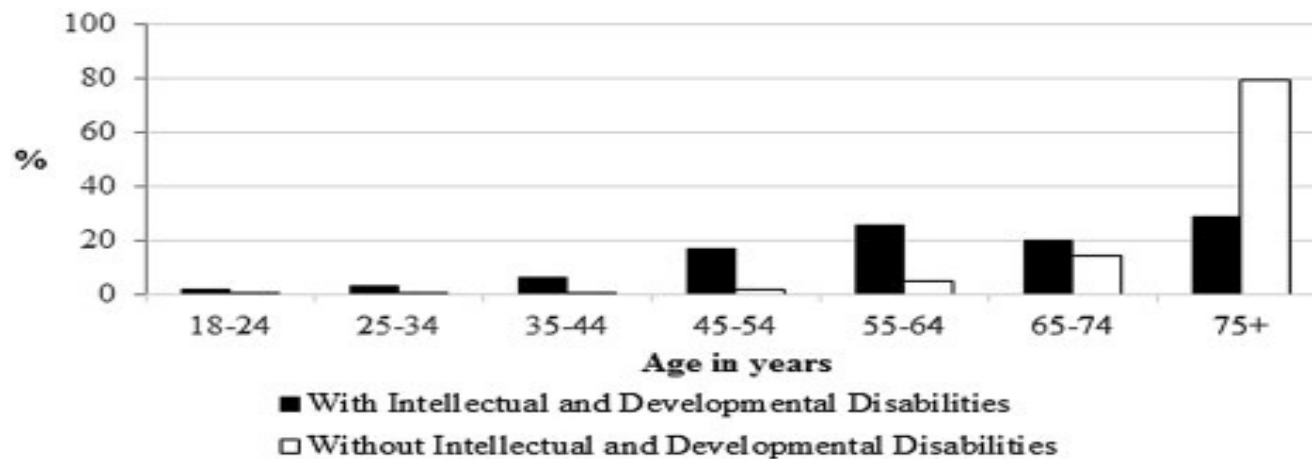


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IDD Increasing Aging Population

641,000 adults aged 60+ with IDD

Number projected to double to 1,242,794 by 2030
(coinciding the aging population) (Heller, T. (2011))

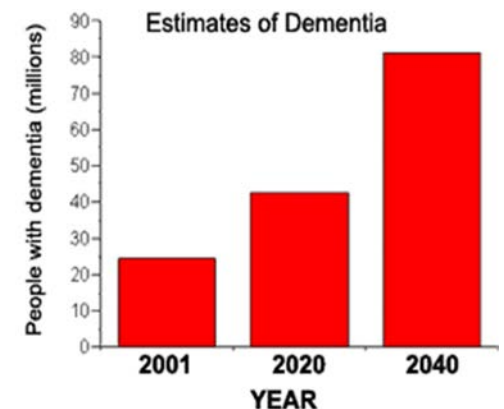


Dementia and the Aging Population

Over **5.3 million** people in U.S. have dementia

Alzheimer's disease is the most common type of dementia 60-80% of dementia cases

By 2050, the number of older adults with Alzheimer's is projected to nearly **triple** to **13.8 million** and it could be as many as 16 million!



Dementia is one of the **greatest healthcare burdens** contributing to **dependence and disability**

Dementia

No cure or disease-modifying treatments at this time; however, appropriate care has the potential for improving *quality of life*

Life expectancy:

- **Typically, 6-8 years after diagnosis made;** however, some persons live up to 20 years
- Older age at onset associated with earlier mortality
- Comorbidities decrease life expectancy

The Challenge:

There is an urgent need for dementia education of clinicians, patients and caregivers to improve their ability to better understand dementia, thereby enhancing competence to make **healthy brain lifestyle changes**. The approach should be “dementia positive” and focus on quality of life.



Dementia and Intellectual Disability

What is known

People with Intellectual Disability have **same rate** of dementia as general population

- Some people with Intellectual Disability have **higher rates** (e.g., Down syndrome, head injury)
- Some % of any adult client pool will be affected
- Early interventions can aid in adapting to changes and prolonging lucid periods
- Effects of dementia will be progressive and eventually lead to death

What is not known

- Who will be affected?
- How pronounced will be early changes?
- How dramatic will be the changes in function?
- What other diseases or medical conditions may be co-incident?
- What particular dementia-related behaviors will be more evident?
- How long will person live after diagnosis?

Key Differences in Adults with Intellectual Disability and Dementia

ONSET & DURATION: Some adults have early onset and shorter duration

- Early onset is found in adults with Down syndrome and head injury
- Most adults with Down syndrome survive less than 7 years after the onset of dementia

SYMPTOM PRESENTATION: Differences in symptom presentation

- Most early symptoms are the same, except in Down syndrome where there are more notable early personality changes

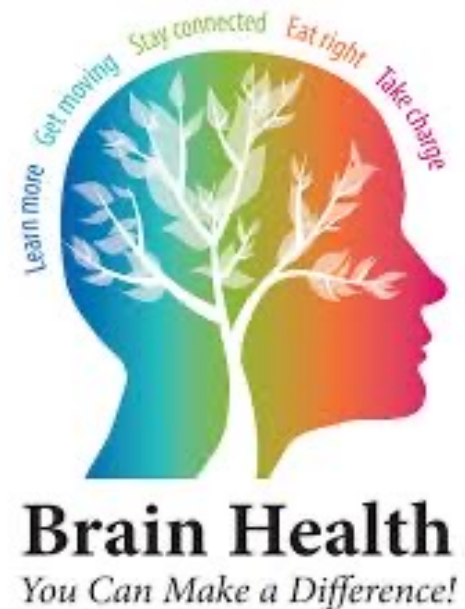
ASSESSMENTS: Assessments are conducted differently

- Standard tests used with typical adults with dementia are not useful – With adults with intellectual disability need to use comparisons of the same individual over time

Definition of Brain Health

“Brain Health is an emerging and growing concept that encompasses neural development, plasticity, functioning, and recovery across the life course.

Good brain health is a state in which every individual can realize their own abilities and optimize their cognitive, emotional, psychological and behavioral functioning to cope with life situations”



WHO (2021). Retrieved from www.who.int/health-topics/brain-health#tab=tab_1.

HBI Community-of-Practice with a “One Stop Space”

1. HealthMatters™ Program

- *Accessible, interactive website*
- *Healthy Brain Webinar Series*
- *Virtual Coach HealthMatters Instructor Training and 12-Week Program for People with IDD*

2. ENGAGE-IL™ GWEP

- 2 CEU Modules on brain health for people with IDD
Pillars of Brain Health for people with IDD within existing 27 CEU modules
- Dementia Guide Expert App

3. Healthy Brain Initiative Road Map for People with IDD

- Nutritional and Dietary Guidelines
- Settings-Based (Home and Work) Solutions for Brain Health and Dementia Positive Memory Care
- Brain Health Risk Appraisal



Learning Objective 2



Describe the role of ENGAGE-IL as a Geriatrics Workforce Enhancement Program (GWEP) to increase access to care and improve health outcomes for older adults with IDD

Health Resources & Services Administration Geriatrics Workforce Enhancement Program (GWEP)

GWEP: An interprofessional collaborative education and practice initiative to enhance care of older adults
HRSA Grant # U1QHP28730



[Engageil.com](https://engageil.com)

Enhance health care professionals' knowledge and competence to integrate geriatrics into primary care to improve health outcomes for our increasing older adult population



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 and health science student scholarship



Visit: engageil.com



HRSA Geriatrics Workforce Enhancement Program

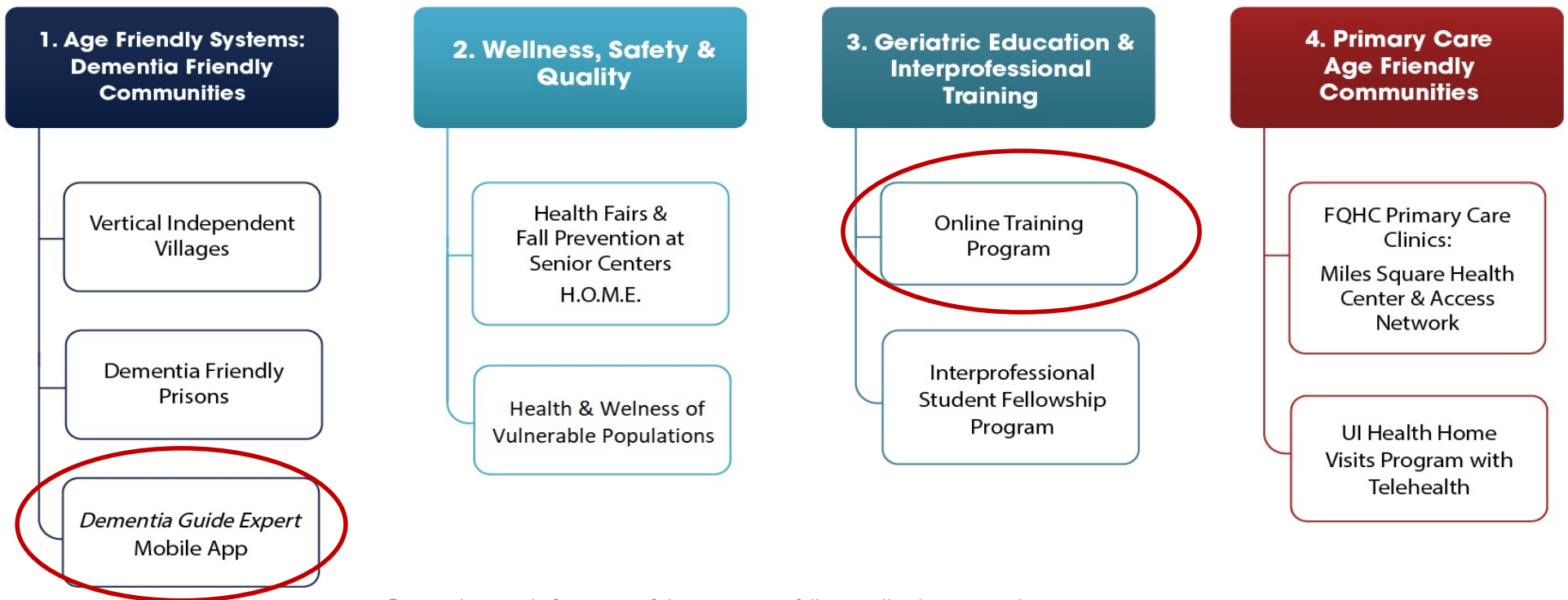
July 1, 2015 – June 30, 2019, \$3.2 million

July 1, 2019 – June 30, 2024, \$3.75 million GWEP

GWEP HRSA Grant # U1QHP28730



9 PROGRAMS



EngageIL Delivers Community Based Wellness Programs for Vulnerable Populations

Senior Centers Wellness Programs (including health screenings)

Delivered in collaboration with community partners at 17 Senior Centers throughout Chicagoland. Hundreds of Seniors screened for high-risk medications, fall risk, hypertension, depression and cognitive impairment. **IMPACT:** > **200 older adults/per month** (pre-COVID-19)

Training Interprofessional Primary Care Professionals at FQHC clinics

- Trained staff on *Medicare Annual Wellness Visits-The 4Ms* [What Matters; Medication; Mentation; Mobility] screening program and a Falls Prevention program
- Action Plan to establish Mile Square as a nationally certified “*Age-Friendly Action Community*”



Optimizing care for homebound older adults through Health Home Visits

- Developed evidence-based protocol for increasing Medicare Annual Wellness Visits and health screenings of homebound older adult patients

New Funding: T1M GWEP Award (T1MHP39059) **COVID-19 Telehealth Award** to implement telehealth into homes of homebound older adults



EngageIL Delivers Community Based Wellness Programs for Vulnerable Populations

Vertical Independent Villages™

Collaborating with the City of Chicago, Age-Friendly Commission, we scaled up our Engage-IL program with the development and implementation of a city-wide dementia training program for building management staff caring for older adult residing in their buildings... Creating Vertical Independent Villages which are age-friendly communities

IMPACT:

Trained over 183 building managers who engage with over 30,000 older adults

Transitioned to virtual trainings due to COVID-19



Engage-IL Delivers Community Based Wellness Programs for Vulnerable Populations

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*”
Transitioning to virtual training due to COVID-19

The Older Inmate



U.S. prisons are experiencing a *graying* of the incarcerated population

- 1999-2016 number of people 55 or older in state and federal prisons increased by 280%

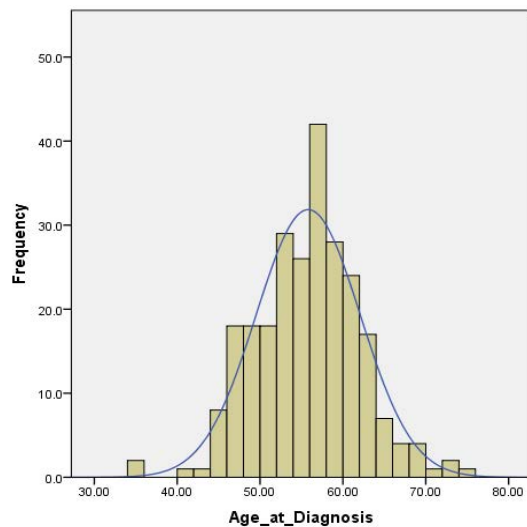
The Bureau of Prisons (BOP) defines “older inmates” as inmates **aged 50 and older**

- This definition is based on studies indicating inmates’ physiological age **averages 10-15 years older** than their chronological age, due to the combination of stresses associated with incarceration and pre-incarceration conditions (including substance abuse)

- **OLDER PRISONERS** now represent 10% of the U.S. state prison population and **18% of Illinois prison population**
- **OLDER PERSONS WITH IDD** comprise 2-3% general population but 4-10% prison population
(Petersilia, 2000)
- **PRISONERS WITH DEMENTIA**
Ranges: 1% - 44% with highest percentage in prison specifically for older prisoners (Maschiet et al, 2021)

Improving health outcomes for older adults with IDD

Begins with knowing the facts about intellectual disability which leads to projecting needs



*Graph shows the range in age at dx - this affects survival and years needing dementia-capable services

Study: 320 adults with DS in the UK

- Mean age diagnosis of dementia:
55.8 years
- Median survival time after diagnosis:
3.78 years
- Median age at death: ~ 60 years
- Survival time was associated with age of diagnosis, severity of ID, history of seizures. Older age at dx was predictive of shorter survival

- These study data provide a basis for understanding the population of adults with intellectual disability – understanding select factors can aid in developing and providing services
- Knowing how long adults diagnosed with dementia may survive can help with planning for stage specific services and housing, and training staff for stage-related care
- Also, can help in initiating screening and surveillance for signs of MCI or dementia

Improving health outcomes for older adults with IDD begins with knowing the facts – Supporting adults with IDD and dementia **at home**

- Persons with intellectual disability who live with parents – and develop dementia – can pose new challenges for parents, as
 - Behavior will deteriorate
 - Person may remain ambulatory for a prolonged time, but eventually become non-ambulatory
 - Physical needs will become more prominent
- Aging parents may be less capable of continuing to provide care at home
- Situation may lead to crisis at home
- On plus side, care at home enables continuity with familiar setting and people
 - Family commitment to supporting aging and problems associated with decline
 - Value enabled if family gets supports for continued home care (respite, home modifications, aides to help primary caregiver, financial assistance)
 - Living at home usually provides safety and security



Differences in families supporting IDD adults with dementia at home

Lifelong caregivers

- Have different experiences from later-life caregivers with respect to adaptation, caregiver roles, and drawing upon networks of support
- Are able to access public support for extended caregiving and receive assistance with respite
- Receive information on aging-related caregiving from formal providers and governmental agencies
- Are 'career' caregivers, with extensive experience in providing supports and adapting to the daily 'ups and downs'
- Have knowledge and experience with public, social, and health care services



Source: Heller, Scott & Janicki, 2018

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Family Caregivers

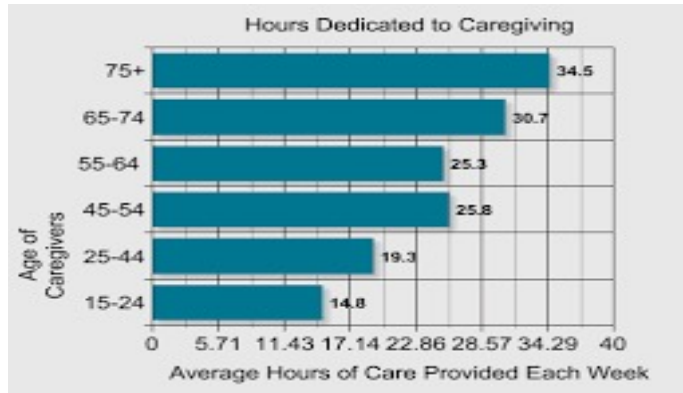
75% of IDD persons reside at home (Heller, T., 2011)

52% caregivers spend at least 40 hours/week

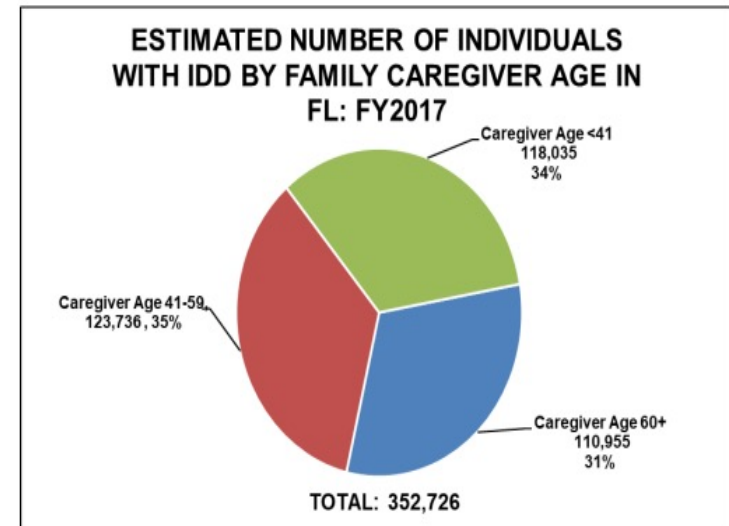
(Heller, T., 2011)

supporting family member with IDD

(U Of Minnesota- national alliance for caregiving/AARP study)



25% family caregivers are over 60 years



The State of the States in IDD, Data Brief, 2019
<https://fddc.org/wp-content/uploads/2021/04/State-of-the-State-Report.pdf>

Learning Objective 3

Introduce the ENGAGE-IL 27 online education modules including new modules specific for people with IDD and describe who can benefit from taking these modules and how they can help to improve health outcomes of older adults with IDD





Information Technology

A mechanism for reaching everyone and providing evidence-based information which is convenient and affordable (free)

Online Learning Modules

- ✓ Library of over 27 modules
- ✓ Evidence based content
- ✓ Flexible program, accessible (online)
- ✓ Cost-effective (free)

Take one or all modules

Access modules at:

engageil.com



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Design: Key elements and strengths of an online learning

Elements of an innovative approach using emerging technologies to positively impact and improve training:

✓ Evidence based content on variety of geriatric topics

✓ Flexible program, accessible (online)

✓ Cost-effective (free)



✓ Offer free continuing education credits for medicine, nursing, pharmacy, social work, occupational therapy, physical therapy, speech therapy, and public health professionals

Key elements

Scalability: Online library of over 27 geriatric educational videos

- Caregiver Burden
- Common Acquired Hospital Complications
- Communication Among Patients & Practitioners
- Community-Based Interprofessional Home Care
- Community Services: Access & Payment Systems
- Dementia: Patient-Centered Dementia Care (1 hour)
- Depression and Delirium
- Driving Safety of the Older Adult
- Drug Therapy in Older Adults
- The Dying Process
- Elder Abuse and Self-Neglect
- End of Life: Hospice and Advance Directives
- Fall Prevention
- Geriatric Health Promotion & Disease Prevention
- LGBTQ Older Adult Management
- Managing Multiple Chronic Conditions
- Medication Management (1 hour)
- Nutrition & the Older Adult
- Older Adults with Visual, Hearing & Cognitive Impairment
- Optimizing Physical Activity in Older Adults
- Oral health & the Older Adult
- Pain Management & the Older Adult
- Palliative Care
- Physical Activity & the Older Adult
- Process of Aging
- Sleep Quality & the Older Adult
- Sexuality and the Older Adult
- Transitions in Care



***Design: Innovative* ways to successfully develop a user-friendly online education program**

Created in three **innovative** film styles, *Narrate*, *Demonstrate*, and *Relate*:

Using documentary film style with actors as narrators, infographics and animation

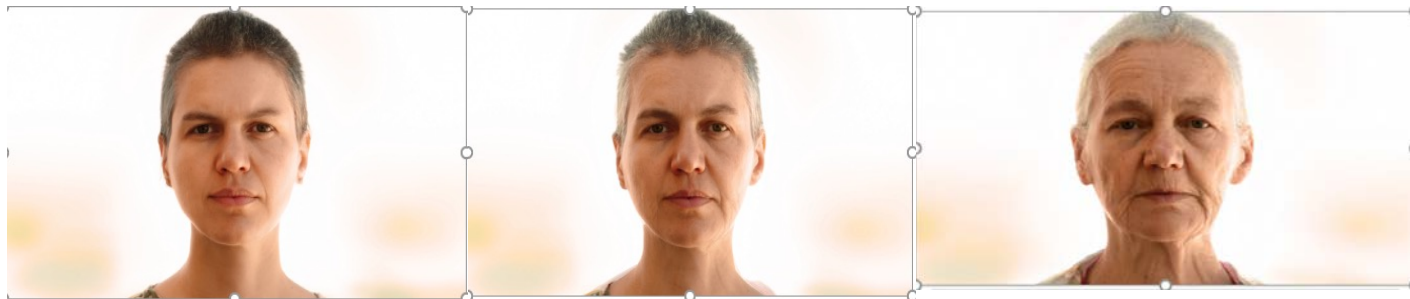
Video interviews with experts who richly demonstrate and illustrate concepts

Learners relate to videos that share rich stories engaging the learner



Design: Film styles

Using documentary film/video style with actors as narrators, infographics and animation to demonstrate and illustrate concepts



IMPACT of Innovation

Online Accredited Learning in Interprofessional Geriatrics (OALIG)TM



Library of 27 Online education modules
available through our website (engageil.com)

IMPACT

Total number of modules completed: **28,258**

Total number of learner profiles: > **6,000**



IMPACT of Innovation

Impact on Practice Change



Program completers listed examples of **changes** they will apply to their practice as a result of participation in the educational activity.

They reported they will:

- ***“Incorporate pharmacologic and non-pharmacologic interventions in the care of older adults”***
- ***“Include recommended resources to be used on instruction printouts and share with caregivers and colleagues”***
- ***“Bring up different aspects in the video and ask coworkers to bounce back ideas on how we can better approach and identify [patient needs]”***

Challenges and Solutions using Technology

Challenge: Increasing aging population with increasing numbers of persons with dementia. **Persons with dementia and families** need information on dementia management, treatment and resources

Solution: Utilize mobile app technology to change the way information on *dementia* is disseminated



Why a Mobile App?



- There were more than 250 million daily **app** downloads between 2020–2021
- There will be 184 billion **apps** downloaded in 2024!

Healthcare mobile apps

- 500 million people were using healthcare mobile apps in 2015¹
- Healthcare providers and consumers are embracing smartphones as a means to improving healthcare²
- Mobile apps are a fundamental component in expanding and improving patient care and meeting needs of older adult population



Design: Mobile App: Needs Assessment

- Hundreds of apps about Alzheimer's disease/dementia
 - Most related to management of persons already diagnosed, including "memory games" and importance of healthy lifestyles
- What was lacking was:
 - **Evidence-based app** created by geriatric experts educating on the types and stages of dementia, risks, symptoms, diagnostic criteria, treatment and management
 - **Appropriate management and communication techniques**
 - **Links to resources and support services** to assist persons with dementia and families as they journey through the trajectory of the illness

Designing a Mobile App: Developing the Concept



Identify practical ‘steps’ to successfully develop mobile app educational tools

- Designing a mechanism which serves as a ‘guide’ for **Persons with Dementia and families and caregivers** as they navigate through the trajectory of their illness

“*Dementia Guide Expert*” mobile app

- Created with interprofessional collaboration of Content Experts & Technology Experts

Transforming the Alzheimer experience with a
Mobile App:

Dementia Guide Expert

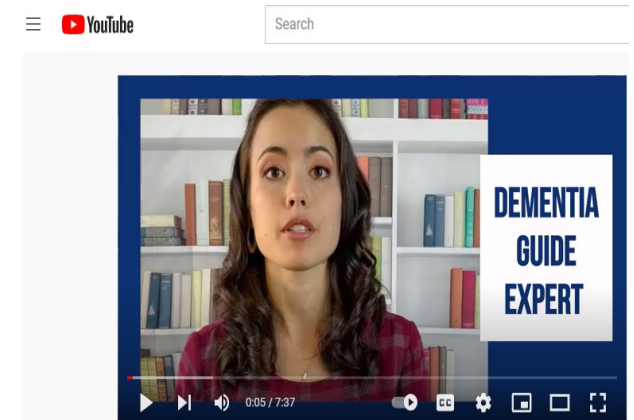
Download the **FREE App now !!**

Available for iOS on Apple iTunes and for
Android on Google Play



Transforming the Alzheimer experience with a Mobile App: *Dementia Guide Expert*

 <https://youtu.be/3RGjbBA7JLc>



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Scalability

- Benefits of digital educational device: easy updates
- *Creating NEW versions for different audiences!*



www.engageil.com

Dementia Guide Expert

Download the **FREE** App now !!

Available for iOS on Apple iTunes and for
Android on Google Play

Spanish: *Guia Experta Sobre La Demencia*

Korean: 치매 안내 전문가

Questions: Contact:

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App Updates

Dementia Guide Expert

NEW Version 2022 !

New design with accessibility features for
Persons with Disabilities



Impact of Innovation:



App Data Analytics:

December 2017-July 2021

- **66,921** Downloads/Views
- 83% iPhone, 17% iPad
- 12 Countries: Australia, Brazil, Canada, China, Germany, Japan, Korea, New Zealand, Spain, Taiwan, U.K., U.S.



Learning Objective 4

Review ENGAGE-IL strategies that can maximize engagement by people with IDD and their supports in Brain Health strategies



Engage-IL Modules

Online Accredited Learning in Interprofessional Geriatrics (OALIG)TM



Library of 27 Online education modules available through our website (engageil.com)

Existing modules will add:

- Will assist health professionals to better communicate with IDD older adults and caregivers
- Culturally relevant materials for people with IDD within existing module objectives
- 1-page information sheet/flyer for IDD relevant resources, links, citations, etc.

Example: “*Caregiver Burden*” module will add content on moral distress and

- List common mental and physical health problems caregivers may experience related to caring for the older adult
- Identify the risk factors associated with IDD caregiver burden
- Discuss assessment instruments for identifying caregiver burden
- Employ resources and assist caregivers to develop coping skills to reduce the stress associated with IDD caregiving



New Engage-IL Modules

Two New Modules:



Healthy Brain Initiative for People with Intellectual and Developmental Disabilities (IDD)

The two Healthy Brain Initiative Modules aim to introduce the need to promote and disseminate evidence-based and -informed home-based/community-based care interventions for people with IDD (including those with dementia) and their caregivers.

The modules also provide an overview of the importance to promote brain health across the lifespan and prevent or mitigate the onset or course of dementias to support people with IDD and their caregivers

2 *New Engage-IL Modules*

Healthy Brain Initiative for People with Intellectual and Developmental Disabilities (IDD)

Module 1.

6 Pillars for Brain Health: Promoting Equity for People with IDD

Module 2.

**Roadmap for Brain Health: Supporting Equitable Healthcare and Health
Outcomes for People with IDD and their Caregivers**



Healthy Brain Initiative for People with Intellectual and Developmental Disabilities (IDD)

6 Pillars for Brain Health: Promoting Health Equity for People with Intellectual and Developmental Disabilities – PART 1

Objectives:

- 1) Provide an overview of intellectual and developmental disabilities (IDD) and brain health across the lifespan.
- 2) Identify six pillars of brain health for people with IDD to empower stakeholders.
- 3) Discuss strategies for people with IDD to achieve health equity through access to quality healthcare where they live, learn, work, and play.

Sections:

- 1) People with IDD: Awareness of Brain Health
- 2) Healthy Brain Initiative: Educate and Empower Stakeholders
- 3) Health Equity: Access to Quality Healthcare to Improve Outcomes

Roadmap for Brain Health: Supporting Equitable Healthcare and Health Outcomes for People with IDD and their Caregivers - PART 2

Objectives:

- 1) Illustrate the intersection of brain health, disability, and engagement of people with IDD and their supports in their healthcare and health status.
- 2) Apply the six pillars of brain health as a resource for people to pursue and live meaningful and productive lives.
- 3) Discuss strategies to support healthy brain lifestyles for people with IDD where they live, learn, work, and play to improve health outcomes.

Sections:

- 1) It's My Health: Promote Brain Health
- 2) Health as an Everyday Resource: Observe Health Status
- 3) Healthy Brain Lifestyle: Support, Treat, and Manage

App Updates *Dementia Guide Expert*

NEW Version 2022 !

New design with accessibility features for
Persons with Disabilities



Summary

- ENGAGE-IL has created a successful **online geriatric training program** that is engaging, accessible, improves learners' proficiency and confidence, and enhances the care and health outcomes of older adults.
- The existing online library of 27 geriatric modules will be enhanced to include **new information and resources** on culturally appropriate care for people with IDD and their care providers.
- This online interprofessional education program will be expanded to include **new learning modules** to educate health professionals to better communicate with and address the needs of people with IDD and dementia and their caregivers.
- The ***Dementia Guide Expert mobile app*** is transforming the dementia experience by guiding clinicians, persons with dementia and their caregivers as they navigate through the trajectory of their illness. The mobile app is being upgraded with accessibility features for persons with disabilities.



Thank You

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