

**MEETING SUMMARY**  
**ILLINOIS DEPARTMENT OF PUBLIC HEALTH**  
**ALZHEIMER'S DISEASE ADVISORY COMMITTEE (ADAC) MEETING**  
**May 10, 2024**  
**9:00 am-12:00 pm**  
**ADAC Spring Bi-Annual Meeting Minutes**

*DRAFT*

**I. Welcome**

- Jessica welcomed members and stakeholders
- Quorum confirmed

**Introductions** (*Listed in the order outlined in the legislation*)

**APPOINTED MEMBERS** – 17 voting members; need 9 for quorum

<b><u>Member</u></b>	<b><u>Representing Required Group</u></b>	<b><u>Term</u></b>	<b><u>RSVP</u></b>	<b><u>Attendance</u></b>
Jen Belkov	A statewide association dedicated to Alzheimer's care, support, and research	5/4/2023-5/4/2025		X
Vikki Ortiz	A non-governmental statewide organization that advocates for seniors	1/7/2022—1/7/2024		
Jessica Link	The Dementia Coordinator of the Illinois Department of Public Health, or the Dementia Coordinator's designee	<i>Ongoing</i>		X
Kelly Rice	Representing the Community Care Program's Home and Community Services Division	6/14/23-6/14/25		X
Brian Pastor	Representing the Adult Protective Services Unit	6/2/2022 – 6/2/2024		X
Erin Hascup	1 of 3 individuals from Alzheimer's Disease Assistance Centers	5/4/2023-5/4/2025		X
Darby Morhardt	2 of 3 individuals from Alzheimer's Disease Assistance Centers	5/4/2023-5/4/2025		X
David Bennett	3 of 3 individuals from Alzheimer's Disease Assistance Centers	1/7/2022—1/7/2024		x
Kathy Rhoads	A statewide association representing an adult day service organization	1/7/2022—1/7/2024		
David Lowitzki	A statewide association representing home care providers	5/4/2023-5/4/2025		X

Smita Patel	A statewide trade organization representing the interests of physicians licensed to practice medicine in all of its branches in Illinois	8/5/2020 – 8/5/2022		X
Patricia “Jane” Williams	representing long-term care facilities licensed under the Nursing Home Care Act, an assisted living establishment licensed under the Assisted Living and Shared Housing Act, or supportive living facilities	5/4/2023-5/4/2025		
Marissa Happ	A statewide association representing the interests of social workers	8/5/2020 – 8/5/2022		X
Cristina Diaz	Representing Area Agencies on Aging	8/5/2020 – 8/5/2022		X
Lisa Gregory	The Medicaid Director of the Department of Healthcare and Family Services, or the <u>Medicaid Director's designee</u>	1/12/24-1/12/26		X
Tom Hughes	A statewide association representing health education and promotion and public health advocacy	1/7/2022 – 1/7/2024		x
James Mastrianni	Individual with medical or academic experience with early onset Alzheimer's disease or related disorders	5/4/2023 – 5/4/2025		x
Kara Helton	State Director or Designee/Illinois Department of Healthcare and Family Services	1/4/2022-ongoing		x
John Eckert	State Director or Designee/Illinois Department on Aging	3/2/2021-ongoing		X
Sarah Smith	State Director or Designee/Guardianship and Advocacy Commission	10/29/19 – ongoing		
Molly Chapman	State Director or Designee/Illinois Department of Human Services	7/22/22 – ongoing		x
Melissa Stalets	State Director or Designee/Illinois Department of Public Health (IDPH)	7/19/21-Ongoing		

- \_14\_ voting members present, Jessica Link Confirmed quorum--more than 9 voting members present.

<b>Stakeholders/Public</b>	<b>Agency/Interest</b>
▪ Nancy Amerson	IDPH
▪ Julie Bobbitt	UIC
▪ Ruby	CASL
▪ Tiffany Pressley	IDPH
▪ Deborah Kuhns	SIU
▪ Krissy Roseberry	IPHA
▪ Mansha Mirza	UIC
▪ Su Jin Song	Hanul
▪ Angela Hogan	Moultrie
▪ Jennifer Schindl	Shawnee
▪ Sumithra Murthy	UIC
▪ Margaux Shields	CDEL
▪ Ruby Tan	CASL
▪ Bridget Moran-McCabe	

**I. Welcome and Introductions**

- Sign up for the Healthy Brain Newsletter—it's quarterly!

**II. Vote on January and August 2023 Special Meeting Minutes\***

- Jessica called for 1<sup>st</sup> Kelly Rice & 2<sup>nd</sup> motion by Jen Belkov to approve January 2023 minutes. Members voted with a majority of yays. Minutes passed.
- Jessica called for 1<sup>st</sup> Brian Pastor & 2<sup>nd</sup> Tom Hughes motions to approve August Special Meeting Minutes. Members voted with a majority of yays. Minutes passed.

**III. Vote on Fall 2023 Meeting Minutes\***

- Jessica called for 1<sup>st</sup> Kelly Rice & 2<sup>nd</sup> Jim Mastrianni motions. Members voted with a majority of yays. Minutes passed.

**IV. Needs Assessment Updates and Discussion Dr. Julie Bobbitt**

- Landscape Report-Services, supports and what is happening in Illinois, prevalence rates of ADRD, IDoA did caregiver round tables around the state, Alzheimer's Association meets with constituents and will be including our questions in their meetings.
- Focus Groups- Some of the AAA's will also be including questions in their caregiver roundtables. Will then review if missing any groups across the state and conduct more specific focus groups.
- Surveys will be put together and sent to professionals, Public Health Departments, AAAs. Will look at workforce, services, and needs.
- Jessica asked if there were any questions or comments on needs assessment-Jim Mastrianni-asked about population of focus groups and age range of services provided to patients? Are we considering younger onset dementia patients in this group? Julie Bobbitt answered saying that they will include PLWD including early onset. Will review data coming back then reach out to set up specialized focus groups including early onset. Jessica said she believes will capture early onset in surveys.

## V. Federal BOLD Program and Progress Updates

- YR1 is underway and YR2 Continuation has been submitted
- SSPP2 was hired to serve in the BOLD Coordinator role—starts next week.
- Illinois Brain Health Project
  - Alzheimer’s Association IL Chapter was awarded this IDPH grant for the IDPH BOLD project that will focus on educating the public about modifiable risks and healthy lifestyle practices that promote brain health, best practice strategies to reduce the prevalence of key modifiable risk factors for cognitive decline, and the importance of recognizing cognitive decline early, particularly for diverse, underserved, and higher risk communities.
- ADRD Training Series for Professionals
  - Grantee has been selected; contract is still being executed.
  - The initial stage of the “ADRD Training Series for Professionals” will include a virtual educational series that will endure online, targeting IDPH project partners and public health professionals. The subsequent stages of the program will include multi-sector ADRD professional training and developing the mechanisms needed for continuing education units (CEUs) to be provided to a wide variety of Illinois professionals. Additional targeted professional groups and sectors will be collaboratively identified between IDPH, the grantee, and the Alzheimer’s Disease Advisory Committee. High level overview of BOLD and what we are doing with Public Health Programs.
- Medical Provider and Health Systems Interactive ADRD Program
  - Grantee has been selected; contract is still being executed.
  - An interactive program to both educate and engage medical providers and health care systems about best practices for all levels of Alzheimer’s Disease and Related Disorders (ADRD) prevention, the importance of caregivers, and models of community-clinical linkages to increase patient access to ADRD care and improve health outcomes for both patients and caregivers. The targeted group for this project is medical systems and medical providers serving rural communities. The program focus includes but is not limited to an annual conference. Engagement of providers outside of the annual conference is expected in some capacity.
    - ✓ Will be annual conference, starting with rural area providers first.
    - ✓ Hoping to include Community Clinical Linkages.
    - ✓ Hope to increase patient access.
    - ✓ David Bennett asked if conference will move around state-not sure yet, will happen in southern region first.
    - ✓ All projects targeting 3-year cycle.
- Caregiver Podcast Series-meant to be a peer-to-peer model, people being lived experience, internal lift project.
- Hospital Discharge Data Analysis-Nancy Amerson-chronic disease epidemiologist.

- Overview-design hospital discharge data analysis project to describe ADRD population, identify ADRD comorbidities, potentially preventable ED.
- ICD-10 Codes discussion-first step is determine which codes. Looking at NHPCO and Alzheimer's Association definitions.
- Analysis Options- Dr. Bennett asked if documenting delirium. Nancy said the other discussion point is are we documenting ADRD as the overall or coming in for something else but also have dementia. State gets data from hospitals. Data is de-identified so one person could be counted multiple times.
- Preliminary Numbers-see more ED visits, many cases look like unspecified data.
- Discussion: Project is In-Kind but is reporting BOLD, will also look at this across race/ethnicity, age, gender, areas, do mapping. Rural vs Urban. Patient zip code/facility zip code.
- Jessica asked if there were any questions: Dr. Bennett asked if there was a plan to connect all of these programs. Jessica said interactive portion will be focused on community clinical linkages.

## **VI. State Funded Program Updates**

- Early Detection Physician Training Program
  - Ending June 30<sup>th</sup>
    - ✓ Jessica gave description of podcast, The Brain Trust. This project will not renew.
- Early Detection Education and Awareness Campaign
  - Ending June 30<sup>th</sup>, (brainstorming how to continue CHW work)-IPHA-done almost 7,000 referrals this year, reached LGBTQ, Black population, Hispanic population. Bi-lingual billboard on Dan Ryan. Will work to continue work with CHWs.
- Early Planning Workshop Series for Underserved Populations
  - NEW--Started YR1 of 3 years on Sept 1, 2023—2 grantees—launched late, Dec/Jan
  - Aligns with the Service Delivery State Plan objective to promote early planning for persons living with dementia, their families, and caregivers, including, but not limited to: Legal and financial planning, guardianship, powers of attorney, other alternatives, and advanced directives.
  - Develop and deliver culturally tailored early planning workshops for persons living with dementia (PLWD) and their caregivers from four diverse groups:
    1. 1-Black Americans
    2. 2-Hispanic/Latinx Americans
    3. 3-Asian Americans
    4. 4-LGBTQ+ persons
  - The purpose of the Dementia Early Planning Workshop Series for Diverse Populations is to create high-quality dementia and advanced care planning workshops for caregivers and individuals living with Alzheimer's Disease and Related Dementias (ADRD) and respond to their unique needs effectively.

- Intros:
  1. Hanul Family Alliance-Anna Kim introduced and explained program. Main focus is Korean Americans in Chicago area and suburbs. Offer variety of social services, focus on
  2. Center for Disability & Elder Law -Liesette Ortegon and Margaux Shields CDEL is legal non-profit. Provides free legal services to seniors over the age of 60 or people under age 60 who are moderate to low income with developmental disability. Target Black, Latino, and LGBTQ+, educate caregivers and caretakers. Educated both sides, principal and agent. Many people may not have an agent, offering Life Affirming directives not legally binding but puts down preferences such as chosen name/pronouns, diet preferences, religion, music. Put down chosen family circle and who they do not want to visit. Check box on what they do not wish to talk about. Partnering with Illinois Legal Aid online to make services more accessible. Worksheets for homework, then meet with attorney and execute documents.
  3. David Bennett asked about continuation of the programs beyond grants
  4. Jessica said the way to support these grantees is spreading the word.
  5. David Bennett said web-based programs could be hosted on their website.
  6. Cristina Diaz will connect with CDEL about linking up with churches and can cross promote there.
  7. Marissa Happ talked about sustainability for graduate student interns for either or both participating in the program with Hanul and CDEL, would like to get contact information to explore this idea. Jessica said she would get ADAC leads from each team's emails.
- Dementia Caregiver Program for Diverse Populations
  - NEW--Started YR1 of 3 years on October 1, 2023, projects started late in February
  - Aligns with State Plan goals:
    - ✓ Public Education and Awareness 2.E.6--*to identify and partner with community-based organizations to assist in the dissemination of culturally responsive caregiving resources and support*
    - ✓ Service Delivery 3.D.3.a--*to promote awareness and use of evidence-based caregiver education*
  - Aims to develop and deliver education and support for caregivers of people with Alzheimer's Disease and Related Disorders (ADRD) from four diverse groups:
    1. Black American Caregivers
    2. Hispanic/Latinx American Caregivers
    3. Asian American Caregivers
    4. Caregivers in Rural Areas

- Purpose is to increase education, support, and community connection for caregivers of people living with ADRD in order to reduce stress, empower, and support caregivers from diverse populations, as well as reduce barriers and stigma that prevent access to care.
- Grantee Intros:
  1. Illinois Public Health Association-Krissy Roseberry spoke, moving from early Detection program is a perfect transition into Caregiver Program-targeting Black, Hispanic, and Asian populations. Have 3 CBO partners that NAACP Madison, LAMDA, and Rainbow. Finishing training program for CHWs for dementia caregiver support. Working with HAP foundation, RUSH University, and Alzheimer's Association. Will be doing 1:1 support, facilitating support groups, memory cafes.
  2. Chinese American Service League-Ruby the program coordinator gave updates. Their program focuses on Chinese Americans and those with limiting English capacity. 3 objectives, Adult day service providers-provide trauma informed training, for family caregivers off community education to improve overall knowledge and awareness. Also provide case management, evidence based programs, skills 2 care, and will launch memory care café to support connection.
  3. University of Illinois Chicago-Peace of Mind, African Americans, South and Southeast Asians. Best practices, accessing community resources, preserving caregivers' mental health, and addressing the future. Adapt curriculum in person/online or hybrid caregiver workshops. Unique-guided by community members many who have lived experience, 2 community advisory boards one for Black community and Asian community. Also have expert advisory board. Using existing dementia caregiving program, will modify curriculum per feedback. Using best practice strategies to culturally adapt materials.
  4. Shawnee Health Service & Development Corporation-Jennifer Schindl FQHC in southern Illinois, have 9 clinics, 2 school based, 2 dental. One is CCU program that Heath Knutt is director of. Heather-working on training for caregivers of PLWD, Savvy Caregiver-Setting up support groups and memory cafes be in a friendly environment. Currently working with senior centers and assisted living to get programs into area. 13 counties on southern tip of IL that are very rural. Hoping to offer program in every single county so transportation will not hinder participation. 40 1:1 caregiver meetings have been held. Offering program hybrid. A lot of advertising is happening, have three interns that have trained. Preparing future program to care for loved one while in training.
  5. Moultrie County Health Department-LHD Angela Hogan-almost 15,000 people, large Amish population. Have a senior center that provides

services and counseling center. No other services are available. Seek to provide caregiver services, have registered nurse in program will focus on the health and wellness of caregiver. Direct public outreach and social media will be used to reach audience. County just became designated as dementia friendly, operate on community based direct model.

- Jessica asked ADAC if they have questions or comments-Dr. Bennett asked about pre and post assessment, Angela Hogan said there is a pre and post assessment that is currently in development. Heather-savvy caregiver has pre and post and will use TCARE. Mansha-plan to do pre and posttest Dementia Knowledge Tool version 2, perceived stress scale, family caregiver survey. Ruby-working with evaluator to finish design of pre and posttest. IPHA does pre and posttest, it is a component of all of the trainings.
- Next steps are meeting with Dr. Julie Bobbitt to determine shared metrics, then gathering with all 5 grantees in June to track shared metrics.

## VII. Break

## VIII. Coordinator Updates and Discussion

- BRFSS Burden Brief Reports & Infographic
  - **The Cognitive Decline Burden Brief**--A report based on the Illinois County Behavioral Risk Factor Survey (IL CBRFS), 2015-2019
  - [cogdecline-burden-brief-2024-idph-comms-approved-3-12-2024.pdf \(illinois.gov\)](#)
    - ✓ Implications & Action
    - ✓ *The higher prevalence of Subjective Cognitive Decline (SCD) for the Non-Hispanic Black population underscores the importance of a focus on improving equity for our Black American Illinoisians.*
    - ✓ *Dementia is not a normal part of aging & knowing the signs is important.*
    - ✓ *There is a relationship between SCD and other health factors.*
    - ✓ *Health professionals can help.*
  - **The Caregiver Burden Brief**--A report based on the Illinois Behavioral Risk Factor Surveillance System (BRFSS), 2021
  - [caregiver-burden-brief-2024-il-dph-03-07-2024.pdf \(illinois.gov\)](#)
    - ✓ Implications & Action
    - ✓ *Illinois caregivers are important and need support.*
    - ✓ *If you care for someone with a health condition or disability, you are a caregiver.*
    - ✓ *Caregivers need support in managing their own health and well-being.*
  - **Caregiver Infographics**

## IX. Sub-Committees



- Overview of Recruitment Process
  - Chairs met and used the BOLD required & recommended lists to recruit multi-sector & diverse members with expertise and lived experience.
  - Sent out capacity & interest forms.
- Member Rosters
  - Presented for each of the 5 subcommittees.
  - ADAC was provided with a brief description of each prospective member.
  - Dr. Bennett asked what the Data and Research committee will be looking at. Committee will be focused on what was mapped out on state plan. Will look at BOLD hospital discharge project, will include cost implications.
  - Jessica asked ADAC to discuss each grouping and state if there were any gaps they see in the groupings.
  - Jen Belkov verbally added PLWD to proposed subcommittee members Public Education and Awareness list, Adam Nielsen was added via the chat and voted on to become a member of the Public Education and Awareness subcommittee.
  - Dave Lowitzki talked about adding more members to his subcommittee that will be voted on at the Fall 2024 meeting by ADAC.
- Next Steps
  - ADAC Vote
    - ✓ **Data & Research**
    - ✓ Jessica Link-Chair
    - ✓ Dr. Ben Shaw, UIC School of Public Health
    - ✓ Andrew DeMott, UIC Roybal
    - ✓ Dr. Judy Rocha, Northeastern, Latinx, caregivers
    - ✓ Dr. Jurkowski, SIU, southern region
    - ✓ Dr. Mehul Trivedi, SIU med Springfield clinical psychologist
    - ✓ Nancy Amerson, IDPH Chronic Disease Epidemiologist
    - ✓ Gene Kuhn, Alzheimer's Association-Data
    - ✓ **Workforce & Training**
    - ✓ David Lowitzki-Chair
    - ✓ Molly Jenkins, CATCH-ON-RUSH
    - ✓ Katherine Thompson, SHARE University of Chicago
    - ✓ Desma Rozovics, IAFP
    - ✓ Chelsey Byers, UIUC Extension
    - ✓ Dr. Tracey Smith, IPHA
    - ✓ Kimberly Stoerger, IL Health Care Association
    - ✓ Christina Karcz, Gardant Management Solutions
    - ✓ **Public Education & Awareness**
    - ✓ Jen Belkov-Chair
    - ✓ Amelia Garza, Alzheimer's Association
    - ✓ Cara/Meghan, IDPH Cardiovascular Program
    - ✓ Angela Hogan, Moultrie County Health Department

- ✓ Brittany Mabry, Alzheimer's Association POINTER Study
- ✓ Courtney Hedderman, AARP
- ✓ Lisa Nation, Southern Illinois Healthcare
- ✓ **Service Delivery**
- ✓ Kelly Rice-Chair
- ✓ Meg Cooch, DHS Developmental Disabilities
- ✓ Anais Cotillas, Howard Brown FQHC
- ✓ Elliot Morris, Illinois Tech
- ✓ Becky Salazar, Egyptian Area Agency on Aging
- ✓ Samantha Olds Frey, Humana
- ✓ Bailey Huffman, Coordinated Care Alliance
- ✓ Terrianne Reynolds, Alzheimer's Association
- ✓ **Community Engagement, Safety & Support**
- ✓ Darby Morhardt--Chair
- ✓ Emily Mysel, Family Service of Glencoe Senior
- ✓ Diane Slezak, Age Options
- ✓ Kerry Peck, Peck Ritchey, LLC
- ✓ Susan Frick, Dementia Friendly
- ✓ David Olsen, Alzheimer's Association
- ✓ Jeanice McDade, IDoA APS

- Members fill out board member applications.
- IPDH legislative & Director Approve
- Chairs schedule meetings—hoping for mid to late summer.
- Vote to Approve Subcommittee Members\*
  - First motion Dr. Bennett gives first motion, Dave Lowitzki does second. Majority members voted Yay, subcommittee rosters were passed with a majority vote.

**X. Other ADAC Discussion or Announcements**

**XI. Fall 2024 Meeting—Rush in Chicago, Date TBD**

**XII. Public Comments**

*\* Action Needed*