

MEETING SUMMARY
ILLINOIS DEPARTMENT OF PUBLIC HEALTH
ALZHEIMER'S DISEASE ADVISORY COMMITTEE (ADAC) MEETING

October 28, 2022 1:00 p.m. to 4:00 p.m.

Rush University Medical Center-Alzheimer's Disease Center
Searle Conference Center-5th floor-Room 502/Billings-Herrick
Professional Building (1725 W. Harrison)
Chicago, IL 60612-3864
Approved April 21, 2023

I. Welcome

- Jessica welcomed members and stakeholders
- Quorum confirmed

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

APPOINTED MEMBERS – 14 voting members; need 8 for quorum

<u>Member</u>	<u>Position</u>	<u>Agency</u>	<u>Attendance</u>
Jen Belkov	A statewide association dedicated to Alzheimer's care, support, and research	Alzheimer's Association	X
Vikki Ortiz	A non-governmental statewide organization that advocates for seniors	AARP IL	
Jessica Link	The Dementia Coordinator of the Illinois Department of Public Health, or the Dementia Coordinator's designee	IDPH	X
Phyllis Roate	Representing the Community Care Program's Home and Community Services Division	IDoA	X
Brian Pastor	Representing the Adult Protective Services Unit	IDoA	
Erin Hascup	1 of 3 individuals from Alzheimer's Disease Assistance Centers	SIU Medicine—Alzheimer's Regional Center	X
Darby Morhardt	2 of 3 individuals from Alzheimer's Disease Assistance Centers	Northwestern--Alzheimer's Regional Center	X

David Bennett	3 of 3 individuals from Alzheimer's Disease Assistance Centers	Rush—Alzheimer's Regional Center	
Kathy Rhoads	A statewide association representing an adult day service organization	Circle of Friends & VP of IL Adult Day Association	X
Vacant	A statewide association representing home care providers— beth.menz@seiuhcil.org		
Raj Shah	A statewide trade organization representing the interests of physicians licensed to practice medicine in all of its branches in Illinois	Rush & Illinois Academy of Family Physicians	X
Vacant	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	Centennial Pointe—Memory Care Assisted Living	
Carol Mauck	A statewide association representing the interests of social workers	University of Illinois School of Social Work & National Association of Social Workers IL Chapter	X
Vacant	Representing Area Agencies on Aging		
Jenny Aguirre (Assistant Director of HFS)	The Medicaid Director of the Department of Healthcare and Family Services, or the Medicaid Director's designee	HFS	X
Tom Hughes	A statewide association representing health education and promotion and public health advocacy	IPHA	

Marsel Mesulam	Individual with medical or academic experience with early onset Alzheimer's disease or related disorders	Northwestern--Alzheimer's Regional Center	X
<u>Non-voting appointed members</u>			
Kara Helton	State Director or Designee/Illinois Department of Healthcare and Family Services	HFS	X
John Eckert	State Director or Designee/Illinois Department on Aging	IDoA	X
Sarah Smith	State Director or Designee/Guardianship and Advocacy Commission	GAC	
Molly Chapman	State Director or Designee/Illinois Department of Human Services	DHS	X
Karen Mancera-Cuevas	State Director or Designee/Illinois Department of Public Health	IDPH	X

- New ADAC members were introduced and shared interest in being an Advisory member.
- Jessica Link Confirmed quorum--more than 8 voting members present.

<u>Stakeholders/Public</u>	<u>Agency/Interest</u>
-----------------------------------	-------------------------------

- | | |
|----------------------|-----------------------|
| • Dr. Crystal Glover | RADC |
| • Dr. Susan Ogwal | Lt. Governor's Office |

II. Lieutenant Governor Julianna Stratton's team

- Dr. Ogwal introduced herself at 1:30pm

III. Review & Approval of April 21, 2022 meeting minutes *

- Jessica Link called for 2 motions & a Vote to approve meeting minutes from April 21, 2022. No comments or edits were given. Jen Belkov called for a 1st motion, Raj Shah called for a second motion. Majority of the votes were Yay/Nay, minutes for April 21, 2022 were passed.

IV. Illinois Department of Public Health Updates

- a. Coordinator Updates (Jessica Link, IDPH)
 - i. New State Plan status—Draft 1 was sent out and a few of you returned some edits. Today, we will discuss some of the narrative sections and then complete our goals in working groups for the last hour of the meeting.
 - ii. Early Detection grants have been renewed for FY23. Jessica will give a progress update on these later this morning.
- b. Update on Alzheimer's Disease Research, Care, and Support Fund (Jessica Link)
 - i. Jessica explained/reminded members that this is the special state fund that comes from tax return contributions. Per the Alzheimer's Disease Research, Care & Support fund, moneys are to be used by IDPH to cover costs associated with the salary & benefits of the Dementia Coordinator position, Behavioral Risk Factor Surveillance System modules & other data collection, and lastly to implement recommendations made in the Alzheimer's Disease State Plan. Currently, the fund is covering the Coordinator's salary, and moneys are allotted for BRFSS coverage.
- c. BRFSS Data Discussion (Jessica Link reporting)
 - i. Nancy Amerson, our IDPH Epidemiologist in Chronic Disease has developed two burden brief drafts for ADAC's review & feedback. We will start by looking at the data sources for these two reports.
 - ii. BRFSS Cognitive data.
 - The BRFSS Cognitive Decline module measures subjective cognitive decline (SCD) and its associated effects on function and daily living (<https://www.cdc.gov/aging/healthybrain/brfss-faq.htm>).
 - The Cognitive Decline module of the Behavioral Risk Factor Surveillance System (BRFSS) was asked on the Illinois statewide survey in 2020. It was also asked on the Illinois County Behavioral Risk Factor Survey (IL BRFS) between 2015-2019.
 - In the 2020 statewide survey, the cognitive decline module only produced reliable data for the first question when looking at demographics. For the additional questions, when analyzed by demographics the data did not meet standards of reliability.
 - Due to the above data issues with the statewide survey cognitive data and given the larger sample size from the county round data, the

Illinois County Behavioral Risk Factor Survey (IL CBRFS) data from 2015-2019 was used for the cognitive burden brief report.

iii. BRFSS Caregiver data.

- The BRFSS Caregiver module is designed to provide information about persons who self-identify as caregivers and provide some form of care to another person with a health problem or disability.
(<https://www.cdc.gov/aging/healthybrain/brfss-faq.htm>)
- The Caregiver Illinois Behavioral Risk Factor Surveillance System (BRFSS) statewide survey 2021 data was used for the Caregiving brief, with some cautionary comments and notes re: the data.

iv. Focus of burden briefs.

- Jessica presented an overview of the two briefs.
- Data to be sent out to the group for additional review and additional feedback.
- Jessica asked if there were any questions. Dr. Shah shared a suggestion to compare results from 2013, 2015, and 2019 data for the question about who is talking to their physicians and create a comparison summary. John Eckert agreed with Dr. Shah's suggestion. Debbie Kuhns shared an observation that there are more elderly people that live in southern Illinois.
- Dr. Mesulam spoke on early onset dementia and suggested an emphasis on early onset. Dr. Shah also mentioned giving absolute numbers and not percentages and that a large amount are in the Chicago area. To help people interpret the fact that we need interventions for the entire state.

V. ADAC Workgroup Progress Updates

- a. Workforce Expansion & Training Workgroup Progress (Reporting: Jessica Link)
 - i. Jessica reported that the workgroup began compiling all of the mandated trainings in Illinois with details about the required groups, content and potential resources—the group discussed that the resources need to be reviewed/vetted and may be moved out of the document to reduce confusion.
 - ii. The group spent the other monthly meetings held since April brainstorming and developing the objectives & strategies for the 2023-2026 Workforce & training goal.

VI. Grant Program [Jessica reporting]

- a. Alzheimer's Disease Awareness of Available Services in Illinois
 - i. In Spring 2022, a new and upgraded "Next Generation Alzheimer's Service Awareness Platform" was created to serve as a one stop shop for ADRD education and resources in Illinois, including:
 - ii. A search by zip code function for local resources.
 - iii. Menu tabs for "living with dementia" journey pages.
 - iv. Community pages that are culturally tailored to people who often feel isolated or underserved.
 - v. CY2022 to date (September 30, 2022), website views have been 16,293 (54% higher than CY2021) by 6,489 (43% higher than CY2021) visitors and 232 posts (60% higher than CY2021) have been created.
 - vi. Search engines (individuals typing in requests) have been biggest source to the site (over 50%)
 - vii. Most viewed pages are home page, Dementia Friendly Illinois, Dementia Friends Illinois, and Your Communities.
- b. Alzheimer's Disease Early Detection & Awareness Campaign
 - i. FY23 Progress:
 - ii. Each of the 10 Community based organizations involved during FY22 have been retained for FY23. These 10 community-based organizations cover the various corners of the state of Illinois, reaching both the urban populations and rural populations as well as focusing on minority populations
 - iii. Approximately twenty outreach workers have been hired by the CBO's—they have completed a core training program with Illinois Public Health Association, as well as ADRD specific training & ongoing consultation.
 - iv. Ongoing trainings are conducted monthly through the Illinois Public Health Association's Lunch & Learn series, which provide the outreach workers with access to field experts as well as new findings within the field of Alzheimer's. In the month of September, the Illinois Public Health Association collaborated with Dr. Shah's team at Rush to provide a Dementia Friends training. Future collaborations are planned with IAFP as well as other leading organizations.
 - v. Monthly advisory board meetings are held with the 10 community-based organizations and leading brain health organizations throughout the state of Illinois. This platform allows for engaging discussions regarding the challenges the community-based organizations are finding within the field as well success stories
 - vi. The Illinois Public Health Association has contracted with Morreale communications to provide an efficient and wide-ranging communications

campaign. Morreale communications has launched the know-ALZ IL landing page while also providing the 10 community-based organizations with ample social media content to promote the program. Future steps include improving the resource map to provide an easier pathway to care for at risk individuals- which will also create a more collaborative environment between outreach workers and health care professionals

- vii. The Illinois Public Health Association has contracted with UIC to provide an independent data analysis. UIC will provide a quarterly report to IPHA with the first report for July, August, September being created by the end of October.
 - viii. In July there were 7 health fairs held with approximately 27 people. In August there were 13 health fairs conducted with approximately 21 people. In both July and August there were 4 separate events held each month. In July there were 100 attendees, in August 114 attendees.
- c. Alzheimer's Disease Physician Early Detection Training
- i. FY23 Progress:
 - ii. The Brain Trust: Seven accredited medical education (CME) podcasts are recorded & currently in the editing/production phase; series is projected to launch in late Fall 2022.
 - Trailer – podcast series announcement/overview
 - Understanding Dementia
 - Screening
 - Diagnosis
 - Health Systems - early detection implementation
 - Rural Communities
 - African American Communities
 - The Brain Trust: Early Detection ADRD Webinar- Wed., Nov. 9th from 12pm to 1pm.
 - Understand the barriers associated with effective early diagnosis and treatment of Alzheimer's disease and dementia
 - Identify the key component of a comprehensive cognitive evaluation.
 - Highlight treatment and research options for individuals with cognitive concerns and their families.
 - iii. Webinar recording will be available online as enduring material, for one year.
 - iv. Dr. Raj spoke about the podcast and how it was a peer learning experience. He also commented on the synergy of the three grants and how it is building the ecosystem for the state.
 - v. Kathy Rhoads had a question about treatment options.

- vi. Dr. Shah spoke about products based on early detection getting approval in 2023 for treatment as well as training physicians to be able to do early detection.
- vii. Dr. Mesulam concurred with Dr. Shah and spoke that an issue with the drugs is that they are not great, have very serious side effects, and are expensive. Which makes diagnosis very important and doctors must be sure before recommending the drugs.
- viii. Jessica mentioned that treatment is not in the state plan and asked how ADAC wants to address this. Jen Belkov expressed that it needs to be addressed and suggested having a section on it. Jen spoke about making sure that everyone has access to all of the components, especially with insurance coverage and that states start having these conversations. Dr. Shah shared that he believes Service Delivery in the 2023-2026 draft captures treatment. He expressed his concerns about making forward thinking statements in the plan because the FDA has not approved the medications yet.
- ix. Group took a break until 2:10 pm

VII. Alzheimer's Disease State Plan 2023-2026 *

a. Review Narrative Areas of Discussion

i. Narratives

- Call to Action-Jessica asked if everyone was in agreement with this section. No concerns were voiced. Dr. Shah voiced his support
- Jessica asked about health care provider wording of geriatricians. It was suggested to broaden the language to include social services. Wording was discussed by Darby, David, Jen, and Raj.
- Raj suggested "representatives and care (or direct care) providers from the aging disability public health networks are all facing shortages." Darby and others concurred.
- Jessica asked if we wanted to keep AD/ADRD or change it to ADRD. Dr. Mesulam concurred ADRD works.
- A discussion about the use of Related Dementias occurred. Jessica to contact Darby to edit the section.
- Jessica proposed deleting the NAPA section under Opportunities and Challenges since it is outdated. No one disagreed. Jen suggested changing the title from Opportunities and Challenges to "Opportunities". Jessica agreed. Raj suggested aiming the title to something that captures here is what the state is doing, here is the

national, here are opportunities in the state, and here are our goals for the next three years.

- Jen suggested removing bullets.
- John suggested an edit.
- David suggested removing a paragraph, Jessica struck it.
- Public Safety and Law Enforcement-Dr. Raj said we may need feedback from SIU colleagues. Dr. Hascup agreed there was an importance but said that getting a reference for this would be difficult. Jessica asked about keeping in this section. Raj said we probably don't need all of it and suggested shortening it.
- Jessica asked group to review Geriatric-Psychiatric Services and provide feedback.
- Raj suggested spending less time in the plan arguing for the need for services and support. Jen thought keeping the problems in there for the legislation. He also suggested referring to an appendix and adjusting the way the story is told.
- John said he refers to table of contents when reviewing document.
- David said most audiences won't read the plan cover to cover.
- Jessica asked if should move public safety and geri-psych to appendices. David pointed out it was addressed in legislative history section so moving to appendices would be fine.

ii. Focus for groups

b. Organize into Work Groups

i. Groups broke out and worked on individual goals.

VIII. State Plan Work Groups for 2023*

- a. ADAC work groups edited & added language to the six priority goals.
- b. Voting plan—new edits & additions from today will be added into the 2023-2026 draft and emailed to ADAC for a vote.
- c. Internal IDPH reviews will begin in November, publication in January 2023.

IX. Other ADAC Discussion

- X. Spring 2023 Meeting**—April at Southern Illinois University Smith Alzheimer's Center, Date TBD—Poll via email in November 2022.

XI. Announcements or Public Comments

Addendum

11/10/22

ADAC Vote

Via email on November 4, 2022, Jessica Link called for a vote of yay or nay to approve the 2023-2026 State Plan draft. Jessica received 8 yay votes, which is a majority of voting members. The 2023-2026 Alzheimer's State Plan draft is approved by a majority vote and will proceed to internal IDPH reviews.

Approved