



State of Illinois  
Illinois Department of Public Health

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# Dementia Annual Report

## Dementia Capability in Illinois

2021

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## Background

The Illinois Department of Public Health (IDPH) Dementia Program promotes dementia capability in the state through the coordination of high-quality statewide services that support the needs of people in Illinois with Alzheimer's Disease and Related Disorders, their families, and caregivers. The Dementia Program is housed within IDPH's Office of Health Promotion, Division of Chronic Disease. The program facilitates the director-appointed Alzheimer's Disease Advisory Committee (ADAC), which oversees the development and implementation of the Alzheimer's Disease State Plan.

The Alzheimer's Disease Illinois State Plan was established in 1987 and is required to be revised every three years in accordance with the Alzheimer's Disease Assistance Act. The Dementia Program is responsible for implementing activities of the Alzheimer's Disease Assistance Act (410 ILCS 405) and the Alzheimer's Disease Research, Care, and Support Fund Act (410 ILCS 410).

The Alzheimer's Disease Advisory Committee (ADAC) was established through the Alzheimer's Disease Assistance Act and currently consists of 17 voting members and five nonvoting members. Voting members are appointed by the IDPH director and membership is specified by the Alzheimer's Disease Assistance Act. The directors of the following state agencies, or their designees, serve as nonvoting members: The Illinois Department on Aging, the Illinois Department of Healthcare and Family Services, the Illinois Department of Public Health, and the Illinois Department of Human Services, and the Illinois Guardianship and Advocacy Commission (IGAC). The ADAC reviews programs and services provided by state agencies directed toward persons with Alzheimer's disease and related dementias, and, by consensus, recommends changes to improve the state's response. ADAC's recommendations are reflected throughout the state plan.

Illinois has three Regional Alzheimer's Disease Assistance Centers funded by the Illinois Department of Healthcare and Family Services that are an integral part of the Alzheimer's Disease network in Illinois. A Regional Alzheimer's Disease Assistance Center (ADA Center) is nationally considered the top tier of dementia care, providing diagnostic evaluation, treatment, referrals, and research. An ADA Center must be a postsecondary higher educational institution having a medical school affiliated with a medical center and having a National Institutes of Health and National Institutes on Aging sponsored Alzheimer's Disease Core Center. ADA Centers are staffed by a network of physicians, medical specialists, social workers, educational specialists, and research scientists with expertise in dementia care and research.

The following Regional Alzheimer's Disease Assistance Centers are funded by the Illinois Department of Healthcare and Family Services:

- Northwestern Alzheimer’s Disease Assistance Center for Northern Illinois, Northwestern University Feinberg School of Medicine, Chicago
- Rush Alzheimer’s Disease Assistance Center for Northern Illinois, Rush University Medical Center, Chicago
- Southern Illinois University, School of Medicine, Center for Alzheimer's Disease and Related Disorders, Springfield

In 2019, the Illinois General Assembly passed legislation authorizing the creation of a Dementia Coordinator within IDPH. This legislation amended both The Alzheimer's Disease Research, Care and Support Fund Act (P.A. 101-0588) and the Alzheimer’s Disease Assistance Act (P.A. 97-0768) with changes effective January 1, 2020. In addition to establishing and defining responsibilities of the full-time coordinator position, other significant changes to these Acts included restructuring the Alzheimer’s Disease Advisory Committee membership, re-naming the fund to include the wording “Care and Support,” adding promotion of the fund, and defining use of moneys in the fund -- to be directed primarily to support the Dementia Coordinator position and, if further funding remains, to then execute data projects, and lastly to implement state plan recommendations.

In January 2021, IDPH published the [2020-2023 Alzheimer’s Disease State Plan](#). The plan’s report and recommendations were updated in conjunction with the Alzheimer’s Disease Advisory Committee (ADAC) and relevant Alzheimer’s disease stakeholders. The recommendations are designed to ensure Illinois becomes a “dementia-capable state,” as defined in the Alzheimer’s Disease Assistance Act (410 ILCS 405), meaning that Illinois and its long-term care services, community-based services, and dementia-support systems have:

- The ability to identify people with dementia and their caregivers.
- Information, referral, and service coordination systems that provide person-centered services to people with dementia and their caregivers.
- Eligibility criteria for public programs that are equitable for people with dementia.
- Coverage of services that people with dementia and their caregivers are likely to use.
- A professional caregiving workforce that knows about Alzheimer's disease and other dementias and how to serve that population and their caregivers.
- Quality assurance systems that consider the unique needs of people with dementia and their caregivers.

# Accomplishments

During 2021, progress has been made toward implementing activities and strategies that support the recommendations of the 2020-2023 Alzheimer's Disease State Plan. Highlights include new legislation that supports professional training for Adult Protective Services (APS) staff and health care professionals regarding Alzheimer's Disease and Dementia, the addition of a Dementia Coordinator position established within IDPH to spearhead the program's efforts, gains and improvements made to dementia services by the three Regional Alzheimer's Disease Centers and other state agencies, the establishment of workgroups under the ADAC to advance state plan strategies, greater collaboration among community stakeholders and partners, and the initiation of three new grant programs that support both greater awareness of the available dementia care services and promotion of early detection, particularly for underserved communities.

## Dementia Coordinator

In February 2021, a full-time Dementia Coordinator joined the IDPH Office of Health Promotion, Division of Chronic Disease. The Coordinator's top priorities are to implement activities related to the strategic state plan recommendations, to strengthen partnerships with community stakeholders and other state agencies, and to coordinate statewide efforts that increase awareness of Alzheimer's Disease and related dementias with improved access to high quality services.

The Coordinator began working with the director appointed ADAC to prioritize recommendations from the 2020-2023 Alzheimer's Disease State Plan.

In addition to working with the ADAC to organize activities that implement the 2020-2023 Alzheimer's Disease State Plan recommendations, the Dementia Coordinator has been building working relationships with other IDPH teams, state agencies, community organizations, and the Regional Alzheimer's Disease Assistance Centers to effectively organize and coordinate resources and services that ensure dementia capability for the state.

## Alzheimer's Disease Advisory Committee

In 2021, the ADAC formed two ad hoc workgroups to advance some of the state plan strategies and make recommendations to the coordinator:

- The Strategic Budget Planning Workgroup was established to strategize an effective budget plan for the state allocated dementia funds, giving multiple stakeholders throughout Illinois an equitable opportunity to serve as a diverse group of subject matter experts who can effectively evaluate statewide dementia program needs and projects to increase dementia capability throughout the state. This workgroup convened four times, identified a list of projects that aligned with

the current state plan recommendations, and two projects were recommended to receive grant funding in fiscal year 2022.

- The Workforce Expansion and Training Workgroup was established to help Illinois' professional caregiving workforce become more dementia capable.
  - This workgroup has been meeting monthly. The group edited and updated IDPH's Core Competencies, a foundational guide for developing high quality Alzheimer's Disease and Related Disorders (ADRD) training programs. The updated [2021 Core Competencies](#) have been published on [IDPH's Alzheimer's Disease webpage](#).
  - This workgroup will also focus on workforce expansion by examining strategies to increase awareness of career paths, partnerships, training programs and certifications that promote the growth of professionals who enter careers serving people who have Alzheimer's or related dementias and their families.

## Regional Alzheimer's Disease Assistance Centers

In April and October 2021, the ADAC convened for the biannual meetings. During the fall meeting, the three Regional Centers shared updates of their dementia care work and accomplishments for fiscal year 2021. Highlights are shared in this report as follows:

### Northwestern Alzheimer's Disease Assistance Center for Northern Illinois

- New partnership with AllianceChicago, a collaboration of Federally Qualified Health Centers (FHQCs) in the Chicago area.
- Buddy program was offered entirely online with 21 students and mentor dyads completing the program. Twenty have signed up for the coming year for what will be a hybrid in-person and remote program.
- One physician fellow completed clinical training; two new physicians began their two-year fellowships.
- Two social workers have completed their Social Work Fellowship in Neurocognitive Disorders; a third fellow started the fellowship in August 2021.
- Mesulam Center Seminar Series -- 13 seminars were held online during this reporting period and were attended by an average of 48 attendees.
- The 27<sup>th</sup> Annual Alzheimer Day was held online May 6, 2021.
- Primary Progressive Aphasia Conference was held in March 2021.

### Rush Alzheimer's Disease Assistance Center for Northern Illinois

- Rush Memory Clinic adapted services to include clinical care via telemedicine (including live video) and mobile phone encounters to supplement in-person clinical care.

- Given the cognitive complications of COVID-19 (such as “brain fog”), the Rush Memory Clinic team developed a tailored neuropsychological testing battery and a new clinical evaluation protocol, which has been offered as one of the subspecialty services within the larger Rush multi-disciplinary long-haulers clinic.
- Without Warning, a support group for persons with early-onset dementia and their family members, continued meetings in a virtual format; created a website with videos from group members; and, in partnership with Lorenzo’s House, provided a one-day virtual day camp in June 2021 for kids of families living with younger onset Alzheimer’s Disease.
- Rush has been leading the ADRD Working Group with CATCH-ON, a Health Resources and Services Administration (HRSA)-funded Geriatric Workforce Enhancement Program. The “train the trainer” program has been provided to more than 186 health professionals and a Geriatric Members Interest Group at the Illinois Academy of Family Physicians was established.
- Rush and Leading Age Illinois offered their newly revised Dementia Leadership Course in a virtual format with an ongoing network component twice in the last year with attendance of around 80 per event.

### Southern Illinois University (SIU), School of Medicine, Center for Alzheimer's Disease and Related Disorders

- SIU Memory and Aging Network primary provider partner sites saw 672 patients for initial clinical assessments and 1,530 follow up visits.
- SIU’s RADAC received a grant to extend non-pharmacological interventions through December 2021 and used this funding to support the evidence-based programs for dementia patients and caregivers.
- Research progress included work on 31 active studies, 12 of which were investigator-initiated, 14 were industry sponsored studies, and five were animal model studies. Faculty and staff contributed to 15 peer-reviewed publications and 13 national and international publications, an increase in both from last year.
- 115 educational programs for caregivers and health care providers were held with attendance of 1,126.
- Implemented a new caregiver training titled “What to Expect When You Are Not Expecting ... to be a Caregiver,” designed to equip family caretakers with tools to provide support to the individual with dementia still living at home.
- Together, in fiscal 2021, CARE faculty and personnel contributed to nine peer-reviewed publications, 10 national/international presentations, five active externally funded bench/translational research grants, nine industry-sponsored clinical trials, eight investigator initiated clinical research studies, and several scientific abstracts presented at national and international conferences.

## State Agencies

In April and October 2021, the ADAC convened for its biannual meetings. During the fall meeting, the state agencies represented on the ADAC shared highlights of their dementia care work and accomplishments for fiscal year 2021. Highlights are shared in this report as follows:

### Illinois Department on Aging (IDoA)

- IDoA has again been awarded \$1 million in state general revenue funds to sustain services for persons living with dementia (PLWD) and their caregivers that were previously piloted and funded with Administration for Community Living discretionary grants.
- Funds are given directly to the 13 Area Agencies on Aging to support: Savvy Caregiver, Stress Busting for Caregivers, and Gap Filling.
- IDoA has also supported other activities, services, and interventions, including:
  - Dementia Friendly Illinois—a Dementia Friendly America movement to establish dementia friendly communities in Illinois that are equipped to support people living with dementia and their caregivers. IDoA redirected one of its long-time state grants to develop this initiative, and each Area Agency on Aging is required to add one dementia friendly community in their area by 2025.
  - TCARE—Tailored Caregiver Assessment and Referral is an on-line care management referral system designed to support family members who are providing care to adults of any age with chronic or acute health conditions, which can benefit people with ADRD and their families. Many of the Area Agencies on Aging have established TCARE with CARES Act Funding, and IDoA has received a small grant from the National Academy for State Health Policy to aid in establishing TCARE throughout Illinois.
  - Adaptive Equipment Corner -- an Illinois-based company that provides instructional videos for caregivers and individuals living alone about how to use adaptive equipment safely. The Area Agencies on Aging are providing the log-in so that the videos and assistance are free to seniors and caregivers. Although this service is not specifically targeted to PLWD and their caregivers, caregivers especially have benefitted by lessening the stress of managing co-morbidities.
  - GetSetUp is— an interactive website that provides education and social interaction to people living with dementia and their caregivers.



### Illinois Department of Healthcare and Family Services (IHFS)

- The IHFS Supportive Living Program (SLP) is an approved Home and Community Based Services waiver for assisted living services. The SLP dementia care setting program was developed to adapt the SLP model to meet the change in needs of people with dementia who would otherwise have to transfer to a nursing facility.
- Of the 155 SLP providers and more than 12,900 apartments, 11 providers and more than 300 dementia care designated apartments are currently certified for dementia care.
- In 2018, IHFS approved 41 applicants to develop new dementia care sites. The pandemic caused a delay in development, but in 2021, eight new dementia care sites were certified.

### Illinois Department of Human Services (IDHS)

- At this time, IDHS does not have programs tailored to individuals with ADRD and their families.
- When individuals receiving IDHS services exhibit symptoms that might indicate Alzheimer's disease or other types of dementia, IDHS systems utilize community resources to assist their dementia need.
- IDHS's ADAC non-voting member attends the bi-annual ADAC meetings to learn about ADRD efforts and be available for suggestions from the ADAC.

### Illinois Guardianship and Advocacy Commission (IGAC)

- IGAC is comprised of three divisions: Office of State Guardian, Legal Advocacy Service, and Human Rights Authority.
- The Office of State Guardian (OSG) serves as the court-appointed guardian for adults with disabilities under the Illinois Probate Act. A significant number of recipients have dementia or dementia-related conditions.
- The guardianship services, which include making health care and financial decisions, provided are not specific to dementia, but when OSG offers guardianship services for someone with dementia, the guardianship representative will cater the services to meet the needs of the ward with dementia.
- IGAC's ADAC non-voting member attends the bi-annual ADAC meetings to learn about ADRD efforts and be available for suggestions from the ADAC.

## Community Partnerships and Collaborations

Community partnerships and collaborations are integral to the effective coordination of quality dementia care in Illinois. The following partnerships highlight just a few of the important collaborations that are advancing dementia capability for Illinois.

### Alzheimer's Association

The Alzheimer's Association is one of the nation's leading organizations in Alzheimer's care, support, and research. Ongoing and regular communication occurs with the Association's Vice President of Public Policy and Advocacy, as well as the Director of State Affairs regarding important policy changes and initiatives. The Dementia Coordinator met with the Alzheimer's Association Illinois Chapter's programmatic leaders to learn about key activities that the IDPH Dementia Program can support and vice versa. These Alzheimer's Association programs include education and outreach, support groups, care consultation, and health care initiatives. An additional meeting was held with the Regional Health Systems Director to discuss potential areas for partnership, including performance improvements within health systems for dementia assessment and care, implementing more evidence-based dementia practices within systems, and involving caregivers in dementia care planning across settings. The Dementia Coordinator met with the national office's Associate Director for the Healthy Brain Initiative to gain insights about how this initiative is being implemented in other parts of the nation, as well as national guidance about the frequency of administering the caregiver and cognitive modules of the Behavioral Risk Factor Surveillance System.

### The Illinois Cognitive Resources Network

The Illinois Cognitive Resources Network (ICRN) is a coalition created by the three Regional Alzheimer's Disease Assistance Centers to build a network between stakeholders to reduce silos and optimize efforts across the state. The ICRN mission is to leverage the strengths of the volunteer health organizations focusing on ADRD, the Regional Alzheimer's Disease Assistance Centers, and organizations in the aging, disability, and public health networks to optimize the cognitive and functional well-being of Illinois residents and their families. In 2021, the ICRN continued its work to advance Dementia Friendly Illinois and Dementia Friends Illinois efforts throughout the state. The ICRN supports information exchange platforms, including hosting 10 virtual meetings in the last year among members for planning purposes. The ICRN also maintains content on a web-based education and resource platform ([ilbrainhealth.org](http://ilbrainhealth.org)). While some efforts were reduced as a result of the COVID-19 pandemic, the ICRN has supported planning calls among the three HRSA-funded Geriatric Workforce Engagement Programs for sharing and disseminating ADRD professional education resources. The Dementia Coordinator attends ICRN's monthly meetings to update the network on IDPH Dementia Program efforts, as well as keeping apprised of the efforts occurring around the state for ADRD. The ICRN's partnership with IDPH, IDoA and multiple community stakeholders is instrumental in advancing dementia capability throughout the state.

## Dementia Friendly Illinois

Dementia Friendly Illinois is a network under Dementia Friendly America seeking to develop and to expand the number of communities in Illinois equipped to effectively support people living with dementia and their caregivers. As of October 2021, Illinois has 19 communities designated as Dementia Friendly, 6,601 Dementia Friends, and 122 people trained as Dementia Champions. Expanding Dementia Friendly communities and training community members who are knowledgeable and equipped to support people with ADRD at a local level are significant initiatives in helping to make Illinois more dementia capable.

## Coroners Webinar

In September 2021, the IDPH Dementia Program collaborated with Rush University Medical Center to deliver a webinar to Illinois coroners and medical examiners. The webinar was titled “Alzheimer's Disease: The Importance of Autopsies in Diagnosis, Treatment, and Research.” It provided information to coroners and to medical examiners regarding the important role of autopsies in diagnosing and researching Alzheimer’s Disease. The Dementia Coordinator invited all coroners and medical examiner(s) from the state and disseminated the webinar flyer through the ADAC networks. The coroners in attendance were awarded one continuing education unit approved by the Illinois Coroners Training Board.

## Age-Centered Civil Society

IDPH and IDoA began meeting quarterly in mid-2021 to discuss efforts around supporting an age-centered civil society in Illinois.

## New Legislation

In August 2021, the Illinois General Assembly passed Public Act 102-0399 to help prepare Illinois’ workforce to become more dementia capable. This legislation requires physicians and other health care professionals who serve adult populations and have direct patient interactions to receive dementia training as part of their licensure renewal requirements. Illinois is the first state in the nation to pass legislation of this kind.

## Training Initiatives

In 2021, legislators passed Public Act 102-004, which amended the Adult Protective Services Act (320 ILCS 20), to include dementia training. Individuals who are involved in the provision of adult protective services are required to have two hours of training on dementia upon hire and two additional hours annually. The Alzheimer’s Association developed two initial trainings including, Dementia Specific Training for APS and Community Workers and 10 Warning Signs of Alzheimer’s. IDoA has distributed these trainings both internally and to the APS network of providers and administrative agencies for completion, which will support this new requirement.

In development for 2022, the new Alzheimer’s Disease Physician Early Detection Training Program will support the new training mandate for physicians and health care professionals by

equipping them with best practices for ADRD early detection methods, efficient clinic procedures, and referral procedures to increase early detection.

### **IDPH Funded Projects**

In collaboration with the Office of the Lieutenant Governor, IDPH released a notice of funding opportunity in spring 2021 to grant special funds for creating an online platform that serves as a one stop shop for people to learn more about Alzheimer’s disease and related dementias, and the services that are available to communities. Rush University Medical Center was awarded the grant, and the project began October 1, 2022. IDPH and Rush meet monthly to discuss progress on developing the platform to benefit all Illinoisans, including those in Black, Brown, and rural communities, as well as individuals and families impacted by younger onset dementia.

The IDPH Dementia Program was allocated \$1 million in general revenue funds for fiscal year 2022. In collaboration with the ADAC Strategic Budget Planning Workgroup, the Dementia Program has developed two additional grant opportunities—the Alzheimer’s Disease Early Detection and Awareness Campaign program and the Alzheimer’s Disease Physician Early Detection Training program. The purpose of the Alzheimer’s Disease Early Detection and Awareness Campaign is to increase public awareness about brain health, the early warning signs and symptoms of cognitive decline and dementia, and the importance of talking to a professional about being screened and assessed for ADRD, with a particular focus on high-risk and underserved populations. The purpose of the Alzheimer’s Disease Physician Early Detection Training grant is to increase early detection and diagnosis of ADRD by physicians and medical providers by equipping them with best practices for ADRD early detection methods, efficient clinic procedures, and referral procedures tailored to their local communities, with a particular focus on high-risk and underserved populations. The projects will take place from February 1, 2022, through June 30, 2022.

### **The Behavioral Risk Factor Surveillance System**

The Behavioral Risk Factor Surveillance System (BRFSS) was established in 1984 as a collaboration between the U.S. Centers for Disease Control and Prevention (CDC) and state health departments and has grown to be the primary source of information on behaviors and conditions related to the leading causes of death for adults in the general population. In Illinois, BRFSS is a state-based program that gathers information on risk factors among adults 18 years of age and older through monthly telephone surveys.

Important to the Dementia Program are the BRFSS cognitive and caregiver modules, both of which are recommended in the Alzheimer’s Disease State Plan to be administered in Illinois based on national guidance. Most recently, Illinois administered the cognitive module in 2020 and the caregiver module in 2021. As in past years, the IDPH

epidemiology team will utilize the data to create burden briefs made available to the Illinois Alzheimer's Disease Network and the public. The goal is to utilize the BRFSS data and other surveillance data to enhance public health programming, including collaborative health promotion in other chronic disease areas.

## Next Steps

The following are 2022 areas of focus for carrying out the recommendations of the 2020-2023 Alzheimer's Disease State Plan.

### Early Detection

- In early 2022, the Dementia Program will begin two new grant projects aimed at advancing the Early Detection of Alzheimer's Disease and other Related Dementia in Illinois. These projects will increase awareness for the public and train the primary care and health communities about the importance of performing cognitive screening, diagnosing ADRD, and talking to people and their caregivers about being diagnosed. These projects will focus on early detection for some of the state's most vulnerable and underserved populations, including Black, Brown, and rural communities.

### Workforce Expansion and Training

- The ADAC's Workforce Expansion and Training Workgroup will continue to meet monthly in 2022 to focus on workforce expansion, which is vital to support the growth and expansion of services that will support the growing prevalence of ADRD. The workgroup plans to use the state plan recommendations to identify strategies and activities to increase awareness of educational programs, career paths, partnerships, training programs, and potentially certifications that promote the growth of professionals who enter careers serving people who have ADRD.
- The Dementia Coordinator plans to promote the use of the updated IDPH Core Competencies by other state agencies and community groups that are involved in training or overseeing the ADRD workforce.
- An examination of all the compiled training statutes related to ADRD, how these are being fulfilled, and what gaps still exist is needed to determine how to best create new trainings or better support community organizations in these training efforts.

### Collaboration

- Integral to the effective coordination of quality dementia care is engaging both public and private partners in planning for and responding to the growing impact of ADRD in Illinois. This includes stronger collaboration between state agencies. In 2022, the Dementia Coordinator will focus on establishing regular patterns of communication between IDPH and other key state agencies that provide dementia care services, including the IDoA, IDHFS, and the IDHS. Specific areas of focus include gaining a better understanding of each agency's ADRD services, identifying gaps in services, coordinating efforts toward improved care, and identifying ways to increase the public's ability to understand and access these services more easily.
- The Alzheimer's Disease State Plan has a section of recommendations aimed at improving residential care for persons living with ADRD. A starting point for early 2022

will be for the Dementia Coordinator to convene meetings with the IDPH Office of Healthcare Regulation to gain an understanding of the Administrative Rules involving dementia care and training requirements in residential settings, how the regulatory teams are implementing oversight of these requirements, and where gaps exist. Subsequently, it will be important to convene with other state agencies and community stakeholders to have conversations about how improvements can be made, including strategizing recommendations for behavioral protocols, evidence-based practices, and improved training protocols.

## Data Collection

- The BRFSS cognitive module was administered during the 2020 survey and the caregiver module was administered during the 2021 survey. The Dementia Coordinator will work with the ADAC and the IDPH epidemiology team to identify the best ways to utilize the data to create burden briefs that are effective in informing strategies for improving public health programming.
- The BRFSS burden briefs will be made available to the Illinois Alzheimer's Disease Network and the public with publication targets of summer 2022 and summer 2023.
- The Dementia Program will look to the ADAC and other community stakeholders to identify other data collection sources and methods that can inform public health programming and response to cognitive health and impairment.
- Similarly, the Dementia Program will work with other IDPH teams, ADAC, grantees, and stakeholders regarding effective programmatic evaluation strategies.

## Conclusion

Progress has been made and important work remains to help support Illinois in becoming a dementia-capable state. Establishing the Dementia Coordinator position has given full-time attention and bandwidth for IDPH to oversee, to organize, and to streamline dementia-specific efforts throughout the state in collaboration with the Alzheimer's Disease Advisory Committee. In 2022, updates to the current state plan will be made to identify priorities, goals, and specific strategies for advancing dementia capability in Illinois.

