



State of Illinois  
Illinois Department of Public Health

# Dementia Annual Report

Dementia Capability in Illinois

2025



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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 living 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: Illinois Department on Aging, Illinois Department of Healthcare and Family Services, Illinois Department of Public Health (IDPH), and Illinois Department of Human Services, and 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 (RADAC) funded by the Illinois Department of Healthcare and Family Services that are an integral part of the Alzheimer's disease network in Illinois. RADACs are nationally considered the top tier of dementia care, providing diagnostic evaluation, treatment, referrals, and research. They 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 and be 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 Mesulam 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, Smith Center for Alzheimer's Disease and Related Disorders, Springfield

In 2019, the Illinois General Assembly passed legislation authorizing the creation of a dementia coordinator position 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, renaming the fund to include the wording “Care and Support,” adding promotion of the fund, and defining use of money in the fund -- to be directed primarily to support the dementia coordinator position. If funding remains, it would be used to execute data projects and to implement state plan recommendations.

In January 2023, IDPH published the [2023-2026 State of Illinois Alzheimer's Disease Plan](#). The plan’s report and recommendations were updated in conjunction with the 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.

### **Public Health’s Response to Alzheimer’s Disease and Related Dementias**

Public health is uniquely positioned to respond to Alzheimer’s disease and related dementias (ADRD). ADRD has become a growing public health crisis as the burden of dementia becomes larger and the far-reaching impacts of the disease expand. Public health protects and promotes

the health of all people, in all communities. Public health practices and activities offer strengths that make a public health approach to addressing ADRD important.

Illinois has joined a nationwide movement to mobilize a public health response to ADRD. 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 goals and recommendations, to strengthen partnerships with community stakeholders and other state agencies regarding ADRD, and to coordinate statewide efforts that increase awareness of ADRDs, with improved access to high-quality services. Having a full-time coordinator positioned at IDPH has allowed ADRD efforts to be prioritized and accelerated. In late spring 2025, this position was vacated with a new coordinator taking over in early summer.

## Accomplishments

Rapid hiring and placement into the dementia coordinator position in 2025 reduced disruption to ongoing dementia activities. The Alzheimer's Disease Advisory Committee (ADAC) formed subcommittees to allow for a more comprehensive approach to review the Illinois Alzheimer's State Plan and create an implementation and evaluation plan for activities to improve the dementia capability of Illinois, which is addressed in the next section dedicated to ADAC activities. Additionally, progress has been made toward implementing activities and strategies that support the recommendations of the [2023-2026 Illinois Alzheimer's State Plan](#). Highlights include the continuation and expansion of:

- Programming that supports early planning for persons living with dementia in the LGBTQ+, Asian American, Black American, and Hispanic/Latinx communities was created and funded, mobilizing two community partners to lead these efforts.
- Programming that supports the caregivers of persons with dementia from Rural, Black American, Hispanic/Latinx, and Asian American populations was created, mobilizing five community partners to lead this work.
- The Illinois Department of Public Health Dementia Program and the University of Illinois Chicago began conducting a statewide Needs Assessment.
- Continued collaborative work on the CDC federal award "BOLD Public Health Programs to Address Alzheimer's Disease and Related Dementias" grant; the strategies align with Illinois' Alzheimer's Plan, and the 5-year project will continue through September 29, 2028.
- Under the CDC BOLD award, three partners are implementing the following programs: The Illinois Brain Health Project, the ADRD Training Series for Professionals, and the Medical Provider and Health Systems programs. Further details are below in the "IDPH Funded Projects" section of this report.

## Alzheimer’s Disease Advisory Committee

After voting to create subcommittees to focus on strategizing implementation of the Illinois Alzheimer’s State Plan in 2024, the Alzheimer’s Disease Advisory Committee (ADAC) identified members and other individuals with experience and expertise in each of the six goal areas outlined in the [2023-2026 State of Illinois Alzheimer's Disease Plan](#). Identified candidates completed the review and appointment process in the first half of 2025. With the new State Plan due in 2026 and the transition of a new dementia coordinator, meetings of subcommittees were paused until 2026.

## Regional Alzheimer’s Disease Assistance Centers—2025 Updates

### Northwestern Alzheimer’s Disease Assistance Center (NADAC) for Northern Illinois

- The Northwestern RADAC is a component of the Mesulam Institute for Cognitive Neurology and Alzheimer’s Disease and serves the Chicago Metropolitan Area, Cook County, 8 collar counties and attracts patients throughout Illinois, nationally and internationally.
- The clinic is staffed by a multidisciplinary team of 6 behavioral neurologists, 5 neuropsychologists, 1 neuropsychiatrist, 3 clinical social workers, 2 social work fellows, 1 nurse and 1 physician assistant.
- There were 1,039 new and 3,617 returning patients seen in the Neurobehavior and Memory Clinic for a total of 4,656 patient visits.
- During FY25 the median age of our patient population was 77. The demographics are female 56% and male 44%. Patients self-report as 71% White, 14% African American, 5% Asian, 8% Hispanic and 10% other or declined.
- Three monthly online care partner support groups: Younger Onset, Primary Progressive Aphasia (PPA), and Frontotemporal Dementia (FTD). The Younger-Onset sees an average of 8 care partners per month and FTD sees an average of 10 participants per month. The PPA group has an average of 31 participants each month and is divided into early, moderate, and advanced stage breakout rooms.
- The 31st Annual Alzheimer Day was held on May 15, 2025, and featured a panel presentation which showcased Chicago’s Dementia Friendly Communities. Dr. Allan Levey, MD, PhD, Director of the Goizueta Alzheimer’s Disease Research Center, Emory University, also presented the Mendelson Lecture.
- The Northwestern University Mesulam Center for Cognitive Neurology and Alzheimer’s Disease News is an annual 25+page newsletter directed to over 8,000 patients, families, health and social service professionals and the general community. During FY25, the e-newsletter reached over 5,000 recipients monthly.

- The Northwestern RADAC/Mesulam Center maintains a website that features The Neurobehavior and Memory Clinic with over 63,000 users and over 79,000 sessions accessed for caregivers, healthcare professionals, investigators, and patients.

### **Rush Alzheimer’s Disease Assistance Center (RADC) for Northern Illinois**

- The Rush ADC primarily serves the communities of Northeastern Illinois and provides services and programs specific to persons with Alzheimer’s disease and/or related Dementias, and for their families and caregivers, as well as those at risk for Alzheimer’s and/or related Dementias.
- RADC’s research programs involved study participants across Illinois, the USA, Brazil, Puerto Rico and Mexico to address health equity in Black and Latino adults and support aging and Alzheimer’s Disease worldwide. To date, over 6,446 brains have been collected from persons aged 18-105.
- The Without Warning Support Groups address the needs of people with early-onset Dementia and their family members. Some of these support groups meet through Zoom on a monthly to bi-monthly schedule. Others meet during regular lunch gatherings.
- RADC created a web-based Toolkit aimed at supporting the creation of other support groups and assisting facilitators nationwide. To date, 360 support group leaders have joined the forum.
- The documentary, Too Soon to Forget, about early onset has been aired 686 times on 235 channels in 96 markets in 36 states and is available in Spanish, in libraries, on Amazon Prime (2020) and PBS. Too Soon to Forget is available with Spanish subtitles and has 13 supplemental features that can be used for training and support groups.
- The Dementia Champions Training has been offered since 2018. This virtual training is offered to help increase the reach of the Dementia Friends program. Through collaboration, a monthly Dementia Friendly Illinois newsletter is sent out to over 643 people.
- Rush has five ongoing community-based cohort studies that enroll older persons without dementia and focus on the prevention of Alzheimer’s disease and other common chronic conditions of aging through the identification of risk factors. These include the Religious Orders Study, which is conducted across the USA, and the Rush Memory and Aging Project, the Minority Aging Research Study, the African American Clinical Core, and the Latino Core, all of which cover Cook and the collar counties. Together, these studies have enrolled and followed more than 10,000 older persons, including about 2,900 non-Latino Black adults and 715 Latinos.

### **Southern Illinois University (SIU), School of Medicine, Dale and Deborah Smith Center for Alzheimer’s Research and Treatment (Smith Alzheimer’s Center)**

- The Smith Alzheimer’s Center is part of the Department of Neurology and the Neuroscience Institute at Southern Illinois University School of Medicine (SIUSOM). The

Smith Alzheimer’s Center’s main clinical component is the Memory Care Clinic. The Clinic broadly serves Illinois regions 1-5, which is comprised of 93 counties. The Smith Alzheimer’s Center provides complete memory and cognitive assessments, treatment, education, counseling and referrals to other resources for patients and their families.

- In FY25, the Smith Alzheimer’s Center saw 547 new patients and had 1,962 follow-up visits.
- In FY25, the Smith Alzheimer’s Center participated in 5 different industry-sponsored clinical trials and 13 investigator-initiated research studies.
- In FY25, the Smith Alzheimer’s team produced 12 peer-reviewed publications and 10 scientific abstracts, which resulted in presentations at regional, national and international conferences and meetings.
- The Smith Alzheimer’s Center’s team provides Dementia related presentations throughout the year for a variety of audiences at various conferences and events. This includes health care professionals, social service providers, clinicians, patients, caregivers and families. In FY25, the Smith Alzheimer’s Center provided 86 educational opportunities.
- Beyond the Medical Center, programs offer non-pharmacological programs and support services for people with dementia and their caregivers. Current offerings include Art Express, Dementia Caregiving 101, Stepping Up, Minds in Motion, Early-Stage Memory Loss Support Group, Sing by Heart, MIND Diet Cooking Classes, and Building Moments Lego Program.
- The Memory and Aging ECHO project offers community professionals virtual education and access to the Smith Alzheimer’s Center dementia and gerontology experts, primarily targeting those living and practicing in rural areas that often experience decreased access to specialized care. There were 77 distinct participants in ECHO in FY25.
- The Smith Alzheimer’s Center was featured in the documentary, “My Mama Joe: Hope and Help,” about destigmatizing Dementia in the Black community, which aired on PBS in the Spring of 2025. The documentary was shown three times in Springfield, IL. The Smith Alzheimer’s Center was able to provide a panel member for one of the discussions and set up a resource table at each event. The documentary is scheduled to be shown nationally by the end of 2025.

## State Agencies—2025 Updates

### Illinois Department on Aging (IDoA)

- The State of Illinois awards funding to IDoA for caregiver support services. IDoA also receives federal funds to provide respite care through two sources: Title III-B and Title III-E of the Older Americans Act. Title III-B funds In-Home, Access and Community-Based Services, and Title III-E funds the National Family Caregiver Support Program (NFCSP). Both the state and federal funds are distributed to the 13 Area Agencies on Aging (AAA) in Illinois. The NFCSP program, established in 2000 under Title III-E of the Older Americans Act, provides funding for a range of supports that assist family and informal

caregivers to care for an older person and other relatives at home for as long as possible. These services include, but are not limited to, counseling, support groups, training and education, case management, access & assistance, and gap-filling funds to support unmet needs.

- The Illinois Department on Aging’s 13 Area Agencies on Aging (AAA) provide support and education to families of persons with Alzheimer’s disease and/or related dementia through several initiatives, including those listed below. For additional information, please see IDoA’s annual Respite Report [respite-report-2024.pdf](#)
  - Savvy Caregiver
  - Caregiver respite through community health workers (CHW)
  - Coordinating with Illinois’ communities to achieve designation as a “Dementia Friendly Community”
  - Many of the AAAs employ caregiver specialists who assist families in navigating caring for an individual with Alzheimer’s disease and/or related dementias
- In addition, Age Options, one of the Chicago Area Agency on Aging facilitated the provision of a training course for the AAA and other caregiver specialists (CHW) specifically focused on persons with Alzheimer’s disease and/or related dementias.
  - T-Care: An evidence-based program that includes a caregiver assessment, care plan, and support through services at the AAA and connects to Trualta, an educational platform that connects individuals/caregivers with community events, educational offerings (both virtual and in person) and brief educational courses.
- Among the services offered under IDoA’s 1915c Medicaid Waiver is Adult Day Services. Although not limited to individuals with Alzheimer’s Disease and related dementias, this service can provide respite to caregivers by providing structured activities, outings, socialization, medication management, nutrition, and more to individuals with Alzheimer’s Disease during business hours. Individuals are referred by IDoA’s case managers (the Care Coordination Units or “CCU), and Area Agencies on Aging. These services count towards the number of hours a participant is assessed to receive by the CCU.

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

The Department of Healthcare and Family Services (HFS) developed and provides oversight for the Supportive Living Program (SLP) as an alternative to nursing home care for low-income older persons and persons with physical disabilities under Medicaid. SLP operations under a 1915(c) Home and Community Based Services waiver to allow payment for services that are not routinely covered by Medicaid. These include personal care, homemaking, laundry, medication assistance, social and health activities, recreation, and 24-hour staff to meet residents’ scheduled and unscheduled needs. The

resident is responsible for paying the cost of room and board. The SLP provides services in both conventional assisted living settings as well as Dementia Care Settings (DCS).

- Residents must be age 65+ or be age 22-64 with a physical disability as determined by the Social Security Administration. A preadmission screening must also be completed to determine eligibility for Medicaid services (those who are financially eligible for Medicaid must meet a minimum score).
- Residents have their own individual apartment, unless they choose to have a roommate in a double occupancy apartment. Apartments must have a lockable entrance, individual heating and cooling, a private bathroom and a kitchen/kitchenette. A variety of services are available based on residents' needs and preferences. Services include assistance with personal care, medication management, nursing assessments and oversight, meals and snacks, health and social activities, well-being checks and an emergency call system.
- SLP DCSs allow individuals with cognitive impairments the option of remaining in a community setting while providing the added safety intervention of delayed egress and other supports. In addition to services and requirements associated with conventional SLP settings, the DCS must provide three daily well-being checks and at least three daily scheduled activities.
- The SLP operates statewide. Currently, there are 160 SLP communities with over 13,400 apartments. Of these, twenty are certified dementia care settings (DCS) with more than 520 apartments. Another forty projects have been approved to proceed towards certification and are in various stages of development, including 33 approved DCS communities.

### Illinois Department of Human Services (IDHS)

- The Division of Rehabilitation Services operates three Medicaid Waivers collectively referred to as the Home Services Program (HSP).
  - Persons with Disabilities
  - Persons with HIV/AIDS
  - Persons with Brain Injury

The HSP provides services to individuals with severe disabilities so they can remain in their homes and be as independent as possible. Individuals with Alzheimer's disease and/or related dementia are not eligible for services based solely upon those diagnoses alone unless there is a clinical diagnosis of acquired brain injury and/or they receive the minimum scoring on the Determination of Need Tool used to assess an individual's functional limitations and unmet needs.

- The Division of Rehabilitation Services offers additional services to individuals with severe disabilities, including vocational rehabilitation, services for people who are blind or visually impaired, and Educational Services, including the Illinois Schools for the Deaf

and Visually Impaired, and the Illinois Center for Rehabilitation and Education, and the Next Steps program for parents of children with disabilities.

- Persons qualifying for the Brain Injury waiver may receive cognitive and behavioral services. These services are not available to family members.
- Unpaid caregivers of eligible individuals who qualify for the HSP waiver can receive temporary respite services.

The goal of the Home Services Program is to provide support and services to individuals with severe disabilities that will enable them to maximize their independence so they can remain in their homes and not be placed in nursing facilities. Eligibility requirements:

- Be under age 60 at the time of application, unless in the AIDS or Brain Injury 1915c HCBS Medicaid Waiver.
- Have a significant disability lasting 12 months or longer, or for the duration of life.
- Be at imminent risk of nursing facility placement.
- Have applied, cooperated and obtained a decision on Medicaid eligibility unless already on Medicaid or spend-down.
- Require services in the home costing the same or less than nursing facility costs.
- Be a State of Illinois resident with U.S. citizenship or show proof of legal entry into the United States.
- Have assets under the asset limit, which is different for individuals under age 18 and those 18 and older.
- Score the required points on the Determination of Need (DON).

HSP Medicaid Waiver Programs are authorized by the Disabled Persons Rehabilitation Act (20 ILCS 2405/3(f) and the federal Centers for Medicare and Medicaid Services (42 CFR 440.180).

The goal of the Vocational Rehabilitation Program is to assist persons with disabilities to locate and retain quality employment. Eligibility requirement:

- Has been determined by qualified personnel to have a physical or mental impairment that constitutes or results in a substantial impediment to employment for the individual;
- Has been determined by a qualified vocational rehabilitation counselor employed by DHS-DRS to require vocational rehabilitation services to prepare for, secure, retain, or regain employment consistent with the customer's unique strengths, resources, priorities, concerns, abilities, capabilities, interests, and informed choice; and

- It is presumed to be able to benefit from vocational rehabilitation services in terms of an employment outcome.

The Vocational Rehabilitation Program is authorized by Section 3 of the Disabled Persons Rehabilitation Act [20 ILCS 2405/3(b)].

All services are available statewide.

Additional training for HSP staff, although not yet mandatory, is also available to help educate people on the warning signs and effective communication strategies for individuals with Alzheimer's Disease.

### **Illinois Guardianship and Advocacy Commission (IGAC)**

The Guardianship and Advocacy Commission (GAC) is composed of: Office of State Guardian, Legal Advocacy Service, Human Rights Authority and the Special Education Initiative. Although GAC does not have programs that are specifically targeted to persons suffering from dementia, due to the nature of both the services GAC provides and the populations served, GAC has significant engagement with persons with dementia and dementia-related conditions.

The Office of State Guardian (OSG) serves as the court-appointed guardian for adults with disabilities under the Illinois Probate Act and has nearly 5000 persons under its care across Illinois.

OSG is designated as the guardian of “last resort”, meaning that no other person or entity is willing and able to serve as guardian. OSG is authorized by the Guardianship and Advocacy Act (20 ILCS 3955/1 et seq.) and provides services pursuant to the Illinois Probate Act, primarily Article 11a on Guardians for Adults with Disabilities (755 ILCS 5/112-1 et seq.), as well as other related acts, such as the Health Care Surrogate Act (755 ILCS 40/1 et seq.), among others.

The individuals under guardianship and in the care of GAC have a variety of intellectual and mental disabilities, which have led to a legal determination by an Illinois judge that there are at least some life decisions outside the capabilities of these individuals to make, at least temporarily. The services provided by GAC (which include making healthcare and financial decisions) are not specific to dementia.

The Human Rights Authority (HRA) conducts investigations of complaints related to the rights of eligible recipients with disabilities who receive services from certain service providers, such as mental health service providers, hospitals, schools and nursing homes, among others. HRA is authorized by the Guardianship and Advocacy Act (20 ILCS 3955/1 et seq.). Complaints submitted to the HRA relate to people with a variety of disabilities, including but not limited to dementia.

GAC also continues to focus on providing and advocating for alternatives to guardianship for adults with disabilities who might need some assistance with decision-making, but for whom legal guardianship would be unnecessary and overly restrictive. In Illinois, the Supported Decision-Making Agreement Act of 2022 provides a structure and protections for adults with disabilities who might want and need a less intensive level of assistance with decision-making. GAC continues work to ensure that all persons with disabilities, including those with dementia, can exercise their own judgement to the greatest extent possible for the longest period.

## **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 between the IDPH legislative affairs team, the association's Illinois vice president of Public Policy and Advocacy, and the association's director of State Affairs regarding important policy changes that may impact ADRD programming and initiatives. The dementia coordinator has continued regular contact with the Illinois chapter leaders, establishing a minimum of quarterly check-in meetings with the chapter's programmatic leaders to learn about key activities and initiatives of the association. Association programs include education and outreach, support groups, care consultation, and health care initiatives. In 2025, the dementia coordinator attended the fourth annual State Dementia Services Coordinator Summit hosted by the Alzheimer's Association's national office. This was an important learning opportunity that highlighted both challenges and best practices for addressing the needs of persons living with dementia and their caregivers, as well as networking with other state dementia coordinators to learn about their approaches for ensuring a coordinated statewide response to ADRD in their respective states.

### **Illinois Cognitive Resources Network**

The Illinois Cognitive Resources Network (ICRN) is a coalition created by the three regional ADA 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 ADA 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 2025, the ICRN continued its work to advance Dementia Friendly Illinois and Dementia Friends Illinois efforts throughout the state. The ICRN also continues to maintain the web-based education and resource platform ([ilbrainhealth.org](http://ilbrainhealth.org)). 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 expand the number of communities in Illinois equipped to effectively support people living with dementia and their caregivers. As of October 2025, Illinois had 48 communities designated as Dementia Friendly, 14,533 Dementia Friends, and 396 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.

## **Illinois State Police**

In 2024, the Illinois State Police Silver Search program issued 124 notices for at-risk individuals residing in 23 counties across the state. Final counts for 2025 are not available at the time of this report. The Silver Search law went into effect in 2016 in response to a growing concern for the safety of missing residents who are at-risk of negative outcomes if not found. Silver Search alerts are disseminated through multiple partnerships with State agencies to facilitate rapid notification and response to improve outcomes. There are plans to expand the reach of Silver Search alerts in 2026. Dementia training is part of police academy training.

## **New Legislation**

In 2024, the Illinois General Assembly passed legislation to help expand access to new FDA-approved treatments that slow the progression of Alzheimer's Disease. Public Act 103-0975 requires coverage in state employee health insurance plans for any FDA-approved treatment that slows the progression of Alzheimer's Disease or other dementias, as well as requiring coverage for diagnostic testing necessary for treatment access. The coverage requirement went into effect July 1, 2025. Additionally, the provisions of Public Act 103-0102 became effective January 1, 2024, requiring Medicaid coverage of cognitive assessments and care planning.

This coverage mandate was expanded by 2025 legislation (P.A. 104-0001) to include all state-regulated insurance plans starting January 1, 2027. Illinois is the first state in the nation to require insurance coverage for Alzheimer's treatments.

## **Training Initiatives**

There were no initiatives in 2025 to add legislatively mandated training requirements. Currently, the State of Illinois has 10 pieces of legislation that require Dementia and Alzheimer's training of 35 licensed professions.

## **IDPH-Funded Projects**

In fiscal year 2025, the Dementia Program continued two new state-funded grant programs that are in alignment with the [2023-2026 Alzheimer's Illinois State Plan](#). In addition, three new projects continued under the IDPH's Centers for Disease Control (CDC) federal grant award, "BOLD Public Health Programs to Address Alzheimer's Disease and Related Dementia".

### State Funded Programs

The Dementia Early Planning Workshop Series for Diverse Populations aims to provide high-quality advanced care planning workshops that are culturally tailored for specific underserved and disproportionately impacted populations in Illinois, including Black American, Hispanic/Latino, Asian American, and LGBTQ+ communities. IDPH selected and mobilized two grantees to deliver this program. Hanul Family Alliance is a community-based organization that serves the Korean American population in Chicagoland: The Center for Disability and Elder Law is a non-profit legal organization that specializes in providing free legal services to low-income seniors and people with disabilities in Chicagoland. FY25 activities for this grant focused on finalizing plans and documents, outreach and scheduling sessions to implement planned activities. Workshops began for both grantees by the second half of the fiscal year, with approximately 225 individuals receiving education and support in advanced care planning. In late 2025, CDEL expanded to offer resources online and provided training to Land of Lincoln Legal Aid to provide education and support across the state.

The Dementia Caregiver Program for Underserved Populations is a multipronged program aimed at providing education, support & community connection for caregivers in Black-American, Latino/Hispanic, Asian-American, and rural communities in Illinois. This program aligns with several areas in the [2023-2026 Alzheimer's Illinois State Plan](#), as well as action E-7 from the 2023-2027 Health Brain Initiative roadmap, to ensure caregivers have information, tools and resources about their vital role and ways to maintain their own health and well-being. Five total grantees were chosen for the first cohort of this project. Three of the five grantees for this program are providing evidence-based or evidence-informed interventions, and all five are providing culturally tailored and relevant interventions that wrap around the caregivers. Grantees spent the first half of the first year of this grant developing the programs and recruiting participants. The second half of FY25 was spent providing programs and support for caregivers. Agencies have been working on evaluating program delivery and finding that programs are helping caregivers reduce their level of burnout. Some agencies have support programs that are multiple sessions over the course of a month. Evaluations of these programs have encompassed the entirety of the session and making data collection difficult and inconsistent. These projects have a statewide reach with a particular focus on high-risk populations and underserved communities.

### Building Our Largest Dementia Infrastructure

In 2024, IDPH was awarded a continuation of federal funding for “Building Our Largest Dementia Infrastructure (BOLD)-- Public Health Programs to Address Alzheimer’s Disease and Related Dementias,” FY25 covered Year 2 of a 5-year project period. This grant supplied financial support for three projects and was supplemented with State funds to provide a more robust opportunity for grantees to provide valuable work to expand and mobilize an equitable statewide response to Alzheimer’s Disease and Related Dementias (ADRD) for people in Illinois living with ADRD, their families, and caregivers. The Illinois Dementia Program accelerated implementation of the 2023-2026 Illinois Alzheimer’s Disease State Plan, prioritizing strategies from the state plan that align with BOLD and the Healthy Brain Initiative roadmap actions. To

do so, the Illinois Department of Public Health (IDPH) utilized a well-coordinated public health systems approach for implementing a strong collaboration with key partners, data collection and analysis to inform activities, public education and awareness strategies to promote prevention of ADRD at all levels, and mobilization of stakeholders, communities, and the workforce to expand their capacity of responding to ADRD at local levels. Three projects were launched to improve knowledge and competency in hopes of making Illinois more dementia capable. Each project focuses on education, including addressing the needs of diverse and disparate populations. The first of the three projects supports a public-facing website that promotes risk reduction for individuals through a series of resources tied to each risk factor. The second of the grants is a professional training series grant that provides professionals in certain settings with asynchronous online learning modules about how their profession may interact with individuals with ADRD in their work environment. The last of the projects is a medical professional development project that provides high-level education to health care providers to improve their ability to identify, treat, and support individuals with ADRD and their caregivers. A continuation application was submitted to CDC for FY26 (Year 3) to continue the great strides that are being made in building Dementia Infrastructure statewide.

## **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 surveys are conducted as random-dialed telephone interviews of adult residents throughout the state.

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. The BRFSS Cognitive Decline module measures subjective cognitive decline (SCD) and its associated effects on function and daily living. 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. Both modules continue to be collected by IDPH regularly with funding from a special state fund overseen by the Dementia Program.

Data from the 2024 and 2025 surveys are being reviewed and finalized. In 2024, participants were presented with the optional caregiver module questions. The cognitive decline modules were used in the 2023 and 2025 surveys. In 2022, IDPH used BRFSS state and county data to develop two burden updates. In 2023, about 15% of the 2,756 participants over 45 years of age answered the trigger question that they feel that their thinking/memory was getting worse. Previously completed Burden briefs from 2020 are published and accessible on IDPH's [Alzheimer's Disease webpage](#).

## Next Steps

Calendar year 2026 will focus on strategizing implementation of the newest version of the State of Illinois Alzheimer's Disease plan, which is an extension of the [2023-2026 State of Illinois Alzheimer's Disease Plan](#) goals, including:

1. Develop, expand, and sustain a dementia-capable, culturally responsive workforce in Illinois.
2. Increase public awareness about brain health, risk reduction, and early detection of ADRDs with an emphasis on underserved communities.
3. Increase equitable access to person-centered, coordinated, and culturally competent care, support, and therapeutic interventions for PLWD, their families, and caregivers.
4. Ensure communities are dementia capable and prepared to respond to the needs of diverse persons living with dementia, their families, and caregivers.
5. Identify, collect, and utilize data to assess the impact of dementia in Illinois and improve public health outcomes.
6. Promote opportunities to expand dementia-related research and support the translation and dissemination of research findings with an emphasis on maintenance of cognitive health, prevention of dementia, early diagnosis, and personalized intervention.

## Conclusion

Progress has been made, but important work remains to help support Illinois in becoming a dementia-capable state. The goals and strategies recommended in the 2023-2026 State of Illinois Alzheimer's Disease Plan have been a considerable undertaking, which is why the 2026-2029 plan has remained relatively unchanged. Collaborative efforts among state agencies, community partners, and stakeholders are integral to the coordinated approach that is needed to address ADRD and to increase dementia capability in Illinois. It is imperative to include the voices of individuals, care partners and families living with dementia, professionals, and stakeholders from across sectors, and those representing underserved communities. The intention is to strategize approaches that are equitable and culturally and linguistically responsive, to create meaningful change on behalf of those living with ADRD, and to reduce health disparities. Illinoisians are invited and encouraged to join this endeavor.