

Illinois Department on Aging

FY 2023 Respite Services Report

March 2024

In Accordance with Public Act 93-864

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PROVISIONS OF THE RESPITE PROGRAM ACT

In 2015, the General Assembly authorized the Illinois Department on Aging (IDoA) through the Respite Program Act to administer a respite program of assistance to persons in need and to deter the institutionalization of frail or disabled adults (Respite Program Act, 2015). The Respite Program Act authorizes IDoA to make grants to or contract with Area Agencies on Aging (AAAs) and other appropriate community-based organizations to provide respite care under the Act.

The State of Illinois recently awarded funding to IDoA for caregiver support services, beginning in Fiscal Year 2023. IDoA also receives federal funds to provide services and respite care through 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 thirteen AAAs in Illinois through the Intrastate Funding Formula. The NFCSP program, established in year 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.

The Respite Program Act requires IDoA to submit an annual report to the Governor and the General Assembly detailing the progress of the respite care services provided under this Act. This report is based on respite services provided during FY 2023 using both federal Older Americans Act (OAA) funding and state funding.

THE AGING NETWORK IN ILLINOIS

THE ILLINOIS DEPARTMENT ON AGING

The Illinois Department on Aging (IDoA) was created by the Illinois State Legislature in 1973 for the purpose of improving the quality of life for Illinois' senior citizens by coordinating programs and services, which enable older adults to preserve their independence for as long as possible. IDoA is the single state agency in Illinois authorized to receive and dispense both federal Older Americans Act funds and state funds through AAAs and community-based service providers.

The legislative mandate of IDoA is to provide a comprehensive and coordinated service system for the state's approximately 2.8 million older adults, giving high priority to those in greatest need, to conduct studies and research into the needs and problems of older adults, and to ensure participation by older adults in the planning and operation of all phases of the service system.

The mission of IDoA is "to serve and advocate for older Illinoisans and their caregivers by administering quality and culturally appropriate programs that promote partnerships and encourage independence, dignity, and a high quality of life" (Illinois Department on Aging, 2024). In fulfilling its mission, IDoA responds to the dynamic needs of society's aging population through a variety of activities including:

- Planning, implementing, and monitoring integrated service systems;
- Coordinating and assisting the efforts of local community agencies;
- Advocating for the needs of the state's older adult population; and
- Cooperating with federal, state, local and other agencies of government in developing programs and initiatives.

AREA AGENCIES ON AGING

The state of Illinois is divided into thirteen Planning and Service Areas (PSAs). IDoA has designated one Area Agency on Aging (AAA) in each PSA. Illinois has twelve not-for-profit agencies and one unit of local government (City of Chicago) which serve as AAAs. Each AAA is responsible for planning, coordinating, and advocating for the development of a comprehensive and coordinated system of services for the older adults and their caregivers within the boundaries of the individual PSAs. Addendum A includes additional information on the PSAs and the AAAs.

IDoA, in accordance with the Older Americans Act (OAA), has decentralized the planning process by delegating responsibilities to the AAAs. This planning cycle begins with assessment of the service needs of local older adults, family caregivers, and older relatives raising children. Through a process of public hearings, surveys, and research, the needs are ranked in order of importance and matched with available resources.

The proposed funding distribution, budget, and other types of planning information are then incorporated into a three-year Area Plan for each of the PSAs, following a format prepared by IDoA. Also included in the plan is an outline of proposed AAA activities for the coming three years. Following public hearings in each PSA, the Area Plan is submitted to IDoA for review and approval. AAAs are required to amend their Area Plans annually in response to changing needs, priorities, and available funding. Federal OAA and state funds are allocated to the AAAs upon review and approval by IDoA of the three-year Area Plan and annual amendments.

The AAAs in Illinois are not, as a rule, direct service providers. They grant or contract with local providers for services addressing the needs identified. The AAAs are responsible for service planning, evaluating, providing technical assistance as needed, and reporting to IDoA. In addition, the AAAs function as advocates for older adults and caregivers and are the primary disseminators of information relating to aging issues within their respective PSAs.

SERVICE PROVIDERS

Service providers offer a wide range of respite services through institutional, home-based, and client directed programs and are a key segment of the aging network in Illinois. The funding sources for the direct service delivery system include State funding, Federal OAA awards, as well as local support and public or private grants.

BACKGROUND AND ANALYSIS

The fastest growing segment of Illinois' older population is the 85 years of age and older population. According to the Census Bureau's 2022 population estimates, Illinois is home to 12.4 million people, with approximately 2.8 million people aged 60 and over. By the year 2030, all Baby Boomers will be over the age of 65, which will place new demands on the state's long-term supportive services. With the progressive projected growth of the older adult population in the state of Illinois, increased attention has been directed to delivering respite services to caregivers who live in the community.

The demands for home and community-based alternatives to nursing facility care will continue to increase; aging Baby Boomers will demand consumer directed information and services based on social and demographic trends. Older adults and caregivers will need increased support and assistance in gaining access to the complex array of federal, state, and community benefits and services. Informal caregivers are the foundation of support for frail older adults who reside in the community. According to a study conducted by AARP and the National Alliance for Caregiving (2020), approximately 47.9 million Americans have provided unpaid care to an adult with limitations in daily activities.

According to 2020 AARP Public Policy Institute's data, caregivers spend an average of 22.5 hours per week providing care, with caregivers in rural areas providing slightly more at 26.3 hours per week. Nearly one-quarter, however, provide 41 or more hours of care per week. (AARP and National Alliance for Caregiving, 2020). Roughly 38 billion hours of care to adults with limitations in activities of daily living were provided by an estimated 38 million family caregivers in the United States in 2021, with their estimated economic value reaching approximately \$600 billion (Reinhard et al., 2023).

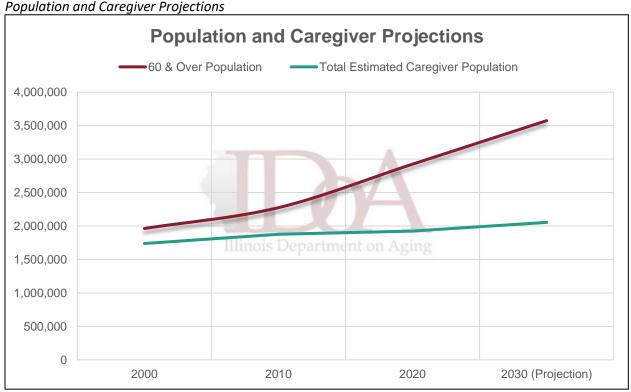
The 2020 AARP and National Alliance for Caregiving provided a demographic picture of the informal caregiver network. Caregivers include individuals of all ages, gender, socioeconomic statuses, and racial/ethnic groups. Nearly 24% of caregivers in the United States are Millennials, 40% are men, and approximately 40% represent multicultural communities. Individual adult caregivers in the U.S. identify their race/ethnicity as the following: White, 61%; African American, 14%; Hispanic (non-White, non-African American), 17%, and Asian-American, 5%.

The study also analyzed the relationships of care recipients and caregivers. A vast majority of the caregivers surveyed (89%) cared for a relative or other loved one. Fifty percent cared for a parent or parent-in-law, 10% cared for a friend, neighbor or another non-relative, 6% cared for a child, and 8% care for a grandparent or grandparent-in-law. Caregivers reported they are increasingly involved in performing a range of complex care tasks such as providing pain management, changing dressings, and managing medications; these tasks go far beyond helping with traditional activities of daily living.

The following chart demonstrates the expected growth of the aged 60 and older and caregiver populations (Illinois Department of Public Health, 2015). In consideration of the increase in the aging population illustrated below, the need for in-home assistance, both formal and informal, will dramatically increase. In addition, by the year 2034, adults aged 65 and older will outnumber children under the age of 18 nationwide. This population shift negatively impacts the number of potential caregivers in the future. The Centers for Disease Control and Prevention (CDC) are projecting that by 2030, there will only be four potential caregivers per older adult compared to the current seven potential caregivers per older adult (Centers for Disease Control, 2018). According to IDoA, by the year 2030, all but one Illinois county will have 25% - 45% of their population that will be ages 60 and older (Bonhoff, 2016). Addendum B provides a map visualization of the population shifts by county in Illinois from 2015 to 2030.

Figure 1

Repulation and Caragivar Projections



Note. Adapted from Centers for Disease Control and Prevention (2015). Caregiving for Family and Friends — A Public Health Issue. CDC.gov. https://www.cdc.gov/aging/caregiving/pdf/caregiver-brief-508.pdf

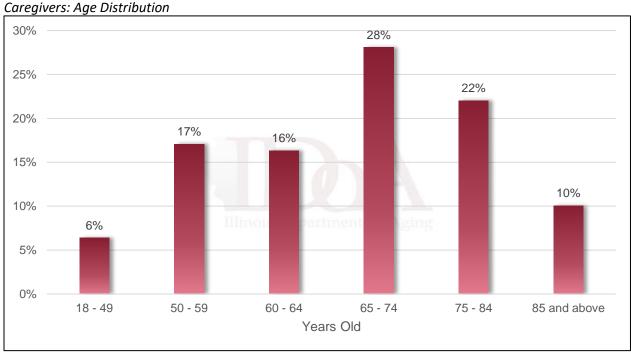
As the federal oversight agency, the Administration on Aging "promotes the well-being of older individuals by providing services and programs designed to help them live independently in their homes and communities" (2024). Since respite services are critical to health and quality of life, the National Family Caregiver Support Program (NFCSP) funded by the OAA is an important component of the home and community-based services network for older adults and their caregivers.

CAREGIVER DEMOGRAPHICS

The following caregiver demographic data is based on the 2023 Older Americans Act Performance System (OAAPS) report. The OAAPS report compiles data from all thirteen AAAs in Illinois during Federal Fiscal year 2023 (October 1, 2022-September 30, 2023). The charts provide the age, race, and gender distribution, as well as the caregiving relationship type.

Caraginara Aga Distribution

Figure 2

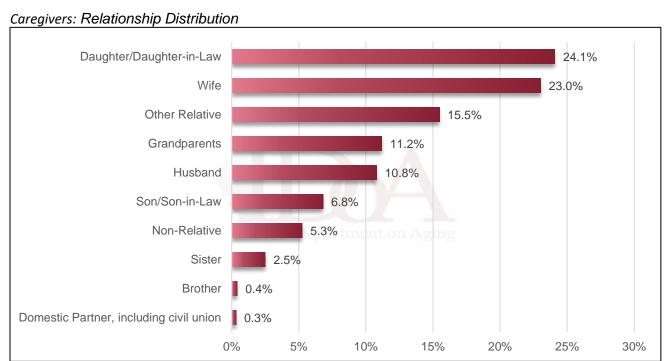


The following data provides the racial and ethnic distribution for caregivers for FFY23 IDoA service recipients:

- 76.6% self-identified as White,
- 20.8% identified as Black or African American, and
- less than 3% identified as Asian, Asian American, Native Hawaiian, Pacific Islander, American Indian, or Alaska Native.

Seventy-one percent of caregivers identified as female, 27% of caregivers identified as male, three individuals selected 'other', and gender data was not collected for 119 individuals

Figure 3



EFFECTS OF CAREGIVING

Research has shown that caregiving can exact a heavy emotional, physical, and financial toll. In reference to health issues, 64.2% of caregivers have reported living with a chronic health condition, 29% report a diagnosis of depression, and 14.3% consider themselves to be in poor health (Centers for Disease Control and Prevention, 2018).

Caregivers may need differing supports depending on their loved one's conditions and needs, as well as their own conditions and needs, strengths, and resources. The AARP and National Alliance for Caregiving study (2020) found that while approximately 51% of caregivers felt their role has given them a sense of purpose or meaning, these positive emotions often coexist with feelings of stress or strain. Forty-one percent of caregivers reported their health status as excellent or very good, while 21% reported fair or poor health. Twenty-three percent (23%) found it difficult to take care of their own health and a similar proportion reported that caregiving has made their health worse.

Many informal caregivers who are employed outside the home often experience conflicts between their responsibilities; and the economic effects of family caregiving can result in financial strain (AARP and National Alliance for Caregiving, 2020):

- 18% of caregivers report high financial strain because of caregiving,
- 45% report to have experienced some financial impact because of their caregiving,
- 28% have stopped saving, and
- as a direct result of caregiving, 23% have taken on more debt.

LGBTQ+ CAREGIVING

According to AARP Illinois's 2021 Disrupting Disparities – Challenges and Solutions for 50+ LGBTQ+ Illinoisans report, it is estimated that nearly one-quarter of Illinois' LGBTQ+ population is over the age of 50. As members of LGBTQ+ communities age in the United States, they face the same challenges and barriers faced by their heterosexual and cisgender peers. There are many additional unique issues that LGBTQ+ older adults face in accessing care services. LGBTQ+ older adults are three to four times less likely to have children and twice as likely to be single than their non-LGBTQ+ peers, and therefore are unable to rely as frequently on the biological family and spousal caregiving models (SAGE and National Center for LGBTQ+ Aging, 2021).

The "Disrupting Disparities" report identified that LGBTQ+ older Illinoisans need improved access to culturally and clinically competent healthcare and relief from high healthcare costs. Over half of LGBTQ+ survey respondents of all ages in Chicago noted health insurance, physical health, and mental/emotional health are issues that need to be addressed. In addition, older LGBTQ+ adults have fewer financial resources and are more likely to be low-income relative to non-LGBTQ+ older adults. Nationwide, nearly one-third of LGBTQ+ older adults live at or below 200% of the federal poverty level, compared to a quarter of non-LGBTQ+ people. Poverty rates are even higher for LGBTQ+ older adults of color, those aged 80 and older, bisexual older adults, and transgender older adults (AARP Illinois and National Center for LGBTQ+ Aging, 2021).

LGBTQ+ caregivers and the caregiving experience also present unique challenges and needs above the general challenges and needs that exist for the larger community. LGBTQ+ individuals engage in caregiving activities at higher rates than non-LGBTQ+ individuals. The following information has been compiled by SAGE and the National Center for LGBTQ+ Aging (2021):

- 21% of older LGBTQ+ individuals have cared for friends vs. 6% of non-LGBTQ+ individuals,
- LGBTQ+ individuals make up 9% of informal caregivers in the United States.
- LGBTQ+ caregivers are more likely to provide care in isolation, which can increase negative impacts from caregiving experience.

The state of Illinois is the third state in the nation to identify LGBTQ+ older adults as a priority population to be included as of "greatest economic and social need." IDoA, the AAA network, and the larger network of aging service providers are in the process of implementing and expanding services funded by OAA that focus on the specific needs of LGBTQ+ older adults, as well as LGBTQ+ caregivers.

Additionally, IDoA staff have completed competency trainings available through SAGE to increase knowledge and skills to better serve the LGBTQ+ older adult community. The AAA network has also been encouraged to complete the cultural competency trainings available through SAGE and several of the AAAs have prioritized implementing the SAGE training with staff and with volunteers.

COVID-19 LESSONS LEARNED

An important lesson learned from the experiences of the COVID-19 pandemic is that the challenges older adults and their caregivers face today may not be the same in the future (Illinois Department on Aging, 2021). COVID-19, which is especially dangerous to older people, continues to disrupt the lives of older people and their family caregivers.

The COVID-19 pandemic caused a disruption of aging, health, and related community services, leading to challenges in continuation of care and service efforts. Most in-person services and programs were closed to slow the spread of the disease. Very often, caregiver responsibilities were downsized to one family member to reduce the risk of exposure and spread of COVID-19. Increasing caregiver duties and responsibilities with little to no support led to significant additional stress for the caregiver.

The AAAs and their provider networks continue to utilize the Tailored Caregiver Assessment and Referral (TCARE) platform and tools, introduced to the Aging Network during the pandemic, to address caregiver needs, including respite care. The agencies are establishing monthly baselines pertaining to the number of caregivers who have completed screening, assessment, and care plans, and reporting to IDoA on a quarterly basis.

CAREGIVER ROUNDTABLES

In response to the growing need for informal caregivers and recognizing the burden that accompanies this role, IDoA partnered with the thirteen AAAs to conduct twenty-four in-person and virtual caregiver roundtables throughout the state. IDoA heard directly from caregivers about their met and unmet needs, the challenges faced by caregivers, and additional supports that could enhance the caregiving journey. IDoA heard from more than 450 participants representing caregivers, older persons, aging network professionals, academics, and elected officials. Participants were asked questions pertaining to the following:

- Strengths and weaknesses of current caregiver resources;
- Opportunities for caregiver resources;
- Threats to caregiver resources.

The information gathered through these statewide roundtables is summarized into a report and will be used to help shape future resources for caregivers and eliminate barriers to obtaining services, supports, and interventions. Several themes emerged from the roundtables including:

People are not aware of respite services and how to access the resources.

- Funding for respite can be challenging, as there are limited public funding sources available, and many families do not have the financial resources to pay for private-pay service.
- The homecare workforce staffing capacity challenges lead to limited accessibility for providers, especially in rural areas of the state. More providers and homecare workers are needed to provide in-home respite services.
- Informal caregivers and professional stakeholders reported the needs for expanded availability of trainings related to caregiving, including Alzheimer's Disease and Related Dementia, for both informal and paid caregivers.
- Current caregivers shared the need of and the positive benefits they have experienced using caregiving support resources, including counseling, support groups, and practical guidance and navigation services. Older Americans Act: National Family Caregiver Support Program (NFCSP)

Conversations both articulated the need for caregiver services and the need to increase visibility for these resources. Across sessions, attendees discussed caregiving from a holistic lens cutting across systems including healthcare, transportation, community supportive services, and individual (both caregiver and care receiver) needs, values, and preferences. Training and education across the domains that fall in the scope of caregiving are also needed for family caregivers and paid caregivers, including better understanding chronic and terminal diseases, navigating healthcare systems including palliative care and hospice, physical caregiving (how to lift, transfer, bathe, groom, etc.), available caregiver resources, available resources for older people, and caring for the caregiver.

These services work in conjunction with other state and community-based services to provide a coordinated network of support. In FY 2023, the AAA network, in partnership with local agencies, provided community-based services and supports to more than 50,000 family caregivers.

FY 2023 RESPITE SERVICE PROVISION

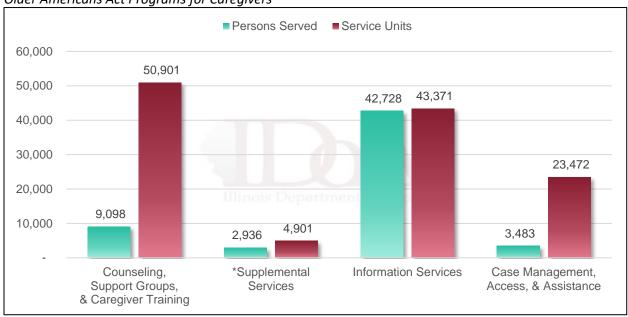
The National Family Caregiver Support Program was established in 2000 and provides federal grants to states based on their share of the population aged 70 and over to fund the following services to assist family and informal caregivers:

- Information and assistance on available services and how to access services
- Individual counseling, support groups, and caregiver training
- Respite care
- Supplemental services, on a limited basis

The following chart depicts the number of caregivers served and the units of each service provided through the provision of OAA caregiver programs in Illinois during FFY 2023:

Older Americans Act Programs for Caregivers

Figure 4



Note.*Supplemental services include: Assistive Technology, Durable Equipment, Emergency Response, Home Modifications/ Repairs, Legal and Financial Services, Consumable Supplies, Transportation, Homemaker/ Chore/ Personal Care, Nutrition Services/Counseling. Source: Administration for Community for Living Title III OAA State Performance Report, FY 2023.

In addition to the above services provided under the Older Americans Act, the AAAs and their local partners also provided 189,398 hours of respite care to support 2,210 caregivers and older adults in FY 2023. In total, \$2,797,395 were expended to provide this service, which includes \$956,971 in OAA expenditures.

FY 2024 RESPITE SERVICE PROJECTIONS

The following table outlines FY 2024 respite service projections (persons to be served) by PSA as funded by the OAA. The service projections are based on FY 2024 Area Plan service projections submitted by the AAAs.

FY 24 Estimated Number of Persons to Receive Respite Services

PSA	Total Projected
01	101
02	882
03	92
04	150
05	25
06	86
07	174
08	155
09	370
10	5
11	30
12	362
13	428
Total Projected	2860

FY 2025 PLANNING

Figure 5

As IDoA and the AAA network are actively planning the programs and services for the FY 2025 – 2027 Area Plan, caregiving has remained a primary priority, based on the needs assessment data and the input provided by older adults, caregivers, and the Aging Network providers and agencies. As shown throughout the report, the number of individuals in need of caregiving supports continue to increase and the Aging Network will continue to collaborate to identify effective, efficient, and evidence-based programs and services that will best support the caregivers in the state.

IDoA has developed a specific statewide initiative to assist the caregiver population in Illinois: "Increase public awareness and knowledge of caregiver needs, as well as resources and services available throughout the state of Illinois to promote increased caregiver engagement in personcentered, trauma informed, and evidence-based programs and services.". The AAAs are including programs and services that meet the objectives of the statewide initiative in their FY 2025-2027 Area Plans.

By increasing awareness of programming and services, additional caregivers will be able to receive access to services demonstrated to improve health, well-being, and quality of life for both caregivers, as well as older adults in Illinois. The caregiver statewide initiative and continued efforts of the Illinois Aging Network will continue to support the mission of IDoA "to serve and advocate for older Illinoisans and their caregivers by administering quality and culturally appropriate programs that promote partnerships and encourage independence, dignity, and a high quality of life"

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ILLINOIS PLANNING AND SERVICES AREAS



AREA AGENCIES ON AGING

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AREA 03

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AREA 04

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AREA 05

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AREA 06

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AREA 09

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AREA 10

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AREA 11

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