



State of Illinois
Illinois Department on Aging

FY2025
RESPITE
SERVICES
REPORT

March 2025

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PROVISIONS OF THE RESPITE PROGRAM ACT

The Respite Program Act (320 ILCS 10) authorizes the Illinois Department on Aging (IDoA) to administer a respite program of assistance to persons in need and to deter the institutionalization of frail or disabled adults. The Respite Program Act also 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 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 Respite Program Act (320 ILCS 10/12) requires that IDoA 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 FY2024 with 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' older adults 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 which is authorized to receive and dispense both federal Older Americans Act funds and state funds through Area Agencies on Aging and community-based service providers.

The legislative mandate of IDoA is to provide a comprehensive and coordinated service system for the state's approximately 2.9 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. 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 13 Planning and Service Areas (PSAs). There is one Area Agency on Aging (AAA) in each multi-county PSA, designated by IDoA. Illinois has 12 not-for-profit agencies and one unit of local government (City of Chicago) which serve as Area Agencies on Aging. Each AAA is responsible for planning, coordinating, and advocating for the development of a comprehensive and coordinated system of services for older adults and their caregivers within the boundaries of the individual PSAs. For additional information on PSAs and AAA locations, please refer to Addendum A.

The Illinois Department on Aging, in accordance with the Older Americans Act, has decentralized the planning process by delegating planning responsibilities to the AAAs. This assures that programs developed and funded by the AAA are integrated into the three-year State planning cycle followed by IDoA. This cycle begins with an assessment of the service needs of local older adults, family caregivers and other relatives raising children. Through a process of public hearings, surveys, research and the assistance of the Area

Agencies' advisory councils, these 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 in each of the PSAs, following a format prescribed by IDoA. Also, included in the plan is an outline of proposed Area Agency on Aging activities for the coming three years. Following public hearings in each PSA, the Area Plan is submitted to IDoA for review and approval. Area Agencies on Aging are required to amend their Area Plans annually (during years two and three) in response to changing needs, priorities and available funding. Federal Older Americans Act and state funds are allocated to the Area Agencies on Aging upon review and approval by IDoA of the three-year Area Plan and Area Plan annual amendments.

The AAAs in Illinois are not, as a rule, direct service providers. They grant or contract with local providers for services that address the needs which have been identified through the planning process. The AAAs are responsible for planning for services, evaluating, providing technical assistance as needed, monitoring their direct service providers, 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

Community-based service providers represent a key segment of the aging network in Illinois because they provide the programs and direct services to older adults and their caregivers.

The direct service delivery system consists of agencies funded with state funds and federal Title III-B and Title III-E funds through Area Agencies on Aging. Service providers offer a wide range of respite services through facility-based, home-based and client-directed programs.

BACKGROUND AND ANALYSIS

Currently, the population age 65 and older is the fastest growing segment of Illinois' older adult population. According to the Census Bureau's 2023 Population Estimates, Illinois was home to nearly 12.7 million people, with approximately 2.9 million people aged 60 and over. By the year 2030, all baby boomers will be older than 65, which will place new demands on the state's long-term supportive services.

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. The informal caregiver is the foundation of support for the frail older person who resides in the community. Nationwide, approximately 47.9 million Americans have provided unpaid care to an adult with limitations in daily activities. According to the American Association of Retired Persons (AARP) Public Policy Institute's most recent 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 (AARP Public Policy Institute, *Caregiving in the US*, 2020). Nearly one-quarter, however, provide 41 or more hours of care per week. The estimated economic value of their unpaid contributions is \$600 billion, \$21 billion in Illinois alone. (AARP Public Policy Institute, *Valuing the Invaluable*, 2023).

Assessing the Needs of the Caregiver Population

AAAs use multiple methods to assess the needs of caregivers in Illinois. In addition to the needs assessment described on page 3, AAAs also assess levels of need on an ongoing basis throughout the year.

AAAs and their providers continue to utilize the Tailored Caregiver Assessment and Referral (TCARE) platform and tools, which was introduced to the aging network during the pandemic to address caregiver needs, including respite care. TCARE is used to complete caregiver assessments and develop care plans tailored to the individual. AAAs use TCARE to ensure the highest level of resources are allocated to caregivers at highest risk. TCARE metrics are reported to IDoA on a quarterly basis.

Beginning with the FY 2025-2027 Area Plan cycle, AAAs are required to increase public awareness and knowledge of caregiver needs, as well as resources and services available throughout the state of Illinois in order to promote increased caregiver engagement in person-centered, trauma-informed, and evidence-based programs and services. In addition, the AAAs are to ensure that all services, including caregiver and respite services, are provided in an efficient, effective, and equitable manner throughout the PSAs. To ensure this objective is met, AAAs are required to complete subgrantee program and fiscal monitoring. Monitoring focuses on program and organizational compliance, performance and outcome evaluation, and technical assistance to all service providers within the aging network. The AAAs are also required to indicate how services are distributed throughout each county in their PSA.

According to FFY 2025 Statewide Area Plans, the AAAs will implement the following methods to improve Caregiver Awareness and Engagement during the FFY2025-FFY2027 Area Plan cycle:

- Provide direct outreach, actively sharing information through various channels, in addition to providing targeted training opportunities for caregivers.
- Seamlessly integrate caregiver information into existing service delivery models.
- Foster stronger partnerships and collaborations with other organizations serving older adults and caregivers.
- Address critical needs like transportation, home modification, and legal assistance.
- Connect caregivers to support groups and peer-to-peer networks for emotional support.
- Utilize social media and online platforms to reach a broader audience.
- Recognize the importance of caregiver mental health by offering evidence-based services, counseling, and support groups.
- Utilize TCARE assessments to identify gaps in caregiver services and provide informed referrals.
- Offer training and education programs to equip caregivers with necessary skills to address the specific needs of their care recipients.

Effects of Caregiving

Research has shown that caregiving exacts a heavy emotional, physical and financial toll on the caregiver. In addition, caregiving can also have a rippling effect on other members of the caregiver's family such as children living at home who may also be called upon to provide care in the absence of a caregiver, or whose needs compete with the needs of the care recipient. According to Caregiving in the U.S 2020, around half of caregivers say there are others in the home who provide unpaid help, and at least 14 percent report one of those unpaid caregivers is a child under age 18. Caregivers are potentially at an increased risk for adverse effects on their own well-being, including their health, quality of life, and financial security (National Health and Aging Trends Study: NHATS: www.nhats.org, 2018). According to the Center for Disease Control and Prevention's 2015-2017 Behavioral Risk Factor Surveillance System (BRFSS), 1 in 5 adults are caregivers, which is similar to the AARP Public Policy data cited earlier. Many caregivers spend approximately 20 hours a week providing care, while 13% of caregivers spend more than 40 hours a week providing care. In reference to health issues, 64.2% of caregivers have chronic health conditions, 29% have depression and 14.3% consider themselves to be in poor health. (Caregiving for Family and Friends cdc.gov)

Caregivers often require different supports depending on their loved one's condition and needs, and their own problems, strengths, and resources. While approximately 51% of caregivers feel 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 report their health status as excellent or very good, while 21% report fair or poor health. Twenty-three

percent find it difficult to take care of their own health and a similar proportion (23%) report that caregiving has made their health worse (AARP Public Policy Institute, Caregiving in the US, 2020). In short, caregivers who cannot care for themselves may become unavailable for their caregiving duties, prompting the question, “who will care for the caregivers?”

For many caregivers nationwide, caregiving is not a short-term obligation; as individuals age, they tend to be in poorer health and require more services than their younger peers. In short, compounding the effects of caregiving is the longevity of providing care. According to The National Study of Caregiving at Johns Hopkins Bloomberg School of Public Health, only 15% of caregivers nationwide had provided care for one year or less. Nearly 70% of caregivers had been providing care for 2 to 10 years and 15% had already provided care for more than 10 years. In addition, adults may be called on to provide care more than once in their lifetime. They may care for grandparents, parents, spouse/partner, siblings and friends (National Health and Aging Trends Study: NHATS: www.nhats.org, 2018).

Many caregivers who are employed outside the home while providing care may experience conflicts between their two responsibilities, and the economic effects of family caregiving can result in financial strain. Eighteen percent of caregivers report high financial strain as a result of caregiving; 45% report to have experienced some financial impact as a result of their caregiving and 28% have stopped saving. As a direct result of caregiving, 23% have taken on more debt, which could have longer-term repercussions on the caregivers’ future financial security. (AARP Public Policy Institute, Caregiving in the US, 2020). In response, in March 2023, Illinois Governor JB Pritzker signed SB208 into law, making Illinois the third state in the nation and the first in the Midwest to mandate paid time off to be used for any reason. The historic legislation provides employees with up to 40 hours of paid leave during a 12-month period, meaning approximately 1.5 million workers will begin earning paid time off starting in 2024. (Paid Leave for All Workers Act, 2024).

In Illinois, there are an estimated 1.3 million family caregivers providing over 1.2 billion hours of care to family members during any given year. The economic value of this unpaid care (at \$17.70 per hour) is more than \$21 billion (AARP Public Policy Institute, Valuing the Invaluable: 2023 Update, 2023). These figures highlight the enormous contribution of unpaid caregivers to our society. Without this unpaid care, the costs of healthcare would be significantly higher.

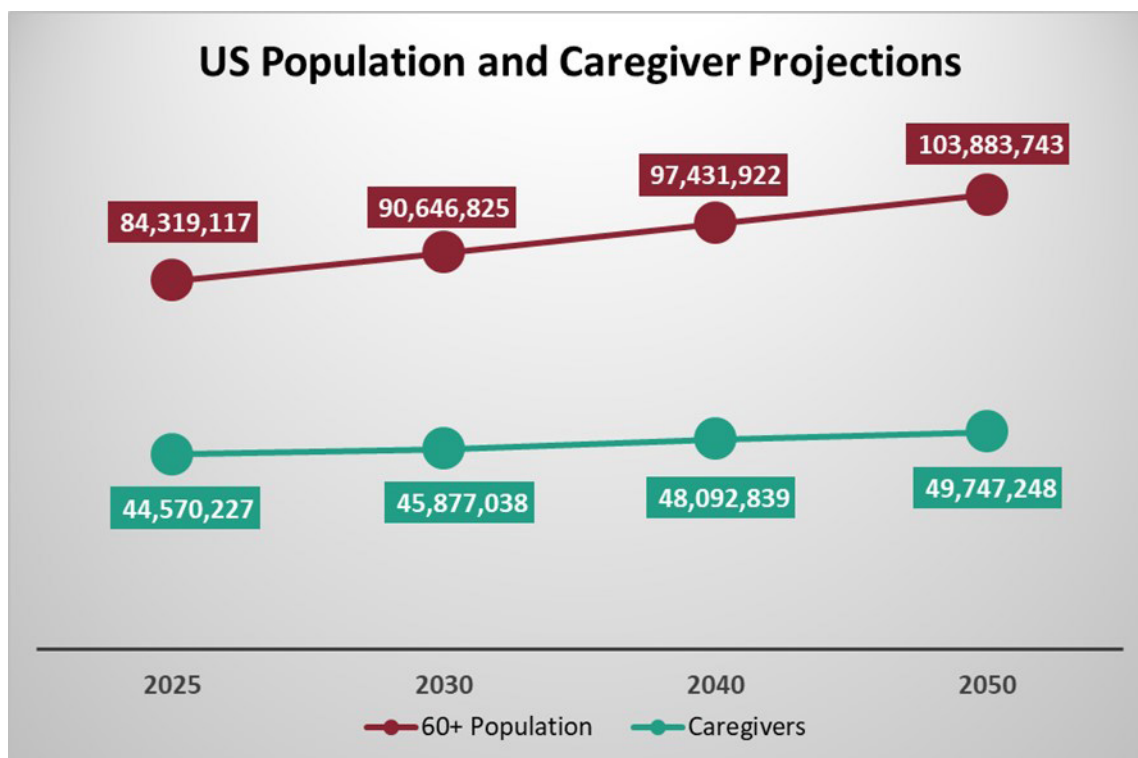
Caregiver Roundtable

In response to the growing need for informal caregivers and recognizing the burden that accompanies this role, IDoA partnered with the thirteen Area Agencies on Aging (AAAs) to conduct 24 caregiver roundtables, both in-person and virtual, throughout the state in the fall of 2023. These roundtables gave IDoA the opportunity to hear directly from caregivers about needs (both met and unmet) and challenges faced by caregivers and explore additional supports that could enhance the caregiving journey. IDoA heard from more than 400 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, and;
- Knowledge and Awareness of Available Respite Services.

Feedback from the roundtables indicate Illinois has strong network and collaboration which is crucial to providing comprehensive support services for the caregiver as well as the care recipient. Overall, caregivers indicated they would like to see more awareness and outreach of available services, more affordable services, and enhanced services to support caregiver well-being. There was also a strong desire for a single hub for all caregiver resources that is easily accessible and user-friendly. Caregivers would also like to see increased availability and affordability of respite services, as well as increased training and education for the caregiver. Statewide, caregivers reported that the biggest challenges to caregiving are financial strain, navigating complex healthcare systems, caregiver stress and burnout, the growing demand for care and a shortage of caregivers, and lack of awareness or education.

Based on US Census Bureau International Database for the years 2025, 2030, 2040 and 2050, including older adult and total population data and applying the percentages from the U.S. Bureau of Labor Statistics, Unpaid Eldercare in the United States-2011-2012 Data from the American Time Use Survey, caregiver populations are projected in the following chart (Unpaid Eldercare in the United States 2011-2012). In consideration of the aging demographic boom illustrated below, the need for in-home assistance, both formal and informal, will dramatically increase. By the year 2034, adults aged 65 and older will outnumber children under the age of 18 nationwide, marking the first time in American history. Given these numbers, the pool of potential caregivers is projected to continue to shrink (AARP Public Policy Institute, Valuing the Invaluable, 2023). According to IDoA, by the year 2030, all but one Illinois county will have 25%-45% of their population age 60 and older (Jean Bohnhoff, 2016). For more information, please refer to Addendum B.



Impact of Older Americans Act Services

The goal of the Administration on Aging (AOA), is to “enable seniors to remain in their homes with high quality of life as long as possible through the provision of home and community-based services for older adults and their caregivers.” Since respite services are critical to health and quality of life, the National Family Caregiver Support Program (NFCSP) funded by the Older Americans Act is an important component of home and community-based services for older adults and their caregivers (ACL Administration for Community Living, 2020).

Based on the most recent (2014) data from the Administration for Community Living (ACL), national surveys of caregivers of elder adults, OAA services, including those provided through the NFCSP show that:

- OAA services are effective in helping caregivers keep their loved ones at home.
- 75% of caregivers report that services enabled them to provide care longer than otherwise would have been possible.
- 89% of caregivers reported that services helped them to be a better caregiver.
- Nearly 62% of the caregivers of nursing home eligible recipients of care would be unable to remain home without the support services.
- Nearly 12% of family caregivers reported they were caring for a grandson or granddaughter.

CAREGIVER DEMOGRAPHICS

According to AARP and The National Alliance for Caregiving, upwards of 61% of all caregivers nationwide are female. 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%. A vast majority of caregivers (89%) care for a relative or other loved one. The National Alliance for Caregiving breaks down the relationships as follows: 50% care for a parent or parent-in-law, 10% care for a friend, neighbor or another non-relative, 6% care for a child, 8% care for a grandparent or grandparent-in-law. (AARP Public Policy Institute, Caregiving in the US, 2020)

In the US, 9% of family caregivers identify as LGBTQ+. While 85% of caregivers in the US are caring for relatives, LGBTQ+ older adults are 3-4 times less likely to have children and twice as likely to be single than their non-LGBTQ+ peers. In addition, they may be estranged from their families of origin. Therefore, they often lack the support that others have from family members and rely on “families of choice” for care (Identifying and Referring LGBT Caregivers, 2020).

With this in mind, IDoA has encouraged the AAAs to partner with SAGE (Services and Advocacy for Gay, Lesbian, Bisexual, and Transgender Elders) to better serve Illinois’ LGBTQ+ seniors. Several of the AAAs have achieved the highest designation of Platinum as SAGECare providers, focusing on knowledge, cultural competency, compassion and service.

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 of community dwelling older adults. Caregivers are as diverse as the state of Illinois as a whole: they come from every age, gender, socioeconomic, and racial/ethnic group. Of the total caregivers in Illinois, nearly 24% are millennials; 40% are men and approximately 40% represent multicultural communities. They are increasingly more 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 (AARP Public Policy Institute, Valuing the Invaluable, 2023). They share positive aspects of caregiving, and they also share many struggles.

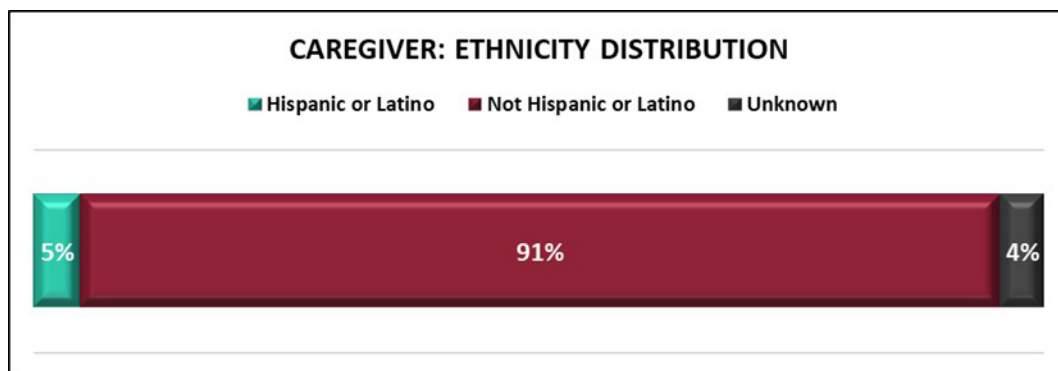
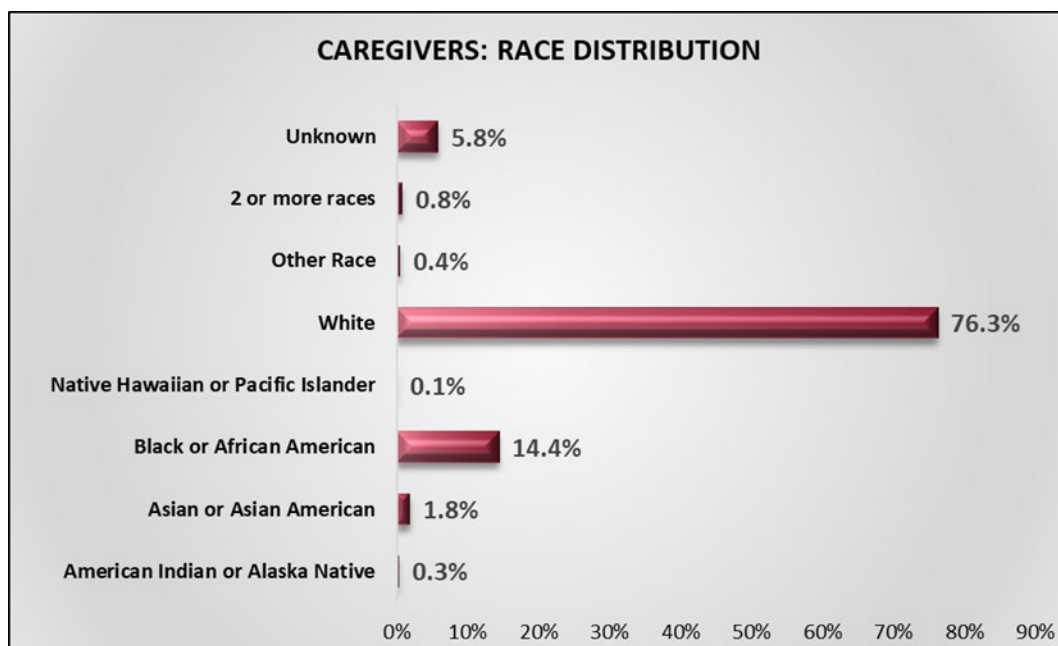
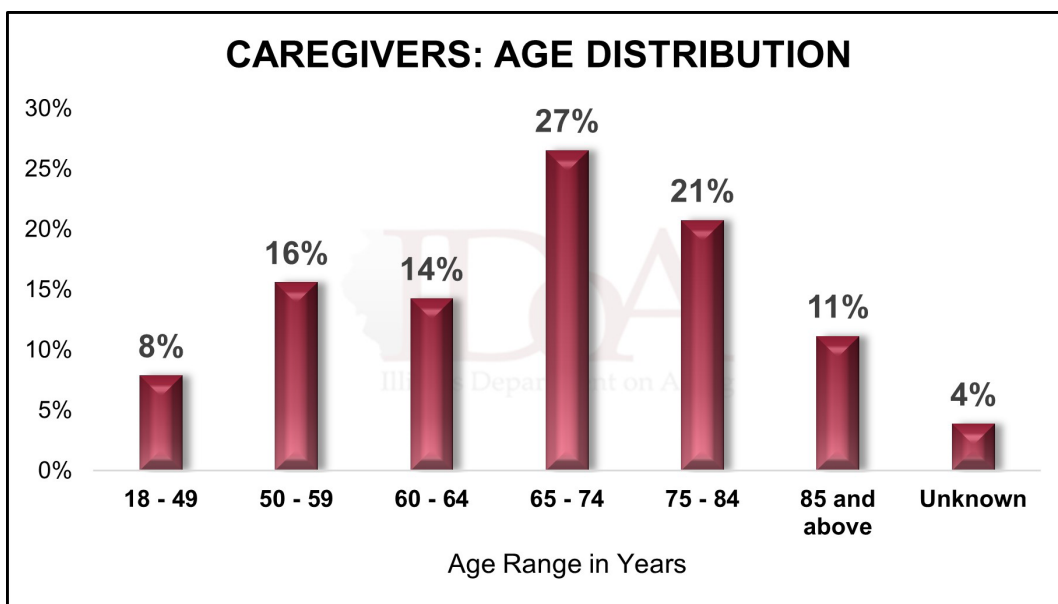
FFY 2024 RESPITE SERVICE PROVISION

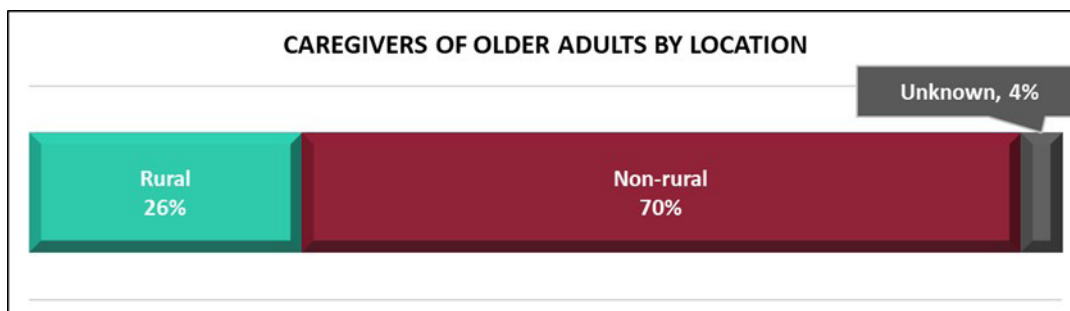
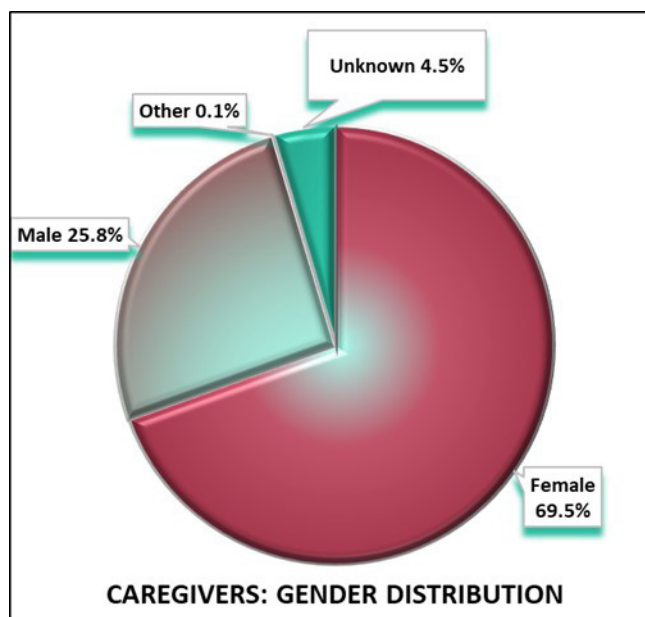
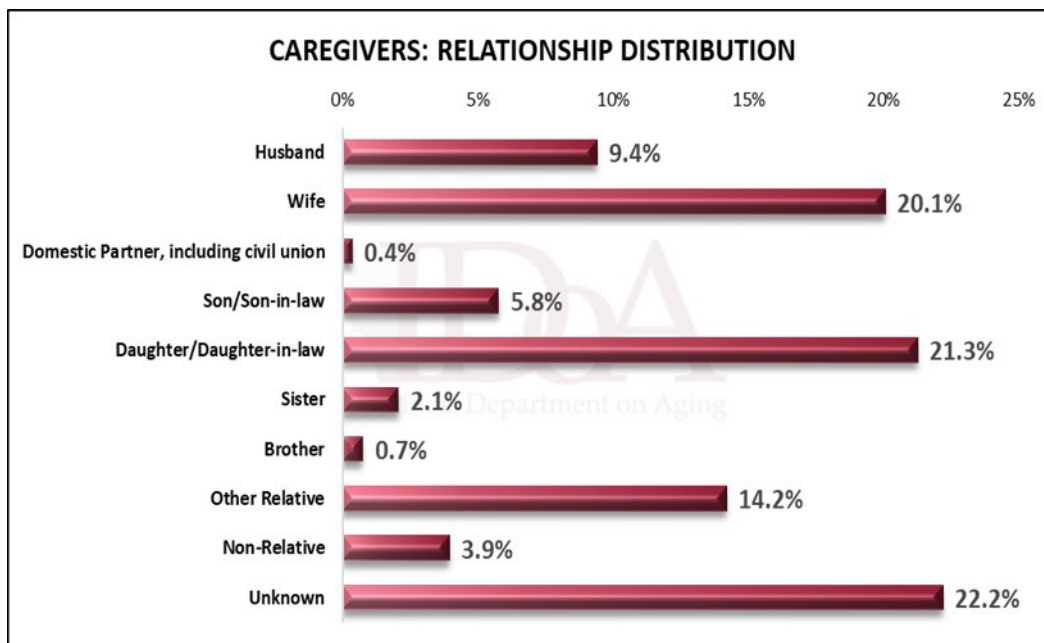
AAAs report the provision of respite services to IDoA on a quarterly basis throughout the fiscal year. Persons, units, and expenditures are reported from AAAs to IDoA within the Periodic Performance & Detail Services Report (PPDSR). One unit of service is defined as one hour of time expended in the provision of care or supervision. Caregiver demographic data is collected from all thirteen AAAs and compiled within the Older Americans Act Performance System (OAAPS) report. OAAPS is the data reporting system for Title III, VI, and VII grantees and sub-grantees of Older Americans Act (OAA) programs. OAAPS can generate various data reports including the State Performance Report (SPR), which includes the total number of persons, units, and expenditures for each federal fiscal year. OAAPS reports from all 13 Area Agencies on Aging are compiled into one SPR and submitted to ACL annually.

The following tables and graphs illustrate the combined respite data for III-B, III-E Older Relative, and III-E Caregiver categories from the FFY2024 SPR:

- 1,988 persons received respite care
- 172,409 hours of respite care provided
- \$2,820,796 of expenditures (see table below for funding sources)
- Price per unit \$16.36

Respite Expenditures	2024
Federal Allocation	\$1,092,192
GRF HDM Allocation	\$1,141,436
ARPA	\$262,361
Local Match	\$315,641
Program Income	\$9,166
Total Expenditures	2,820,796

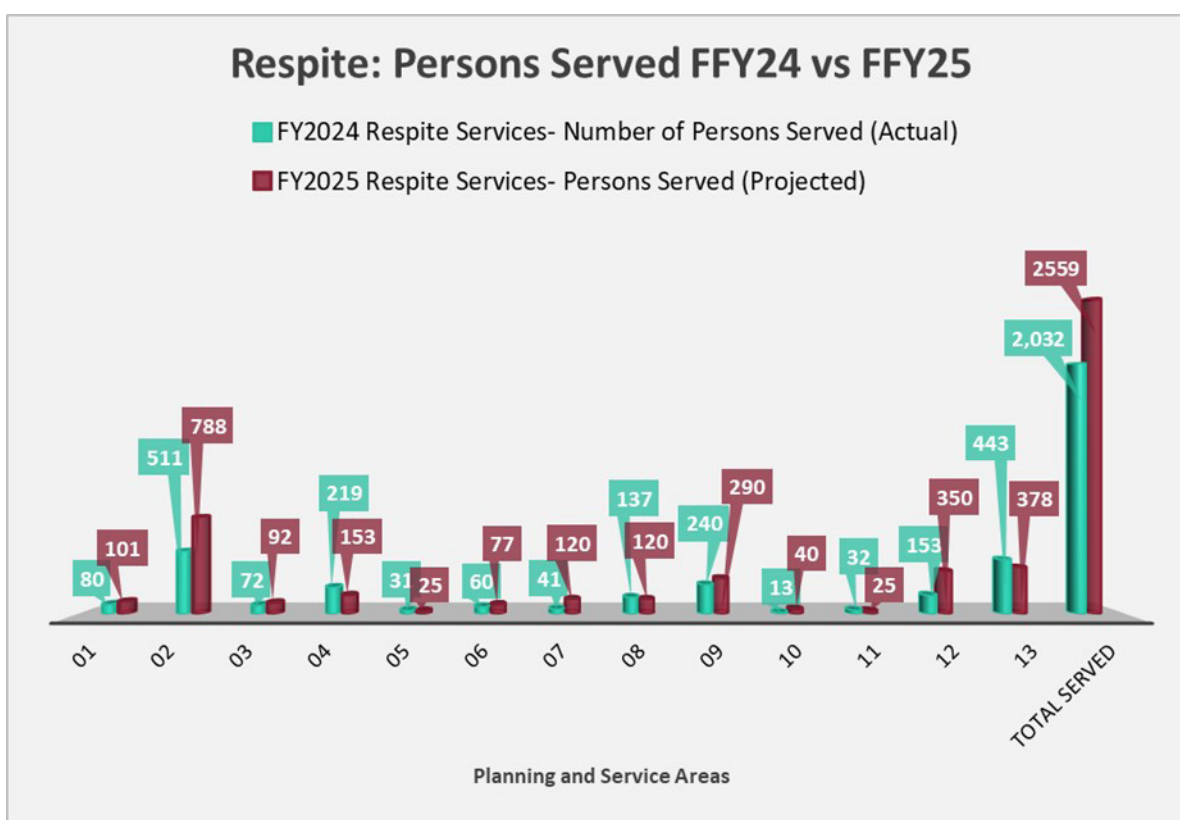




FFY 2025 RESPITE SERVICE PROJECTIONS

The following table outlines FFY 2025 respite service projections (persons to be served) by PSA as funded by the federal Older Americans Act, compared to FFY 2024 actual persons served. The service projections are based on FFY 2025 Area Plan service projections submitted by the 13 Area Agencies on Aging. For more information on Area Agencies on Aging, please refer to Addendum A.

During FFY 2024, approximately 2,000 caregivers received more than 172,000 hours of respite services provided with both state and federal funding. Estimates for FFY 2025 project approximately 2,500 caregivers will receive more than 140,000 hours of respite service to support their caregiving duties.

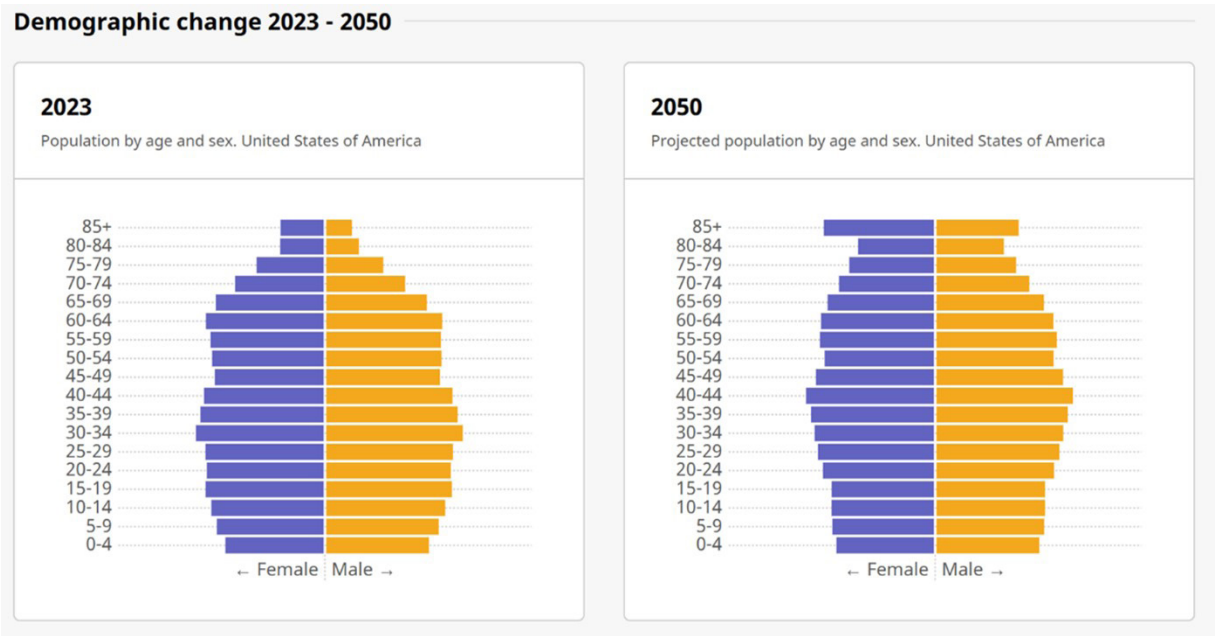


The above graph highlights a significant projected increase in the number of caregivers served through respite services for FFY25, with some variations across different Planning and Service Areas. Federal Fiscal Year 2024 represents actual data reported on the 2024 SPR versus FFYear 2025 which represents projected data from the FY2025 Area Plans across 13 Planning and Service Areas.

LOOKING FORWARD

With the growing older adult population in Illinois, Area Agencies on Agency continue to see an increased demand for supportive Caregiver services, including the need for short-term and long-term respite services; however, in some areas the need outweighs the availability of resources. With caregivers providing the equivalent of \$21 billion of informal care per year (Valuing the Invaluable: 2023 Update, 2023), it is important for Illinois to understand the need and continue to invest in much needed services that support family caregivers and are crucial to the health, economic, and social well-being of caregivers and recipients. Concurrently, over the FFY2025-FFY2027 Area Plan cycle, the Area Agencies on Aging plan to place more focus on outreach to make caregivers more aware of the availability of services, provide training and education to assist with the provision of informal care, and provide more opportunities to reduce the stress and burden on caregivers and their families.

According to the World Health Organization, the aging population will see a significant expansion of the older adults age 65+ from 2023 to 2050, with the largest increase found in the 85+ population (World Health Organization, retrieved 11 March 2025). See charts below for more detailed information. The projected population landscape will have an impact on areas of society including, but not limited to, workforce, economy, social structures, and community needs. In addition, this dramatic change speaks to the immediate need for more healthcare services, more options for long-term care, and more investments in comprehensive programs and services to support the growing number of older adults and their caregivers.



World Health Organization- depicting change in population from 2023 to 2050 broken down by age range and sex.

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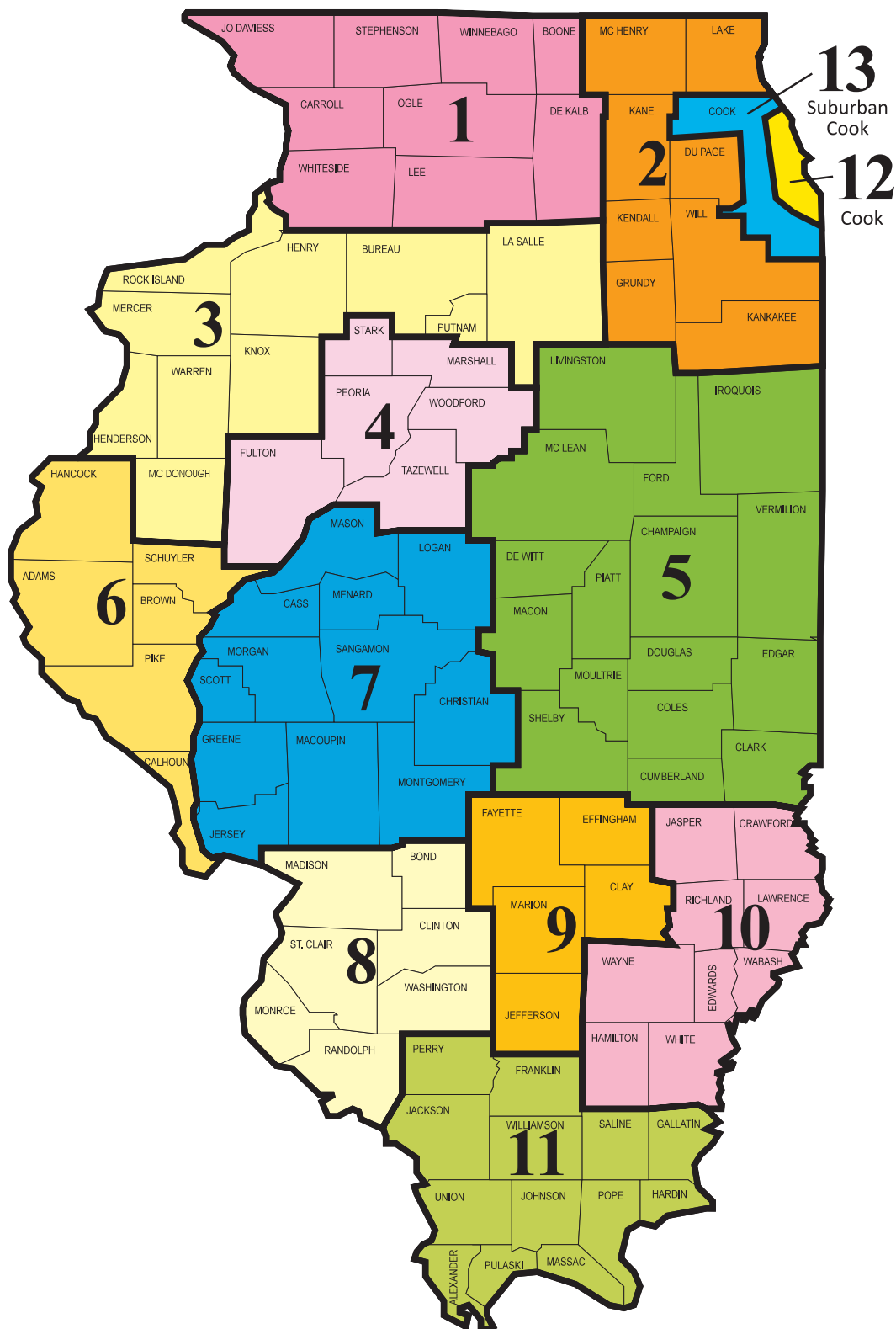
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ADDENDUM A

Illinois Planning and Service Areas



AREA AGENCIES ON AGING

AREA 01

Northwestern Illinois Area Agency on Aging

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AREA 02

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AREA 05

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AREA 06

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AREA 07

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Regional Coordinator: Elizabeth Hagemann

AREA 08

AgeSmart Community Resources

Joy Paeth, Chief Executive Officer
7 Bronze Pointe S; Ste B; Swansea, IL 62226-8303
618/222-2561; FAX: 618/222-2567;
www.AgeSmart.org // Email: jpaeth@AgeSmart.org
Fiscal: Nancy Lonsdale, NLonsdale@AgeSmart.org
Regional Coordinator: Joe Danner

AREA 09

Midland Area Agency on Aging

Tracy Barczewski, Executive Director
Mailing Address: 434 South Poplar; Centralia, IL 62801-1420
618/532-1853; FAX: 618/532-5259; 1-877-532-1853
www.midlandaaa.org // Email: tracy@midlandaaa.org
Fiscal: Heather Fontanez, heather@midlandaaa.org
Regional Coordinator: Stefanie Eisele

AREA 10

Southeastern Illinois Agency on Aging, Inc.

Shana Holmes, Chief Executive Officer
602 E. 5th Street; Mt. Carmel, IL 62863-2152
217-262-0678; FAX: 610-854-9117;
1-800-635-8544 (618 area code ONLY)
www.seiaoa.com
Email: southeasternaaaceoshana@gmail.com
Fiscal: Christine Baize, seiaoa.christineb@gmail.com
Regional Coordinator: Stefanie Eisele

AREA 11

Egyptian Area Agency on Aging, Inc.

Becky Salazar, Executive Director
200 East Plaza Drive; Carterville, IL 62918-1982
618/985-8311; FAX: 618/985-8315; 1-888-895-3306
www.egyptianaaa.org
Email: Becky.salazar@egyptianaaa.org
Fiscal: Krista Velarde, krista.velarde@egyptianaaa.org
Regional Coordinator: Joe Danner

AREA 12

Senior Services Area Agency on Aging

Chicago Department of Family and Support Services

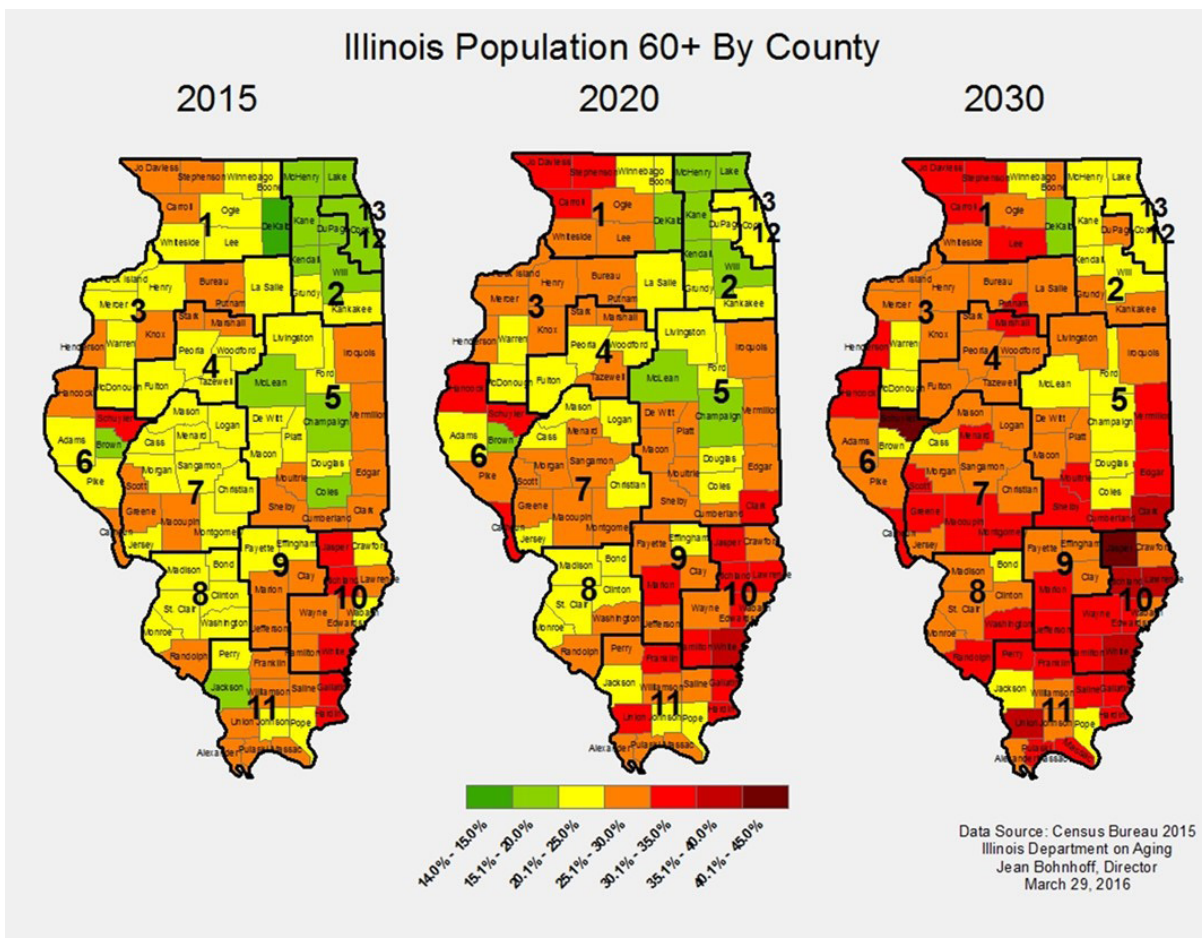
Margaret Laraviere, Executive Director
1615 West Chicago Avenue, 3rd Floor; Chicago, IL 60622
312/746-5682; FAX: 312/744-8168; 312/744-6777 (TTY)
www.cityofchicago.org/aging
Email: Margaret.Laraviere@cityofchicago.org
Fiscal: Nancy Delgado, Nancy.Delgado@cityofchicago.org
Regional Coordinator: Michael Schumacher

AREA 13

AgeOptions, Inc.

Diane Slezak, President & CEO
1048 Lake Street, Suite 300; Oak Park, IL 60301
708/383-0258; FAX: 708/524-0870; 708/524-1653 (TTY);
1-800-699-9043 (Suburban Cook County area ONLY)
www.ageoptions.org // Email: diane.slezak@ageoptions.org
Fiscal: Mike Giuntoli, Mike.Giuntoli@ageoptions.org
Regional Coordinator: Stefanie Eisele

ADDENDUM B



RESPITE SERVICES REPORT



Illinois Department on Aging
One Natural Resources Way #100
Springfield, Illinois 62702-1271
ilaging.illinois.gov

Senior Helpline:
1-800-252-8966; 711 (TRS)
(8:30am to 5:00pm, Monday through Friday)

The Illinois Department on Aging does not discriminate against any individual because of his or her race, color, religion, sex, national origin, ancestry, age, order of protection status, marital status, physical or mental disability, military status, sexual orientation, gender identity, pregnancy, or unfavorable discharge from military service in admission to programs or treatment of employment in programs or activities. If you feel you have been discriminated against, you have a right to file a complaint with the Illinois Department on Aging.

For information call the Senior Helpline: 1-800-252-8966; 711 {TRS}.