

State of Illinois
Illinois Department on Aging

FY 2021
RESPITE
SERVICES
REPORT

February 2021
In Accordance with Public Act 93-864

PROVISIONS OF THE RESPITE PROGRAM ACT

The Respite Program Act 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 and other appropriate community-based organizations to provide respite care under the Act.

State of Illinois funds have not been appropriated for the establishment of a state-funded respite program. The Department receives federal funds to provide respite care through two sources: Title III-B and Title III-E of the Older Americans Act. Title III-E (National Family Caregiver Support Program) provides funding which is distributed to the 13 Area Agencies on Aging (AAA) in Illinois. The program, established in 2000 under Title III-E of the Older Americans Act, provides funding to states based on their share of the population aged 70 and over to fund a range of supports that assist family and informal caregivers to care for an older person at home for as long as possible.

The Respite Program Act also requires that the 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 with **federal** Older Americans Act (OAA) funding, since state funds have not been appropriated to provide respite services under the Respite Program Act.

THE AGING NETWORK IN ILLINOIS

THE ILLINOIS DEPARTMENT ON AGING

The Illinois Department on Aging 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. It is the single state agency in Illinois authorized to receive and dispense Federal Older Americans Act funds, as well as specific 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 2.8 million older adults, giving high priority to those in greatest need; to conduct studies and research into the needs and problems of the elderly; and to ensure participation by older adults in the planning and operation of all phases of the service system. The mission of the Illinois Department on Aging 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 quality of life. In fulfilling its mission, the Illinois Department on Aging 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 elderly 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) designated by the Illinois Department on Aging located within each PSA. In Illinois, 12 not-for-profit agencies and one unit of local government 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 the elderly 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 by, and services funded by, the AAA are integrated into the three-year planning cycle followed by IDoA. This cycle begins with an assessment of the service needs of local older adults, family caregivers and 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 an Area Plan in each of the PSAs, following a format prepared by the Illinois Department on Aging. Also included in the plan is an outline of proposed Area Agency on Aging activities for the coming years. Following public hearings, the Area Plan is submitted to IDoA for review and approval. Area Agencies on Aging are permitted to amend its Area Plans annually 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 approval of the Area Plan or Area Plan annual amendments after review and approval from the Illinois Department on Aging.

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 monitoring, evaluating, planning for services, and providing technical assistance as needed. 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 also 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 Title III-B and Title III-E funds through Area Agencies on Aging. Service providers offer a wide range of respite services through institutional, home-based and client directed programs.

During FY 2021, it is estimated that approximately 2000 caregivers will receive more than 94,000 hours of respite services under Title III-B and Title III-E of the Older Americans Act.

BACKGROUND AND ANALYSIS

The population age 85 and older is the fastest growing segment of Illinois' older population. According to the Census Bureau's 2019 Population Estimates, Illinois was home to 12.7 million people, with approximately 2.8 million people age 60 and over. By the year 2026, the leading edge of the baby boomers will enter their 80's, placing new demands on the state's long term supportive services (The National Academies of Sciences, Engineering, Medicine, 2016). With this aging demographic boom, the need for in-home assistance, both formal and informal, will dramatically increase, since these individuals tend to be in poorer health and require more services than the young elderly. In 2010, 234,912 of the 60+ population in Illinois was age 85+; in 2030, this number is projected to be 402,311, which is an increase of 109% from 1990 (State Plan on Aging for FY 2017 - FY 2019, 2017).

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. During the past 12 months, caregivers spent 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 \$470 billion. (AARP Public Policy Institute, Valuing the Invaluable, 2019).

The COVID-19 pandemic, which is especially dangerous to older people, has disrupted the lives of older people and their family caregivers. While studies about caregiving and COVID-19 are not yet available, it is highly likely that due to a combination of social distancing, shelter-in-place or stay-at-home orders, and the disproportionate impact of the virus on older adults, caregivers of adults living in the community are in need of different types of caregiving supports (Lightfoot & Moone, 2020).

In the US, 9% of family caregivers identify as LGBT. Eighty-five percent of caregivers in the US are caring for relatives; LGBT older adults are 3-4 times less likely to have children and twice as likely to be single than their non-LGBT peers; 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)

For many caregivers nationwide, caregiving is not a short-term obligation. 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).

Research has shown that caregiving exacts a heavy emotional, physical and financial toll. Caregivers are potentially at an increased risk for adverse effects on their own wellbeing, including their health, quality of life, and financial security. (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. In Illinois, workplace benefits for family caregivers are not yet in place. These include: Paid Family Leave; Unemployment Insurance for Family Caregivers, and; Paid Sick Days (Family Caregiver Alliance, 2020).

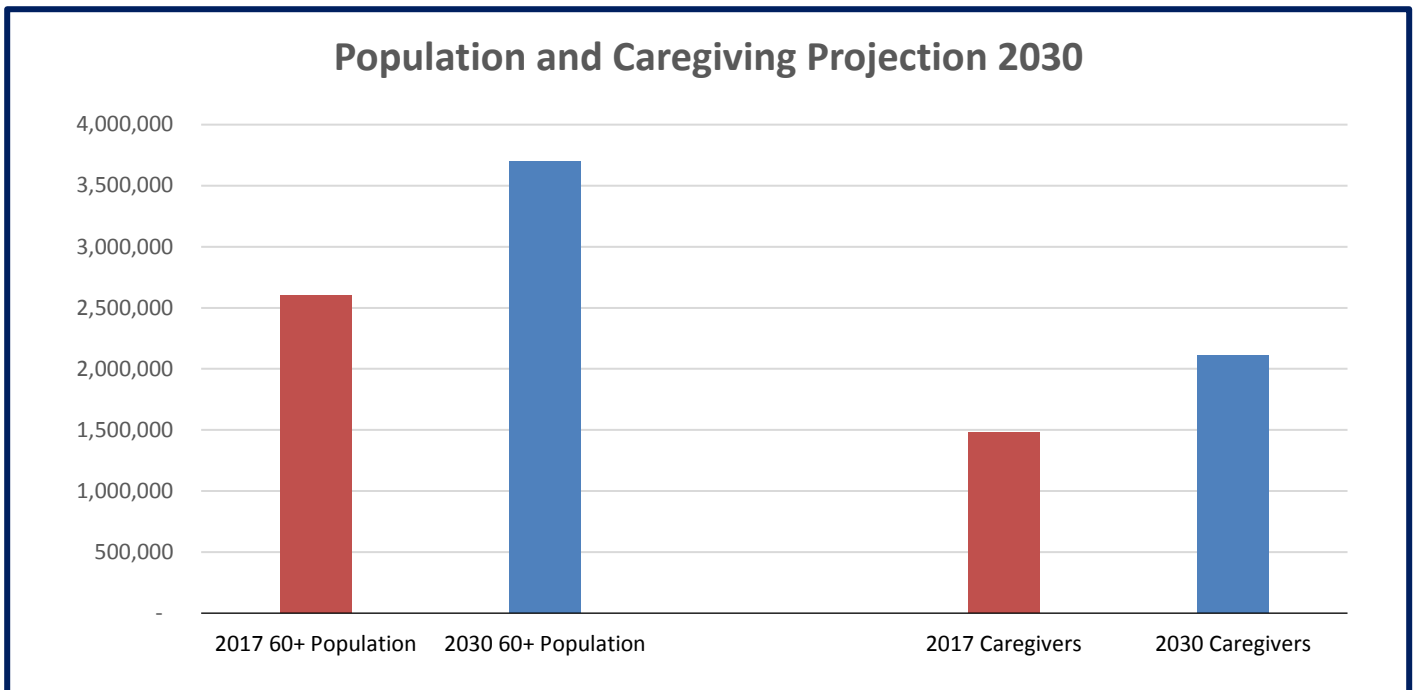
Caregivers may need differing support depending on their loved one's condition and needs, and their own problems, strengths, and resources. While approximately 51% of caregivers feel their role has given them a sense of purpose or meaning, these positive emotions often coexist with feelings of stress 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?"

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 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. The inability to access affordable services can be an issue, with one out of four caregivers nationwide stating it is very difficult to get services in their communities (AARP Public Policy Institute, Caregiving in the US, 2020).

With the progressive projected growth of the senior population in the state of Illinois, increased attention has been directed to delivering respite services to caregivers of community dwelling seniors. Caregivers are as diverse as the state of Illinois as a whole: they come from every age, gender, socioeconomic, and racial/ethnic group. Nearly 24% are millennials; 40% are men and approximately 40% represent multicultural communities. 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 (AARP Public Policy Institute, Valuing the Invaluable, 2019). They share positive aspects of caregiving, and they also share many struggles.

Currently in Illinois, there are an estimated 1.5 million family caregivers providing an estimated 1.4 million hours of care to family members during any given year. The economic value of this unpaid care (at \$13.22 per hour) is \$18.5 million (AARP Public Policy Institute, Valuing the Invaluable, 2019).

According to the Illinois Department of Commerce and Economic Development and the US Census Bureau, the age 60+ population will grow from the 2019 population of 2.8 million to 3.7 million by 2030, which is a 32% increase. Approximately 57% of older adults currently have family caregivers; as a result, it is estimated that the number of family caregivers will grow to 2.1 million. Because of the toll that caregiving can take on the caregivers' health and financial security, these informal caregivers would directly benefit from expanded respite services. It is estimated that by 2030, 844,000 family caregivers would benefit from respite 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 elderly clients, 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 definitely 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.

FY 2020 RESPITE SERVICE PROJECTIONS

The following table outlines FY 2021 respite service projections (persons to be served) by PSA as funded by the federal Older Americans Act. The service projections are based on FY 2021 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.

Estimated Number of Persons to Receive Respite Services

Planning and Service Area	Title III-B	Title III-E	Total
01	1	75	76
02	0	390	390
03	2	98	100
04	4	54	58
05	1	25	26
06	3	50	53
07	1	67	68
08	0	125	125
09	50	170	220
10	0	20	20
11	0	75	75
12	0	40	40
13	160	300	460
State Total:	222	1489	1711

Title III-B funds In-Home, Access and Community-Based Services; Title III-E funds the National Family Caregiver Support Program (NFCSP).

OLDER AMERICANS ACT/NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM (NFCSP)

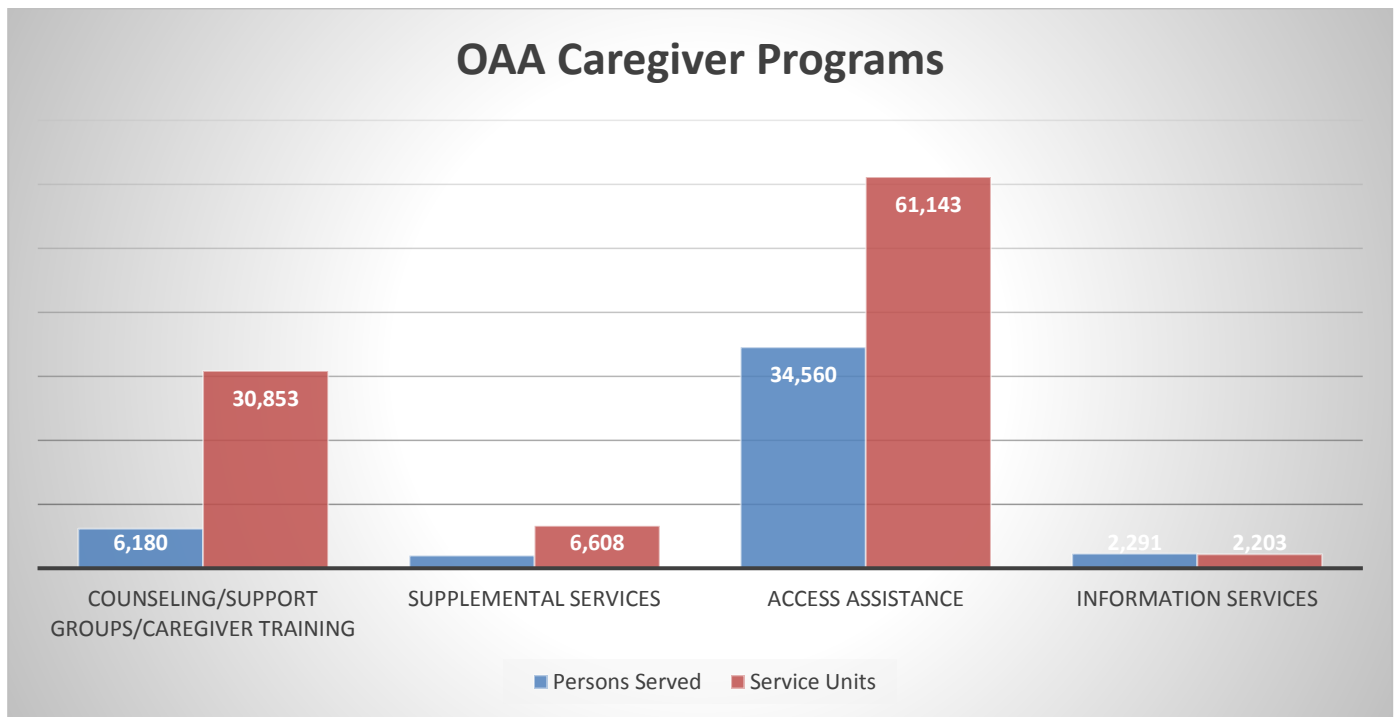
The NFCSP was established in 2000 and provided federal grants to States based on their share of the population aged 70 and over, to fund five categories of services that assist family and informal caregivers:

- Information about available services
- Assistance to caregivers in accessing services
- Individual counseling, support groups and caregiver training
- Respite care
- Supplemental services on a limited basis

These services work in conjunction with other state and community-based services to provide a coordinated network of support. In FY 2020, the thirteen Area Agencies on Aging in Illinois, in partnership with local agencies, provided community-based services and supports to more than 50,000 family caregivers through the five categories of services listed above.

Service	Persons Served	Service Units	Title III Expenditures	Total Service Expenditures
Caregiver Respite	1,979	102,209	\$928,335	\$1,497,161

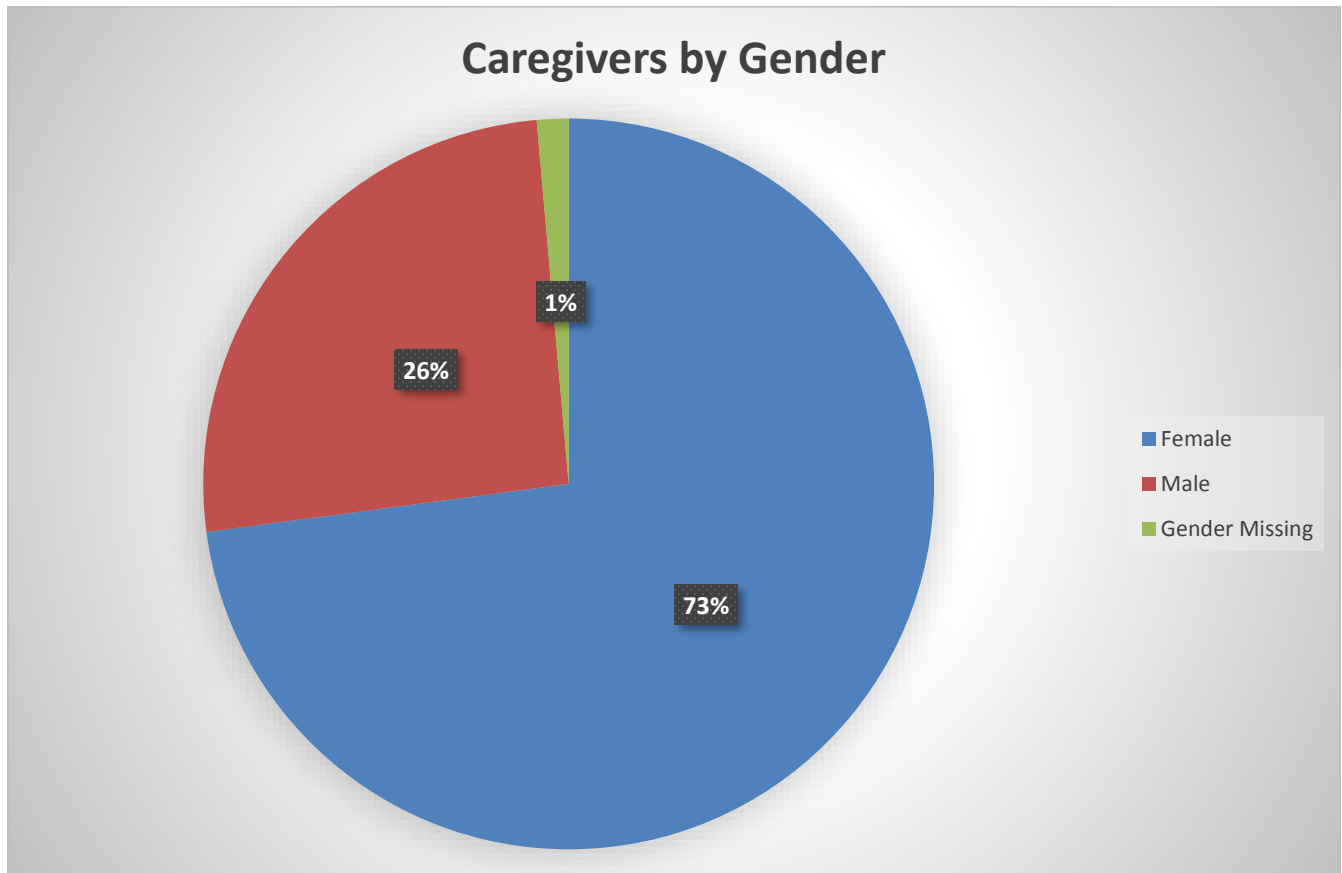
The following chart depicts the client and service profile of OAA caregiver programs in Illinois during FY2019:



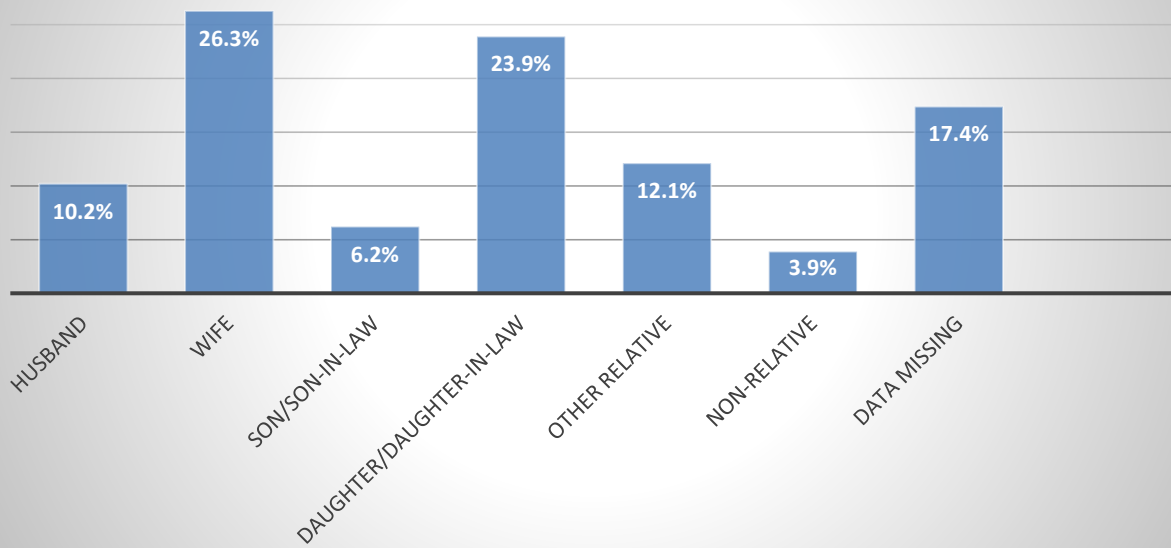
Caregiver Demographics

According to AARP and The National Alliance for Caregiving, upwards of 61% of all caregivers nationwide are female. Nine percent of caregivers self-identify as LGBT (National Alliance for Caregiving and AARP, 2015) 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)

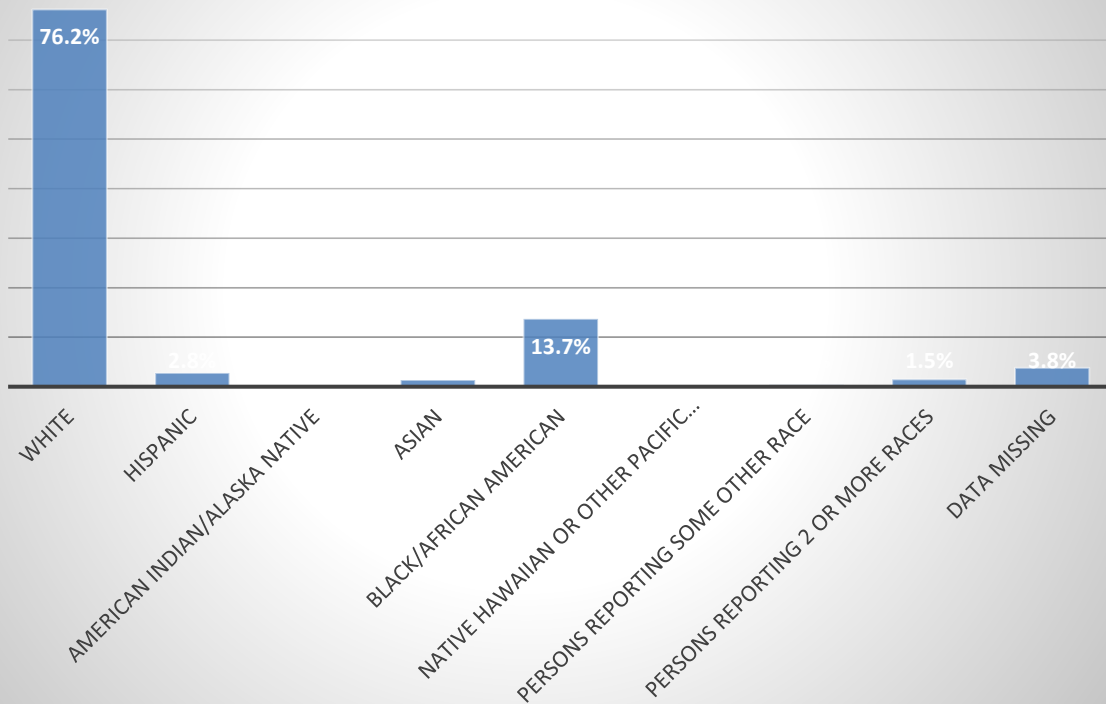
Based on the 2020 National Aging Program Information System (NAPIS) report compiled from information from the 13 Area Agencies on Aging, Illinois is indicative of the national trends, as shown in the following graphs:



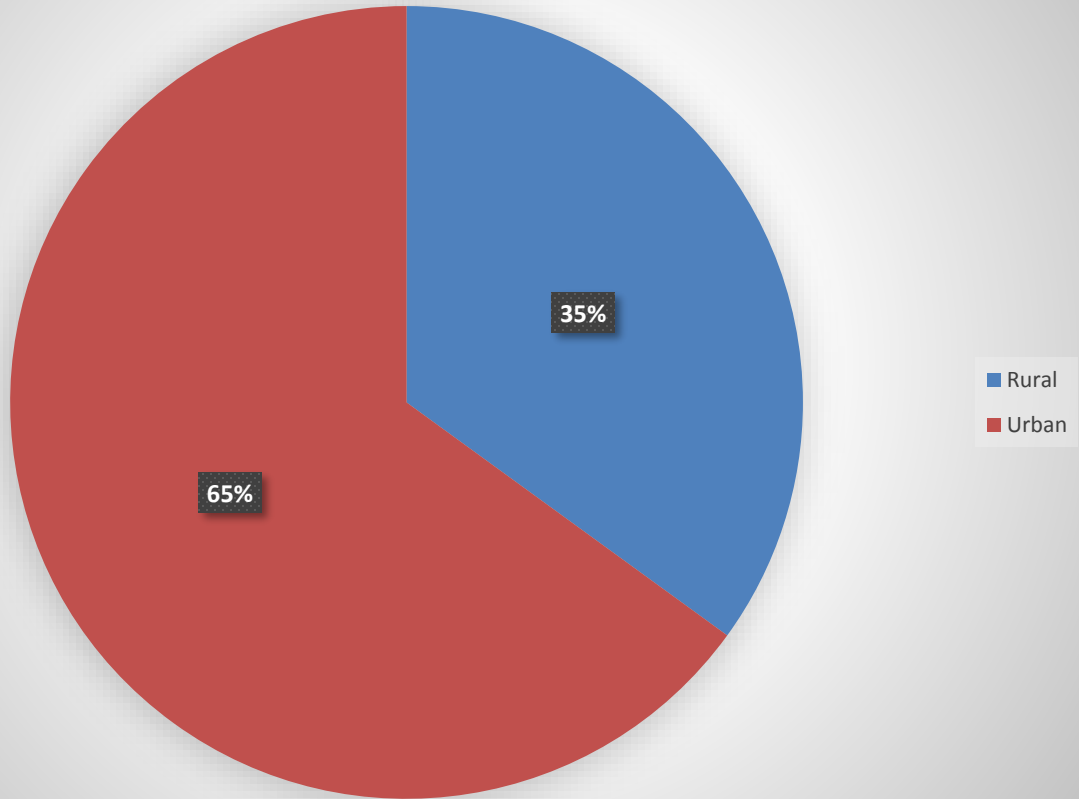
Caregivers by Relationship



Caregivers by Race or Ethnicity



Caregivers by Location



ADDENDUM A

ILLINOIS PLANNING AND SERVICE AREAS



AREA 01

Northwestern Illinois Area Agency on Aging

Grant Nyhammer, Executive Director & General Counsel
1111 South Alpine Road, Suite 600
Rockford, IL 61108
815/226-4901; FAX: 815/226-8984;
1-800-542-8402 (nine county area ONLY)
Web: www.nwilaaa.org
E-Mail: gnyhammer@nwilaaa.org

AREA 02

AgeGuide

Marla Fronczak, CEO
Main Office:
1910 S. Highland Ave., Suite 100
Lombard, Illinois 60148
630/293-5990; 800/528-2000; Fax: 630/293-7488
Email: info@ageguide.org or mfronczak@ageguide.org
Fiscal Office:
100 College Dr, Building 5
Kankakee, Illinois 60901
Web: www.ageguide.org

AREA 03

Western Illinois Area Agency on Aging

Barbara Eskildsen, Executive Director
729 - 34th Avenue
Rock Island, IL 61201-5950
309/793-6800; FAX: 309/793-6807;
1-800-322-1051 (I & A)
Web: www.wiaaa.org
E-Mail: beskildsen@wiaaa.org

AREA 04

Central Illinois Agency on Aging, Inc.

Keith Rider, President & CEO
700 Hamilton Boulevard
Peoria, IL 61603-3617
309/674-2071; FAX: 309/674-3639;
1-877-777-2422; 309/674-1831 (TTY)
Web: www.ciaoa.net
E-Mail: krider@ciaoa.net

AREA 05

East Central Illinois Area Agency on Aging, Inc.

Susan Real, Executive Director
1003 Maple Hill Road
Bloomington, IL 61704-9327
309/829-2065; FAX: 309/829-6021;
1-800-888-4456 (I & A) (sixteen county area ONLY)
Web: www.eciaaa.org
E-Mail: sreal@eciaaa.org

AREA 06

West Central Illinois Area Agency on Aging

Michael Drew, Director
Mailing Address:
P. O. Box 428, Quincy, IL 62306-0428
(Non-U.S. Post Office deliveries):
639 York Street, Room 204, Quincy, IL 62301
217/223-7904; FAX: 217/222-1220;
1-800-252-9027 (I & A) (Voice & TTY)
Web: www.wciagingnetwork.org
E-Mail: michael.drew@wciagingnetwork.org

AREA 07

AgeLinc

Carolyn Austin, Executive Director
2731 MacArthur Blvd.
Springfield, IL 62704
217/787-9234 (Voice & TTY); FAX: 217/787-6290;
1-800-252-2918 (I & A) (217, 309 & 618 area codes ONLY)
Web: www.agelinc.org
E-Mail: caustin@agelinc.org

AREA 08

AgeSmart Community Resources

Joy Paeth, Chief Executive Officer
801 W. State
O'Fallon, IL 62269
618/222-2561; FAX: 618/222-2567;
1-800-326-3221
Web: www.AgeSmart.org
E-Mail: jpaeth@AgeSmart.org

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
Web: www.midlandaaa.org
E-Mail: tracy@midlandaaa.org

AREA 10

Southeastern Illinois Agency on Aging, Inc.

Shana Holmes, Chief Executive Director
516 Market Street
Mt. Carmel, IL 62863-1558
618/262-2306; FAX: 618/262-4967;
1-800-635-8544 (618 area code ONLY)
Web: www.seiaoa.com
E-Mail: holmes.AAA@protonmail.com

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
Web: www.egyptianaaa.org
E-Mail: beckysalazar@egyptianaaa.org

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
312/744-4016; FAX: 312/744-8168;
312/744-6777 (TTY)
Web: www.cityofchicago.org/aging
E-Mail: Margaret.Laraviere@cityofchicago.org

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)
Web: www.ageoptions.org
E-Mail: diane.slezak@ageoptions.org

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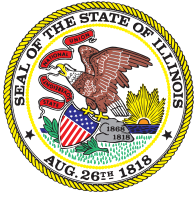
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