

State of Illinois
Illinois Department on Aging

FY 2020
RESPITE
SERVICES
REPORT

February 2020
In Accordance with Public Act 93-864

PROVISIONS OF THE RESPITE PROGRAM ACT

The Respite Program Act authorizes the Illinois Department on Aging 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 the Illinois Department on Aging to make grants to or contract with Area Agencies on Aging and other appropriate community-based organizations to provide respite care under the Act.

General Revenue 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 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 Illinois Department on Aging 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 State Legislature in 1973 for the purpose of improving the quality of life for Illinois' senior citizens by coordinating programs and services enabling 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 the Illinois Department on Aging 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 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 Area Agency on Aging is responsible for planning, coordinating, and advocating for the development of a comprehensive and coordinated system of services for the elderly and caregivers within the boundaries of the individual PSAs. For additional information on PSAs and Area Agency on Aging 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 Area Agencies on Aging. This assures that programs developed by, and services funded by, the Area Agencies on Aging are integrated into the three-year planning cycle followed by the Illinois Department on Aging. This cycle begins with an assessment of the needs of local older adults, family caregivers and relatives raising children for services. 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 planning information are then incorporated into an Area Plan on Aging 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 on the proposed Area Plan, the Area Plan is submitted to the Illinois Department on Aging 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 Area Agencies on Aging 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 Area Agencies on Aging are responsible for monitoring, evaluating, planning for services, and providing technical assistance as needed. In addition, the Area Agencies on Aging function as advocates for older adults and caregivers, and are the primary disseminators of information relating to aging issues within their respective Planning and Service Areas.

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 2020, 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 2018 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 alternatives to nursing home 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 41 million Americans have provided unpaid care to an adult with limitations in daily activities. During the past 12 months, caregivers spent an average of 24.4 hours per week providing care. The estimated economic value of their unpaid contributions is \$470 billion. Nearly one-quarter, however, provide 41 or more hours of care per week. (AARP Public Policy Institute, Valuing the Invaluable, 2019).

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).

Caregivers may need differing support depending on their loved one's condition and needs, and their own problems, strengths, and resources. When surveyed, 40% of U.S. caregivers report a high burden of caregiving, 18% report moderate burden, and 41% report a relatively low burden. 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 (NAC and AARP Public Policy Institute, 2015).

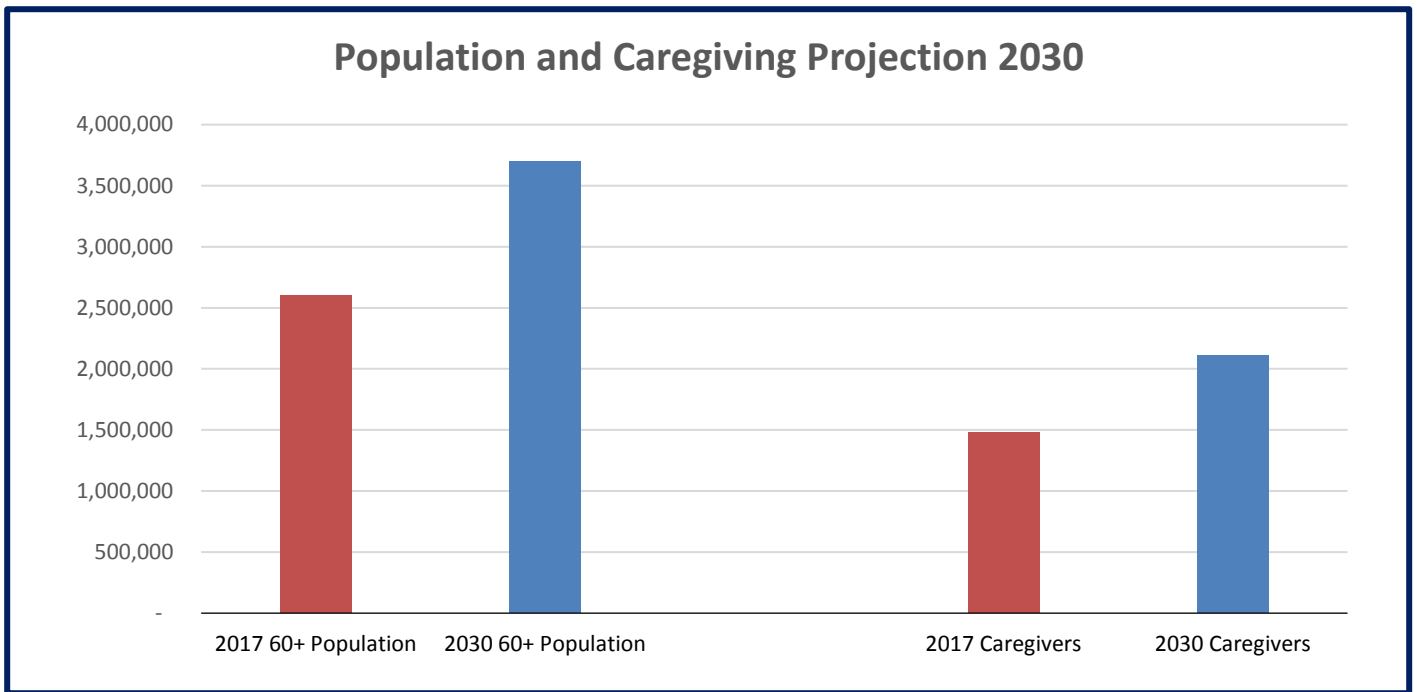
Research has shown that caregiving exacts a heavy emotional, physical and financial toll. Caregivers are potentially at an increased risk for adverse effects on their own wellbeing, including their health, quality of life, and financial security. (National Health and Aging Trends Study: NHATS: www.nhats.org, 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).

Today's family caregivers come from every age, racial and socioeconomic group, and include both men and women. 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).

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. 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 (NAC and AARP Public Policy Institute, 2015).

According to the Illinois Department of Commerce and Economic Development, the age 60+ population will grow from the 2017 population of 2.6 million to 3.7 million by 2030, which is a 42% 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. As previously cited, 40% of family caregivers report a high burden regarding their caregiving responsibilities. These are the caregivers who would directly benefit from expanded respite services. Thus, 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.
- 74% of caregivers report that services definitely enabled them to provide care longer than otherwise would have been possible.
- 88% 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 2020 respite service projections (persons to be served) by PSA as funded by the federal Older Americans Act. The service projections are based on FY 2020 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	389	389
03	2	98	100
04	4	54	58
05	1	25	26
06	3	40	43
07	1	119	120
08	100	100	200
09	70	140	210
10	0	14	14
11	0	75	75
12	70	95	165
13	160	300	460
State Total:	412	1524	1936

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)

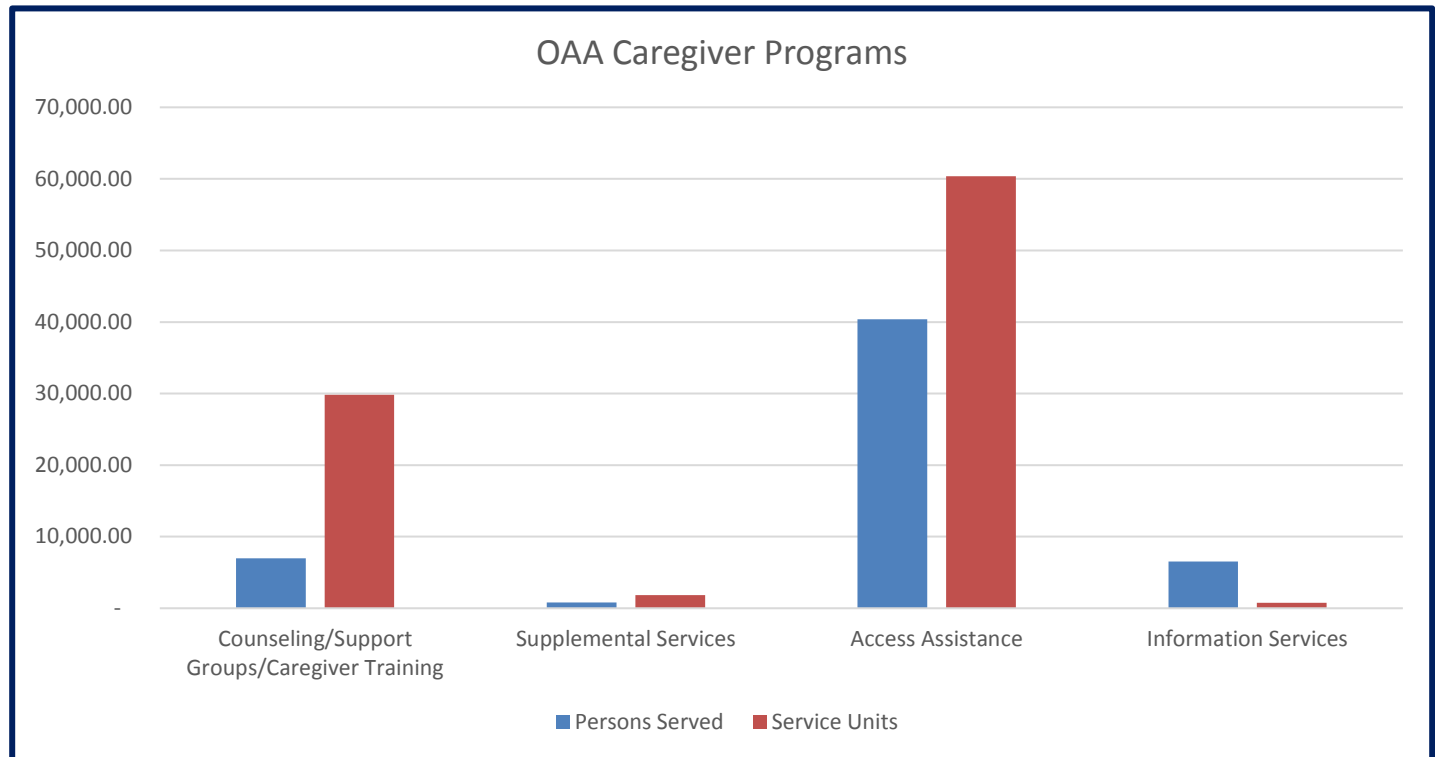
The NFCSP was established in 2000 and provided federal grants to States based on their share of the population aged 70 and over, to fund five categories of services that assist family and informal caregivers:

- 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 2019, the thirteen Area Agencies on Aging in Illinois, in partnership with local agencies, provided community-based services and supports to more than 59,700 family caregivers through the five categories of services listed above.

Service	Persons Served	Service Units	Title III Expenditures	Total Service Expenditures
Caregiver Respite	2,230	134,625	\$1,276,549	\$1,430,837

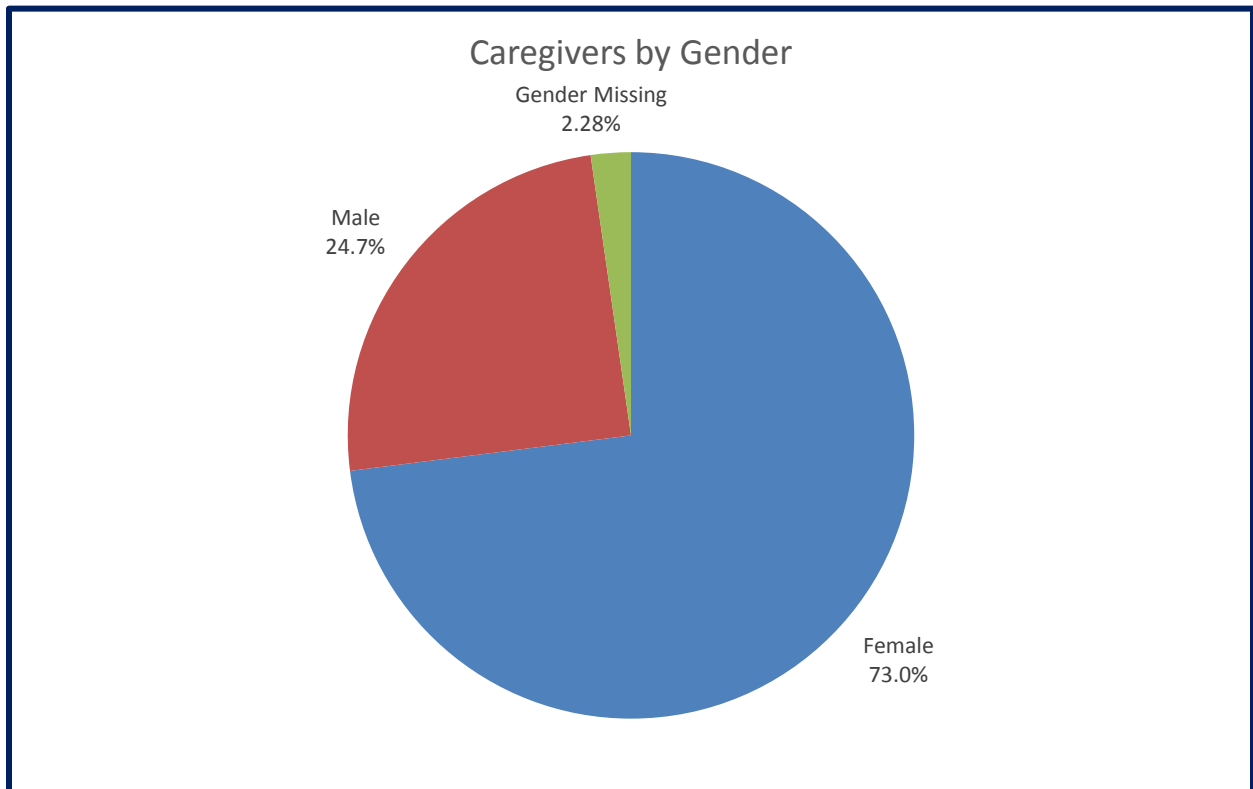
The following chart depicts the client and service profile of OAA caregiver programs in Illinois during FY2019:

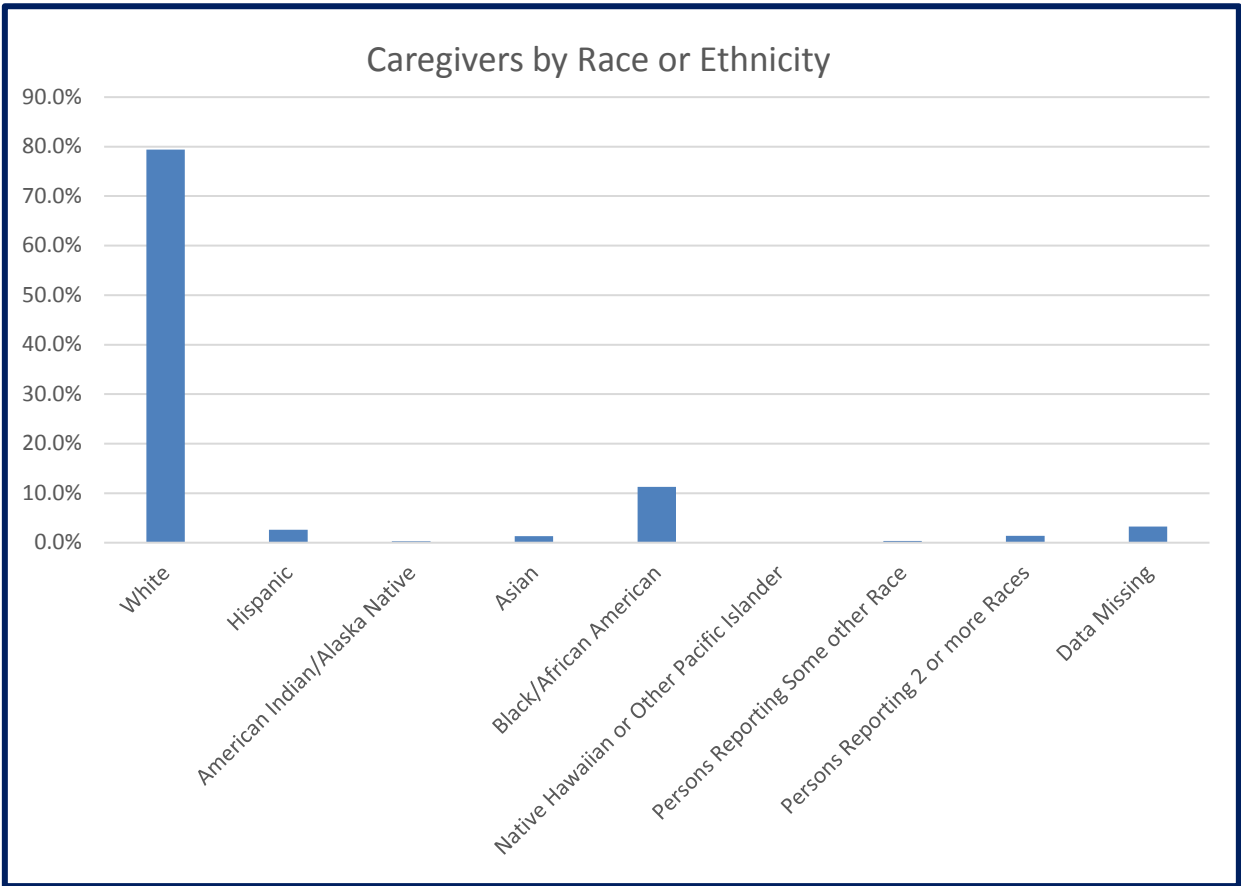
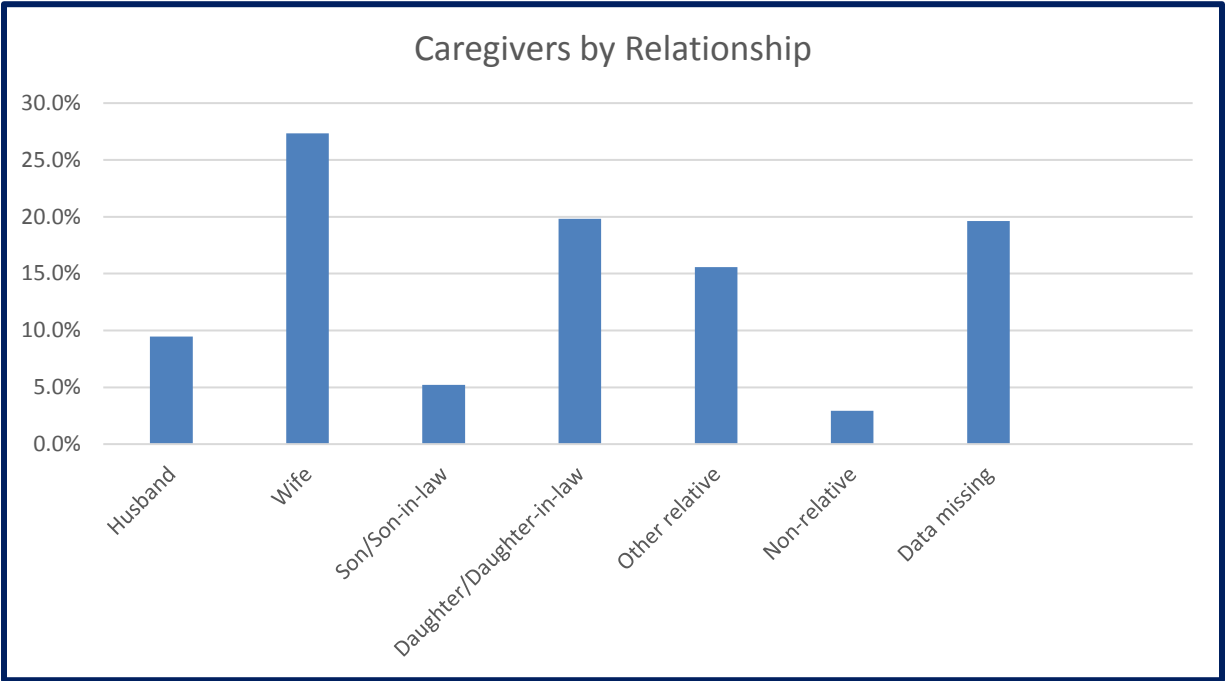


Caregiver Demographics

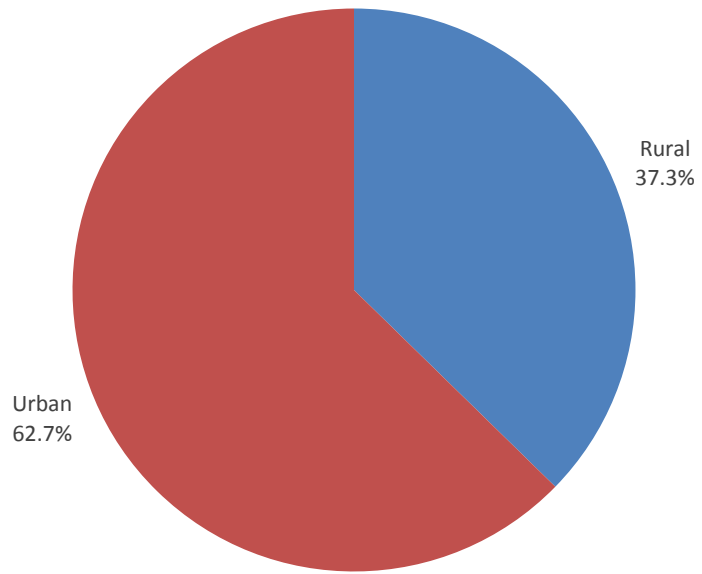
According to The National Alliance for Caregiving, upwards of 75% of all caregivers nationwide are female. Nine percent of caregivers self-identify as LGBT (National Alliance for Caregiving and AARP, 2015) Individual adult caregivers in the U.S. identify their race/ethnicity as the following: White, 62%; African-American, 13%; Hispanic (non-White, non-African-American), 17%, and; Asian-American, 6%. A vast majority of caregivers (85%) care for a relative or other loved one. The National Alliance for Caregiving breaks down the relationships as follows: 42% care for a parent, 5% care for a friend, neighbor or another non-relative, 14% care for a child, 7% care for a parent-in-law, and 7% care for a grandparent or grandparent-in-law (Family Caregiver Alliance, 2020).

Based on the 2019 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:



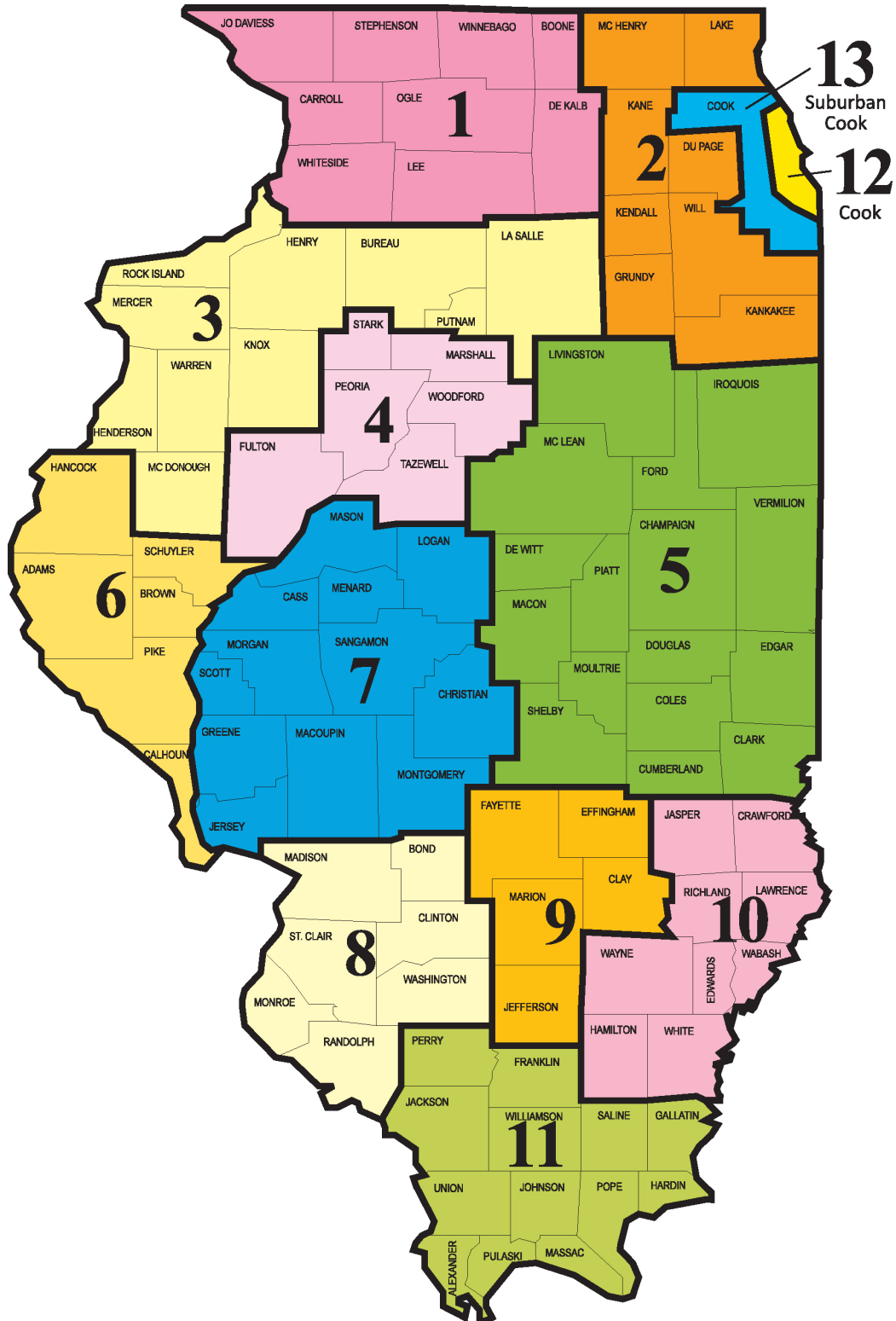


Caregivers by Location



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;
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Web: www.nwilaaa.org
E-Mail: gnyhammer@nwilaaa.org

AREA 02

AgeGuide

Marla Fronczak, Executive Director
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Kankakee Community College
River Road, West Campus - Building 5
Kankakee, IL 60901
815/939-0727; FAX: 815/939-0022
1-800-528-2000 (calls will be directed to proper source)
e-mail: mfronczak@ageguide.org
Field Office:
1910 S. Highland Ave. Suite 100
Lombard, IL 60148
630/293-5990; FAX: 630/293-7488
1-800-699-9043 (Suburban Cook County ONLY)
Web: www.ageguide.org
E-Mail: info@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.wiaaaa.org
E-Mail: beskildsen@wiaaaa.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.ciaaa.net
E-Mail: krider@ciaaa.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;
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Web: www.eciaaaa.org
E-Mail: sreal@eciaaaa.org

AREA 06

West Central Illinois Area Agency on Aging

Michael Drew, Director
Mailing Address:
P. O. Box 428, Quincy, IL 62306-0428
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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

Area Agency on Aging for Lincolnland, Inc.

Carolyn Austin, Executive Director
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Springfield, IL 62704-4278
217/787-9234 (Voice & TTY); FAX: 217/787-6290;
1-800-252-2918 (I & A) (217, 309 & 618 area codes ONLY)
Web: www.aginglinc.org
E-Mail: caustin@aginglinc.org

AREA 08

AgeSmart Community Resources

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AREA 09

Midland Area Agency on Aging

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AREA 10

Southeastern Illinois Agency on Aging, Inc.

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618/262-2306; FAX: 618/262-4967;
1-800-635-8544 (618 area code ONLY)
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E-Mail: southeasternaaaceoshana@gmail.com

AREA 11

Egyptian Area Agency on Aging, Inc.

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618/985-8311; FAX: 618/985-8315;
1-888-895-3306
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E-Mail: egyptianaaa@egyptianaaa.org

AREA 12

**Senior Services Area Agency on Aging
Chicago Department of Family and Support Services**

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312/744-6777 (TTY)
Web: www.cityofchicago.org/aging
E-Mail: mary_joyce.gallagher@cityofchicago.org

AREA 13

AgeOptions, Inc.

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1-800-699-9043 (Suburban Cook County area ONLY)
Web: www.ageoptions.org
E-Mail: diane.slezak@ageoptions.org

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FY 2020

**RESPITE
SERVICES
REPORT**



Illinois Department on Aging

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

Senior HelpLine: 1-800-252-8966 (Voice)
1-888-206-1327 (TTY)
(8:30am to 5:00pm, Monday through Friday)

24-Hour Adult Protective Services Hotline: 1-866-800-1409
1-888-206-1327 (TTY)

The Illinois Department on Aging does not discriminate in admission to programs or treatment of employment in programs or activities in compliance with appropriate State and federal statutes. If you feel you have been discriminated against, call the Senior HelpLine at 1-800-252-8966, 1-888-206-1327 (TTY).