

## Illinois Department on Aging

# FY 2023 Respite Services Report

July 2023

In Accordance with Public Act 93-864

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## 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 (AAAs) and other appropriate community-based organizations to provide respite care under the Act.

Historically, State of Illinois funds have not been appropriated for the establishment of a state-funded respite program; however, the State of Illinois has recently awarded funding for caregiver support services, beginning in fiscal year 2023. IDoA currently 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 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 had not yet been appropriated in FY 2022 to provide respite services under the Respite Program Act.

## 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 which is 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 a high 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) in each PSA, designated by the Illinois Department on Aging. 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 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 a three-year Area Plan in each of the PSAs, following a format prepared by IDoA. Also included in the plan is an outline of proposed Area Agency on Aging activities for the coming three years. Following the public hearings, the Area Plan is submitted to IDoA for review and approval. Area Agencies on Aging are permitted 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 or 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, 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 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 2023, it is estimated that approximately 3100 caregivers will receive more than 150,000 hours of respite services under state funding, 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 2023 Population Estimates, Illinois was home to 12.4 million people, with approximately 2.8 million people age 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. 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 2019 - FY 2021).

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 AARP Public Policy Institute, 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. (AARP Public Policy Institute, Valuing the Invaluable, 2023).

#### COVID-19

A 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 (State Plan on Aging for FY 2022 - FY 2024). The COVID-19 pandemic, which is especially dangerous to older people, disrupted the lives of older people and their family caregivers.

One of the most impactful changes to the caregiving role during the COVID-19 pandemic was the disruption of community-based and volunteer support both in and outside the home. Many programs such as in-home respite were shut down in order 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 (Sarah Cormell, 2022). In response, the Illinois Department on Aging has requested that the Area Agencies on Aging and their providers increase the use of respite services by 3%, beginning in FY 2024. Additionally, the use of respite services by caregivers of persons living with dementia should increase by 5%.

The AAAs and their providers will also utilize the Tailored Caregiver Assessment and Referral (TCARE) platform and tools to address caregiver needs, including respite care. They will establish monthly baselines pertaining to the number of caregivers who have completed screening, evaluation and care plans, and demonstrate that the highest level of resources is allocated to caregivers at the highest risk, reporting to IDoA on a quarterly basis.

#### LGBTQ+

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).

While paid care is available at nearly every stage along the continuum of care, entrusting the care of a loved one to a stranger can be a difficult decision and one that can be compounded by fear of inadequate treatment or discrimination for being LGBTQ+. A recent survey of LGBTQ+ baby boomers found that a growing number of LGBTQ+ aging adults expect to be treated with respect and dignity at the end of their life. In spite of this, one in five of the LGBTQ+ adults surveyed cited fear of double discrimination (for being older and LGBTQ+), as a significant concern about aging. Too often, LGBTQ+ older adults can allow this fear to postpone seeking assistance or support, which further increases stress and isolation, and decreases mental and physical health (Family Caregiver Alliance, 2023).

In response, IDoA has encouraged the Area Agencies on Aging 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.

#### **EFFECTS OF CAREGIVING**

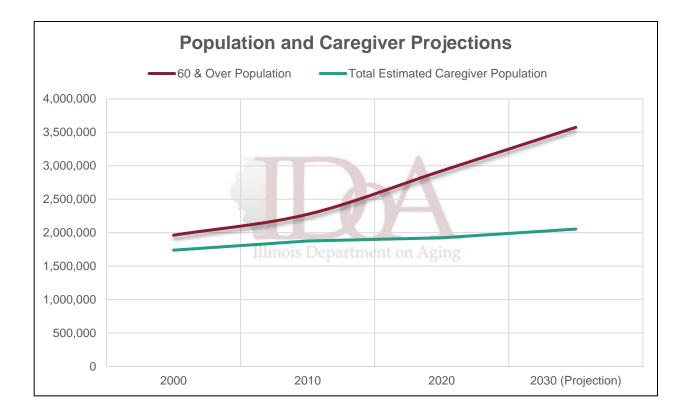
For many caregivers nationwide, caregiving is not a short-term obligation; as individuals age, they tend to be in poorer health and require more services than the younger elderly. According to The National Study of Caregiving at Johns Hopkins Bloomberg School of Public Health, only 15% of caregivers 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, 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 impact as a result of their caregiving and 28% have stopped saving. As a direct result of caregivers' future financial security. (AARP Public Policy Institute, Caregiving in the US, 2020). 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).

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?".

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).

Based on US Census Data for the years 2000, 2010 and 2020 including older adult and caregiver data, and applying the percentages from the Illinois Department of Public Health's latest Behavioral Risk Factor Surveillance System, the 60+ population and caregiver populations are projected in the following chart (Caregiver Burden Brief). In consideration of the aging demographic boom 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. Given these numbers, the pool of potential caregivers is projected to continue to shrink. (AARP Public Policy Institute, Valuing the Invaluable, 2023).



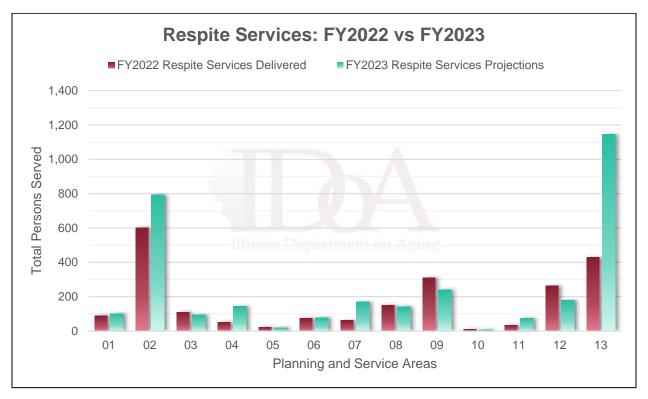
The goal of the Administration on Aging (AOA), is to "enable seniors to remain in their homes with high quality of life as long as possible through the provision of home and community-based services for older adults and their caregivers." Since respite services are critical to health and quality of life, 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 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 2023 RESPITE SERVICE PROJECTIONS

The following table outlines FY 2023 respite service projections (persons to be served) by PSA as funded by the federal Older Americans Act. The service projections are based on FY 2023 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

PSA	Title III-B	Title III-E	Total Projected
01	1	100	101
02	0	794	794
03	2	92	94
04	4	140	144
05	0	20	20
06	2	75	77
07	1	168	169
08	0	141	141
09	70	170	240
10	0	8	8
11	0	75	75
12	0	180	180
13	100	1,046	1,146
Total Projected	180	3,009	3,189

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)

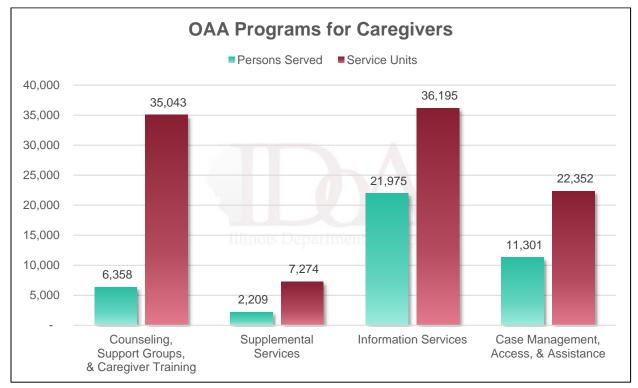
The NFCSP was established in 2000 and provided federal grants to States based on their share of the population aged 70 and over, to fund five categories of services that assist family and informal caregivers:

- 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 2022, the 13 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	2,039	96,176	\$1,086,557	\$1,624,109

The following chart depicts the client and service profile of OAA caregiver programs in Illinois during FY 2022:

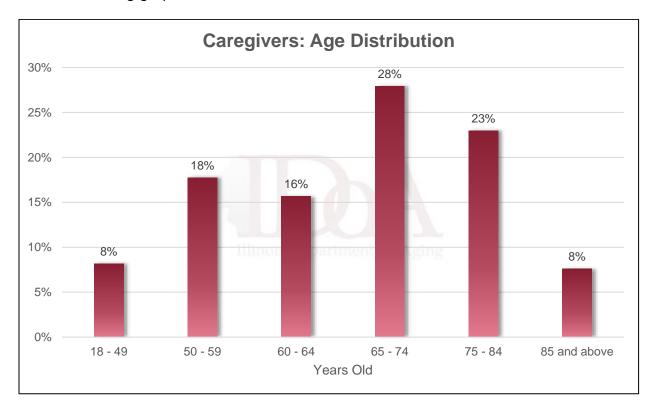


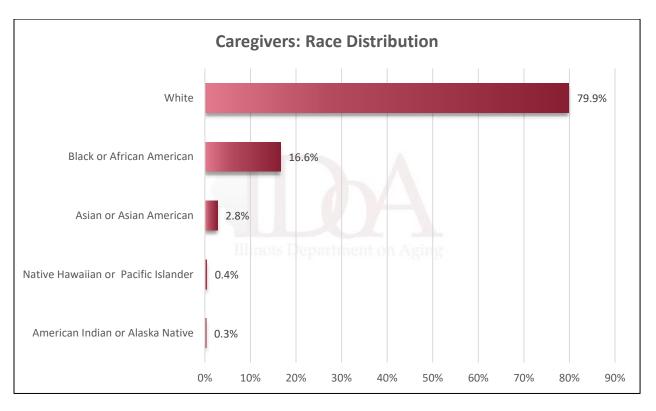
## CAREGIVER DEMOGRAPHICS

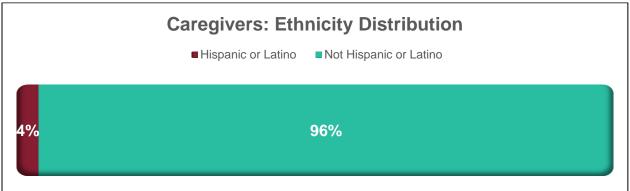
According to AARP and The National Alliance for Caregiving, upwards of 61% of all caregivers nationwide are female. Nine percent of caregivers self-identify as LGBT (National Alliance for Caregiving and AARP, 2020). Individual adult caregivers in the U.S. identify their race/ethnicity as the following: 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)

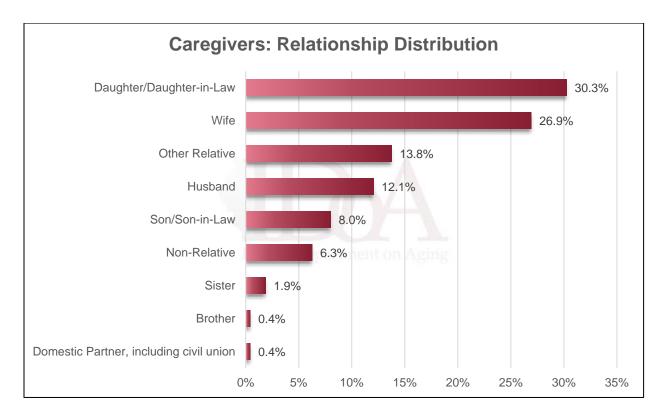
With the progressive projected growth of the senior population in the state of Illinois, increased attention has been directed to delivering respite services to caregivers of community dwelling seniors. Caregivers are as diverse as the state of Illinois as a whole: they come from every age, gender, socioeconomic, and racial/ethnic group. Of the total caregivers in Illinois, 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.

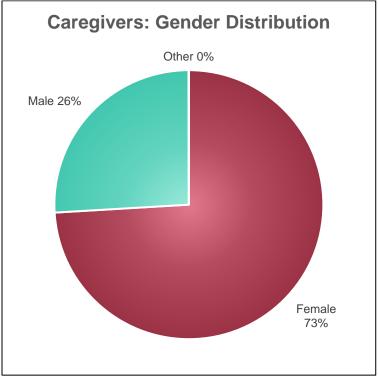
Based on the 2022 National Aging Program Information System (NAPIS) report compiled from information from the 13 Area Agencies on Aging, Illinois is indicative of the national trends, as shown in the following graphs:

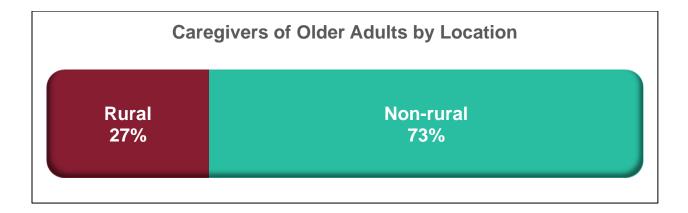












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ILLINOIS PLANNING AND SERVICES AREAS

#### **AREA AGENCIES ON AGING**

#### 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

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#### 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@aqequide.org or mfronczak@aqequide.org Fiscal Office: 100 College Dr, Building 5 Kankakee, Illinois 60901 Web: www.aqequide.org

#### AREA 03

#### Western Illinois Area Agency on Aging

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#### 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: <u>www.ciaoa.net</u> E-Mail: <u>krider@ciaoa.net</u>

#### 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.wciaqingnetwork.org E-Mail: michaeldrew@wcian.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 Reso

#### 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; TTY: 312/744-6777 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