

STATE OF AGING IN CENTRAL INDIANA



SECTION 11 CAREGIVING

April 2021



In this report, we refer to three subsets of older adults.

Younger-old: age 55-64

Middle-old: age 65-84

Oldest-old: age 85+

CAREGIVING

Caregiving by and for friends and loved ones is an important part of most older adults' lives. Caregiving impacts the well-being of both those being cared for and those providing care. This section of the report discusses caregiving by and for older adults, including the benefits, risks and associated resources. Key findings include:

- Four out of five older adults in Central Indiana provide care to a friend or loved one.
- Two in five older adults provide care to someone over 60.
- One in four older adults in Central Indiana is physically, emotionally or financially burdened by caregiving responsibilities, and most adults do not believe support services are available for caregivers.

A large majority of older adults provide care to a friend or loved one.

Percent of Central Indiana CASOA respondents who provide care to...

Someone under 18

27%

Someone age 18-59

27%

Someone 60 years or older

41%

A friend or loved one

78%

Source: CASOA, 2017

CAREGIVING OF FRIENDS AND LOVED ONES

Caregiving of friends and loved ones encompasses a variety of activities and levels of assistance depending on the condition of the friend or loved one needing care. Administering care (e.g., assisting with dressing, showering and medication adherence) can become challenging for an individual to manage alone when such assistance is required on a continuous basis. Most Central Indiana respondents to the Community Assessment Survey for Older Adults (CASOA) reported providing care to a loved one.¹

“Who these older adults with dementia are today is not going to be who they are next year. It is very hard to slow this down. These people are not the same person. They think we have more effective medicines than we do. We can’t change the progression of the disease.

The medicines are not that great. It is better to have help in place. It is about staying active and engaged...”

Diane and Pat Healey, Indianapolis Geriatricians

Older adults often care for other older adults, such as a spouse, friend or family member, with a cognitive disorder, physical disability, comorbidities or other health problems that arise through the aging process. Mild cognitive impairment, dementia or Alzheimer’s disease are common cognitive disorders that require a caregiver and often 24-hour-a-day care when the impairment is more severe. Caring for someone with an impairment can be a demanding and unrelenting job for the caregiver depending on caregiver’s knowledge of the illness, acceptance of the outcome of the illness, available resources and ability to accept assistance in caring for the friend or loved one with the impairment. Aid in caring for an individual with cognitive impairment may be provided from other family members, friends or outside agencies

structured to provide services to those in need. The support received can benefit the caregiver in numerous ways including emotional respite, financial planning and management, health care system navigation and other social services.

Similarly, older adults can also provide care for other older adults with physical impairments. Physical impairments are typically due to chronic illness (such as arthritis or a stroke) and can have varying degrees of impact on the day-to-day life of the older adult and the caregiver. Activities of daily living that may be influenced by disability include general hygiene activities, dressing, preparing meals or transferring to bed or to a chair. Assisting friends or loved ones with physical impairments with daily activities also may place a tremendous burden on friends or loved ones over time. Community support is available for caregivers in the form of transportation, home renovations to increase accessibility (e.g., building a ramp or widening a doorway), assistive devices (e.g., cane, walker, or shower chair) for rent or loan and in-home care (e.g., cooking, cleaning, snow shoveling or yard work) from a service agency.

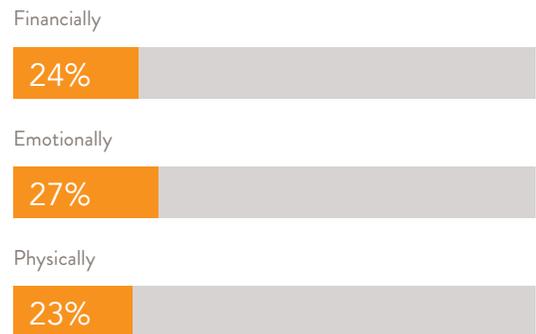
IMPACT ON CAREGIVER

The impact of caregiving on the caregiver is significant, and informants² to this report say that it is not unusual for the caregiver to suffer along with their friend or loved one. The physical and psychological strain of providing care may become increasingly burdensome and can impact family relationships, friendships, and the caregiver's ability to participate in activities outside the home. In addition to the negative impact of caregiving, older adults can experience some benefit from caring for friends or loved ones including positive emotions such as compassion, satisfaction, and confidence.

Older adult caregivers who were interviewed for this report indicated positive benefits most frequently when caregiving was a newer or short-term experience or when the individual was not the sole caregiver. Caregivers reported positive self-esteem and the ability to build additional skills in order to better care for their friends or loved ones. Additionally, the need to provide care for a friend or loved one resulted in joining support groups and making new friends who had similar experiences. Support groups could not only provide emotional help but also offer the opportunity for the caregiver to help others. Those who had larger families experienced their families

One in four older adults in Central Indiana are physically, emotionally, or financially burdened by their caregiving responsibilities.

Percent of Central Indiana CASOA respondents who are burdened by caregiving in the following ways



Source: CASOA, 2017

“They are very prideful, but not in a negative way. They are prideful of heritage, families, and they take a lot of pride in what they do. They are prideful as Senior Companions and let people know why they do it. The women are very prideful of what they have accomplished in their life...Pride is part of the way of coping and gets them through hard stuff. Pride and spirituality keep them going every morning.”

Joyce Bleven, Senior Companions

frequently coming together to offer support for a friend or loved one, which provided the opportunity to create new family memories and positive experiences. Finally, informants reported that providing care for a friend or loved one gave caregivers the opportunity to feel more optimistic about their own physical and cognitive abilities.

While caregiving for friends or loved ones in smaller doses can be rewarding and purposeful, ongoing demands can have negative effects for the caregiver. The burdens of 24-hour-a-day care may result in feelings of frustration, irritability, isolation, despair and exhaustion. Informants reported that older adults caring for spouses often found it often difficult to seek external assistance or support. Informants reported viewing the caregiver role as solely their responsibility and not wishing to burden others. Another reason a caregiver may decline to accept outside assistance is a general lack of trust in asking a stranger to care for a vulnerable friend or loved one. Informants also reported that the caregiver’s sense of pride left them feeling that they could manage their caregiving responsibilities alone and may prevent caregivers from seeking outside assistance.

Positive Impact
A sense of purpose
Social inclusion
Feeling a part of something greater than themselves
Strong family cohesion
An appreciation for their own cognitive and physical abilities

Negative Impact
Social isolation with spouse/ person they are caring for if needs are too great
Feelings of guilt
Emotional distress
Poor sleep quality
Poor dietary habits
Financial burden

IMPACT ON PERSON BEING CARED FOR

Caregiving demands impact the caregiver and may also influence the person receiving care in both positive and negative ways.

Informants reported that “aging in place” is a well-understood concept. People want to stay in their own homes and as independent as possible for as long as possible. Caregivers help older adults remain in their familiar surroundings.

This is especially helpful for an older adult with cognitive impairments that may find a new living environment disorienting. For further discussion on aging in place see the associated section in this report. Informants also report that caregiver support likely increases the longevity of the older adults receiving care and the likelihood that those older adults will remain active not only in their homes but in their communities. Being physically and socially active improves health outcomes.

Positive Impact	Negative Impact
Aging in place	Neglect
Increased longevity	Abuse

“Being alone is as detrimental to health as cigarette smoking.”

Daniel O. Clark, Indiana University Center for Aging Research

When cognitive impairment is present in the older adult receiving care, neglect and abuse are more likely to occur.³ Mistreatment happens as the situation becomes increasingly intolerable to the caregiver. This creates a harmful environment for the older adult receiving care that may include living in isolation with unmet needs or physical trauma and violence.⁴ Informants also report financial abuse where money or property belonging to the older adult receiving care is stolen. Older adults who are the recipients of abuse or neglect typically do not seek external help due to shame or fear that the caregiver will learn of the complaint and retaliate.⁵ To address this problem, services are available to both the victim and the caregiver. For further discussion of safety and abuse, see the associated section in this report.

Senior Care

Caring Place

Shepherd Center

Continuing Care Retirement
Communities

CICOA Flourish Care Management (in-
home care)

Community Centers

PrimeLife

Flanner House

Jewish Community Center

John H. Boner Neighborhood Center

Hendricks County Senior Center

Education, Advocacy, and Support Groups

CareAware

Alzheimer's Association

Joy's House

Other Resources

Meals and More (home-delivered meals)

Safe at Home (home modifications)

Way2Go (transportation)

RESOURCES AVAILABLE TO CAREGIVERS

While caregiving can be a rewarding experience, it can also create a stressful, difficult and exhausting environment for both the caregiver and their friend or loved one. In Central Indiana, there are resources available that offer support, many of which are provided or coordinated by CICOA. The list at left is not exhaustive but provides examples of services available to caregivers and their friends or loved ones.

All informants for the current report agreed that a clearinghouse of services for caregivers and their friends or loved ones would be quite useful but were not all aware that local information and referral organizations exist, such as CICOA Aging & In Home Solutions (CICOA)⁶ and Indiana 211.⁷ Informants also reported the need for better coordination of services and for agencies to better understand gaps in services and unmet needs. In early 2021, CICOA launched a technology solution, called Duett, to match older adults and people with disabilities who need in-home care with providers who offer the services.⁸

"We are so fragmented in everything we do. When we look at the continuum of care, you can have a discharge planner and they don't know they have a case manager... We need to make better use of the Health Information Exchange and better communication, so we are not operating in silos. If policymakers made it so we're all talking together for betterment of the patient, it would be better."

Donata Duffy, CICOA



HIGHLIGHTING EQUITY

LATINX POPULATIONS FACE GREATER CAREGIVING BURDENS

Latinx individuals are more likely to provide care for an older adult loved one than any other racial or ethnic group.⁹ Although Latinx caregivers report higher levels of caregiving satisfaction than White caregivers, forty-four percent report feeling stressed and overwhelmed by their caregiving responsibilities.¹⁰ Additionally, these individuals on average spend more time and money caring for their loved ones than the rest of the population.¹¹ Several factors can lead to high rates of caregiving and caregiving burden among Latinx adults, as described below:



INDIVIDUAL FACTORS: HIGH RATES OF DEMENTIA

Compared to non-Latinx Whites, Latinx individuals are at greater risk of developing Alzheimer's and other dementias. This is due to longer life expectancies and higher rates of chronic disease such as diabetes and heart disease.¹² Studies have shown that caregivers of loved ones with dementia experience greater caregiver burden, with roughly 25 percent providing at least 40 hours of care per week to their loved one, compared to only 16 percent of nondementia caregivers.¹³



INTERPERSONAL: EMPHASIS ON FAMILY

A value common among Latinx individuals of various national origins is familism, or the emphasis on and importance of family. Priority is often placed on the interdependence between family members, and support is most often sought within the family system rather than from more formal or institutional supports.¹⁴ As a result, one study found that Mexican-American caregivers were the least likely to use formal care for their loved one compared to Whites, Blacks and Asian Americans.¹⁵ It should also be noted that familial care is most often provided by women due to cultural expectations of women as natural caregivers who prioritize the needs of the family first.¹⁶



ORGANIZATIONAL: LACK OF CULTURALLY-SENSITIVE AND SPANISH-SPEAKING RESOURCES

Only around half of Latinx older adults are proficient in English,¹⁷ and 57 percent of Latinx adults have reported encountering language or cultural barriers when interacting with healthcare providers. Less than half of Latinx adults who participated in a long-term care survey felt that they could easily find nursing homes, assisted living facilities or home health aides that spoke their language, while less than 30 percent felt that these services would provide the food that they were used to eating.¹⁸ Additionally, Latinx caregivers felt that they had a lack of understanding of topics around caregiving, with 41 percent stating that they did not understand government programs such as Medicare and SSI, and 27 percent sharing that they encountered issues with finding educational resources. When asked what Spanish-language resources would be helpful for Latinx caregivers, roughly half mentioned trainings on stress management, government programs and caregiving techniques.¹⁹

ENDNOTES

- 1 National Research Center Inc., "Community Assessment Survey for Older Adults: 2017 Report Results for Central Indiana" (Boulder: CICOA Aging and In-Home Solutions, 2017), <https://cicoa.org/news-events/research/>.
- 2 Thirty-five key informant interviews with caregivers and service providers and nine focus groups with older adults were conducted during 2019 and 2020 to collect input on issues facing the older adult population in Central Indiana. Public and not-for-profit sector leaders and service providers who are knowledgeable about service systems and issues pertaining to older adults in Central Indiana were identified and interviewed as key informants during report preparation. Focus groups composed of older adults were assembled with the identification and recruitment assistance of community service providers. These focus groups were conducted by researchers, in person prior to the COVID-19 pandemic, and by Zoom after the pandemic began. The questions asked of the focus group participants were discussed and agreed upon by research faculty and staff.
- 3 Mark S. Lachs et al., "Risk Factors for Reported Elder Abuse and Neglect: A Nine-Year Observational Cohort Study¹," *The Gerontologist* 37, no. 4 (August 1, 1997): 469–74, <https://doi.org/10.1093/geront/37.4.469>.
- 4 Mark Johannesen and Dina LoGiudice, "Elder Abuse: A Systematic Review of Risk Factors in Community-Dwelling Elders," *Age and Ageing* 42, no. 3 (May 2013): 292–98, <https://doi.org/10.1093/ageing/afs195>.
- 5 Toshio Tatara et al., "The National Elder Abuse Incidence Study," n.d., 136
- 6 "CICOA Aging & In-Home Solutions | Indianapolis, IN," accessed February 16, 2021, <https://cicoa.org/>.
- 7 FSSA, "Indiana 211," accessed February 16, 2021, www.in211.org.
- 8 Mary Roberts, "CICOA Launches Tech Startup For In-Home Care," *Inside Indiana Business*, February 3, 2021, <https://www.insideindianabusiness.com/story/43287298/cicoa-launches-tech-startup-for-inhome-care>.
- 9 "Final-Proceedings-Caregiving-Thought-Leaders-Roundtable-Washington-DC-1.Pdf," accessed January 26, 2021, <http://www.nhcoa.org/wp-content/uploads/2017/04/Final-Proceedings-Caregiving-Thought-Leaders-Roundtable-Washington-DC-1.pdf>.
- 10 Sunshine M Rote et al., "Caregiving Across Diverse Populations: New Evidence From the National Study of Caregiving and Hispanic EPESE," *Innovation in Aging* 3, no. 2 (September 9, 2019), <https://doi.org/10.1093/geroni/igz033>.
- 11 "Status of Hispanic Older Adults: Insights from the Field," 2018, 28.
- 12 "Status of Hispanic Older Adults: Insights from the Field."
- 13 Henry Brodaty and Marika Donkin, "Family Caregivers of People with Dementia," *Dialogues in Clinical Neuroscience* 11, no. 2 (June 2009): 217–28.
- 14 Yvette G. Flores et al., "Beyond Familism: Ethics of Care of Latina Caregivers of Elderly Parents With Dementia," *Health Care for Women International* 30, no. 12 (December 2009): 1055–72, <https://doi.org/10.1080/07399330903141252>.
- 15 Rote et al., "Caregiving Across Diverse Populations."
- 16 Flores et al., "Beyond Familism."
- 17 "Status of Hispanic Older Adults: Insights from the Field."

- 18 Tomas Okal, "Communication and Long-Term Care: Technology Use and Cultural Barriers among Hispanics – The Long-Term Care Poll," accessed January 26, 2021, <https://www.longtermcarepoll.org/project/communication-and-long-term-care-technology-use-and-cultural-barriers-among-hispanics/>.
- 19 "Status of Hispanic Older Adults: Insights from the Field."

Download the data used in this chapter.

Download spreadsheets containing our source data
by [clicking here](#) or scanning the QR code below.



